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14. ABSTRACT: The goal of this program is to develop and recommend a model of care that enhances the quality of life for DOD children with life-threatening conditions and their families. Our strategy is to maximize current benefits and coordinate medical care with existing community resources and services, tailored to support the family's specified needs and requirements. The first year of work focused on a feasibility study to gather data on the intent, interpretation and implementation of the benefit; status of service delivery; available resources through the Military Health System, contract providers, community and other government agencies; and to conduct an assessment of needs of families. A distinct research protocol was designed to use individual interviews and focus groups to determine family and provider needs. The benefits likely to be used by military families and their children were analyzed. A data assessment collection tool has been designed to capture descriptors regarding community resources. The plan is to web enable the database in order to provide maximum availability and accessibility to the various potential users. An existing education curriculum for providers, Initiative for Pediatric Palliative Care, developed by the Education Development Center, was selected as one that best aligns with the CHI PACC® model.					
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Status of Work by Project Objectives

Referenced Documents Satisfying Project Objectives

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EXECUTIVE SUMMARY

This project is designed as a feasibility study to explore the capability of providing pediatric palliative care within the Military Health System (MHS). The ultimate goal is to make recommendations for a program of pediatric palliative care that would integrate palliative care interventions with therapeutic approaches to disease management from the time of diagnosis and provide a smooth transition to hospice care, when the child and family is ready to make that choice (a Children's Hospice International Program of All-inclusive Care for Children and their families (CHI PACC®) model). The overall approach is to optimize currently available healthcare benefits as well as military and community resources in a manner that responds to the individualized needs of children with life-threatening conditions who are beneficiaries of the MHS.

Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care provided across the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice. The current CHAMPUS/TRICARE authorized benefit for hospice is based on a Medicare model for adults, and the requirements for these services severely restrict pediatric access and do not provide appropriate pediatric care.

The project team researched the following areas related to the delivery of pediatric palliative care in the MHS:

- Assessment of needs of children, families and healthcare providers in the MHS
- Analysis of the benefit and the current status of service delivery
- Determination of eligibility criteria and an estimate of the numbers of children who would benefit from palliative/hospice care and the costs to serve them
- Description of availability and accessibility of community resources
- Exploration of case management and care coordination
- Documentation of formal and informal education curricula and strategies
- Investigation of current approaches to pediatric palliative care through site visits to existing programs
- Application of the standards of effective quality management systems

The published literature describes four types of children with life-threatening conditions based on trajectories of dying: those with incurable disease (some chromosome disorders), manageable disease (cystic fibrosis), possibly curable disease (childhood cancers), or those with significant co-morbidities that are often associated with hospitalization and death (child with a tracheostomy). A count based on diagnostic codes chosen for each type of condition was executed through data searches of the MHS administrative database for FY 2001 through FY 2002 and revealed 3,871 children who would be eligible for palliative care services. This number of children was verified by the prevalence rate of life-threatening conditions in a comparable population.

Analysis of the benefit showed the key services necessary for the provision of a comprehensive program of pediatric palliative care, not available through the current CHAMPUS/TRICARE

benefit, are care coordination, respite care, flexible home health care, bereavement counseling, and the ability to provide hospice care to enhance quality-of-life concurrently with life-sustaining treatment.

The gap analysis collated and synthesized the findings of this feasibility study by bringing together the needs of families and providers, the MHS benefit, and the availability and limitations of resources and services in order to determine the existing gaps. The identified gaps are the following:

- Processes are needed to improve families' access to needed services within the MHS.
- Comprehensive care coordination and continuity of care is vital for children with life-threatening conditions and their families but are inconsistently available.
- While the TRICARE benefit provides for care that addresses a child's medical needs, the complexity and duration of care needed by children with life-threatening conditions creates challenges that require extra coordination.
- A Medical Home, as recommended by the American Academy of Pediatrics, is generally not available to children with special needs in pediatrics or family medicine clinics in the MHS.
- Administrative challenges frequently create barriers to access of care and services for children and families.
- Families and providers are not trained or equipped to advocate for these children, and there is no specific resource to assist in filling this role for individual patients and families.
- Many providers remain untrained in effective communication techniques for discussing palliative and end-of-life care and in the medical options available for palliative care.
- Many of these children and families have various unmet needs for both emotional and social support.
- There are limited knowledge and resources available to families for either advice or support financially, a frequent need during relocation of the family to a medical center.
- Not all professional clinical and pastoral counselors are qualified to provide counseling for parents under the extreme stress of the initial diagnosis of a life-threatening condition.
- End-of-life care for children is inconsistent, rarely planned with a child and family, and, when done without sensitivity, can increase child and family suffering.
- Both providers and families lack sufficient knowledge about pediatric palliative care and how to identify and provide the support and services necessary for a comprehensive approach to care.
- Military issues such as transfers and deployments create unique problems and added stress for these families. Additional care coordination and services are needed to support families before, during, and after deployments.

This study concluded that it is not feasible to implement pediatric palliative care as a model based on CHI PACC[®] within the MHS. However, it *is feasible* to implement the principles of pediatric palliative care within the MHS as set out by the CHI PACC[®] core standards, the

Institute of Medicine, and the National Quality Forum. Military treatment facility commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population. Services can be provided by the direct care system and by medical resources in the community using CHAMPUS/TRICARE. Non-medical community resources are also important to families, but require additional coordination to facilitate access.

Program models vary across the nation in their structure, staffing, and service delivery model. Models differ according to the needs of the children and families they serve as well as factors such as the availability and qualifications of staff, budget constraints, and the population density of children with life-threatening conditions. The key aspects of palliative care are: education of all who provide care and services to children with life-threatening conditions and their families and care coordination across all aspects of care throughout the entire course of the child's illness and in all settings of care.

It is recommended that:

1. Education and information appropriate to the provision of pediatric palliative care and access to necessary resources and services be made available to all healthcare providers and families of children with life-threatening conditions.
2. Care coordination be made available to facilitate communication, promote continuity during transitions, and assist in identifying and obtaining necessary resources and services for all children with life-threatening conditions and their families.
3. TRICARE Management Activity establish an interdisciplinary process team on palliative and end-of-life care for children and adults to review options, make guidance available, and address challenges within the MHS.

FINAL REPORT CHILDREN'S HOSPICE

STATE THE PROBLEM

Recent advances in medicine have greatly reduced infant and child mortality. Providers caring for children with life-threatening conditions are usually committed to pursuing all curative and life-prolonging options until death is close and inevitable. Effective, compassionate, reliable palliative and end-of-life care has not been a priority and most providers lack the knowledge and experience on how to advise families and approach end-of-life decision-making. Even when a child is gravely ill, parents want to feel they did everything possible. In addition, families and providers are bound by the limitations of what the health care system can and will provide.

The goal of this project was to conduct a feasibility study to explore how pediatric palliative care has been implemented in the medical community, particularly through the use of Medicaid waivers and the application of the principles promoted under the Children's Hospice International Program of All Inclusive Care for Children (CHI PACC[®]) goals and standards; to identify and analyze issues relevant to providing pediatric palliative care within the Department of Defense (DoD) Military Health System (MHS); and to make recommendations and provide strategies for implementation of such a program that would enhance the quality of life for these children with life-threatening conditions and their families.

Definitions

Care Coordination

Care coordination is “a collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality, cost-effective outcomes.”¹ In this report, care coordination also addresses the needs of the family, is proactive (especially in obtaining palliative care and integrating palliative care with disease-directed care), and ensures that the family obtains the support they need while planning for the peaceful and meaningful death of their child and that the family receives needed bereavement support following the death of the child.

Care coordination is a component of medical management, which also includes utilization management, case management, and disease management, as directed by the TRICARE Management Activity Department of Defense Instruction (DoDI 6025.20) and in the *Medical Management Guide*.² The DoD TRICARE Management Activity defines care coordination as clinical case management or individually-based case management when provided by a clinical case manager rather than another member of the health care team, and recommends clinical case management be available across the entire health care continuum.³

CHAMPUS

Title 10, USC, which defines the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), is now known as TRICARE. It outlines the health care benefits to which uniformed service members and their dependents are entitled.

Disease-Directed Care

Disease-directed care is medical care that is intended to cure or slow the progression of a medical condition.

Exceptional Family Member Program (EFMP)

The Exceptional Family Member Program (EFMP) is a military personnel function used during the assignment process to identify active duty service personnel whose family members have special needs. The purpose of early identification is to coordinate the assignment of the active duty service member with the medical needs of their dependents. The program serves to ensure the availability of necessary medical services upon change of duty stations

Life-Threatening Condition (LTC)

A life-threatening condition (LTC) is a medical condition that has a substantial likelihood of leading to the death of an individual before the age of 24 yrs. This term includes children born with lethal conditions as well as those who develop a life-threatening illness. As used in this report, it does not include children who die soon after birth, an injury, or a sudden illness.

¹ Case Management Society of America, *Standards at a Glance, Accreditation Program Guide for Case Management Standards*; version 2.0, URAC, 2002.

² DoD TRICARE Management Activity, *Medical Management Guide*; January 2006.

³ DoD TRICARE Management Activity, *Population Health Improvement Plan and Guide*, December 2001.

Military Health System (MHS)

The MHS provides medical care for active duty and retired service members and their dependents. The direct care component includes 70 hospitals and 411 medical clinics in the U.S. and throughout the world. Medically necessary care is also purchased from the civilian sector as described in CHAMPUS and implemented by TRICARE.

Military Treatment Facility (MTF)

A military treatment facility is any clinic, hospital or regional medical center within the Military Health System that delivers direct health care to military beneficiaries.

Palliative Care

Palliative care, as defined by the Centers for Medicare and Medicaid Services in its proposed Hospice Conditions of Participation and as adapted from the World Health Organization, refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.

Quality of Life

Quality of life is satisfaction and pleasure derived from living. Quality of life is affected by one's physical, interpersonal and social setting. Each person and family may view quality of life differently, depending on their circumstances and values. Factors that affect their own ability to derive satisfaction and pleasure from living determine each child and family's quality of life.

TRICARE

TRICARE is the managed health care program that is established by the Secretary of Defense under authority of chapter 55 of title 10, United States Code, principally section 1097 of such title, and includes the competitive selection of contractors to financially underwrite the delivery of health care services under the Civilian Health and Medical Program of the Uniformed Services.⁴ TRICARE uses military health care as the main delivery system augmented by a civilian network of providers and facilities. TRICARE contractors oversee the purchase of care from the civilian sector, ensure that it is medically necessary and appropriate, and adjudicate payment of the provider and/or reimbursement of the service member.

⁴ USC Title 10, Section 712© Public Law 104-201, September 23, 1996.

BACKGROUND:

Summary of the Issues from the Literature

For many reasons, current approaches to care for children with life-threatening conditions leave children, families, and health care providers with unmet needs and unresolved quandaries. Children account for a relatively small percentage of all deaths in this country because of their general good health. The causes of death in children are substantially different from the causes of death in adults and vary considerably with age. Many children are born with rarely seen medical conditions, which create uncertainty in diagnosis, prognosis, and medical management. Therefore, limited knowledge and experience leave parents and health care providers unsure about how to provide care for these children. Even for common medical problems, children's general physiologic resiliency complicates predictions about survival and other outcomes.

“Palliative care seeks to prevent or relieve the physical and emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decision-making. Such care and assistance is not limited to people thought to be dying and can be provided concurrently with curative or life-prolonging treatments. End-of-life care focuses on preparing for an anticipated death.....and managing the end stage of a fatal medical condition.....Together palliative and end-of-life care also promote clear, culturally sensitive communication that assists patients and families in understanding the diagnosis, prognosis, and treatment options, including their potential benefits and burdens.⁵”

Current insurance models for end-of-life care are based on a Medicare model for adults, and the requirements for these services severely restrict pediatric access. Due to third-party reimbursement and state licensing requirements, hospice programs generally must limit their populations to individuals expected to be within six months of death who have elected to forego curative care and treatment. Few parents or physicians are willing to make such predictions or to forego curative care for children. As a result, this stipulation restricts the availability of hospice services to children, given the numerous therapeutic options that are often available, as well as the unpredictability of the length of survival of this population. Parents, physicians, and other health care providers move from treatment and curative therapy to palliative care much more hesitantly with children than adults. There are few hospice programs dedicated specifically to hospice care for children and most programs are unable to address the unique needs of children and their families. Palliative care for children requires an integrated interdisciplinary approach among the child, the family, and all providers of care and services that spans the spectrum of all the physical, emotional, psychosocial, and spiritual needs of children and families.

Children with life-threatening conditions (LTC) who are entitled to services from the Military Health System (MHS)- do not receive care in the comprehensive pediatric palliative care and

⁵ Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, p 2.

hospice model called for by the Institute of Medicine⁶, Medicaid⁷, the Children's Hospice International⁸, and the National Quality Forum⁹. This model is rapidly becoming the standard-of-care for dying children. Children with LTC include those who have irreversible progressive conditions in which treatment is exclusively palliative from diagnosis to death; conditions requiring long periods of intensive treatment aimed at prolonging and improving quality of life; conditions for which curative treatment is possible but may fail; and conditions with severe, non-progressive disability causing extreme vulnerability to health complications and death.¹⁰ The Institute of Medicine recommends "insurers should restructure hospice benefits for children to ... eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care [and] reimburse bereavement services for parents and surviving siblings of children who die."¹¹ These key features of a pediatric palliative care and hospice program are not available to most children with life-threatening conditions in the MHS.

Children's Hospice International-Program for All-inclusive Care for Children (CHI-PACC[®])

The mission of Children's Hospice International (CHI) is as follows

- To create public awareness of the needs of children with life-threatening conditions and their families, and of what children's hospice care can do to meet those needs
- To promote the establishment of CHI's Program for All Inclusive Care for Children and Their Families (CHI-PACC[®]), which provides an increased array of integrated medical, social, and spiritual services to children with life-threatening conditions and their families from the point of diagnosis to the provision of bereavement counseling for family members if cure is not obtained, on both national and international levels
- To include palliative care and hospice perspectives in all areas of pediatric care and education
- To include hospice children in existing and developing hospice and home care programs
- To create and maintain a sustaining resource base

Children's Hospice International (CHI) created their Program for All-Inclusive Care for Children and Their Families (PACC) model, during a two-year period from 11/97-11/99. The CHI's Demonstration Task Force who created the model was comprised of leaders from pediatrics, hospice and palliative care, home care, and related national organizations. The model promotes a philosophy that seeks to expand access to curative and palliative services beyond the scope of the traditional hospice benefit. Children with life-threatening illnesses and their families would

6 Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, pp 1-16.

7 Children's Health Services, Home and Community Waiver, Center for Medicaid and Medicare Services

8 <http://www.chionline.org/programs/> Last accessed June 20, 2006

9 www.nationalconsensusproject.org/guideline.pdf Last accessed January 5, 2006.

10 Association for Children with Life-Threatening Conditions and Their Families (ACT) *A Guide To The Development Of Children's Palliative Care Services* 2nd ed; London, 2003.

11 Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, pp 1-16.

have access to this approach to care from the time of diagnosis through cure or, if cure is not attained, through end-of-life care to include bereavement. This model of pediatric palliative care (PPC) is in accordance with the recommendations made by the 2003 Institute of Medicine report on PPC as well with the American Academy of Pediatrics paper from 2000 which also recommends that PPC commence at the time of diagnosis of a life-threatening condition. Furthermore, it follows the guidelines from the National Quality Forum (NQF) published in 2004, which provide an extensive outline for the delivery of palliative care.

The CHI PACC[®] model consists of four core standards, each of which contains 16 categories related to practice guidelines that are required to be in place in order for a program to be recognized as a CHI PACC[®] program. See Appendix 1: CHI PACC[®] Standards of Care and Practice Guidelines. The four core standards are the following:

- Comprehensive care delivered by an interdisciplinary team
- Simultaneous curative and palliative care
- Care from point of diagnosis with single entry into system
- Ample and flexible funding.

The CHI PACC[®] model stresses family-centered care and creation of an interdisciplinary team. The guidelines propose development of a broad range of services that provide for medical, nursing, psychological, and spiritual care for eligible patients and families. While hope for cure is important, the CHI PACC[®] model includes structured and adequate bereavement services in the event of the death of the child. Ethical considerations, volunteer services, plans for management and operations, and a plan for governance and administration comprise part of the guidelines as well.

CHI PACC[®] seeks to ensure that funding will follow the child/family into the most appropriate treatment setting. CHI has worked very closely with the Centers for Medicare and Medicaid (CMS) to promote that each state apply for a Medicaid waiver to cover CHI PACC[®] services. These waivers must be shown to be cost neutral or have cost savings for Medicaid prior to their implementation.

The CHI PACC[®] program is based on the concept of 1915(b) and 1915 (c) federal waivers. The Social Security Act authorizes multiple waiver and demonstration authorities to allow states flexibility in operating Medicaid programs. Within the parameters of broad Federal guidelines, states have the flexibility to develop Home and Community Based Service (HCBS) waiver programs designed to meet the specific needs of targeted populations, such as children with life-threatening conditions. Under the 1915 (b), states can implement managed care delivery systems, or otherwise limit individuals' choice of provider. The 1915 (c) allows states to waive traditional Medicaid provisions in order to allow long-term care services to be delivered in community settings. This program is the Medicaid alternative to providing comprehensive long-term services in institutional settings. For CHI PACC[®] programs, the cost of hospital or institutional care is compared to the cost of community care. In addition, key services such as care coordination and bereavement are incorporated in the programs as they are not traditionally

available under other Medicaid programs. Federal requirements for states choosing to implement an HCBS waiver program include:¹²

- Demonstrating that providing waiver services to a target population is no more costly than the cost of services these individuals would receive in an institution.
- Ensuring that measures will be taken to protect the health and welfare of consumers.
- Providing adequate and reasonable provider standards to meet the needs of the target population.
- Ensuring that services are provided in accordance with a plan of care.

This is a major issue when considering the feasibility of implementing a CHI PACC[®] Program in the military system. Based on the nature of the military demographics, and the fact that the military system has national and international reach, there is no mechanism for the system to apply for a waiver as the system is beyond the boundaries of a particular state. In addition, the CHAMPUS authorization for military health care is determined by law and does not allow for deviation from or flexibility of the authorized benefit.

As of 2007, there have only been two waivers submitted to CMS that have come from CHI PACC[®] Demonstration Projects. Florida Medicaid was approved for a 1915 (b) Managed Care Waiver in mid 2005. This waiver includes the comprehensive services as listed above with the exception of bereavement. It has 900 slots for eligible children. Colorado Medicaid was approved in January 2007 for a 1915 (c) Home and Community Based Waiver which covers all CHI PACC[®] suggested services including bereavement and has slots for 200 eligible children. The New York CHI PACC[®] Demonstration Project hopes to include the CHI PACC[®] model as part of a larger 1115 Medicaid waiver. Finally, CHI is working closely with the state of California to help with submission of a 1915 (c) waiver by the end of 2007. The success in obtaining the waivers clearly signals that the CHI PACC[®] model is becoming a standard of care with respect to pediatric palliative care. As more states move to approve Medicaid waivers based on the CHI PACC[®] model of PPC, it would be anticipated that private insurance companies and other entities that provide health care, such as the Department of Defense, would also move to establish similar models of care, that would prove to be cost neutral or demonstrate cost savings once implemented.

National Consensus Project (NCP) /National Quality Forum (NQF)¹³

In December 2001, development of palliative care consensus guidelines was discussed during a national leadership conference coordinated by the Center to Advance Palliative Care. Under the direction of a 20-member steering committee, nearly 100 nationally recognized palliative care experts reviewed and contributed to the development of the guidelines. In addition, over 1000 organizations, representing significant national constituencies, were invited to review and endorse the guidelines. The Clinical Practice Guidelines, published in 2004, were designed to

12 Centers for Medicare and Medicaid web site, <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/>, last accessed May 1, 2007.

13 National Quality Forum: A National Framework and Preferred Practices for Palliative and Hospice Care Quality. Washington, DC, 2006.

promote care of consistent and high quality and also to guide the development and structure of new and existing palliative care services.

The NCP agreed upon the following key elements of palliative care:

- Patient population – to include patients of all ages experiencing a debilitating chronic or life-threatening illness, condition, or injury
- Patient- and family-centered care
- Timing of palliative care – to ideally begin at the time of diagnosis through cure, or until death, and into the family’s bereavement period
- Comprehensive care – to alleviate physical, psychological, social, and spiritual distress
- Interdisciplinary team
- Attention to relief of suffering
- Communication skills
- Skill in care of the dying and the bereaved
- Continuity of care across settings – to include hospital, emergency department, nursing home, home care, assisted living facilities, outpatient, and nontraditional environments such as schools
- Equitable access – to include access to palliative care across all ages and patients populations, all diagnostic categories, all health care settings, and regardless of race, ethnicity, sexual preference, or ability to pay.

Eight different domains were subsequently identified by the NCP and provide the framework for the Clinical Practice Guidelines. They are as follows:

1. Structure and processes of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious and existential aspects of care
6. Cultural aspects of care
7. Care of the imminently dying patient
8. Ethical and legal aspects of care.

Institute of Medicine (IOM) Report on Pediatric Palliative Care¹⁴

In 2003, the IOM published its report, “When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families”. The working principles in this document regarding pediatric palliative, end-of-life, and bereavement care include appropriate family-centered care for children with life-threatening medical conditions and their families designed to fit each child’s physical, cognitive, emotional, and spiritual level of development from the time of diagnosis through death and bereavement, special responsibility on the part of professionals caring for these children to educate themselves and others about the identification, management,

14 Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003.

and discussion of the last phase of a child's fatal medical problem, change at both the organizational and individual levels to provide consistently excellent palliative, end-of-life, and bereavement care for children and their families, and more and better research to increase understanding of clinical, cultural, organizational, and other practices or perspectives to improve palliative, end-of-life, and bereavement care for children and families.

Comparison of CHI-PACC[®] and National Quality Forum (NQF)

Both the CHI PACC[®] model of care and the Clinical Practice Guidelines as outlined in the NQF represent very comprehensive approaches to palliative care. Both approaches stress the need for an interdisciplinary team that can provide care in four domains – physical, psychological, social, and spiritual. Despite CHI PACC[®] focusing on only children with life-threatening illnesses, both models virtually discuss the same concepts with respect to an ideal palliative care model. Most importantly, both stress the need for palliative care to begin at the time of diagnosis of a life-threatening illness, a concept which is clearly only beginning to be practiced in health care today.

There are however some subtle differences between the two models. CHI PACC[®] explores the concept of a single point of entry into a comprehensive system of palliative care for children with life-threatening illnesses and their families. This concept would clearly ease the burden on primary caregivers and families in terms of having to contact each individual “domain” separately in order to arrive at a comprehensive care team.

The CHI PACC[®] model discusses the concept of funding which will follow the child and family throughout the health care system. This is clearly based on the premise that the CHI PACC[®] will ultimately be presented to a state Medicaid agency so that an appropriate waiver can be drafted to move this model forward. With respect to the MHS, this is not applicable. NQF does not discuss any funding issues per se. In addition, the CHI-PACC[®] model discusses governance and administration as related to a CHI-PACC[®] program; these issues are not addressed in the NQF Guidelines.

An important clinical difference between the two models is the emphasis in the NQF guidelines on care of the imminently dying patient. Specific and important end-of-life care issues are outlined in this domain. While ethical considerations are discussed in both models, common ethical concerns encountered in palliative care are listed specifically and in more detail in the NQF guidelines.

Because of its pediatric focus, the CHI-PACC[®] model includes a very important aspect of care under its category, continuity of care. This concept relates to transitioning a child/adolescent, who reaches adulthood, into the adult system of medical care, allowing for continuity of medical care to continue. This is an extremely important concept given that many children with life-threatening illnesses that were once fatal in childhood are now living into adulthood. Transitioning these patients to adult care providers ensures that they will receive the care they need by providers, who are knowledgeable about adult onset diseases and health care issues.

Curative therapies concurrent with palliative care is a hallmark of the CHI-PACC[®] model of care and is representative of the patient population enrolled in such a program. This concept is discussed in greater detail than in the NQF Guidelines.

Finally, both the NQF and CHI-PACC[®] approaches to palliative care stress the importance of a commitment to research that is aimed at quality improvement within the program. The CHI-PACC[®] model also emphasizes research activities that have scientific value or meeting reporting requirements.

Despite the subtle differences outlined above, both approaches to palliative care are solid and, for most part, interchangeable. They are both complete with respect to those services which should be in place in order to provide a complete program of palliative care. Even if all components are not in place, implementation of any aspect of this model would enhance the care, services and quality of life for these children and their families. The CHI PACC[®] Standards are specifically designed for children, but the NQF Guidelines are more comprehensive and were developed by a nationally recognized panel of experts. Together the CHI PACC Standards and NQF Guidelines establish the standard for how Pediatric Palliative Care (PPC) should be approached and implemented.

Challenges of Integrating of the CHI PACC[®] Model of Care into the Military Health System (MHS)

The MHS, while providing excellent medical care for patients and families, is often complex and difficult to navigate for health care providers, patients, and families. Services at each of the many military treatment facilities vary with respect to availability and access. Incorporating PPC into any institution necessitates a change in culture with respect to how care is provided and when it is provided. This challenge becomes even more pronounced when attempting to initiate pediatric-oriented services into facilities that primarily serve adults. New services may need to be established or existing services made more creative when initiating a PPC program. The discussion below explores the challenges of implementation of a CHI PACC[®] program into military treatment facilities, addressing each of the core standards.

Challenge 1 – Development of Comprehensive Care, Interdisciplinary Team

An interdisciplinary team with the ability to address the medical, nursing, psychosocial, and spiritual needs of a patient and family is key to a successful PPC program. Individuals must be identified who can assess the needs and resources appropriate to the provision of PPC in each military treatment facility. The individuals must have the explicit support of the commander and be willing to effect a change in the cultural thinking towards palliative care of the staff within the institution, particularly if PPC is going to be implemented at the time of diagnosis. Communication between parents of children with life-threatening conditions and their health care providers is a very sensitive area and is sometimes difficult. Therefore, it would be imperative that the individuals providing care have expertise in palliative care or the willingness to learn. The **challenge** is to ensure a commitment within the MHS and the specific military

treatment facility for providing PPC and to identify providers, knowledgeable in pediatric palliative care, who are willing to assume a leadership role in implementing these concepts.

A comprehensive, multidisciplinary approach to care is necessary in order to address all the needs of the patient and family. This is done through a multidisciplinary team of providers, often representing a spectrum of professional disciplines. The **challenge** is the identification of the appropriate individuals in a single military treatment facility, who are willing to work as a team to identify, access, and coordinate the needed services. Meeting this standard may be particularly challenging given the varied resources available and the current deployment cycles of health care providers.

Challenge 2 – Providing Curative and Palliative Care Simultaneously

Providing curative care along with palliative care services usually means changing the culture and philosophy of an institution. In many arenas, palliative care is seen as synonymous with hospice care rather than the supportive type of care it actually represents. The medical components of palliative care (pain and symptom management) are more readily available in the MHS through the direct and purchased care system if authorized as medically necessary care. Resources for social, emotional, and spiritual needs are more limited and access for counseling or treatment often requires a specific mental health diagnosis. The main **challenge** is integrating the concept of PPC within the institution through the education of providers, staff and families. An additional **challenge** is the provision of psychosocial services and spiritual support in all settings of care without the need for mental health labels and offered by providers who have specific expertise in caring for children with life-threatening conditions.

Challenge 3 – Provision of Care from Point of Diagnosis with Single Entry into System

This core principle encompasses the concept of availability of interdisciplinary services not only in the hospital setting but also through community services, home care, respite care, and traditional hospice. For the child, who continues to survive into adulthood, continuity of care to assist with the transition from pediatric to adult health care providers, is a critical factor. A care coordinator is critical to the development of a complete plan of care, to the identification of and access to the services necessary to implement the plan, and to the facilitation of continuity across all setting of care. Case management and care coordination become even more important with military reassignments and deployments. Transitions and the variability of resources and services from one region to another offer unique challenges to ensuring continuity of care. The **challenge** is the guarantee of a seamless coordination of services across all settings and throughout all transitions.

Research and program evaluation also fall under this core principle. Program evaluation is important in order to assess the quality of the processes and services and to measure patient and family satisfaction. The **challenge** is the development of the appropriate assessment tools for the program and the accomplishment of on-going evaluation and change.

Challenge 4 – Provision for Ample and Flexible Funding

The CHI PACC[®] model was designed around utilizing the concept of a Medicaid waiver program, which would allow a CHI PACC[®] program to exist in that state under the auspices of the state Medicaid services. The waiver then authorizes Medicaid funds to be available to provide a more flexible benefit to care for eligible patients and their families as long as cost savings can be demonstrated. Most military families do not meet eligibility requirements for disability programs under the Social Security and Supplemental Security Income programs. Therefore, enrolling these children into a Medicaid waiver following the CHI PACC[®] model of care is not feasible. The **challenge** is to provide the comprehensive services necessary for PPC within the bounds of the military benefit as established by Congress and to supplement the medical care with identification and access to resources and services within both the military and civilian communities. An additional **challenge** is to identify funding for those services not covered by the benefit.

METHODS

This project is designed as a feasibility study to explore the ability to provide PPC within the MHS. The goal is to make recommendations for a program of pediatric palliative care that would integrate palliative care interventions with therapeutic approaches to disease management from the time of diagnosis and provide a smooth transition to hospice care, when the child and family is ready to make that choice. The overall strategy is to understand and maximize the utilization of the current benefit and to coordinate the medical care with existing military and community resources and services tailored to support the child's and family's specified needs.

It is first necessary to identify the medical and non-medical care, resources and services that are currently available to families of children with life-threatening conditions, and to determine which of the required resources and services were not available, in order to focus on unmet needs. In order to gain knowledge of what is already available, what should be available, based on community standards and experience of providers and families within the MHS, and what might be proposed to meet unmet needs, the project team researched the following areas relevant to understanding the applicability of pediatric palliative care to the MHS:

- Assessment of needs as perceived by families and health care providers in the MHS
- Analysis of the benefit and the current status of service delivery as it relates to the goals and principles of PPC
- Determination of eligibility criteria and an estimate of the population among existing beneficiaries
- Availability and accessibility of resources through the MHS, TRICARE managed care support contract providers and services, and resources through the military and civilian community and other federal, state and local government agencies.
- Exploration of case management and care coordination principles as they apply to the implementation of PPC
- Documentation of formal and informal education curricula and strategies for the education for both providers and families
- Utilization of site visits to existing programs to understand current approaches to implementing PPC
- Application of the standards of effective quality management systems to PPC in a military setting

These data are used to ascertain whether it is feasible to provide the key aspects of a pediatric palliative care plan within the MHS, as outlined by the core CHI PACC[®] principles, namely identification of committed individuals to form an interdisciplinary team, development of a comprehensive plan of care, provision of curative and palliative care simultaneously, provision of care from point of diagnosis with single entry into the system, and provision for ample and flexible funding.

FINDINGS:

Needs Assessments – Methods and Results

The medical literature provides some insight about needs of children with life-threatening conditions and their families. The American Academy of Pediatrics has issued recommendations about palliative care for children based on the work of the Committee on Bioethics and the Committee on Hospital Care.^{15,16} An essay in the *Journal of the American Medical Association* called for improvements in palliative and hospice care for children.¹⁷ A few pediatric palliative care programs have described their approaches to care.^{18, 19} These efforts report recommendations based on the clinical experience of healthcare providers.

Some studies and formal assessments of the needs of children with life-threatening conditions and their families have also been reported. In 2004, Children's Hospice International provided a summary of the needs assessment efforts of CHI-PACC® programs. (See Appendix 2 CHI PACC® Needs Assessments for the DOD mCare Project). At that time, Utah and Kentucky had completed focus groups and interviews with parents of 40 and 23 children who had died of a life-threatening condition. Comments from the focus groups and interviews were summarized, but there was not a formal analysis of the data. Virginia and Florida had done limited needs assessments but no information was available about their methods or results. New York did a systematic survey of healthcare providers in that state and identified priorities for care and service from healthcare providers' perspectives. The priorities were pain, decision making, dignity and respect, family-oriented care, spirituality, and psychosocial issues.²⁰

Other published research reports needs described by bereaved parents. This literature describes need for pain and symptom management for children with cancer;^{21,22} concerns about communication between healthcare providers and parents, difficulties with policies and procedures, needs of siblings and a need for bereavement care; parents' perspectives on decision-making and improving quality of life in the pediatric intensive care unit;^{23,24} and the importance

15 Toce S & Collins MA (2003) The FOOTPRINTS Model of Pediatric Palliative Care, *Journal of Palliative Medicine*, 6(6), 989-1000.

16 American Academy of Pediatrics (2000) Palliative Care for Children, *Pediatrics*, 106(2), 351-357.

17 Stephenson J (2000) Palliative and Hospice Care Needed for Children with Life-Threatening Conditions, *JAMA*, 284(19), 2437-2444.

18 Donnelly JP, Huff SM, Lindsey ML, McMahon KA & Schumacher JD (2005) The Needs of Children with Life-Limiting Conditions: A Healthcare Provider-Based Model, *American Journal of Hospice & Palliative Medicine*, 22(4), 259-267.

19 Truog RD, Meyer EC & Burns JP (2006) Toward Interventions to Improve End-of-Life care in the Pediatric Intensive Care Unit, *Critical Care Medicine*, 34(11) Suppl, S373-S379.

20 Donnelly JP, Huff SM, Lindsey ML & Schumacher JD (2003) Progress in Pediatric Palliative Care in New York State—A Demonstration Project, Appendix H in *When Children Die*, Institute of Medicine, National Academies Press, available at <http://www.nap.edu/catalog/10390.html>.

21 Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, Emanuel E & Weeks JC (2000) Symptoms and Suffering at the End of Life in Children with Cancer, *NEJM*, 342(5), 326-333.

22 Contro N, Larson J, Scofield S, Sourkes B & Cohen H (2002) Family Perspectives on the Quality of Pediatric Palliative Care, *Archives of Pediatric and Adolescent Medicine*, 156, 14-19.

23 Meyer EC, Burns JP, Griffith JL & Truog RD (2002) Parental Perspectives on End-of-Life Care in the Pediatric Intensive Care Unit, *Critical Care Medicine*, 30(1), 226-231.

of continuity of care.²⁵ Two programs assessed needs more comprehensively from the perspectives of both healthcare providers and parents of bereaved children.^{26,27} Three other studies investigated particular aspects of pediatric palliative care: acceptance of support by parents of children with profound disabilities,²⁸ spiritual care for hospitalized children and their families,²⁹ and preparation for the end-of-life.³⁰

No reported studies have systematically and comprehensively investigated the needs of children with life-threatening conditions who receive care in the same large healthcare system, including the perspectives of a representative sample of both parents and healthcare providers, and no previous studies have investigated the needs of children with life-threatening conditions in military families. In addition, most of the needs assessments that have investigated parents' perspectives on care needs have included primarily bereaved parents, with few parents of children living with life-threatening conditions. The study reported here addresses these gaps.

Researchers from the Uniformed Services University conducted a needs assessment of children with life-threatening conditions and their families who are MHS beneficiaries, using data gathered from parents and health care providers at 6 military medical centers (the National Naval Medical Center, Walter Reed Army Medical Center and Malcolm Grow Air Force Base in the National Capital Area; the Madigan Army Medical Center; the Naval Medical Center, San Diego; and the Medical Center at Wright Patterson Air Force Base). The inclusion of these sites provided representative information reflecting the military population, as the sites represent major medical centers of the Army, Navy and Air Force in diverse geographic locations.

At each of the sites, the following data collection strategies were employed to gather information about the needs of children and families, the services available to address those needs, and access and barriers to available services:

- Focus groups and interviews with parents of children with life-threatening conditions (both newly diagnosed and advanced) and parents of children who have died in the previous two years from a life-threatening condition.
- Focus groups and interviews with pediatricians, pediatric residents, family medicine physicians and residents, care coordinators, case managers, social workers and other health care providers that provide care for children with life-threatening conditions.

24 Meyer EC, Ritholz MD, Burns JP & Truog RD (2006) Improving the Quality of End-of-Life Care in the Pediatric Intensive Care Unit: Parents' Priorities and Recommendations. *Pediatrics*, 117, 649-657.

25 Heller KS & Solomon MZ (2005) Continuity of Care and Caring: What Matters to Parents of Children with Life-Threatening Conditions, *Journal of Pediatric Nursing*, 20(5), 335-346.

26 Contro NA, Larson J, Scofield S, Sourkes B & Cohen HJ (2004) Hospital Staff and Family Perspectives Regarding Quality of Pediatric Palliative Care, *Pediatrics*, 114, 1248-1252.

27 Browning DM & Solomon MZ (2005) The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational Approach for Healthcare Professionals, *Journal of Pediatric Nursing*, 20(5), 326-334.

28 Brett J (2004) The Journey to Accepting Support: How Parents of Profoundly Disabled Children Experience Support in Their Lives, *Paediatric Nursing*, 16(8), 14-18.

29 Feudtner C, Haney J & Dimmers MA (2003) Spiritual Care Needs of Hospitalized Children and Their Families: A National Survey of Pastoral Care Providers' Perceptions. *Pediatrics*, 111, e67-e72.

30 Steinhäuser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J & Tulsky JA (2001) Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers. *Journal of Pain and Symptom Management*, 22(3), 727-737.

- Informal observations and conversations with individuals in the medical centers, with field notes about available care and services and collection of brochures about available services.

Appendix 3 contains a schematic diagram of care for children with life-threatening conditions and their families. The diagram includes curative care, palliative care during all phases of disease, and a full array of support services from the time of diagnosis through the time of bereavement. This tentative model was adapted from Feudtner et al.³¹ and Hutton et al.³² and modified after initial discussions with parents to include support services at all points on the continuum of care. The modified model guided interviews and focus group discussions with families and health care providers in the case studies, as described below.

Institutional Review Board Review and Approval

The needs assessment protocol was reviewed and approved by the Institutional Review Boards (IRBs) at the following sites:

1. Uniformed Services University of the Health Sciences (USUHS)
2. Malcolm Grow Air Force Medical Center (MGMC)
3. Walter Reed Army Medical Center (WRAMC)
4. National Naval Medical Center (NNMC)
5. Keesler Air Force Base Medical Center (Note: This site was not available for the study after Hurricane Katrina)
6. Madigan Army Medical Center (AMC)
7. Naval Medical Center (NMC), San Diego
8. Wright Patterson Air Force Base Medical Center (AFMC)

In addition, the protocol was reviewed by the Health Services Research Review Board (HSRRB) at Ft. Detrick, which agreed to assign oversight of the protocol to the Uniformed Services University. See Appendix 4: Research Protocol

Sampling strategy and research participants

Parents and health care providers were invited to participate in interviews or focus groups using IRB-approved recruitment flyers and verbal invitations at the study sites. Participants were recruited and interviewed in the National Capital Area until the themes in their responses began to repeat, which indicated that the sample adequately represented the group in this geographic area. Subsequently, parents and health care providers were recruited and interviewed at Madigan AMC, NMC San Diego, and Wright Patterson AFMC. Although the same major themes were described in the focus groups and interviews at all the sites, differences within the themes were evident outside the National Capital Area. The Army, Navy and Air Force bases surrounding Madigan AMC, NMC San Diego, and Wright Patterson AFMC included actively deploying

31 Feudtner, C, DiGiuseppe, DL, & Neff, JM (2003). Hospital care for children and young adults in the last year of life: a population-based study. *BMC Med*;1:3.

32 Hutton, N, Schechter, NL, & Wolfe, J (2004). *Pain and Symptom Management in Pediatric Palliative and End-of-Life Care*. Mini Course presented at the Pediatric Academic Societies meeting, San Francisco, CA, May 2004.

populations of military service members, and the support needs and stresses were different among these families and health care providers.

Criteria for parents to participate in the study included the following:

- Having a child with a life-threatening illness (as interpreted by the parent) or a child who had died from a life-threatening illness within the prior two years.
- Being available for a focus group, interview, survey and/or review of written materials for this study.

Criteria for health care providers to participate in the study included the following:

- Providing health care or care coordination for children with life-threatening illnesses and their families within the MHS (i.e., residents, staff physicians and other health care providers in pediatrics or family medicine).
- Being available for a focus group, interview or survey for this study.

In consultation with the study team for the Children's Hospice project, the description of children with life-threatening conditions referenced by Himmelstein et al. was chosen to define the group of children for the study. The children of parents who participated represented all four categories in the Himmelstein description. Several parents who participated had experienced the death of a child. Families represented the Army, Navy, Air Force, and Marine Corps. Health care providers included staff pediatricians, pediatric residents, staff family medicine physicians, family medicine residents, social workers, case managers, care coordinators and nurses. Tables with demographic information about the research participants appear in Appendix 5. A summary table of participants appears below:

	Health Care Provider Participants	Parent Participants
National Capital Area Total	31	19
<i>USUHS</i>	6	15
<i>WRAMC</i>	8	2
<i>NNMC</i>	6	1
<i>MGMC</i>	11	1
Madigan AMC	28	35
San Diego NMC	24	24
Wright Patterson AFMC	17	15
<i>TOTAL</i>	<i>100</i>	<i>93</i>

Advisory group of parents in the National Capital Area

An advisory group of research collaborators was developed by contacting parents of children who have had, currently are ill with, or have died from a chronic life-threatening illness. This group of parents, initially invited to participate from a group previously assembled under another project, reviewed focus group and interview plans, provided information regarding adaptation of a quality of life survey for caregivers, and assisted with interpretation of data analysis. This

group helped researchers develop an understanding of parents' experiences and provided insight about whether themes that emerged during data analysis accurately reflected their experiences.^{33,34} Focus group and interview topic guides for the advisory group appear in Appendix 6. Four focus groups meetings with this advisory group were also taped, transcribed and included in the analysis.

Focus group and interview plans

The following surveys informed the development of questions and data collection strategies for focus groups and interviews, with guidance from the advisory group:

- The End-of-Life Survey developed by the Foundation for Accountability (FACCT) (integrated in questions for focus groups and interviews, with guidance from the advisory group of parents).
- The Quality of Life of Caregivers of Children with Special Health Care Needs survey developed by Dr. Randall and Dr. Hanson³⁵ (integrated in questions for focus groups and interviews, with guidance from the advisory group of parents).
- The Medical Home Assessment Questionnaires and the Medical Home Index (family and provider versions), which are available from the American Academy of Pediatrics website.³⁶

In consultation with the advisory group, the researchers developed a set of interview and focus group questions for parents and a second set of interview and focus group questions for health care providers. These questions, along with the interview and focus group topic guides, provided a framework for one-to-one interviews and focus group discussions at all four study sites, and can be seen in Appendix 7.

Parent focus groups and interviews

Parent focus groups and interviews addressed the following broad topics: (1) how parents define the needs of children and families when a child has a life-threatening illness; (2) the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs; (3) the experience of children and families in finding and using services in their communities (both military and civilian communities); (4) education and information necessary to enable them to find and access the health care and services that they need; and (5) the degree to which the children's care has been coordinated and what the mechanisms of coordination have been. In order to allow unanticipated themes to emerge, questions were open-ended. Focus groups and interviews were audiotaped and transcribed. In order to make study participation accessible to as many parents as possible, researchers traveled to parents' homes to conduct one-

33 Osher, TW, & Telesford, M (1996). Involving families to improve research. In Hoagwood, K, & Fisher, CB (Eds.), *Ethical Issues in Mental Health Research With Children and Adolescents* (pp. 29-39). Mahwah, New Jersey: Lawrence Erlbaum Associates.

34 McBride, SL, Sharp, L, Hains, AH, & Whitehead, A (1995). Parents as co-instructors in preservice training: A pathway to family-centered practice. *Journal of Early Intervention*;19:343-389.

35 Randall V, Hanson J. (May 2004) *Quality of Life of Caregivers of Children with Special Health Care Needs, A Survey Tool Constructed in Collaboration with Parents*. Unpublished manuscript. Bethesda, MD: Uniformed Services University of the Health Sciences.

36 American Academy of Pediatrics, Medical Home Measurements, available at http://www.medicalhomeinfo.org/tools/med_home.html. Accessed May 3, 2007.

to-one interviews. In addition, researchers conducted interviews and focus groups with parents at the Uniformed Services University, Madigan AMC, San Diego NMC and Wright Patterson AFMC.

Health care provider focus groups and interviews

Health care provider interviews and focus groups were conducted to discuss three broad topics: (1) how residents, pediatricians, family medicine physicians, and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care; (2) participants' experiences with the MHS (direct care system and TRICARE) in meeting those needs; and (3) education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families.³⁷ Interns/residents and staff physicians participated in separate focus groups. Focus groups and interviews were audiotaped and transcribed. Health care providers were interviewed at the Uniformed Services University, Walter Reed AMC, the National Naval Medical Center, Madigan AMC, NMC San Diego and Wright Patterson AFMC.

Data Analysis

Interview and focus group audiotapes from all four sites were transcribed, analyzed using the constant comparative method of qualitative data analysis, and coded using HyperResearch™ software. Two researchers read most of the transcripts from two sites, developed preliminary themes, and agreed on a set of themes to use for coding. These two researchers then read and coded all transcripts from these two sites. A research assistant learned the coding scheme and entered all coded comments in the HyperResearch™ software, noting any disagreements in coding by the two primary researchers. All disagreements were discussed until agreement was reached.

The overall approach to data analysis is described by Pope and Ziebland³⁸ and in volumes 5 of *The Ethnographer's Toolkit, Analyzing and Interpreting Ethnographic Data*.³⁹ The constant comparative method is described in *The Discovery of Grounded Theory* by Glaser and Strauss.⁴⁰

Report of parent focus groups and interviews

This report focuses on these four facets of the needs assessment from parents' perspectives:

- Child and family needs as described by parents.
- Resources families use in the MHS and community.
- Resources needed but not accessible, available or adequate and the barriers families experience when trying to obtain these resources.
- Families' needs for information and education regarding these needs, resources and gaps in services.

37 American Academy of Pediatrics (2002) The Medical Home, *Pediatrics* 110(1), 184-186.

38 Pope, C & Ziebland, S (2000). Analyzing qualitative data. *BMJ*; 320:114-117.

39 LeCompte, MD & Schensul, JJ (1999). *Analyzing and Interpreting Ethnographic Data*. Vol. 5, Ethnographer's Toolkit. Walnut Creek, CA: Altamira Press.

40 Glaser, BG, & Strauss, AL (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine Publishing Company.

Report of health care provider focus groups and interviews

This report focuses on these four facets of the needs assessment from health care providers' perspectives:

- How residents, pediatricians (both general pediatricians and subspecialists), family medicine physicians and other health care providers define the needs of the children and families for whom they provide care.
- Their experiences with the MHS (direct care and TRICARE benefit) and community services in meeting those needs.
- How residents, pediatricians, family medicine physicians and other health care providers describe gaps in needed care and services.
- Education necessary to help physicians and other health care providers provide care in a Medical Home model for children with life-threatening illnesses and their families.

Results

The researchers have completed initial reports for two study sites, the National Capital Area and Madigan AMC. Interviews and focus groups have also been completed and transcribed for Wright-Patterson AFMC and NMC San Diego. Data gathered at all 4 sites that describe experiences overseas and at small bases have also been analyzed. Results reported here represent an integrated set of themes that summarize findings across sites. Each report describes the needs of children and families, the resources used and the resources needed but not accessible, available or adequate, incorporating the perspectives of both families and health care providers. The data have been organized according to the themes that emerged from the qualitative analysis. A separate gap analysis (see pages 72-103) has been completed based on the themes that resulted from the needs assessment. The gap analysis delineates gaps in services and support, with program and policy recommendations for the MHS to address these gaps. The themes also summarize relevant needs of families, physicians and other health care providers for education and information about care and services and how to access them.

THEME GROUP 1: SYSTEMS

1. Access to Care and Services

1a. Available resources

Children with life-threatening conditions in the MHS receive a wide array of health care, including pediatrics, subspecialty care, surgeries, treatment procedures, diagnostic procedures, medications, rehabilitation hospitals, hospitalizations, equipment,

speech/occupational/physical/feeding/water therapy and nursing. They receive care in military treatment facilities, Children's Hospitals, other major medical centers, emergency rooms, urgent care centers and outpatient settings. There is generally a low dollar cost to families for care covered by TRICARE if the children are enrolled in TRICARE Prime. Some families benefit from the catastrophic cap (an annual maximum for cost-shares and co-pays). Some parents have entered or remained in the military to obtain or retain health care coverage for their children. They may drive some distance to military treatment facility or civilian care facilities, or may be air-lifted or compassionately re-assigned to get the care their children need. Parents described care received while stationed at different bases in the United States and overseas. They described getting access to all needed physician visits, hospitalizations and related procedures, and medication, although they sometimes had to work around the barriers described below. They also described access to physical therapy, occupational therapy, speech therapy, and equipment, but with some limitations and delays also addressed in theme 1b-barriers. The ECHO program in TRICARE provides up to 40 hours per week of respite care for some children. Some military treatment facilities have well-developed special services, such as a Developmental Clinic, Cystic Fibrosis Clinic or Hematology/Oncology Service. Military physicians work hard to help families access health care, learn the TRICARE system, fax and re-fax forms, and give parents back-up phone numbers and pager numbers to improve access.

1b. Barriers to access in the MHS (TRICARE and Military Treatment Facilities)

Both parents and health care providers encounter barriers when trying to access care and services for children. Physicians spend a great deal of time completing paperwork, writing letters, and helping with appeals. Physicians may have somewhat less time for clinical care because of limited ancillary staff at military treatment facilities. Low reimbursement rates for care paid by TRICARE make it difficult to find providers in the civilian network. Sometimes it appears that the TRICARE contractor may try to shift costs to other payers (Medicaid, schools) and the other payers may in turn try to shift costs to TRICARE. Some areas have experienced many denials for physical therapy, occupational therapy, speech therapy, oral motor therapy, and equipment.

Other services that are hard to access include anesthesia for pediatric procedures (lack of providers at Military treatment facilities), social work, child life, intensivists, any equipment (e.g. orthotics, wheelchairs) and help with travel expenses when children are referred to distant civilian facilities. At the military treatment facility, access is often difficult for families because of long waits, no day care for other children, or limited parking. Limitations related to staffing resources at military treatment facilities include the following: very limited child life and nutrition services, physicians who are too busy to focus on pediatric palliative care, deployment of physicians, no good system for continuity of physician care, no personnel to track children for follow-up, few general pediatricians available to follow medically complex children, few pediatric case managers, few social workers, an overload in follow-up clinics, the loss of a nurse advice

line with a new TRICARE contract, limited acute pediatric appointments, and little physical therapy, occupational therapy and speech therapy at military treatment facilities.

When using military treatment facilities, barriers to care include needing repeated referrals, no same-day appointments, scheduling challenges, driving long distances to get to a large hospital, limited parking, not having a general pediatrician, long pharmacy lines, medications not in pharmacy formularies, no new prescriptions filled at the drive-through pharmacy, poor maintenance at the large military treatment facilities, inflexible front-desk staff and poor coordination between facilities. Whether at a military treatment facility or a civilian facility, civilian providers don't understand military culture or regulations. When services are not available at a military treatment facility, parents encounter excessive "red tape" with TRICARE contractors. Again, they need repeated referrals, services are sometimes denied several times, there are months-long waits for equipment, getting authorizations requires repeat phone calls, the contractor does not return phone calls, rules and processes change with no communication, administrative staff are poorly informed and there are inconsistencies in what is approved. Retirees do not have ECHO coverage. Even when therapy, home nursing and equipment are authorized, parents cannot always find providers in the TRICARE network, or the service is far from their home, or home care is not available. There is little help navigating the system. The military treatment facilities seems understaffed and underfunded, especially to parents who have experienced care at Children's Hospitals. Parents with a spouse deployed have no one to help them navigate the system, and little or no help caring for children. Parents with several children sometimes have a hard time getting them to all appointments.

1c. Other payers and community resources

Some families qualify for Social Security Income (SSI), Medicaid and Division of Developmental Disabilities/Developmental Disabilities Administration services on the basis of low income, but rules for eligibility determination vary by county and state. Medicaid is available to children with SSI, and qualification for SSI changes with moves between states, availability of base housing, military promotions and payment of child support. When a family does not qualify on the basis of income, there are income waiver programs that enable families to access Medicaid-provided services, but there are limited slots and long waiting lists. When families qualify, Medicaid may cover TRICARE co-pays, diapers and related supplies, formula, personal care hours, respite care or home nursing. Sometimes families are later asked to repay costs of services provided if eligibility has changed. The TRICARE contractor may require a written denial from Medicaid before providing some services (e.g. physical therapy, occupational therapy, speech therapy), even for families with higher incomes.

Schools and early intervention programs also provide some therapy and equipment. Home nursing of any kind is extremely limited, even for occasional visits. Care coordinators may help families negotiate complicated applications for service and payment from community, state, and federal sources. Some families have purchased

supplemental insurance, which covers co-payments and deductibles not paid by TRICARE. The Women, Infants, and Children WIC program covers formula up to a certain age for financially eligible families. Some families have experienced tension about who should pay for some services – schools call them health care and TRICARE calls them educational. In some cases service may be delayed or denied. No parents reported difficulty with TRICARE paying for early intervention services. As with TRICARE, some services that are covered by Medicaid or a community program lack available providers at the rates paid. Community programs that provide some funds include county Developmental Disabilities Administration and private organizations (the ARC, United Cerebral Palsy, Easter Seals, Quantus Foundation, Muscular Dystrophy Association). When a child turns 18, he/she is eligible for Supplemental Social Security Income if he/she meets disability criteria. If the child will be dependent life-long, military members can apply for life-long TRICARE for that child. If a child dies, some expenses may be covered through the military (transportation of the body to a funeral home, burial in a government cemetery).

Services in communities include early intervention, schools, emergency care registries, limited visiting nurses, and community libraries for families with children with special health care needs, county social workers, 911 services, a care coordination center, and therapeutic horseback riding.

2. Care Coordination

2a. Needed care coordination

“During an already chaotic and stressful time, families are providing the large majority of the care coordination. It is exhausting and the process is exhausting.”

Children with life-threatening conditions need many health care and community resources, as do their families. Parents provide most of the care coordination to locate and utilize these resources, especially when services are not available on base. They need help coordinating information and records about their child’s medical history (especially when on leave and during moves; see theme 2c – transitions), help finding child care and respite care (especially when one parent is deployed and especially for children with special needs), help negotiating systems, and help finding needed resources in the military and civilian communities. They need help negotiating TRICARE, Medicaid, SSI, the Exceptional Family Member Program (EFMP) and state services. In TRICARE, referrals and faxes get lost in the system. There are few care coordinators and case managers apparently fewer since the change in TRICARE contractors—and many of these children have been dropped from case management. Parents spend hours and hours on the phone; they get tired, frustrated, and overwhelmed and don’t have the time, energy or knowledge of resources necessary to find everything their children need. They need help with denials, appeals and authorizations, and need help coordinating large numbers of follow-up appointments even keeping track of dates for prescription renewals and new

appointments. They don't know the system and they don't know the resources available until someone helps them.

Some care coordination is available and tremendously appreciated (see theme 2b—available care coordination), but much more is needed. More local care coordinators are needed and an MHS-wide network of care coordinators is needed to communicate across the MHS. Within a military treatment facility, families need coordination of several appointments in one day when care is complex and/or when they travel long distances to get care in a military treatment facility. Within TRICARE, they need someone to help them figure out TRICARE requirements, to keep track of the timing of needed re-authorizations, to negotiate requirements for services such as medical supplies and to communicate with TRICARE contractors who tell parents they will communicate only with physicians. Both parents and physicians need care coordinators who are knowledgeable about TRICARE and community resources.

Specific needs that are not well met include follow-up for complex patients with long-term needs, follow-up for consults that are not completed, facilitation of provider-to-provider communication, care coordination of community resources that go beyond medical care, assistance for physicians who don't have time to do all needed care coordination, and coordination for families whose children require care in civilian hospitals. Neither physicians nor families know how to navigate the TRICARE system, and families sometimes struggle with resolving bills or become frustrated trying to navigate the system independently. Case management for TRICARE-covered care is more available than coordination of care across community resources.

2b. Available care coordination

Madigan AMC health care providers spoke highly of the Referral Coordination Center, which finds resources to fulfill referrals for TRICARE-authorized medical appointments either at the military treatment facility or in the civilian medical community. There are, in addition, a few mental health case managers with TRIWEST, but there are many fewer nurse case managers than there were under the previous contract. A care coordinator in the Developmental Clinic at Madigan AMC helps families order durable medical equipment; navigate TRICARE, SSI and of Developmental Disabilities services; find respite care, therapies, and home nursing; coordinate end-of-life care; meet paperwork requirements; and arrange all needed care and services when families first arrive in the area. Physicians also provide care coordination, which requires a lot of time without generating Relative Value Units RVUs. There are also social workers in the Neonatal Intensive Care Unit (NICU) and inpatient units at the military treatment facility.

Care coordination is provided in the National Capital Area by pediatric nurse case managers at WRAMC who focus on equipment, home care, hospice care, moves from other locations and transition to other payers (each nurse case manager does about 1,400 case management interventions per year); clinical nurse specialists for hematology-oncology and for cystic fibrosis who coordinate equipment, home care, hospice care and

with schools; a nurse discharge planner for the NICU at NNM; case managers through HealthNet who focus on home care and equipment for medically complex children; family medicine physicians and pediatricians; and a nurse care coordinator in the pediatric clinic at Malcolm Grow AFMC. The referral management center at Malcolm Grow AFMC helps arrange appointments. TRICARE service centers help physicians and families figure out what TRICARE covers. Family support centers may help families find support and financial help in communities. Some limited care coordination may be available through Army Community Services (ACS). Exceptional Family Member Program (EFMP) offices in Europe provide some care coordination. Early intervention (birth to three) programs have service coordinators to help coordinate community resources. Available care coordinators help parents find care, make arrangements to get care and get care paid for. When parents describe available care coordinators and case managers, they always express appreciation and explain how they made it easier to get the care their children needed.

2c. Transitions

“On average for the special needs families when they relocate, it takes six to nine months before you get all your care providers, educators, and anyone that has to deal with that child, it takes six to nine months to get settled in.”

Transitions require additional care coordination in order to proceed smoothly. Care coordination is especially needed at the time of a transition from pediatric to adult care and services (during ages 18-21), from active duty service to retirement, from a military treatment facility to a Children’s Hospital or back again, from hospital care to home care or hospice care, when a family uses civilian health care with TRICARE (whether Prime or Standard), to coordinate care between military treatment facilities, at the time of a move between bases or a medical evacuation from overseas, at the time of a deployment or when TRICARE contractors or procedures change. Rules change, service delivery changes, new authorizations are needed and parents don’t know who to contact to find resources. Even if coordination, care and services were going smoothly, a move or other transition creates a huge need for care coordination.

3. Long-Term Care Needs of Survivors

3a. Needs and resources for cancer survivors

Cancer treatment can take several years. If a remission is achieved, there follows a period of watching for a relapse and wondering about options for further treatment if cancer recurs. If long-term remission is achieved, then questions arise about the late effects of chemotherapy or radiation. Parents feel a burden of responsibility to watch for relapse and late-effects and to help their children deal with long-term consequences of cancer therapy. A late-effects clinic has been established in the National Capital Area, but not all long-term survivors have been connected with it, and not all questions and issues have been addressed by this clinic or pediatricians. There remains a need to help parents

maintain vigilance and answer questions that arise for cancer survivors over time. Children and families also have some needs for support and emotional healing after an experience with cancer.

3b. Long-term follow-up

Many children with life-threatening conditions live for many years with incredibly complex needs for care and support. They need good primary care, but they need much more than that. They need an extensive array of subspecialty care, equipment, supplies, and support. They need medical care and coordination and follow-up that goes far beyond what is required for well-child care and resolution of acute illnesses. They need care not only directed toward cure or improvement, but also focused on achieving a good quality of life. They need every bit as much care, coordination and support as children who are at the end of their lives. The need for care can go on for a very long time.

3c. Continuity

When parents and children live with complex conditions that require sophisticated understanding and complicated care, it is especially hard to change physicians due to a move of the family or a move or unavailability of the physician. Once a physician understands the child's needs, it is hard to lose continuity of care with that physician. Parents worry about disruptions in communication and about physicians who may not have knowledge and experience with their child's health condition. They will sometimes go to great lengths to maintain the continuity they need—for example, one parent voluntarily remaining in one geographic location while the other moves with the military. Dealing with lack of continuity exacts an additional emotional toll from parents. Some parents have been in one location with the same physicians for a long time; some have physicians who have given them phone numbers and pager numbers that make it possible for them to experience more continuity of care. Parents always appreciate this and feel more confident about their children's care.

Physicians described two important aspects of continuity of care—seeing a care provider who understands the child's and family's needs over time, and having access to a physician via phone, cell phone or pager to ask questions about scary things that happen or care that needs attention. Health care providers acknowledged that continuity with a physician can be difficult to accomplish with limited appointments being available, but they are willing to help the family work around the system to accomplish continuity of care. The continuity clinics for residents can sometimes address this need, but often the residents are not available for continuity clinic when their patients come so there is some breakdown here. Sometimes relationships with pediatricians or family medicine physicians break down during long-term complex care as the subspecialists become the main source of continuity instead. If a child enters a formal hospice program, continuity may be disrupted again—although care providers from the hematology-oncology program do remain involved as a child approaches death. If a child gets better, they need to transition to a primary care physician for continuity. Continuity of care is sometimes

harder in the MHS, where both families and physicians move and deploy. Still, planning and attention to the importance of continuity can make these transitions a bit easier.

4. Descriptions of a Medical Home

Few health care providers were familiar with the concept of a medical home. One did provide a succinct and accurate definition: “It’s the idea for patients to have one facility or group of doctors or medical clinic that is their medical home and they are not tied to one person but there is a set that manages their shot records and their chronic health needs. The place where things are coordinated. That’s their base.” A family medicine resident described the concept in detail and called it “the core of family medicine.”

A medical home in general pediatrics or family medicine is generally not available in the MHS. The hematology-oncology clinic provides many aspects of a medical home for children in treatment there, with hematology-oncology physicians also serving as primary care managers. Some but not all pediatricians, family medicine physicians and other health care providers are familiar with the medical home concept, but care in the military treatment facility is not organized to provide a medical home. Some aspects of a medical home are available in some places – case management at WRAMC, family physicians who coordinate some care and individual general pediatricians or pediatric subspecialists who make themselves available for continuity and coordination of care. There are pediatric resident continuity clinics, but it has been hard to establish continuity of care in these clinics. There are also family medicine resident continuity clinics, but the family medicine residents do not follow medically complex children.

5. Roles and Administration

5a. Administrative issues

Administrative problems and conundrums have slowed down the health care system and over-burdened physicians to the point where there is less time for adequate patient care because of unnecessary, redundant and in-the-end ineffective administrative responsibilities. Physicians have few secretaries or support staff, and without ancillary support there is less time for physicians to meet with patients and engage in providing actual health care. A large amount of bureaucratic “red tape” limits physicians’ productivity and effectiveness, as they must deal with greater amount of paperwork for small approvals, such as orthotics, physical therapy, speech therapy and home health care equipment. The time required to fill out the paperwork, fax letters, handle missing paperwork or jammed fax machines, and then re-write letters for specific terminology or

to appeal a denial challenges physicians' efficiency and results in a great deal of wasted time and fewer contact hours with patients.

Military treatment facilities are understaffed and under-resourced. Families have trouble scheduling appointments and are sometimes sent to the emergency room for non-emergency situations. The EFMP representatives are also overloaded; more staff would be needed to enable these staff to help families find information and support. It sometimes seems to families that physicians are doing tasks that could be done by staff in other positions, were staff available to fill these other roles. Inadequate maintenance of hospitals and clinics was also mentioned by parents as a concern. Lack of information about military regulations, policies and administrative procedures sometimes complicates care as well. For example, lack of clarity about procedures following the death of a child created additional heartache for one family.

5b. Family medicine excluded

Some family medicine physicians and residents are excluded from caring for children with life-threatening conditions, despite a willingness to coordinate these children's care and remain their primary care manager. While they cannot provide subspecialty care, they could fill an important role in providing support to families and coordinating medical care and communication among a child's physicians.

5c. Need coordination between military treatment facilities in the National Capital Area

While most services are available between the different military treatment facilities in the National Capital Area, it is difficult to coordinate and communicate between facilities when different specialties are at different sites.

5d. Definitions and eligibility for services: vocabulary

Some health care providers identified a fine distinction in the vocabulary of a life-threatening condition versus a life-threatening condition. For a general definition, health care providers described life-threatening conditions as a more immediate, intense threat on the child's life where death could be expected within the next year, and described life-threatening conditions as a condition putting the child at risk for a long time period, with no specific time-line for death. This distinction may help physicians advocate for additional support for families when a child's life is imminently threatened by illness.

5e. Issues with TRICARE rules, interpretations of benefit, and TRICARE Management Activity oversight

Apparent inconsistencies in interpretation of the TRICARE benefit lead to confusion and frustration for both parents and health care providers. For example, some parents have

been told they cannot leave their houses when a nurse is providing respite care; others have been told they must sleep while the nurse is there; others have been able to leave their child in the care of the nurse and accomplish errands or health care appointments. Rules also change with little communication, creating not only confusion but also denials and delays in services. Some military treatment facility health care providers see a role for TRICARE Management Activity (TMA) in overseeing consistency of benefit interpretation across TRICARE contractors.

THEME GROUP 2: RELATIONSHIPS

6. Advocacy

Parents who participated in this study persist until they get the care their children needs. They often have to fight to get what their children need in the health care system and in schools, and sometimes have to fight to get health care bills paid. They take them to doctors and emergency rooms until they find out what they need; they pursue medical care at military treatment facilities, civilian providers and in community organizations; and they find the physicians and care coordinators who will help them find and get what they need. Parents express gratitude for the health care providers who advocate for their children. Some parents also think about and try to influence care for children and families in general. These parents also go to great lengths and personal sacrifice to care for their children, meet their physical needs and improve their children's quality of life as much as possible.

Many health care providers in the National Capital Area are equally determined, faithful advocates for individual children and families, finding and connecting families with needed services, contacting TRICARE or case managers directly, making phone calls and completing paperwork. They also recognize the important role that parents fill as advocates for their children, and they encourage and support them in this role.

7. Relationships and Communication with Health Care Providers

7a. Health care provider/family communication

Comments about communication between health care providers and families came from different types of health care providers: a hospice nurse, a neonatologist, a pediatric hematologist/oncologist, a pediatric cardiologist, a NICU discharge planner, a family physician, a pediatric intensivist. They discussed many special circumstances in which sensitive, relationship-based communication is important to families. Families need different communication during different phases of care (diagnosis, treatment, end-of-life). A child's mother and father may each need different communication. A family may be overwhelmed by a lot of information from many providers and need someone to help them sort it out. Conversations about end-of-life care and what dying is like should occur between parents and a physician with whom they have a relationship, before they get to

the Pediatric Intensive Care Unit (PICU). In hospice care, families build close relationships for communication with those who visit their homes, but still want to hear from the physicians who cared for their children earlier, just to know they care. Children with long-term conditions like cystic fibrosis and their families need supportive communication to build motivation to take care of themselves when well. Overseas, communication may be hampered if a child is born or diagnosed in a host nation hospital and the physicians either do not speak English or do not talk to parents; a translator may be needed. Parents of children with special health care needs want relationships with pediatricians, and many pediatricians go out of their way to build these relationships and be accessible to families. Family physicians can also build these relationships with families and can sometimes convey families' needs to other team members. Respect for families and their differing needs is paramount.

Parents expressed some angst about communication with physicians. They find themselves explaining their child's conditions to physicians who do not know about unusual health conditions or their children's individual problems - sometimes with the burden of knowing that their child's life may depend on their communication of urgency and accurate information. They have learned to speak up loudly on behalf of their children. They educate new physicians about their child's history, and sometimes grow weary of the emotional energy required to tell painful stories again and again. They have a deep need to have doctors listen to them and believe them. The time of diagnosis creates special communication challenges; several parents received confusing, contradictory and upsetting information in insensitive ways. Many parents expressed the need to build trust and good communication with physicians and a deep appreciation for the physicians with whom this had occurred. Once parents establish a relationship of trust with a physician they can contact with a need, it makes all the difference for them.

7b. Health care team communication

Families need to know that the health care team members are communicating among themselves about test results and treatment plans and that someone is communicating about these plans with the families. Health care team communication works well within a small team (like the hematology-oncology team or the cystic fibrosis team), and quite well between providers in the same military treatment facility. If available to a family, a primary care physician can coordinate this communication. Challenges to health care team communication arise when the team includes providers both in the military treatment facility and in the community. Most often, physicians at the military treatment facility do not receive information about test results or subspecialty consults for referrals to the civilian community. Often, the parent becomes the one who conveys information to a physician at the military treatment facility about test results, needed labs and subspecialists' information, without anything in writing. Case managers, social workers and referring physicians help facilitate team communication, even between the military and civilian communities.

7c. Cultural issues

Parents discussed several aspects of culture that can affect communication between families and health care providers. One is the language spoken - do the health care provider and family speak the same language well, and if not are there some resources for helping them communicate well? Several families had experienced physicians with whom they could not communicate easily because of language differences. A second area comprises the culture of an individual family's belief systems, values, religion, and priorities as they affect care for the child and communication with providers. Third, the military culture has an effect on communication, particularly when attitudes about rank and authority exert an influence. Finally, there is a culture of parents who have children with serious health care needs. These parents often become strong advocates for their children, and their advocacy is not always understood or interpreted by health care providers as a strength.

8. Decision Making

Parents find it very hard to make decisions for their child, and often have to do so in the face of great uncertainty about outcome, big risks, and huge implications for quality of life. They want to be included in decisions, but need the information necessary to make good decisions and don't want to feel like they are all alone in making the decisions. Sometimes they have to make decisions between options that all have a likelihood of negative outcome.

THEME GROUP 3: FAMILY NEEDS

9. Social and Emotional Needs

9a. Families' emotions and need for support

Physicians, care coordinators and social workers recognized the emotional needs of families in some detail. They described parents' stress, grief, isolation, and difficulty coping. They noted needs for one-to-one counseling, support groups, respite care, help with appeals, and help funding community resources. They noticed needs for concrete support in the hospital – meals for breastfeeding mothers, a comfortable place to sleep, support for staying with a sick child. They described respite care as an opportunity for parents to spend time with their healthy children or attend medical appointments for themselves and other children. They also realized parents' need for someone to listen to their stories – someone to listen without counseling, just listen and try to understand.

Parents of children with life-threatening conditions in an actively-deploying military community described social and emotional needs in three broad categories: dealing with the intense emotions evoked by their children's suffering, coping with continuous and

strenuous care demands, and living in settings with limited informal social support. They feel scared, worried, sad, anxious, weary, angry, isolated, discouraged, frustrated, upset, confused, and stressed. They sometimes have trouble communicating as spouses and experience stress on their marriages. They are often mentally and emotionally exhausted. Their children's care demands are often exhausting also, requiring 24-hour daily care, heavy lifting, complex and repeated care procedures, and long-term care. They need help with care, time for their other children, time with their spouses, time to sleep, and a break from continuous care-giving. The military situation sometimes makes it hard to find informal social support. Families move near a major military medical center to get health care for their children, but this often leaves them far from family and friends. Deployments mean separations from spouses and no break at all for the parent or grandparent who cares for the child. Concrete social supports like temporary housing, accessible base housing, help with a child's care, respite care, child care for healthy children during hospitalizations of the sick child and transportation to health care when their cars have been left overseas make a big difference when available, but are not always available.

9b. Children's needs for emotional support

"We ought to have a vibrant Child Life program that interacts integrated with social work and case management and psychologists."

Parents worry about their children's social needs (a wig when they don't have hair, participation in social activities), coping with procedures and medicines, pain and fears. They see the psychological stress of being different or losing abilities and worry about how to talk about death and how to support living children after a child dies as they grieve and need support. They worry about long-term anxiety in their children and how to ameliorate it. They wonder how to provide as much of a normal life as possible, and often struggle to do so. They do not want their sick children to be alone in the hospital, and wish the hospital had a more comfortable and interesting environment for them. Many parents have seen Child Life and social workers at Children's Hospitals and wish for these services at the military treatment facility. They see the needs of their healthy children for time with their parents, care while a brother or sister is in the hospital and the opportunity to participate in childhood activities. They also see a need for support groups or other ways to help siblings cope with their brother or sister's special needs. They worry about their children witnessing or experiencing too much suffering. They see strength in their children and are proud of them for helping one another, but they still worry that their needs are compromised by the demands on a family of a condition that requires constant care and creates continual uncertainty and stress. They see their children's reactions to the lack of understanding from healthy children and adults around them.

9c. Health care providers need support

Some health care providers mentioned their own reactions to caring for children with life-threatening conditions and their families. Some wished for more time to build relationships with these patients. A few health care providers mentioned that it is hard for them to think about people dying, and they mentioned meeting among themselves to talk about it. One mentioned an educational program about pediatric palliative care that was educational and provided some support for her. Some health care providers go to memorial services for children who die, and one mentioned a chaplain who had been available for the staff when they were caring for an especially complicated baby and his parents. Parents notice and comment upon the emotional responses of physicians and nurses to their children, especially when their children die. They appreciate their compassion and how they have emotional support as caregivers. They see and appreciate the sacrifices these health care providers make in spending time with and caring for their children.

9d. Available support, counseling, and other mental health resources

Health care providers know of some limited one-on-one counseling for adults or children and parents. They know about Military OneSource, but think a website is inadequate. They are very aware that parents need a break, during deployments but also just because of the demands of caring for sick children. A care coordinator knows of community resources and funding for respite care and helps parents find these resources.

Parents described EFMP support group meetings and social activities, respite care through ECHO, Medicaid and the state Division of Developmental Disabilities, Muscular Dystrophy association support groups, accessible base housing and equipment that made a house functional for a child with disabilities. They described siblings who helped and loved each other and family who lived in the area, flew in or moved to the area. They often had spouses who helped with care and support when they were not deployed, neighbors who helped care for children and friends who helped healthy siblings participate in activities. Formal and informal support was available from support groups for children with special needs, Special Olympics, talking with other parents, social workers and Child Life workers at Children's Hospital and Madigan AMC, the county Zero-to-Three program and a social worker in the NICU. They also experienced support from health care providers at the hematology-oncology clinic and developmental clinic, counseling and marriage counseling through the Life Skills Center, the family support center and Air Force Aid Society. Some have obtained help in receiving TDY pay and getting belongings shipped from overseas. Other sources of support included the Footprints support group for parents of children with cancer, the Fisher House, friends from church and workshops for siblings. They found ways to support one another within their families, such as taking walks together, finding a way to take a family vacation, reading books about special needs, watching movies at home and enrolling healthy children in activities they enjoy. Some commanders made it possible for an active duty parent to take time off or return from the field to participate in critical care. The active duty parent found some support and a break from child care by going to work; sometimes the caretaking parent found a way to work part-time or go to school, thus also relieving

the constant stress of caregiving. Parents also found joy in their children and strength in themselves, their families, and their network of friends as they met the challenges they faced with their children's needs.

The pediatric hematology-oncology service provides a great deal of support for children with cancer and their families through a clinical nurse specialist, case managers, physicians, and a parent support group. This service sometimes goes to families' homes and children's schools to provide support; they routinely spend a great deal of time with a family when a child is dying. Many health care providers are personally supportive in their interactions with children and families and aware of the importance of sensitivity. Some find themselves in the role of informal counselor for families. Health care providers in general know of some child psychology and psychiatry services, chaplains, some pediatric social work and case management. The NICU also provides a social worker, a discharge planner and a support group with educational resources for parents, as well as extra support if a baby is going to die. They follow-up with parents of babies who have died. The NICU also knows of some military and community support resources (New Parent Support program, Navy/Marine Corps Relief), but sees them as "diminishing rapidly." The NICU knows that 8 counseling sessions are available to parents through the TRICARE network but they do not know of parents who have used this benefit, although they have made referrals. The Cystic Fibrosis clinic has a full-time nurse who provides follow-up, support and information for both children and parents. She knows of websites for children and links them by email, which is a better source of support for children with cystic fibrosis because in-person support groups expose them to infections. Parents of children with cystic fibrosis are also linked by email. Hospice services are available, and they provide support and some respite for families. Family medicine physicians know of behavioral health services available through Family Medicine clinics and Life Skills clinics in the Air Force. Short-term behavioral health services are available to help families figure out if they need more extensive care through the TRICARE network. Case managers point parents to support groups. There is limited Child Life in the hospital. Some health care providers know about the ECHO program through TRICARE; they are also familiar with family support centers, Army Community Services, family advocacy and social work, and some are aware of Military OneSource. There is a clinical nurse specialist through the EFMP program. In general, more support is available through special clinics/services (hematology-oncology service, Cystic Fibrosis clinic, NICU). There are general behavioral health services but they are not especially equipped for families with children with life-threatening conditions or children who die. An individual physician, nurse, social worker, or case manager can make a big difference for a particular family.

Families experienced a wide variety of informal social and emotional support, from family, friends, colleagues at work, neighbors and churches. Community and non-profit organizations provided respite care programs, funds for respite care, parent support groups, sibling support groups, education, and advice. Parents devised their own coping strategies – making scrapbooks, stopping at Starbucks, eating take-out food, buying another car when theirs was overseas. Doctors, nurses and social workers provided

important emotional support in the context of providing care – listening, understanding, writing referrals, writing prescriptions for medications labeled properly for camp, holding a baby, and even crying with parents during especially difficult times. “Experienced parents” of children with special needs helped each other. Doctors, nurses, and social workers shared books and websites. Several families commented about support that was available because they were able to live in one location for a long time or return to an area where they had lived before. Formal support was occasionally available also – a social worker in a hospital, a counselor, medication to help parents cope or sleep, a Medicaid waiver program to pay for home nursing, emergency leave, compassionate re-assignments, pastors and chaplains. Flexibility in response to extenuating circumstances helped, too – a supportive commander, last-minute appointments, someone watching a child in the hallway so a parent could go to the bathroom or stay with a sick child for a procedure or welcoming young siblings in the hospital.

9e. Barriers to support and mental health resources

“They said, ‘You are on compassionate reassignment, you’re supposed to have your family help you.’ I said, ‘My family is in Nebraska.’ ‘Okay,’ they said, ‘friends or neighbors.’ I said, ‘I don’t know anyone. I just moved here.’ They said, ‘Don’t you have a neighbor?’ I said, ‘She works.’ I asked my case manager ‘So what are you doing tonight?’ She said ‘Oh, I have such and such to do.’ I go, ‘So you probably couldn’t come over and watch my son while I go to the store.’ She said, ‘Well, that’s not fair, I have obligations.’ I said, ‘So do other people.’”

“Well, we were supposed to have a compassionate reassignment after my husband lived in Germany for three and a half years and the compassionate reassignment was supposed to be to the West Coast. They sent us to Virginia. I just looked at this one guy and he said, ‘What made you think you were going to get the West Coast?’ I said, ‘It’s a compassionate reassignment. Everyone we know in the world is on the West Coast, but you are sending us to the furthest east that you can.’ And it didn’t make a bit of difference. No difference whatsoever.”

Many parents of children with life-threatening conditions do not have the energy to attend support groups or figure out how to negotiate the system of services. Health care providers do not always have enough time to listen or training to listen effectively or counsel informally. Referrals needed for formal counseling can be a barrier – resources in a primary care setting would be easier to access. Formal counseling and social work resources in the military treatment facilities are very limited – even more limited for children than adults. Some counseling is available through TRICARE, but low reimbursement rates make it hard to find providers. In addition, few available counselors have experience with issues regarding very sick children or children who die. Families also need care coordination to access counseling, respite care and the various community resources that could provide support. There is some care coordination but not enough. Finally, parents have been told not to leave the home when respite care is provided through the ECHO program limiting its effectiveness.

Barriers to respite care from parents' perspectives include difficulty qualifying, difficulty finding providers if you do qualify and requirements for parents to stay with nurses who provide respite under ECHO. Distance from family and friends is another barrier. Many families were compassionately reassigned to a major military treatment facility to get medical care, but their families are on the opposite coast or overseas, and they left a familiar base to go to a place where they do not know neighbors or have a network of friends. Parents also have a hard time finding informal support because no one wants to talk about hurtful, sorrowful stories, and sometimes because their children have rare diseases and they cannot find other parents with similar experiences. Formal support services are hard to access because counselors are not effective for their needs, they worry about implications for their careers if they seek mental health support, and there are no pediatric social workers or child life workers available to them at the military treatment facility.

Other barriers to meeting families' emotional and social needs in the National Capital Area include the following: limited staff in psychology, psychiatry (especially pediatric), behavioral health, social work and nursing; limited case management or care coordination; lack of providers knowledgeable about palliative care or dying children and the related needs of families; physicians and nurses not knowing about available community resources; limited funding for military community resources; and limited knowledge about how to access the system. Services are available but inadequate in scope and amount. Recently, services have focused primarily on active duty service members and service members wounded in Iraq and Afghanistan, with less available for children and their families.

10. Financial Toll

When children need care not covered by the military treatment facility, care can quickly become expensive. In addition to co-pays and cost-shares, families need to pay travel costs, sometimes driving long distances to get their child's care, and must pay for specialized child care and child care for other children during hospitalizations - especially if one parent is in Iraq. Families struggle with SSI and Medicaid income requirements, sometimes qualifying as E-4 or E-5 but losing benefits when the military service member is promoted. Diapers and formula, for example, are covered by Medicaid but not TRICARE and their costs can become a financial burden. Families sometimes also get thousands of dollars in bills inappropriately and spend a great deal of time and energy fighting them. Overall, though, most families are very grateful for access to military health care, and many remain in the military because they could not get health insurance for their child otherwise.

Items typically not covered by TRICARE or not adequately covered include special formulas, diapers, home nursing, respite care, some equipment, home ramps and other modifications, special clothing, special toys and expenses of moving to get care. Families

also need to pay for child care for other children during treatment, funerals and other expenses. Even when care is covered by TRICARE, they may have prescription co-pays or co-pays and cost-shares for civilian health care. Medicaid helps but few families qualify, or they qualify only for a short time. Army Community Services and Relief Societies may offer a small grant or loan and supplemental insurance, which helps parents if they have it, helps too. Still, the financial toll can be substantial.

11. Search for Meaning/Spiritual Care

Both children and parents need spiritual care and a chance to talk about spiritual issues and questions about the meaning of what is happening to them. Sometimes they want to talk with a nurse or other health care provider about these things. A chaplain service is available at most military treatment facilities and can arrange for religious rites such as baptism. However, some chaplain services tend to offer more religious practice than support or counsel about the spiritual questions and need for care that arise when a child is very sick, and many families rely on their own pastors or religious leaders rather than hospital chaplains.

Parents of children with serious illnesses seek meaning for their children's lives and their own lives. They may try to understand how God fits into the things that have happened to them and their children. Many turn to God or a religious community or leader for support, religious rituals and an understanding of what their lives mean. Sometimes they yearn for something of themselves or their lives from the time before they had a sick child. They may see having to fight for the care and services their child needs as an injustice - the care should be available to them without a fight. Many parents move through this search and emerge with a desire to help someone else who has a child with serious health issues, to make life better for other children and families. These parents love their children and see all the special, wonderful things about them. They are grateful for the time they have with them and the things they learn from them.

THEME GROUP 4: PALLIATIVE CARE

12. Palliative Care

Parents focus on quality of life for their children. This may mean being with people who love them, finding a way for the child to communicate or walk, or supporting children's participating in typical activities such as school. Quality of life may mean listening to voices, laughing and being at home. Helping a child be comfortable and controlling symptoms is very important. Palliative care may also mean making decisions together, honoring a child and family's wishes or taking care with a child's appearance.

Health care providers' understanding of palliative care varied widely in the National Capital Area. Some see it as pain management while a child is dying, some as care that enables a child to live but with limitations rather than a full cure, some as interventions to

increase comfort and quality of life while living, some as all of these. Several health care providers described a sharp line between curative care and palliative care, such that palliative care is only provided when all hope for cure or recovery has past. Others saw palliative care integrated with curative care - trying to help a child live but also trying to make them comfortable and enable them to enjoy life.

13. End-of-Life Care

Health care providers' experience with end-of-life care varies widely, from none or nearly none to a great deal. Those with more experience emphasize the importance of beginning conversations with families about end-of-life care early, long before the last crisis, preferably in the context of a well-established relationship with a pediatrician. Families' choices vary; their preparation and a chance to talk about the choices is very important. Some families want their child to remain the hospital to die. When this is a family's choice, Military treatment facilities have the flexibility to create a supportive environment. Others want their child to be at home to die. In this instance, a transition to hospice care is usually possible. Military treatment facility physicians and nurses sometimes stay involved in a child's care and a family's support after the involvement of hospice services; some communication with physicians and nurses who have been involved with a child's care is very important to families. Hospice nurses are very attuned to pain management and handle this well, and some pediatric hospice workers are available.

Parents and children need information about what death will look like and an opportunity to talk about it before the last crisis. Parents don't want their children to be alone. Parents and close family often want to be in the hospital together if a child dies there, and they may need a comfortable sleep chair in the last days. Parents need information and communication and an opportunity to make decisions together. Parents need some support after a child dies, and wish a physician would call afterwards to see how they are doing. They also need help with logistical details - a "death checklist" with information about what forms to fill out and what details need to be handled. The hospital can provide a supportive environment for a child and family at the time of death, and parents appreciate this immensely when it happens.

THEME GROUP 5: EDUCATION

14. Education for Health care Providers and Families

14a. Parents' education needs

Parents described a need for a clear understanding of their child's diagnosis, the treatment plan, associated symptoms, and possible outcomes. A need was clearly identified for education in how the child's diagnosis would impact their development and future abilities. Parents also need practical education in how to care for their child in the

home and handle necessary medications and equipment. Beyond their child's specific medical needs, parents identified a need for education about available resources for their diagnosed child and also for the child's siblings. There is a need for parent education in how to advocate for themselves and their children, and education in the appropriate points of contacts and how to reach them. The need for education about the MHS and the military health benefit, as well as local procedures and practical information about the hospital, was also identified. Education on the death process was a clear need, especially among parents who had lost children, and parents saw a need for education in what dying looks like, what the health care providers will do at the end-of-life, and what happens after death.

Health care providers also identified a need for parent education about end-of-life care and hospice, and saw a need for parents to understand the death process and feel prepared for the possibility or reality of a child's death.

14b. Health care providers' education needs

While the MHS provides excellent medical care to children with life-threatening conditions, there are a number of educational needs for health care providers caring for these children. Physicians and care coordinators need education and frequent updates on the policies, regulations, and programs both within the hospital administration and within TRICARE, possibly from a central, accessible information center, and should specifically receive education about military-specific programs for children with special health care needs, such as EFMP and ECHO. In order to feel comfortable and provide appropriate care, health care providers need exposure to caring for these children's ongoing or chronic health care needs, even if the provider will only see these children in an occasional emergency situation. Individual providers may further need targeted education on how to address a pediatric patient's specific medical need when the provider has limited experience in that area, such as a rare condition or a specific piece of equipment. All physicians, nurses, and care coordinators who provide care to these children need education about pediatric palliative care and pain management. End-of-life care is also a specific area in which health care providers need education, both in how to provide end-of-life care to pediatric patients and also how to guide parents of dying children through the death process and beyond with necessary paperwork and appropriate psychosocial support. Beyond caring for these children's specific medical needs, health care providers need education in how to advocate for children and families and must be knowledgeable about available support services and resources for families. They also need training in counseling and communication skills, cultural sensitivity, and handling both their own and the families' emotional reactions.

14c. Resources for education

Parents at Madigan AMC identified two specific educational resources. A booklet outlining the diagnosis, treatment plan, possible reactions, and contact information was given to parents at Children's Hospital for them to take home, allowing parents to clearly understand each step of their child's medical care. Another resource was found in classes paid for by TRICARE for parents to learn how to give medications at home and take care of their child's basic health care needs without bringing them in to the clinic.

Parents in the National Capital Area identified several specific resources that have been helpful to them in caring for their children with special health care needs. The National Institutes of Health was mentioned for its exemplary care coordination and the support given to parents, and other institutions could benefit from contacting the National Institutes of Health to see how they handle this particular area of care. Compassionate Friends was another specific resource identified for its bereavement care, and could be a resource for institutions looking to provide better care for grieving families. Parents also found it helpful to receive information about the military health benefit and the MHS, such as the TRICARE benefits manual or the ECHO program, in a simple brochure format that they could take home with them and refer to in the future.

A number of existing sources of information and practical knowledge about pediatric palliative care were mentioned by health care providers in the National Capital Area. Existing mechanisms for health care provider education in the MHS include TRI Service required Continuing Education through computer modules, home visits and required residency education. Palliative care curricula and pain management education already exist within the medical education field, and these resources can be accessed and adapted for use at specific institutions. Home visits are another valuable resource for information and knowledge, allowing a health care provider the opportunity to learn about chronic, complex care in a different, often more intimate environment than in-clinic appointments. Finally, the internet is a helpful resource with a wealth of information not only for health care providers but for parents raising a child with special health care needs as well.

THEME GROUP 6: MILITARY

15. Military Issues

For most families, unique military administrative issues are a major determinant in the experience of air evacuation or transfer to a higher level of medical care. For most, the experience of moving and settling into a new location, beyond being traumatic because of the child's condition, is also confusing, lengthy, costly, and disrupts their ability to attend to their child. Administrative issues such as the type of orders, the type of leave, whether the sponsor is reassigned to a valid military role, availability of appropriate housing and unexpected changes in pay (often to the detriment of the service member) make a bad situation even more difficult to negotiate. Disruption of the support system they had previously established contributes to their sense of powerlessness. The situation is worse for families coming from overseas to stateside Military treatment facilities, leaving

behind their car, their housing uncleared, and having to establish temporary living arrangements near the military treatment facility without a car, without the location housing allowance, without furniture, without friends and with an overwhelming need to understand their child's medical condition, learn to trust their child's new doctors and keep their family together.

The support or antipathy of command strongly influences the transition experiences of the families as does finding or not finding someone with knowledge and ability to apply suitable regulations. Most families did not find EFMP efficient or effective, leaving the family to coordinate many issues which could have been addressed by others on the installation.

Stress of frequent and lengthy deployments, both of the active duty member and the primary care physician for the child, adds another difficulty for families wherein the uncertainty associated with their child's medical condition is exacerbated by the absence of trusted advisors and helpmates. Yet, many families emphasize their commitment to the military community and culture, and to the service of their country. They wish that their commitment and willingness to sacrifice was matched by a commitment on the part of the command to make their difficult transitions easier.

FINDINGS:

Analysis of CHAMPUS/TRICARE Coverage of Medically Necessary Services for Children with Life-Threatening Conditions

The CHAMPUS/TRICARE benefit provided to beneficiaries in the MHS (MHS) was analyzed for the availability and accessibility of services pertaining to care for children with life-threatening conditions (LTC) that are found in a comprehensive pediatric palliative care and hospice program. The actual health care benefits likely to be used by a military family and child with a life-threatening illness were analyzed with specific citation, description, definitions and comments. (See Appendix 8: Military Health System Analysis Report - Care for Children with Life-Threatening Conditions, for the complete report on analysis of the benefit). Medical services needed to serve children with life-threatening conditions and their families may include: medical care, occupational, physical, and speech therapy, respite care, home health care, custodial care, homemaker services, skilled nursing facility care, prescription drugs, dental care, counseling services including pre-bereavement and bereavement care, care coordination/case management, hospice program, expressive therapies (music, art, play), durable equipment, durable medical equipment, structural alterations to dwelling, and transportation by other than an ambulance. Most of these services are provided to all TRICARE beneficiaries under the Basic Program or to family members of active duty service members under the Extended Care Health Option (ECHO) Program. Some of these services are not available under CHAMPUS/TRICARE to any beneficiary. (See Appendix 9: Benefits Available in TRICARE/CHAMPUS for Children with Life-threatening Illnesses and Their Families.)

CHAMPUS/TRICARE authorizes extended home health care only to children who meet a high threshold of disability and who are dependents of active duty service members.⁴¹ The patient's condition must qualify under one of the following eligibility criteria: mental retardation, serious physical disability, extraordinary physical or psychological condition, an infant/toddler with serious disability, or multiple disabilities. ECHO includes Extended Home Health Care (EHHC) that provides benefits to patients who (i) meet ECHO definitions and (ii) who are homebound and (iii) require medically necessary skills services that exceed the Basic Program home health care benefit, or (iv) require frequent interventions such that respite care is necessary. Pre-authorized ECHO/EHHC services are paid for by the government up to \$2,500 per month. There is a monthly co-pay based on the rank of the sponsor. Family members receiving services under ECHO cannot receive those same services under the Basic Program, but can receive other services under the Basic Program such as prescription drugs, acute care visits, and medically necessary hospital care. (See Appendix 10 for the Table 12 on Summary of Benefits.)

There is currently no unique TRICARE-defined hospice benefit; rather, the Basic Program authorizes hospice care in a Medicare-approved hospice and only when the patient meets Medicare/Medicaid criteria: life expectancy of less than six months and the requirement to forgo disease-directed care. Most available Medicare-approved hospices care for adults, and skilled care for children may not be available. The services, however, are interdisciplinary, delivered

41 Title 32, CHAMPUS, Part 199.5 - TRICARE Extended Care Health Option

under a plan of care, include intermittent skilled nursing as well as health aide and homemaker services, and provide counseling to beneficiary and family members prior to the death. Bereavement counseling is *explicitly excluded* as a benefit under CHAMPUS/TRICARE unless the beneficiary meets a definition of mental illness⁴².

There are significant gaps in services available to children with LTC and their families when the Institute of Medicine (IOM) recommendations for pediatric palliative care and hospice services are addressed. Specifically, the IOM recommended that “Public and private insurers should restructure hospice benefits for children to ... eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care (possibly in a case management framework.)”⁴³ The IOM report also calls on policy to “reimburse bereavement services for parents and surviving siblings of children who die.”⁴⁴ These benefits are unavailable through the CHAMPUS/TRICARE benefit structure. The IOM also recommends specific clinical care practices. Many of these aspects of clinical care could be delivered (and in some cases are being delivered) to children with LTC if staff are available with the time, training, and experience in the MHS direct care system. (See Appendix 11: MHS Benefits and Services vs Institute of Medicine Recommendations).

The Children’s Hospice International has developed a model Program for All Inclusive Care for Children and Their Families (CHI-PACC) in coordination with the Centers for Medicare and Medicaid Services. (See Appendix 12 “Services/Resources Proposed in Developing CHI PACC® Models” Chart.) The CHI-PACC Implementation Manual⁴⁵ provides a list of core domains for clinical care. The clinical care called for is only available in the MHS where adequately trained and experienced staff is available and have time to provide it, either through the direct care system or through purchased care. If using purchased care, the following care and service listed in the CHI-PACC core domains cannot be reimbursed: care coordination, respite care, flexible home health care, and bereavement counseling. Furthermore, bereavement counseling, an important component of clinical care, is explicitly excluded as a benefit under TRICARE/CHAMPUS. Appendix 13 discusses the availability of this clinical care through the MHS.

The National Consensus Project represents a consortium of five leading national organizations (American Academy of Hospice and Palliative Care, Center to Advance Palliative Care, Hospice and Palliative Care Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization). The project has compiled a list of preferred practices for palliative and hospice services that are based on evidence of effectiveness, unique to palliative/hospice care, and endorsed by these professional organizations.⁴⁶ For these reasons,

42 Title 32, CHAMPUS, Part 199.4.- Basic Program

43 Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, pp 290

44 Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, pp 291

45 Zarbock S, *Childrens’ Hospice International Program for All-Inclusive Care for Children and Their Families: CHI-PACC Implementation Manual*, 2003.

46 www.nationalconsensusproject.org/guideline.pdf. Last accessed January 5, 2006.

these preferred practices are used as one standard against which to measure the benefits and services available through CHAMPUS/ TRICARE for children with LTC. Appendix 14 lists the preferred practices versus the benefits and services available to children in the MHS.

In summary, the key services necessary for the provision of a comprehensive program of pediatric palliative care, that are not available through the current CHAMPUS/TRICARE benefit are care coordination, respite care, flexible home health care, and bereavement counseling, and the ability to provide supportive care to enhance quality-of-life concurrently with life-sustaining treatment.

FINDINGS:

Eligibility Criteria and Estimate of the Population

Eligibility Criteria

Methods are available for estimating the numbers of children with “special health care needs” in a population. See Appendices 15, 16, and 17. However, methods to estimate the actual numbers of children with life-threatening conditions (LTC), which is a subset of the children with special health care needs, are not readily applicable to the military population, and they depend upon the definition of LTC and the purpose for which the estimate is being done. As a first step in estimating the numbers of these children in the military population, several methods of defining cases of children with life-threatening conditions (LTC) were examined:

1. *Based on pre-determined ICD-9 codes.* The ICD-9 codes proposed by Kentucky for eligibility criteria for a Medicaid waiver for a pediatric palliative care program (See Appendix 17, pages 5-6.) were reviewed and the frequency of specific ICD-9 codes appearing in records of children who were seriously ill and enrolled in a case management program in the MHS were tabulated. Redundant coding for the same patient and omissions in coding made this method of defining children unreliable for data retrieval for the purpose of program design or planning.
2. *Based on cost data.* States preparing an application for a CHI PACC[®] Medicaid waiver calculated costs retrospectively for hospice and related services paid for children through Medicaid and then constructed a way of identifying children that they could serve through flexibility of the benefit, while maintaining cost neutrality. In the DoD, the difficulty of accounting for direct care costs makes this method unreliable. Further, conceptually, cost does not always correlate with the presence of an LTC, at least in the years prior to the year of death.
3. *Based on characteristics of the condition.* The descriptive definition of “Conditions Appropriate for Pediatric Palliative Care,” proposed by ACT 47 in 1997 and endorsed by Himmelstein, Hilden and Boldt⁴⁸ in 2004 is widely used by pediatric hospice policy makers. This is the definition of eligibility chosen for this study for medically necessary pediatric hospice services in the MHS. The Himmelstein definitions of conditions requiring pediatric hospice care describe a different death trajectory for each condition. In *When Children Die*⁴⁹ the Institute of Medicine describes different patterns of death in children, ranging from death

47 ACT/RCPC. *A Guide to the Development of Children’s Palliative Care Services: Report of the Joint Working Party.* ACT/RCPC; London, 1997.

48 Himmelstein B, Hilden J, Boldt A, et al. Medical progress: pediatric palliative care. *N Eng J Med* 2004; 350:1752-62.

49 Institute of Medicine, *When Children Die: Improving Palliative and End-of-life Care for Children and Their Families.* The National Academies Press, Washington, DC. 2003, pp 41-71.

moments after birth or trauma, to death months and years after a diagnosis of a LTC with the utilization of health care services varying from intermittent to continual. A case definition based on characteristics of conditions, therefore, has implications for program design, service delivery, and costs, making this a reasonable definition to use for retrieval of data on numbers of children and costs. ICD-9 codes were selected for each condition that would account for the majority of children with that condition and would be a reasonable search string in the DoD medical databases.

The following table (Table 1), based on the work of ACT and Himmelstein, displays the case definition and the ICD-9 codes used for the searches:

Table 1
Life-Threatening Conditions in Children

Designation for data retrieval purposes	Description of condition	Examples chosen for this study	ICD-9 codes used to search databases
<i>“incurable”</i>	Progressive conditions in which treatment is exclusively palliative from diagnosis.	Spinal muscular atrophy, trisomy 13 or 18, severe infantile asphyxia	335.0, 335.10, 335.11, 758.1, 758.2, 758.3, 768.0, 768.1, 768.2, 768.5
<i>“manageable”</i>	Conditions requiring long periods of intensive treatment aimed at prolonging life and improving quality of life.	Cystic fibrosis, muscular dystrophy	277.00, 277.01, 359.1
<i>“curable”</i>	Conditions for which curative treatment is possible but may fail.	Any childhood malignancy	191.x, 204.xx, 206.xx, 207.xx, 208.xx, 209.xx
<i>“co-morbid”</i>	Conditions with severe, non-progressive disability causing extreme vulnerability to health complications.	Spastic quadriplegia, presence of a tracheostomy with any diagnosis	343.2, V55.0

Data was extracted from the MHS Master Data Repository (MDR), which contains administrative inpatient and outpatient records for all care provided in MHS facilities as well as care from other sources that has been purchased by the MHS. For each inpatient discharge or outpatient encounter, data were available on diagnoses, procedures, associated costs or payments, and certain patient demographics. The data existed in separate tables (e.g., home health), by both year and record source, but could be linked by a unique patient identifier field across all tables. These data were organized and combined in the following manner. All inpatient and outpatient records for dependent children aged 24 years and below, from FY2001-FY2002 were selected

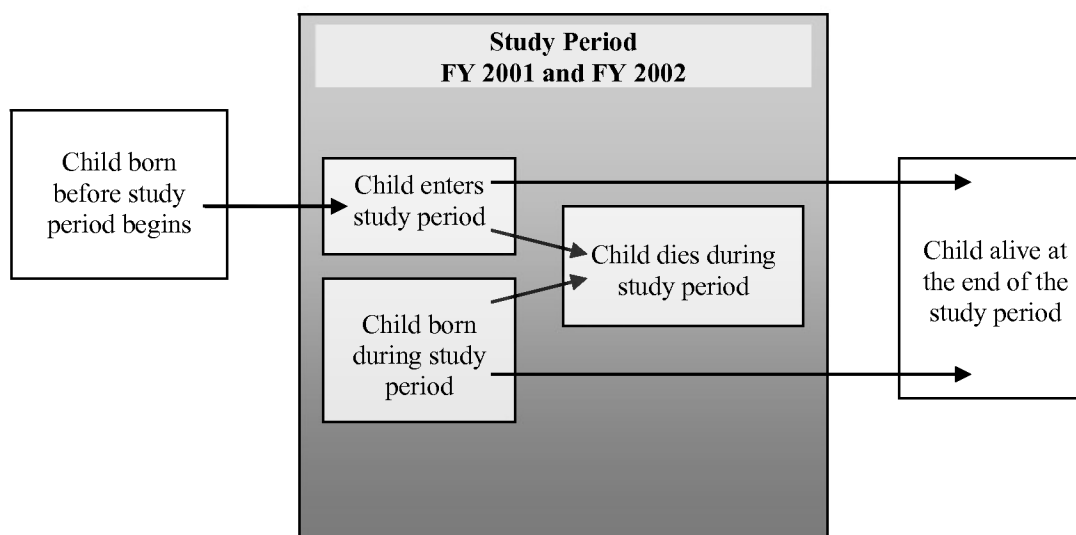


Table 2
Children Included in the Study Population

from the original tables. Any child with LTC alive during the study period was included (See Table 2). Deaths were identified based on either a Defense Eligibility and Enrollment Record System (DEERS) record date of death within the two years in question or by a clinical record having a disposition code indicating death. Records for both years were combined, creating a non-duplicate record analytic data set for the period under examination.

Using the previously published Himmelstein “criteria” (see Table 1 above for definitions), four trajectories of patients were selected from the data: those with incurable disease, manageable disease, curable disease, or those with significant co-morbidities that are often associated with hospitalization and death. For each of the four categories, total encounters, inpatient admissions, use of special services, and associated costs were tabulated separately by whether or not the patient had died during the two-year period of observation. All data manipulations and tabulations were conducted using SAS software version 9.1.

Estimation of the Population

Two methods were used to determine the approximate *number* of children who meet the case definition for LTC who are entitled to care in the MHS.

- *An estimate* was made based on the numbers of children registered in DEERS, and to which prevalence rates from the United Kingdom (UK) were applied. A search of the literature found three reports of prevalence data for children with LTC that were judged appropriate for use in this study because: (1) the definition of LTC closely matched that chosen for this study; (2) data came from actual counts of UK records, and (3) the purpose of the studies was for program planning. The prevalence rates found are:

1:1000 (0.1%)^{50,51}
 1.2:1000 (0.12%)^{52,53}
 1.72:1000 (0.17%)^{54,55}

Applying these prevalence rates to the numbers of children in DEERS provides an estimate of from 2,642 to 4,543 children entitled to care in the MHS during FY01/02 who have a life-threatening condition.

The numbers of children in DEERS by age groupings were tabulated as follows (Table 3):

Table 3
Numbers of TRICARE-Eligible Children in DEERS
During FY 01/02 by Age Group⁵⁶

Age Group	Numbers of Children
<1 yr	180,909
1-4 yrs	471,752
5-9 yrs	584,566
10-14 yrs	591,247
15-19 yrs	579,227
20-24 yrs ⁵⁷	233,853
Total	2,641,554

50 Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*. 2nd ed, London; 2003.

51 Davies RE. Mortality in all children in South Glamorgan. *Welsh Paed J*, 2001

52 Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*, 2nd ed, London; 2003.

53 Lenton et al. Prevalence and morbidity associated with non-malignant life threatening conditions in childhood. *Child Care, Health and Development*. 2001, 27(5), 389-398.

54 Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*. 2nd ed, Longon; 2003.

55 Maguire H. *Assessment of the need of children with life-limited children in Northern Ireland*. Northern Ireland Children's Service, 2000.

56 Children who died or disenrolled from the MHS during FY01 are included using their FY01 age, all others using their FY02 age. These departures add roughly 250,000 children to the total vs a midpoint population count.

57 Includes only children still entitled to care, i.e., those with permanent dependency and those in college. Does not include spouses in this age range.

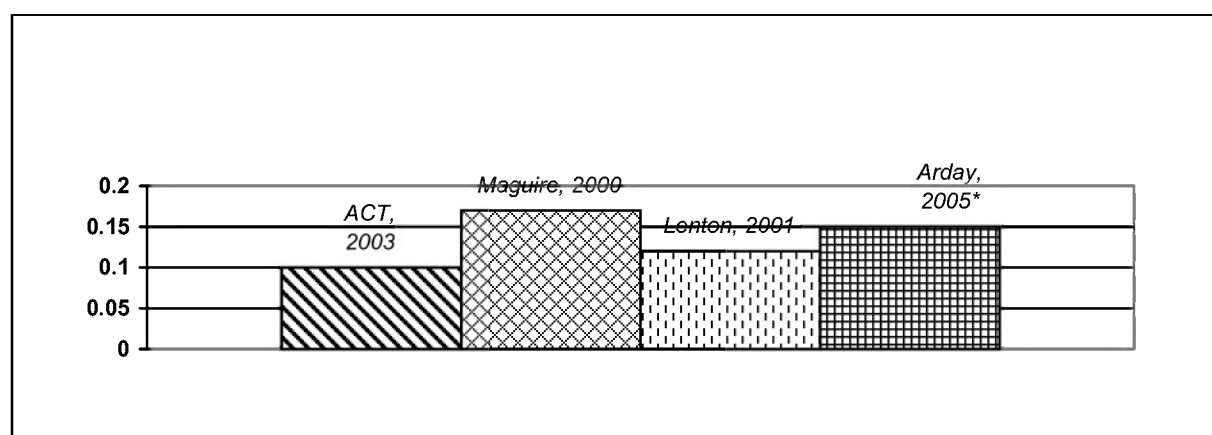
2. A count based on the ICD-9 codes chosen for each case-definition was executed through the data searches of the Defense Enrollment Eligibility Reporting System (DEERS), Standard Inpatient Data Record (SIDR) inpatient direct care, Standard Ambulatory Data Record (SADR) outpatient direct care, Health Care Services Record (HCSR) institutional purchased care and Health Care Service Record Non-institutional (HCSRN) non-institutional purchased care) records described above. The counts determined for FY 2001 through FY 2002 were as follows (Table 4):

Table 4
Counts of Children with Life-Threatening Conditions
in the MHS (by Condition), FY01/02

Designation for this condition	Description of condition	Numbers of children alive at any point in study period FY 01/02
<i>“incurable”</i>	Progressive decline to death	728
<i>“manageable”</i>	Intermittent periods of intensive care to maintain quality of life	964
<i>“curable”</i>	Curative treatment is possible but may fail	1239
<i>“co-morbid”</i>	Severe, non-progressive with extreme vulnerability	940
Total		3,871

The prevalence rates of children with LTC found in the literature (0.1%, 0.12%, 0.17%) and that determined in this study (0.15%) are in close agreement and provide reassurance of the accuracy of the methodology of counting cases of LTC used for this population (See Table 5).

Table 5
Percent of Children with Life-Threatening Conditions in Four Studies



Estimation of Number of Deaths

To estimate the numbers of deaths per year among the population of children with LTC, data provided in the Institute of Medicine, *When Children Die*, pp 41-71; 2003 “Deaths: Leading Causes for 1999” from NCHS, 2001 data⁵⁸ was extrapolated and these rates were applied to the total number of children in DEERS in each age category. (See Table 6)

Table 6
Estimated Number of Children Dying
From Complex Chronic Conditions in the MHS per Year

	<1 yr old	1-4 yrs old	5-9 yrs old	10-14 yrs old	15-19 yrs old	Totals
Rate (all causes/yr)	705.6/ 100,000	34.7/ 100,000	17.4/ 100,000	21.1/ 100,000	69.8/ 100,000	
Rate not related to trauma or immediate newborn	“1/4 th of all infant deaths due to complex chronic conditions” Feudtner 2001 or rate of 176.4/ 100,000	19.6/ 100,000	9.2/ 100,000	11.5/ 100,000	17.1/ 100,000	
# of children in MHS	181,000	472,000	585,000	591,000	579,000	2,408,000
Estimated # children dying from complex chronic conditions/year	319	93	54	68	99	633

This estimate of 633 child deaths/yr from LTC was compared to a count obtained by a search for deaths in the FY01/02 DEERS and M2 database using the ICD-9 codes in each case definition. The number of deaths counted was 105. These data were a known undercount because the M2 database did not record children who died at home and missed some children who died in civilian institutions. Furthermore, the rate estimated from the NCHS data may include children whose diagnosis and method of counting LTC does not fit the definition used in here. While 105 children is likely an undercount, an estimate of 633 from NCHS “Causes of Death” data may be an over estimate. A thorough search of the literature found one study deriving a death rate from LTC as 10% of those with children identified with LTC⁵⁹. Using this rate would estimate 400 deaths per year among DoD children with LTC. Hence, this number was chosen as the most reasonable estimate. (See Table 7)

⁵⁸ Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, 41-71.

⁵⁹ Davies RE. Mortality in all children in South Glamorgan. *Welsh Paed J*. 15:31-36; 2001.

Table 7
Summary of Numbers of Children Suggested for Program Planning

	Estimate based on 2,408,000 children ages 0-19 yrs and prevalence of life-threatening illness of 0.17% (Britain) with 10% deaths/year	Based on projections from IOM death rate tables	Counted from study period FY01/02 in DEERS and M2 databases	Numbers Suggested for Program Planning
Non-trauma deaths per year in MHS	400	633	105	400
Numbers of children with life-threatening conditions in MHS	4093	N/A	3976	4000

FINDINGS: Resources for Children

Background

Children with life threatening conditions and their families can benefit from a variety of resources to support their numerous and complex needs. Although third party health care funders provide services and funding to meet many of the medical needs, often other non-medical supports are overlooked or left to the family to locate, fund and access.

As described by the American Academy of Pediatrics, children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. Children with life-threatening conditions would be included as having special health care needs. These resources and services that support children and families in these extraordinary situations and are beyond the typical need and are often provided by organizations other than those funding health care services. These services may include such services as family support, family counseling and education, care coordination and respite care. Other related services can be early intervention, special education, transportation, and social services.⁶⁰ In some situations, using naturally existing community supports can reduce or offset costs of care to traditional health care systems while supporting the family beyond the immediate and obvious medical service needs.

A component of the Children's Hospice project is to evaluate community resources that may be available to children of military families in the National Capital Area (NCA) with a focus on children with life threatening conditions. See Appendix 18: Resources for Children for full analysis. As part of this evaluation, community based resources are examined to identify types of existing community-based services, as well as their availability from several perspectives including location and accessibility. The primary purpose for this evaluation is to identify opportunities for supportive services that exist outside of the scope of the military health care system that may be unknown to or underutilized by families' who could benefit from such support and promote the concept of palliative care. This aspect of the study is designed to answer the following questions:

- What types of supports are available to children with life threatening conditions and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

⁶⁰ A New Definition of Children With Special Health Care Needs PEDIATRICS Vol. 102 No. 1 July 1998, pp. 137-139 , <http://pediatrics.aappublications.org/cgi/content/full/102/1/137>

Method

The method of resource review includes a broad literature review; development of a resource assessment tool and identification and analysis of federal, state, and local programs and resources. Military specific resources were also reviewed in light of the needs of children with life-threatening conditions. The literature review is conducted through a health science library, local public libraries, a military site library, the Internet as well as journals, resource directories, local newspapers, brochures, local health department literature and information provided at community based events.

In addition to this literature review, a resource assessment tool is developed and designed to serve as a template for collecting resource information in any community or geographic area. See Appendix 19: Resource Assessment Tool. The purpose of the resource assessment tool is to ensure that data elements collected about resources are useful and captured through an organized method. Specific resources and their attributes are collected and entered into a database using the resource assessment tool. The resources collected are compared to the types of resources children with life-threatening conditions could benefit from. They are further characterized as federal, state, local or military specific.

As part of the methodology of studying resources for children, the process for accessing resources has been dissected and is depicted as a data flow diagram. The purpose of this diagram is to identify possible areas of vulnerability that may preclude completion of the process to the point of service delivery. The basic tasks identified are: identification of a resource need by family, professional or other non-professional; research for possible option for desired resource; application to obtain resource; identification of a service provider; locating a funding source; delivery of the service; and reimbursement for the cost of the service or resource. See Appendix 20: Process for Accessing Resources; Data Flow Diagram.

Findings

The MHS is rich in resources to support families and troops and does so in a number of ways. Military HOMEFRONT is a web site designed to provide reliable quality of life information to help troops and their families, leaders and service providers. A feature of the Military HOMEFRONT web site is the electronic discussion forum that serves as a mechanism for parents to utilize the experience and wisdom of others to assist in problem solving issues that arise when caring for a child with extraordinary needs. Specialized Training of Military Parents (STOMP) is yet another example offering an electronic discussion forum for parents of children with special needs. Although some of the information may be personal opinion or experience, encouraging parents to ask “how to” questions and network using the website may assist other families by identifying some strategies and techniques to assist in solving resource related problems. It appears that the electronic discussion forum is currently underutilized and optimizing awareness or knowledge of this resource could improve usage and assist more families.

In addition to information provided on the web site, the military system provides access to Military OneSource. Military OneSource is an employee assistance program for active service

members and their families. This program has the capacity to provide targeted resource information provided by a master's prepared individual called a Consultant Specialist. Additionally, Military OneSource houses and distributes publications upon request that support the distribution of resource information for the military system. See Appendix 21: Military OneSource Report. The Exceptional Family Member Program (EFMP) exists across all branches of the military and its purpose is to identify family members with special medical needs and/ or educational needs and considers those needs in the personnel assignment process. In some branches of the service the program also provides a family support function.

External to the military specific resources discussed above and based on an extensive review of potential resources for children with life-threatening conditions, there appears to be numerous possible sources of support available to military families that could supplant the many needs of these families. Many of these resources are either nationally based, government related and therefore are available in all or many areas of the country, or otherwise commonly available in most communities. Hence, the information gleaned from this study can be generalized to communities other than the NCA. Appendix 22: The Resource Profile Chart depicts a variety of resources that exist and further identifies areas of the system that parents, professionals and others could pursue to access such resources. The Resource Profile Chart can serve as a reference for developing PPC programs and providers who are seeking sources for resources to support children and their families.

The exercise of locating information about resources can be time consuming and frustrating. Using the Internet to locate information requires some level of skill to conduct an effective search. Too often, queries for these resources yields an overwhelming and an unmanageable volume of results that is not effective in finding specific useful information. In some situations, information can be outdated, incomplete or lack credibility. Keeping in mind the many burdens on families while caring for an ill child, time consuming research to find resources is incompatible and often is not pursued effectively by the family to get the support that they desire.

It is important to note that most organizations and programs that house resources for families have specific factors and guidelines that determine a child's and family's eligibility for the specific service. Often there are varying criteria that must be met to determine eligibility and application processes that end abruptly or are delayed due to incomplete paperwork exercises. Some services have costs associated that may or may not be affordable to families. See Appendix 23: Resource Overview Analysis.

Locating basic information regarding a resource is typically the first step toward accessing that resource. However, the information may not be useful unless it yields actual delivery of the needed service. Much of the problem seems to lie in the barriers to accessing services rather than in their lack of availability. Types of barriers include limits set by specific diagnostic or financial eligibility criteria, geographic limitations, lack of knowledge or skills with the pediatric population, prohibitive costs, waiting lists or enrollment caps or poor quality of providers.

Results of this work have led to the following considerations specific to accessing resources for children with life-threatening conditions in the military system:

Education

- Educate families and providers regarding the types of resources that exist and where they may be located.
- Educate families of children with life threatening conditions to utilize existing military services such as Military OneSource and Military HOMEFRONT.
- Educate Military OneSource staff on the variety of specific resources that exist for families who have children with life threatening conditions to enhance dissemination of information to families who are seeking community support.
- Encourage and educate on family networking through such chat forums as Military HOMEFRONT and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may get information to assist them in navigating systems and accessing services to support their children's needs.

Coordination and Facilitation

- Consider care coordination as a means to assist families in accessing existing resources both in the military and private sectors.
- Develop linkages for families with Military OneSource to optimize an information and referral role they are currently contracted to deliver to active military personnel.
- Encourage the collaboration of existing community programs that provide various types of coordination such as public libraries, Infant and Toddler Programs, school programs, Military OneSource, etc. that already exist within the military or civilian world.

System Design

- Design information systems to support the dissemination and access to resource information focused on supporting children with life threatening conditions. See Appendix 24: Web Based Resource Database Note.
- Incorporate quality indicators and metrics to measure usage and access to all possible resources that support families. By optimizing the use of resources within the military system, such as TRICARE and Military One Source, and supplementing these with resources that families can access outside of the military system, a full spectrum of services appears to be available to support families. This type of quality review may assist the developing model to better identify potential areas for process improvement, especially related to the process for accessing the resource, and help to address some of the areas of vulnerability.

FINDINGS: Care Coordination

Care coordination is emerging as a major focus of this project and is consistently identified as a key service for pediatric palliative care. Often, the term *care coordination* is used synonymously with *case management* and/ or *care management*. There are various definitions for these terms and these definitions share some important commonalities.

The case management industry often uses the definition from the Case Management Society of America. *Case management* is defined as “a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost effective outcomes.”⁶¹ The American Academy of Pediatrics uses the term *care coordination* and defines it as a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health.⁶² The Maternal Child Health Bureau defines *care coordination* services for children with special health care needs as “those services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families.”⁶³

TMA refers to this service as *case management* and typically includes activities such as disease management, benefits management and utilization review⁶⁴, while “care coordination” occurs when an individualized plan of care is implemented by a variety of service providers⁶⁵. *Care coordination* is often the preferred term used in context of family centeredness as parents play such an integral role in the management of their child’s care. Therefore, for the purposes of the Children’s Hospice Project, case management will be presented within a conceptual framework best described as child and family centered and the term care coordination seems to better describe this service for children with life threatening conditions. Although the verbiage used to define case management and care coordination differ, the concept and process remains consistent.

Care coordination activities may offer benefits to families and to providers. Some specific activities that care coordination can provide in relationship to accessing resources may include but are not limited to the following:

⁶¹The Case Management Society of America is an international, non-profit organization founded in 1990 dedicated to the support and development of the profession of case management and is a recognized industry resource for the provision of case management practices. <http://www.cmsa.org/Portals/0/PDF/MemberOnly/StandardsOfPractice.pdf>, Last accessed January 5, 2007.

⁶²PEDIATRICS Vol. 116 No. 5 November 2005, pp. 1238-1244 (doi:10.1542/peds.2005-2070) Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs, Council on Children With Disabilities.

⁶³ Title V Information System Glossary, [Title V Sec. 501(b)(3)] <https://perfddata.hrsa.gov/mchb/mchreports/Glossary.html>, Last accessed January 16, 2007.

⁶⁴ Medical Management Guide, DoD and Tricare Management Activity, January 2006.

⁶⁵ Committee on Children with Disabilities, Pediatrics, 1999.

- Assess the individual needs of the child and family
- Develop an individualized plan of care for the child incorporating the multidisciplinary team
- Understand the range of available community resources and public benefits
- Identify, locate and monitor community resources to assist the child and family
- Facilitate access to health and other services that support the needs of the child and family
- Optimize resources that are available to the child, while avoiding duplicative or unnecessary services and costs
- Facilitate effective communication between families and providers
- Assist the family to become more effective advocates for their child's needs

"Care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families".⁶⁶ This same concept is widely accepted by the American Academy of Pediatrics (AAP) based on their support of the medical home concept. As defined by the AAP, a medical home is an approach to comprehensive primary care that is accessible, continuous, comprehensive, and family centered, coordinated, compassionate, and culturally effective. The AAP Committee on Children with Disabilities recently concluded that care coordination is an integral component to the efficient management of the multiple complex issues related to caring for children with special health care needs to result in optimal outcomes for children and their families. In addition, based on the needs of children across multiple health and human service systems, care coordination is a process that links children and families to services and resources.

Although the medical home concept promotes coordinated care for children with complex health care needs, it is often not provided by the pediatrician based on lack of time and staff.⁶⁷ When care coordination is provided by professionals for children with medically complex needs, it is commonly accomplished by nurses and social workers; however primary care physicians, physical and occupational therapists or other professionals can lead or participate in the coordination process.

Care coordination is not a profession in itself, but an area of practice within one's profession. There are no specific educational requirements to be a care coordinator, but certification in the specialty is possible. In some settings, experienced parents sometimes fill the role. This practice varies greatly depending on the program and needs of the population for which care coordination is being implemented.

Some barriers to providing effective care coordination for professionals are lack of knowledge and information about either the condition, community resources or coordination process, as well as the extra time and effort needed to provide such services, lack of adequate reimbursement for care coordination and the existence of multiple care coordinators.

⁶⁶ Care Coordination: Definition and Principles, Massachusetts Consortium for Children with Special Health Care Needs prepared by the Care Coordination Work Group, Oct 2005.

⁶⁷ Gupta, O'Connor and Quezada-Gomex, Pediatrics 2004.

There are pockets and degrees of care coordination being delivered within the current military system that could be optimized to support children with life-threatening conditions but do not specifically target the population. For example, individualized care coordination is available to children who are eligible for Extended Health care Option (ECHO) benefits and is provided by many pediatric hematology-oncology clinics, and may be provided through the direct care system by a pediatric clinic-based nurse or the social worker. However, the direct care system resources are often not robust enough to meet the need of every child with a life-threatening condition or their family. Training is needed for most care coordinators in understanding the needs of this unique population, in coordination of palliative care, and in approaching end-of-life issues.

Care coordination is a service commonly found in state level programs and waivers and is often present in those state and federal programs serving children with special health care needs. For example, care coordination is a component service provided with early intervention programs, and developmental disability programs as well as the community based waivers for children. Care coordination is also identified by Children's Hospice International as a key component of the CHI PACC[®] model.

Although care coordination practice standards include the processes of assessment, planning, implementation, evaluation and advocacy, there are some existing community resources that provide elements of these process steps. For example, Military OneSource has “coordinators” on staff whose focus is described as disability issues. The scope of involvement with the family is information and referral regarding resource supports. This is similar to the role of a public librarian in the general community setting. In many situations, library staff are skilled at searching for information about resources in the local community, however are not equipped to deal with the more specific needs of a child with a life-threatening condition.

Care coordination can be an effective strategy to promote appropriate access to quality care that is safe, timely, and cost effective by maximizing the use of available resources.⁶⁸ See Appendix 25: Military Health System Analysis Report - Care for Children with Life-Threatening Conditions pages 33-35 for the TMA cost analysis report. Considering the limited availability and constraints of care coordination within the current system, children with life-threatening conditions who have such complex care needs could benefit from such a service to support palliative care. However, obtaining care coordination through TRICARE depends on the effectiveness and criteria established for case screening. Children with life-threatening conditions are at risk to be overlooked in this process.

⁶⁸ Medical Management Guide, DoD and Tricare Management Activity, January 2006, Section II – 2.

FINDINGS: Education

Background

Education is consistently identified as a key component to support the growth and development of programs for palliative care. It transcends all levels of a program and is a need for the child and family as well as the providers of care. In addition, other community entities that interface with a child, who has a life-threatening condition, could benefit from some targeted training when they are working with these families. The development of a pediatric palliative care program within military treatment facilities requires that providers have a clear understanding and working knowledge of the medical, nursing, psychosocial, and spiritual aspects of PPC. Because the concept of pediatrics in palliative care is relatively new when compared to the adult model of palliative care, there are limited educational resources available at the present time that focus solely on children.

Perspectives for Education of Providers

The information obtained from the site visits to pediatric palliative care programs suggested a variety of approaches for educating the providers in PPC within an institution. One option was to provide formal training, using one of the standard curricula, for a daylong conference or in individual training modules. Hospitals chose to either sponsor training hospital-wide, using formal educators in specific curricula, or to send some of their providers to attend training to become palliative care educators for the rest of the staff. The Children's Mercy Hospital used a more generalized approach by providing education initiatives and care-oriented updates in palliative care at departmental meetings and grand rounds, targeting a wide scope of professional disciplines, to include physicians, nurses, social workers and child life workers. An individualized physician education initiative, offered at Children's Mercy and Seattle Children's Hospitals, allowed residents to spend a month's rotation with the palliative care team for a direct, hands on experience. Denver Children's Butterfly Program developed an Outreach Program to educate hospice programs and providers in their geographic referral area.

Much of the education of both staff and families at the sites visited was informal. Bedside teaching, family care conferences, and discussions with providers oriented to specific patients and families offered numerous opportunities to promote the principles of palliative care, while simultaneously providing treatment. Some hospitals established informal networks of interested providers and families, who met periodically for educational sessions or informal discussions on pediatric palliative care topics, such as the "Good Grief at Noon" sessions at The Denver Children's Hospital.

The Harriet Lane Children's Center (HLCC) at The Johns Hopkins University Hospital chose to use education only as their formal PPC program. The PPC initiative at the HLCC was not oriented towards direct patient care. The main focus of the program was to provide education and support for the staff, both inpatient and outpatient. At its inception, the decision was made to work first with staff by helping them acquire skills which would then enable the staff to provide PPC effectively. When consulted, members of the HLCC Palliative Care Program facilitated patient care conferences with the care providers with a focus on how to integrate palliative care into their care plans. The palliative care education team was also dedicated to providing

emotional support to the primary care team and helped the providers reconnect with the “meaning” of what they were doing. The education program team began with small, incremental changes in the thinking and orientation of providers, targeting the staff of those departments that expressed the most “angst” regarding issues related to dying children. (See Appendix 26 for individual reports on site visits and Appendix 27 for Site Summary Report.)

Perspectives on Education for Families

Families, who have a child with a life-threatening condition, need to be aware of the resources available to them in order for them to be more informed of the child’s disease process, to be able to navigate the intricacies of the health care system, and to derive emotional support during the course of their child’s illness and beyond the end-of-life. During visits to the various programs providing PPC, it became clear that much of the education for families on issues related to their child’s illness or on how a more holistic approach could meet the family’s needs was done on an informal basis through bedside conversations or family care conferences. The NQF identifies the following palliative care areas for education of the child or adolescent and family:

- Disease process/ diagnosis
- Treatment alternatives/ options
- Goals/ plan of care, pain management
- Symptom management, psychological effects
- Medications
- End stages and the dying process
- Advance directives
- Legal issues
- Bereavement counseling
- Spiritual counseling
- Respite options
- Resources

Palliative Care: Education for Providers

The education curricula which are currently available that could be beneficial to the implementation of PPC include:

- The Initiative for Pediatric Palliative Care (IPPC)
- End-Of-Life Nursing Consortium (ELNEC)
- Education on Palliative and End-of-Life Care (EPEC)
- The National Palliative and Hospice Care Organization’s (NHPCO) Children’s Project on Palliative/Hospice Services (ChiPPs)
- The Program in Palliative Care Education and Practice sponsored by the Center for Palliative Care/Harvard Medical School.

(See Appendix 28: Education Curricula on Pediatric Palliative Care)

There are also a variety of PPC conferences held throughout the country that might be helpful to providers as well as families. Both the CHI PACC[®] model and the NQF National Consensus Project provide an in depth summary of what constitutes state of the art palliative care and

should be used as a template when deciding on educational curricula. (See Background pages 5-10.)

IPPC is one of the most extensive curricula in pediatric palliative care. The curriculum is both an educational and quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. It consists of five separate modules, which are available on the Internet free of charge. Each module has a number of related activities. The curriculum addresses the knowledge, attitudes, and skills that health care providers need in order to better care for children and their families. The five modules are:

- Engaging with Children and Families
- Relieving Pain and Other Symptoms
- Analyzing Ethical Challenges in Pediatric End-of-Life Care Decision Making
- Responding to Suffering and Bereavement
- Improving Communication and Strengthening Relationships.

The target audience for this curriculum is any member of the PPC team (physicians, nurses, social workers, chaplains). IPPC also offers regional retreats throughout the year. Specific dates can be found on the IPPC website.

ELNEC is a national educational initiative to improve end-of-life care in the U.S. Its curriculum provides end-of-life training for undergraduate and graduate nursing faculty. The ELNEC Pediatric Palliative Care course has been adapted from ELNEC Core Curriculum and will be offered twice in 2007. Information about pediatric trainers in each state is available on the website.

NHPCO's Children's Project on Palliative/Hospice Services seeks to make the best-known practices in the field of PPC more widely available to care providers via newsletters, information about conferences related to PPC, and materials for PPC providers available for purchase.

The EPEC project is more adult-oriented in its approach, but does offer a solid curriculum in palliative and end-of-life care. The project offers individuals the opportunity to participate in a "Become A EPEC Trainer" conference which is a two day conference discussing the principles of palliative care and effective teaching approaches for dissemination. Once completed, a "trainer" may then use EPEC materials available for purchase to lead future EPEC training sessions locally. The target audience for this curriculum is physicians.

The Harvard Medical School Center for Palliative Care is currently offering an intensive two session course for medical and nursing educators who wish to become experts in the clinical practice and teaching of comprehensive, interdisciplinary palliative care. This program allows individuals to gain expertise in leading and managing improvements in palliative care education and practice at their own institutions. The course is delivered in two sections. The first part consists of seven days of intensive learning on all aspects of palliative care followed by a six-month interim where participants work on an individual project and contribute to weekly discussions of problematic cases presented by other participants through e-mail exchanges. The

second part is a second seven-day block that includes continued experiential learning and leadership. The target audience for this course includes physicians and nurses.

Finally, incorporation of a specific PPC curriculum into residency training programs is essential in order to ensure that future generations of pediatric providers in the military are comfortable with providing solid pediatric palliative and end-of-life care to their patients and families. This training is required by the residency accreditation boards and is often lacking at both the residency and medical school levels.

Palliative Care: Education for Families

Providers play a major role in offering information on palliative and end-of-life care to the families of children with life-threatening conditions. Part of the formal training on PCC is dedicated to inform providers about how to relate to families at the level of the families' understanding and knowledge. When speaking to families or presenting educational materials to families, the information must be age appropriate, culturally relevant, delivered in a language best understood by the family, and in the manner in which the family learns best. Modules on joint decision-making and breaking bad news in the IPPC curriculum, for example, focus on these skills

There are informal sources of education available to families on PPC. The NHPCO website offers a section on educational resources for parents including Tips for Parents, Children's Neuroblastoma Cancer Foundation, and Parents Speak Out on End-of-Life Decisions for a Child. There is also a specific link entitled Children and Family Support which provides additional information on organizations that can assist parents with children with life-threatening conditions. "A Lion in the House" is a recently released film dealing with pediatric palliative and end-of-life care. The website, as part of its community engagement campaign, provides an extensive overview on pediatric palliative, end-of-life, and bereavement care written for parents. The American Academy of Pediatrics provides a list of brochures, articles, publications and support groups on palliative care for families and caregivers which is located on The National Center of Medical Home Initiatives for Children with Special Needs website.

Family Needs: Education for Providers and Families

It is critical that providers of PCC understand that their main role is a supportive one to children and their families. Providers must understand how to conduct a comprehensive assessment of the patient's and family's needs and assist with finding and accessing the services. In addition to the medical care required, the provider is obligated to understand and find support for the psychosocial, emotional, and spiritual well-being of the family. The provider, therefore, needs training in how to develop a comprehensive plan of care with the family, how to provide those supports to the family, as well as how to resource those needs and services that go beyond the medical care. In reviewing the curricula that are available to train PPC providers, the IPPC modules on family centered care, ethics, suffering and bereavement, and communication offer a solid framework for delivering the psychosocial and emotional support.

The provider should enlist the assistance of any local spiritual leaders that the family has identified so that spiritual care for the patient and family can continue once the patient is

discharged to the home. Individuals providing spiritual care must also be trained in and comfortable with helping patients, particularly children, with existential issues such as the meaning of life. Chaplains interested in providing PPC can participate in an IPPC regional retreat or familiarize themselves with the IPPC modules. Currently the Pediatric Chaplains' Network is developing a standardized curriculum on pediatric palliative care. Further information is available on their website www.pediatricchaplains.org

Knowledge of what information may be available to both families and providers through military resources, such as the Exceptional Family Member Program, Military OneSource, and MilitaryHOMEFRONT, can assist in families in locating financial counseling and relief agencies and in getting emotional support outside of traditional mental health services. In turn, staff of such entities as Military OneSource, need education on the variety of specific resources that exist for families, who have children with life threatening conditions, to enhance dissemination of helpful and accurate information.

Families should be encouraged and educated on how to network through such chat forums as MilitaryHOMEFRONT and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may get information to assist them in navigating systems and accessing services to support their children's needs

Systems and Administrative Needs: Education for Providers and Families

Access to services authorized in the MHS benefits can be complex and difficult to navigate for both families and providers. When providers don't understand what is available through the benefit and how to access services through the purchased care part of the system, they are unable to assist families in accessing their needed resources. Families often find themselves in the role of prime advocate for their child and attempting to navigate the complex health care system themselves without sufficient knowledge or guidance. Both providers and families must fully understand what is authorized through the benefit and how to access those services. Case managers and care coordinators need to become exceptionally knowledgeable.

Establishing measurable goals and assessing patient and family satisfaction are key components of any program in order to ensure that processes are working. This is a way to "educate" the administrative components of a program on how to improve the provision of care. IPPC has quality improvement tools available to institutions. The first is Recommended Domains, Goals, and Sample Quality Indicators (for family centered palliative care) and the second is the Pediatric Palliative Care Institutional Self-Assessment Tool. This tool allows organizations to assess their status on issues related to family-centered palliative care for children with life-threatening illnesses and serves as a means for further discussion and planning. There are two components to the self-assessment tool, a hospital administrative form and a unit level form. The self-assessment tool would be an ideal means by which a military treatment facility could assess what existing services are available at the institution to promote effective PPC.

FINDINGS:

Site Visits

Site visits were conducted by members of the Children's Hospice team to six PPC programs around the country. Sites were selected based on length of time in existence and, therefore, level of experience of the facility in providing pediatric palliative care. Each site had a different approach to the implementation of PCC, which afforded the team a variety of models for care and education.

The six sites visited were:

- Children's Mercy Hospital: Pediatric Advanced Care Comfort Team (PACCT)
- Children's Hospital Denver: Butterfly Program
- Johns Hopkins Children's Center: Harriett Lane Compassionate Care
- St. Mary's Healthcare System for Children, Bayside
- Johns Hopkins Health Plan: The Omega Life Program
- Seattle Children's Hospital: Palliative Care Consulting Service

The strengths of each program were examined for the following parameters in order to determine what constitutes a good PPC program: Program Description, Population Description, Service Delivery, Funding for Services, Research Component, Education Component, Strategies Used for Implementation, Current Challenges for the Program, and Possible Application to the Military Environment. See Appendix 26 for the complete site visit reports, and 27 for the detailed comparison of the programs.

The information gleaned from the six site visits indicate the many ways an organization can approach initiating PPC. All of the programs visited have had extensive experience (4-25 years) in providing palliative care. All of the programs embrace the basic concepts of palliative care that address the physical, emotional, psychosocial, and spiritual well-being of the patient and family. Each one of the programs, however, is different in its approach to program design, staffing structure, and implementation strategies for PCC. The success and obstacles that each of these programs has experienced during the growth of their palliative care program can help guide the DoD in strategizing how to incorporate PPC into the MHS. There are several important components that the MHS could address with respect to programmatic development. Several of these components are listed below along with possible strategies that could be used for successful implementation of pediatric palliative care into military treatment facilities.

Each program has a different strategy for their approach to PPC: in- versus out-patient; direct service versus consultative; focus only on education or care coordination. All have at least one provider who is knowledgeable in the principles of PPC and serves as a program champion. The configuration of the teams varies in number, discipline, roles, and responsibilities, but all ensure that all domains of PPC are addressed and that the care is interdisciplinary. The population served is generally from the immediate geographic area that reflects the referral network of the hospital. The Butterfly Program also serves children from a larger geographic area, but only in consultation with local providers and resources. The life-threatening conditions of the children usually includes a wide variety of diagnoses; however, some programs focus on specific subspecialty populations, such as cystic fibrosis or infants from the neonatal intensive care unit,

as a strategy to introduce the concepts of PPC gradually. St. Mary's Hospital is a chronic care facility and tends to have a population that is more severe and more neurologically involved. The services provided are also variable, but generally include development and implementation of an interdisciplinary plan of care and some level of care coordination. All have a plan for formal or informal education of the providers and families. (See education section, pages 57-61). Most programs do not have a specific research project on PPC, but will conduct surveys of the families to ensure patient satisfaction and quality of care and service delivery.

Except for Omega Life, which is part of the Hopkins Health Plan, all of the programs are based in children's hospitals. Because the overall mission of these hospitals is wholly dedicated to the care of children, support for PPC by the administration and hospital governing boards is strong, unquestioning, and given without reservation. None of these programs has independent funding; therefore, most of the cost of these programs is underwritten by the hospitals.

In a military system environment where the fiscal priority is a war effort, the financial aspects of delivering care for a relatively small population of children seem impractical. However, in all the programs visited, the population of children with life-threatening conditions constituted a small portion of the overall population served within the broader organization or institution. Therefore, many of the programs expressed challenges related to growth of their palliative care efforts. Without exception, taking small yet consistent and deliberate steps to promote the development and advancement of palliative care was identified as a key strategy in the implementation of the specialized program. Education and some effort to provide coordinated care to the population were heavily weighted as an opportunity for improvement in delivering palliative care. In some settings, staff roles were re-defined or slightly modified to address the needs of the palliative care population. In addition to taking deliberate and consistent steps to implement program elements at the various sites, the need to create a cultural change in the way care is provided and viewed at the end-of-life is a significant accomplishment that helps to pave the way for growth of the palliative care effort. Collaboration within an individual facility and the development of partnerships with existing community efforts can promote the growth of PPC and improve the delivery of care for children and families from time of diagnosis of a life-threatening condition to end-of-life.

FINDINGS:

Designing a Quality Program Plan for Pediatric Palliative Care in a Military Setting

In organizations with effective quality management systems, quality becomes a central point of the organization's operations and not just an afterthought or add-on. Quality can be defined as the results the program provides for the people it serves. When an organization develops a plan for providing palliative care, it is important to consider how quality will be defined and measured prior to program implementation

Quality management involves a deliberate and systematic approach to increase the likelihood of desired outcomes to ultimately improve quality of care and services. This is done through continuous monitoring, analysis, correction and performance improvement.

Similarly, the Wisconsin Department of Health and Family Services explains: "The quality management system is designed to measure the extent to which consumers are achieving their desired clinical, functional, and personal–experience outcomes, and to improve the program's performance in supporting outcome achievement."⁶⁹

Some possible ways to use and interpret results are:

- To establish baseline information
- To identify areas for further inquiry
- To identify areas for focused quality improvement
- To measure program or system performance.

Quality management is most efficient and effective when it is done as close to the child or family as possible. An efficient quality management system uses data and information that are already being collected for other program purposes. For example, information from assessments and care plans, from grievances and complaints, and from billing records can contribute towards the quality management system. Satisfaction surveys can yield feedback and information that can be incorporated to promote positive program changes.

This section is intended to provide a guide for entities within the MHS that have an interest in implementing palliative care to assist them in incorporating processes that promote quality. It can be used in its entirety or as a component to an already existing quality plan. The plan outlines a framework that can serve as a template for developing programs and incorporates concepts from CHI PACC[®] programs as well as the NQF National Framework and Preferred Practices for Palliative and Hospice Care Quality.

In addition, gaps identified by military families and providers relating to their experiences with providing care to children with life-threatening conditions have been incorporated in the

⁶⁹ Quality Close to Home: A Preliminary Design for an Integrated Quality Management System, Sept. 2006, The Wisconsin Department of Health and Family Services, APS Healthcare, The Management Group, Inc.

monitors and outcomes for quality. The monitors are designed to develop effective child/family partnerships. The MHS faces the challenges of soldier deployment and relocation as a norm and, therefore, it is even more important to promote seamless transitions across the healthcare system for children and families dealing with such complex situations. Key elements in providing palliative care include education and effective coordination and communication with families and other providers of service.

The Quality Plan typically includes the following sections:

- Purpose of the Quality Plan
- Goals for Quality Plan
- Framework for Quality Improvement in Palliative Care
- Oversight of the Quality Program including a description of roles
- Quality Improvement Monitoring Process
- Quality Improvement Education
- Review of the Program and Update of the Quality Plan
- Palliative Care Monitors and Anticipated Outcomes
- Family Satisfaction Survey

A sample Quality Plan for palliative care has been prepared for use as a template. See Pediatric Palliative Quality Plan; Appendix 29. The plan is an example and should be customized to reflect the scope and specific goals for the individual program. If the program's primary focus is education, then it would be appropriate to choose indicators that reflect the educational goals or modify them to fit the scale of the program.

Palliative care monitors that accompany a Quality Plan are defined in the Palliative Care Monitors and Outcomes Document. The organizational and child/family/provider monitors are developed based on NQF domains, CHI PACC[®] standards and Joint Commission standards for hospital, home health, and hospice. In addition, the monitors are designed to reflect gaps identified by military families as part of the Children's Hospice Project. See Palliative Care Monitors and Outcomes; Appendix 30.

The final component for the Quality Plan is the Palliative Care Satisfaction Survey designed for military families is based on findings identified from focus group assessments, see pages 67-97, discussed earlier in this document. See Palliative Care Survey; Appendix 31. The goal is to capture and identify trends within a program that can result in opportunities for improved processes and interventions, ultimately increasing family satisfaction during their palliative care experience. A program that can measure its' effectiveness and demonstrate success will be better positioned for growth and sustainability.

RESULTS:

Gap Analysis

The gap analysis collates and synthesizes the findings of this feasibility study by bringing together the needs of families and providers, the MHS benefit, and the availability and limitations of resources and services in order to identify the existing gaps. The gap analysis is organized according to the needs assessment themes as informed by the results of the qualitative research on family and provider needs in the MHS. The corresponding resources and services that are available, and any associated limitations of availability and accessibility, are briefly described. The resources considered encompass the benefit itself and what is provided within the direct care system, community resources and services, education programs, and those systems and services that are required under the standards of the JCAHO, which are mandatory for all healthcare institutions. Each theme provides a quote from either a family member or provider to clearly illustrate the need, plus a statement summarizing the issues reflected in the theme. For each theme, there is a gap statement to succinctly delineate the needs and suggested options for addressing the gap.

THEME GROUP 1: SYSTEMS, ACCESS TO CARE, AND COORDINATING CARE

Theme 1: Access to Care and Services

“So in the beginning you may have a resource on paper, but if there is not a body providing the service [you can’t get the service]. And that’s the same with the nursing services in the [Medicaid] model waiver. We have been truly blessed by the nurse that has come into our lives. It wasn’t easy getting our model waiver. It wasn’t easy finding the individual whose schedule would mesh with ours and who has the right personality for our family. So once again, you may have a resource on paper, a resource that’s approved, but it may still take a while to find the individual that’s really going to fulfill that need for you. And do you remember how long it took from the time when we were approved on the model waiver to until our nurse came? It was about 6 to 8 months. So once again you have truly a remarkable resource that we couldn’t utilize for a significant amount of time.”

A Parent

Theme summary statement:

While comprehensive, the MHS is complex, confusing, and at times inflexible. Health care and other services for children with life-threatening conditions and their families are often available but both families and healthcare providers encounter barriers when accessing the benefit.

Resources and limitations:

The MHS includes a world-wide system of military treatment facilities and purchased health care available through TRICARE contractors, designed to deliver health care covered in the TRICARE benefit. Children with life-threatening conditions, who are beneficiaries of the MHS, are entitled to all medically necessary health care. The benefit through the MHS is generally robust, but has certain limitations for these families. Families and providers find it difficult to understand how to access many of the services that are available through TRICARE contractors. The Extended Health Care Option (ECHO) has strict requirements, which limit access to services under this program, and ECHO is not available to dependents of retirees. Case managers within the direct care system and through the Managed Care Support Contractors are available to assist families with access to care and services. However, often there are insufficient numbers of case managers or they lack sufficient knowledge to assist families with issues outside of medical care. Providers may attempt to assist families with access but may also lack sufficient knowledge as well as time.

The military community has numerous programs for information on resources and support for families: the Exceptional Family Member Program (EFMP), Military OneSource, and MilitaryHOMEFRONT. MilitaryHOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services." These programs are often limited in their knowledge of resources and services for families of children with life-threatening illnesses and may provide only information on the resource, but no assistance with access.

Federal, state, and local programs are available, but there are significant barriers to accessing these programs, including lack of awareness of the resources, variability of availability from region to region, eligibility criteria, fiscal requirements, inadequacy of resource capacity, and unavailability of appropriately knowledgeable and trained providers.

GAP STATEMENT

Processes are needed to improve families' access to needed services within the Military Health System. Similar access issues arise for military and publicly available community supports and resources. Even with good access to existing care and services, gaps still exist for some services, particularly those that do not fall within the TRICARE benefit.

Options for addressing gaps:

1. Provide education and individualized information for parents of children with life-threatening conditions and the physicians, nurses, therapists, case managers, and care coordinators who help them find and obtain access to needed services.
2. Provide additional case management and care coordination for children with life-threatening conditions and their families.
3. Work with other organizations to identify additional resources.

Theme 2: Care Coordination

“During an already chaotic and stressful time, families are providing the large majority of the care coordination. It is exhausting and the process is exhausting.”

A Parent

Theme summary statement:

Some care coordination is available within the MHS, and it is helpful to the families when it occurs. But there remain limitations in the care coordination available to military families from both military and community resources. Families are providing the large majority of the care coordination, and it is exhausting and inefficient, leaving gaps in the services the child and family receives.

Resources and limitations:

JCAHO standards support that, whenever services are provided to a child or adolescent, family or guardian involvement is facilitated and coordination is provided throughout the process. Care coordination appears to be an option that is encouraged by the Medical Management Guide, published in 2006 by the TRICARE Management Activity (TMA). Care coordination is described as a component of case management and discharge planning. The Guide further describes identification of potential candidates based on the following criteria:

- Cases complicated by psychosocial or environmental factors
- Cases impacted by family and/or military circumstances
- Catastrophic, extraordinary conditions that incur high costs or large amounts of resources
- Chronic conditions complicated by traumatic events
- High-risk, multiple, or complex conditions or diagnoses
- Need for close coordination between the patient and healthcare team
- Requirements for extensive monitoring and coordination.

Case managers within the direct care system and through the Managed Care Support Contractors (MCSC) are sometimes available to assist families with access to care and services. Most case managers help families with care provided by the TRICARE benefit. Military treatment facilities use case managers to overlap services between case management and that of care coordination. Case managers do provide both case management and care coordination when families under case management move from one duty station to another. The MCSC provide case management for beneficiaries when they are high cost or have a high utilization of the system. The MCSC case managers also provide care coordination when a beneficiary in their care moves from one duty location to another.

Often there are insufficient numbers of case managers or they lack sufficient knowledge to assist families with issues outside of medical care. Some case managers in the MHS help families find community-based resources or other sources of funding for health care, but this is less frequent than case management for TRICARE-covered services. Providers may attempt to assist families with access but may also lack sufficient knowledge as well as time. General pediatricians and family medicine physicians provide some coordination of medical care and may be available to

facilitate communication between members of the healthcare team. However, primary care managers are not always available to coordinate care for children with complex medical needs.

The Army Exceptional Family Member Program (EFMP) provides some coordination through the EFMP Installation Coordinator. The EFMP installation coordinators may provide some care coordination of non-medical needs when the family is relocating through referrals to the gaining installation. The Beneficiary Counseling and Assistant Coordinator (BCAC) is another resource for assisting a family with care coordination issues. The BCACs are the persons most familiar with resources outside the doors of the military treatment facilities. However, the availability, capability, and knowledge of these coordinators is variable and not specific to this population. Military OneSource has “coordinators” on staff whose focus is described as disability issues. The scope of involvement with the family is information and referral regarding resource supports. Families tend to find information from Military OneSource too general to assist them with the complex needs of children with life-threatening conditions..

Care coordination is a service commonly found in some of the state administered programs, particularly those serving children with special healthcare needs such as early intervention programs, developmental disability programs as well as the Medicaid community-based waivers for children. Military families are often not eligible for these programs.

GAP STATEMENT

Comprehensive care coordination and continuity of care is vital for families of children with life-threatening illnesses, but is inconsistently available. Often parents provide much of the care coordination their family needs, without the education necessary to fill this need efficiently and at great cost in time and emotional energy.

Options for addressing gaps:

1. Provide information for parents that will help them coordinate care more easily.
2. Provide education for existing case managers and care coordinators about the needs of children with life-threatening conditions and their families and about care and services available to address these needs.
3. Provide education for case managers and care coordinators about how to efficiently access care covered by TRICARE.
4. Provide more care coordinators for this population of children and families.

Theme 3: Long-term Care Needs

“[My daughter] will never be cured. There is no cure. [She] is vulnerable to every possible illness that can come along because her resistance is low because she’s got bad lungs, because she’s got this and because she’s got that. She’s got severe scoliosis, her bones are frail, her bones break easily. It’s just a lot. The only thing that we can do is that once she gets sick try to get her through that illness and make her feel comfortable but she will never be cured or healed. She’s very vulnerable to pick up everything and anything. For example, if there’s some illness going around the school, I can’t send her and I don’t. There was a bad virus going around and [she] had developed a rash on her face. I didn’t know what it was from so I immediately called our doctor and said this is the situation the rash isn’t that big but there’s this bad bug going around school. And automatically it was like no you can’t send her. That’s how we have to live our life. I never know from day to day what is going to happen. We’re at that point where we are have the understanding [she] will not be cured and that we have to keep her as comfortable and as healthy as we can for as long as we can.”

A Parent

“I would think people derive a lot of confidence from having one doctor who’s there for them throughout the course of something and who can help put the pieces together. We have a very disjointed healthcare system, especially for patients who are not medically educated. Sometimes they just need a family doctor to decipher the language. I also think that the families that have appreciated me the most, it hasn’t been for the medical stuff that I do, but it’s because I give them the ways to contact me. And I call them and tell them I’m going on leave this week, I’m not going to be available but someone else is available. There are not that many families that I do that for, but these families know that they can call me no matter what and those are the ones that because they can’t get in or they don’t have respite or they don’t have a car, they will just call and say she’s sick she’s needed a little more oxygen today, how many days can I watch her like this before you make me bring her in. I think families need someone, that’s what hospice does, they provide them someone they can call.”

A Family Physician

Theme summary statement:

Many children live for a long time with life-threatening medical conditions that require complex care. Other children, particularly those with cancer, may enter a long-term remission or even be cured, but even then their disease and treatment have life-long physical and emotional consequences that require care. Continuity of healthcare providers is especially important for these children and families, yet is difficult to ensure in the MHS.

Resources and limitations:

Each patient enrolled in TRICARE Prime has a primary care provider who, theoretically, is available to coordinate care for the child across multiple domains of medical and psychosocial need. The MHS also provides pediatric subspecialists who can sometimes provide continuity for all medical services while caring for a child’s main areas of medical need. Since both physicians and families move and deploy, special attention must be paid to a child and family’s need for

long-term, coordinated care, especially at times of transition. Although children will continue to receive health care as long as they remain beneficiaries, their needs will continue into adulthood and they may age out of the system. Children who are significantly disabled at age 18 may continue to remain beneficiaries of the MHS throughout their lifespan, when this option is exercised by their parents.

The medical home concept for care has been supported by the Maternal Child Health Bureau and promoted by the American Academy of Pediatrics. The medical home concept is designed to address the comprehensive needs of children beyond traditional medical needs. A medical home means primary care that is accessible, continuous, comprehensive, family-centered and coordinated. Although this concept of a medical home, designed to provide broader and more comprehensive care, may address the long term needs of a child with a life-threatening condition, the successful implementation of this concept varies among physician and medical system practices and is generally not supported by the managed care processes. Theme 4: Medical Home goes into more detail about the medical home concept.

GAP STATEMENT

While the TRICARE benefit provides for care that addresses a child's medical needs, the complexity and duration of care needed by children with life-threatening conditions creates challenges that require extra coordination. Providing ongoing relationships with physicians, nurses, and care coordinators, who can come to understand a child and family's complex needs, is especially difficult.

Options for addressing gaps:

1. Develop an approach to healthcare administration that plans for a medical home in pediatrics or family medicine for each child with a life-threatening condition.
2. Enhance care coordination by primary care physicians, case managers, and care coordinators available to these children and families.
3. Develop and implement specific processes to help families transition between military treatment facilities, from pediatric care to adult care, and between physicians when care needs change and when physicians move or deploy.

Theme 4: Medical Home

"So a medical home, I would appreciate that. I would appreciate that now, especially if we are going to stay here. And someone who could easily bring all of the records, everything about our family having to deal with illness, in one place so that it is easily transferable"

A Parent

Theme summary statement:

A medical home is a pediatric or family medicine setting that provides primary care for children with special needs and coordinates health care and other services that cannot be provided by primary care physicians. Few healthcare providers in this study were familiar with the concept of a medical home. A medical home in general pediatrics or family medicine is generally not available in the MHS. Some subspecialty clinics (e.g., hematology/oncology) provide many aspects of a medical home for children while they are receiving treatment through those clinics.

Resources and limitations:

There is no specific TRICARE benefit regarding a medical home. Every beneficiary enrolled in TRICARE Prime has an assigned primary care manager who could, and in some cases does, provide some aspects of a medical home, especially coordination of medical care. However, the MHS is not currently organized to facilitate provision of a medical home in a primary care setting for most children with life-threatening conditions.

The American Academy of Pediatrics promotes the concept of a medical home. Extensive educational resources about the medical home are available through the American Academy of Pediatrics⁷⁰ and American Academy of Family Physicians websites.⁷¹

GAP STATEMENT

While some military pediatricians and family medicine physicians are familiar with the concept of the medical home and provide many aspects of this approach to care in their practices, a medical home is generally not available to children with special needs in pediatric or family medicine clinics in the Military Health System.

Options for addressing gaps:

1. Provide opportunities for pediatricians in the Military Health System to participate in the American Academy of Pediatrics' Medical Home Initiative.
2. Provide opportunities for family medicine physicians in the Military Health System to participate in education about the medical home through the American Academy of Family Physicians.
3. Enhance care coordination for children with life-threatening conditions and their families through primary care settings in military treatment facilities.

⁷⁰The National Center of Medical Home Initiatives for Children with Special Needs, available at <http://www.medicalhomeinfo.org/>, Last accessed May 6, 2007.

⁷¹ American Academy of Family Physicians webpage, <http://www.aafp.org/online/en/home.html>. Joint Principles of the Patient-Centered Medical Home, Last accessed May 6, 2007.

Theme 5: Military Health System roles and administration

“The PCM [primary care manager] is not really what it should be for the general pediatric patients. I mean they really don’t see the same person every time, they see different people. And even though on paper they have a PCM they don’t really have a PCM. We do serve as PCMs or our clinic serves as a PCM for those patients.”

A Pediatric Sub-specialist

“Physicians spend an hour or two doing things that a case manager can do in the absence of having one.”

A Pediatric Sub-specialist

Theme summary statement:

Administrative challenges at the military treatment facilities, such as lack of clarity regarding healthcare provider roles or limited availability of ancillary staff, affect access to health care for children with complex needs and availability of needed support for families. When children need care provided through TRICARE contractors, apparent inconsistencies in interpretation of the TRICARE benefit lead to confusion and frustration for both parents and healthcare providers.

Resources and limitations:

All military treatment facilities within the MHS are expected to meet the same JCAHO standards as all other hospital systems. These accreditation standards are designed to facilitate patient oriented administrative processes and continuous operational improvement.

Care coordination is endorsed by the TRICARE Management Activity as an effective means to meet the complex needs of complex illnesses and circumstances. Most military treatment facilities have some care coordination available, although not sufficient to meet the needs. TRICARE contractors can institute care coordination, however, this tends to focus on benefit management rather than proactive, individualized care coordination.

Community-based care coordinators and service coordinators may be of some assistance to families who must negotiate administrative challenges, but this is not an area best addressed by the community.

Education for administrative staff about the TRICARE benefit and how to help beneficiaries access the benefit would help provide more consistent assistance for families. Clarification from the TRICARE Management Activity to the TRICARE contractors about interpretation of the benefit for children with complex and incurable health conditions may result in more consistent access to the benefit in different TRICARE regions.

GAP STATEMENT

Administrative challenges sometimes create barriers to access to care and services for children and families.

Options for addressing gaps:

1. Consider organizing primary care in ways that facilitate a medical home for children with special needs.
2. Review administrative practices in relation to recommendations in the Medical Management Guide published by the TRICARE Management Activity in 2006.
3. Provide guidance about interpretation of the TRICARE benefit in relation to children with special needs.
4. Provide education for physicians, healthcare administrators, and others about the medical home.

THEME GROUP 2: Relationships

Theme 6: Advocacy

“He didn’t have services for four months. We paid some out of pocket but he didn’t have services for four months because I was fighting in the appeal system and it took four months. I started fighting in February. I lost services in June. I didn’t wait until the end. I lost services in June and they didn’t have services from June to September. And I was fighting the whole time.” **A Parent**

Theme summary statement:

Many parents of children with life-threatening conditions become determined advocates for their children, working long and hard to overcome barriers to the care and services their children need. They need help filling this role and education about how to advocate well. Many healthcare providers in the MHS are equally determined, faithful advocates for children and families. Parents express gratitude for healthcare providers who advocate for their children; healthcare providers also recognize the important role that parents fill in this regard.

Resources and limitations:

The complexity, exclusions, and ever-changing interpretations of the CHAMPUS policy manual, as well as local interpretations by TRICARE contractors, can make advocacy on the part of the healthcare provider difficult, frustrating, and ineffective. Processes are in place for patients and families to dispute a decision regarding TRICARE benefit coverage, to request assistance in coordination or obtaining services through the direct care system, and to make a formal complaint or request a formal investigation of an incident or policy regarding health care. The medical treatment facilities have in place individuals who act as ombudsmen and/or patient advocates. These individuals assist patients and families when a conflict arises between the healthcare provider’s decisions, clinic policy, and the needs and wishes of the patient and family. The military services and the Department of Defense each have a trained group of investigators (the Inspector General (IG)) who will investigate a failure to follow established policy or regulation, allegations of fraud or mismanagement, and, occasionally, individual patient complaints, if the complaint points to a system-wide concern.

Specialized Training of Military Parents (STOMP) can be an effective resource for parents who can benefit from other military parents’ experiences. However, information obtained from the STOMP listserv has the potential of being inaccurate or influenced by a parent’s personal experience and values. Misinformation is a possible outcome.

Protection and advocacy systems exist in each state to protect the legal and human rights of individuals with disabilities. The state protection and advocacy systems typically advocate for population-based issues and may not be as helpful for individual situations.

GAP STATEMENT

Families and providers are not trained or equipped to advocate for these children, and there is no specific resource to assist in filling this role for individual patients and families. Advocacy takes energy and time. Some parents are so consumed with the care of their sick child that they may not effectively advocate, particularly if they lack support and information from healthcare providers about how to fill this role.

Options for addressing gaps:

1. Provide education for both families and healthcare providers about how to negotiate the system of services.
2. Provide opportunities for parents who would like to help other families to contribute to improving care and services by sharing insights and suggestions from their experiences.

Theme 7: Relationships and Communication with Healthcare Providers

“Part is to question clarity not validity. Often in the medical profession you state something and the provider would say ‘Are you sure that happened?’ As if it’s invalid, as if you don’t know what you’re talking about. Somehow we need to move towards questioning clarity not validity. You know what your child does, you know what you observed. That’s part of creating an adversarial relationship. I am not going to have my child be treated but I’m going to have to prove to them that my child did that last night. Somehow a lot of this comes from staff development and training.”

A Parent

“It’s like why can’t you who have a relationship with this family talk about end-of-life issues and what they desire for their child when the natural progression of this disease takes hold. Rather than a stranger in the middle of the night when they are all stressed out because they know the child is acutely ill and possibly might die.”

A Pediatric Intensivist

“I would rather them say ‘I haven’t worked with this diagnosis or this chronic illness, could you explain how you take care of your child at home? And we’ll try to do our best to follow that here.’ You know, it makes a big difference!”

A Parent

Theme summary statement:

Communication between parents of children with life-threatening conditions and their healthcare providers is sometimes difficult, always important, and remains a very sensitive area for families who are dealing with serious medical situations that evoke deep emotion. Communication between parents and healthcare providers is affected by military culture, family background, and whether healthcare providers and families speak the same language. Communication among the many healthcare providers who provide care for a child is equally important. Healthcare team communication generally proceeds well within a military treatment facility but often proves more challenging when the team includes providers both in the military treatment facility and in the community.

Resources and limitations:

The primary care manager is in the ideal position to establish the pro-active communication with a family about their child with a life-threatening illness and about possible complications and decisions that they may face in the future and to coordinate communication among members of the healthcare team. Often, however, continuity of care with a primary care manager is disrupted when a child has complex needs requiring on-going subspecialty care.

Many educational resources about pediatric palliative care include education about communication between healthcare providers and families. Some more general approaches to physician/patient or healthcare provider/family communication may also be helpful for providers who work with this population of children and families.

Formal and informal training in communication skills with families is available through residency training programs and can be provided as a part of continuing medical education. Some training programs are utilizing the Initiative for Pediatric Palliative Care (IPPC) curriculum as a means to educate their staff in topics of communication, particularly for end-of-life issues. The IPPC training is divided into modules and includes a module entitled “Improving Communication and Strengthening Relationships.” The goal of this module is to enhance healthcare professionals’ communication and relational skills.

JCAHO identifies the standard that families have the right to participate and that providers ensure family participation in all aspects of their care. This standard requires that any communication with families must be appropriate to their level of understanding and ability to learn. Language barriers between providers and families can contribute to communication issues. Language interpreters are usually identified within each military treatment facility and should be available to assist with communication with families whose primary language is not English. Resources that offer services to assist with language barriers include the Women Infant and Children (WIC) programs, developmental disability programs, infant and toddler early intervention, departments of social services, the military direct care system (available during hospitalization), as well as other local community groups.

Gap statement:

Although some healthcare providers and supportive organizations are beginning to access training in the area of palliative care, there is no specific requirement, and provider training is variable. Thus many providers remain untrained in effective communication techniques for palliative care. Translation services are not available consistently in all programs that serve children and families.

Options for addressing gaps:

1. Provide formal education for healthcare providers and informal education for families about communicating effectively in difficult circumstances.
2. Develop a pediatric palliative care team that focuses on communication, perhaps using the Decision Making Tool developed at Children’s Hospital of Seattle.
3. Provide extra support for healthcare providers and/or families who must engage in stressful, difficult communication and decision-making.

Theme 8: Decision Making

“In relation to the information, specifically we want the right information to make the decisions we have to make and we want to be included in decisions about our children.”

A Parent

“That speaks to shared decision making and them not taking the time to find out why you feel that way and share with you why they feel that way because they might alleviate a lot of fear if they would involve you in the shared decision making.”

A Parent

“Help the family look there and make some decisions about the end-of-life issues when it’s comfortable with everyone to do that or if it’s not comfortable and it needs to happen anyway. Sort of beginning to bridge some of those conversations even fairly early.”

A Parent

“A lot of times it was hard, really hard, it’s hard to see your child go through that and have to make all these awful decisions for them and make them hurt for the treatments or something. It’s not you, but it’s like you can’t give up. As long as, like I said she could understand, she’d say she had a bug in her head or something and I’d say ‘It’s back. Should we get it out?’ and she’d say ‘Yes!’ and I couldn’t stop. She never stopped so I couldn’t either. She kept on.”

A Parent

Theme summary statement:

Parents find it very hard to make decisions for their children, and often have to do so in the face of great uncertainty about outcome, big risks, and huge implications for quality of life. They want to be included in decisions, but need the information necessary to make good decisions and do not want to feel like they are all alone in making decisions. Sometimes they have to make decisions between options that all have a likelihood of negative outcome.

Resources and limitations:

In accordance with JCAHO standards for hospital care, the process that allows patients to fully participate in decisions about care, treatment, and services is the informed consent process.⁷² This is identified as an individual right; however, a mere list of rights cannot guarantee they are enforced. The Maternal and Child Health Bureau, at the Federal level, in partnership with State Title V Children with Special Health Care Needs (CSHCN) programs, family leaders, and other professional and advocacy organizations have focused a significant level of effort on defining, describing, and making family-centered, community-based care available to all CSHCN and their families.

The TRICARE Management Activity has endorsed and promoted the concept of family-centered care, which includes family participation in decision making, throughout the MHS. However, the

⁷² Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to RI 2.40, p. 144.

training and experience of providers in these concepts and how they apply in daily practice is variable. Education to build communication skills of healthcare providers who work with children with life-threatening conditions and their families may address ways to engage in supportive shared decision making with children and families. Care coordinators, primary care managers, subspecialists, chaplains, and nurses can assist families in weighing options during times when difficult decisions need to be made. Family counseling is available as a benefit to families.

Gap statement:

Although federal and professional organizations promote the concepts of family-centered care, the medical home, and informed decision making in the delivery of healthcare for children, individual professionals and organizations practice these concepts with varying levels of knowledge, resources, support, and effectiveness.

Options for addressing gaps:

1. Provide education for children, parents, and healthcare providers (especially physicians) about shared decision making.
2. Provide decision aids and other informational resources for parents about treatment decisions they must make with or for their children.

THEME GROUP 3: Family Needs

Theme 9: Social and Emotional Needs

“They said, ‘You are on compassionate reassignment you’re supposed to have your family help you.’ I said, ‘My family is in Nebraska.’ ‘Okay,’ they said, ‘friends or neighbors.’ I said, ‘I don’t know anyone, I just moved here.’ They said, ‘Don’t you have a neighbor?’ I said, ‘She works.’ I asked my case manager, ‘So what are you doing tonight?’ She said, ‘Oh, I have such and such to do.’ I go, ‘So you probably couldn’t come over and watch my son while I go to the store.’ She said, ‘Well that’s not fair, I have obligations.’ I said, ‘So do other people.’”

A Parent

“It changes your thinking but you have to cope. When you are in a situation like this, it doesn’t end; I can honestly tell you that I love my child very much, but when Dr. D told me a few weeks ago and said that she can live a lot longer, like a few more years, I walked out of there thinking I’m going to be loony by the end. I can’t do it. That was my first thought. How am I going to be able to cope with it? She is already getting heavy, she is already putting strain on me. How am I going to do this? You only think that for a brief time because you are in a situation that you can’t get out of it. You can’t jump off a cliff and say bye see you later. I never thought about that because I love my family. I love my child and it’s not something that you can run away from.”

A Parent

“I have longed for something like[respite care] that especially that I am from the islands. We come from Guam. We have no family here and I have my other little kids and that’s why we had to have them learn how to deal with our child.”

A Parent

“Our current system relies very heavily on friends and family. Absorbing more of that and taking care of it would cost more than what we do now. Families are basically left to fend for themselves. It’s very difficult.”

A Pediatric Subspecialist

Theme summary statement:

Parents of children with life-threatening conditions in the military community describe social and emotional needs in three broad categories: dealing with the intense emotions evoked by their children’s suffering, coping with continuous and strenuous care demands, and living in settings with limited social support. The whole family is affected – the child with a life-threatening condition, parents, and other children in the family. Physicians, care coordinators, and social workers recognize families’ need for emotional and social support and do what they can to address the needs with limited resources. Healthcare providers who work with these children and their families need support, too.

Resources and limitations:

JCAHO requires that accredited facilities conduct a psychosocial assessment of a patient and family with the understanding that identified problems are addressed during the course of care. Mental health services are available as a TRICARE benefit. Social workers, psychologists, and

psychiatrists are available in military treatment facilities through behavioral health clinics, family medicine clinics, and life skill clinics. Many military treatment facilities limit appointments to active duty members. Up to 8 outpatient visits per year are covered by the TRICARE benefit without a referral or diagnosis, with appointments available through the network of providers organized by TRICARE contractors. Additional visits are possible with a diagnosis and approved plan of treatment. However, formal counseling may result in labeling the military parent as having a mental health diagnosis that can have implications for their military career opportunities.

Counseling for normal bereavement is not an authorized benefit under CHAMPUS/TRICARE for patients with a “diagnosis” of normal bereavement. Some parents worry about implications for their careers of pursuing *any* counseling, although the MHS tries to provide education to allay this concern. Families may be able to access family counseling without a mental health diagnosis, and a behavioral health specialist may be available through family medicine clinics at some military treatment facilities. With education about pediatric palliative care, physicians and nurses may be able to provide additional emotional support for children and families informally, in the context of health care they already provide.

Military OneSource provides information and referral assistance for active duty service members and their family members to seek professional, non-medical counseling. Six visits per year per individual per issue are available at no cost to the service member or family.

Child life is a service typically available in a pediatric hospital setting. A child life specialist is a professional who is trained to assist children and families in understanding and managing difficult life events and stressful healthcare experiences. However, these services may not be available in all settings. A number of community-based organizations may offer bereavement support or support for families of children with special needs in some areas. Some organizations who may offer this resource include religious settings such as churches, synagogues and mosques, pastoral counseling centers, hospitals, mental health or social service agencies, funeral homes (some have after care hours), hospices, YMCA or similar organizations, and other less formal support and discussion groups. Services of organizations may vary from place to place and some charge dues or fees for their services. Some remote locations of the country may have less access to local resources. Sibling workshops or support groups are also sometimes available through community groups.

GAP STATEMENT

Although a variety of resource options exist to address the social and emotional needs of children with life-threatening conditions and their families, many of these children and families have many unmet needs for both emotional support and social support. This is particularly true for families who move either because of the active duty service member's job or to relocate near military medical resources, as these moves often disrupt a family's social support network.

Options for addressing gaps:

1. Consider options for minimizing moves for families who have children with complex medical needs.
2. Develop a network of care coordinators across the Military Health System, with processes for assisting with transitions of care and services when families re-locate.
3. Focus care coordination on meeting both medical needs and social support needs, so that care coordinators are educated, authorized and resourced to help families negotiate the TRICARE system to obtain medical care and locate military and civilian resources that can provide social support.
4. Provide some additional education about counseling that physicians can provide for families in the context of providing care.

Theme 10: Financial Toll

“It wasn’t so bad in the beginning, the formula. He was tube fed, the formula was being taken care of under the WIC program. So we didn’t realize...we didn’t know the expense of the formula. When he was too old for WIC then all of the responsibility to provide the food is ours. Now you go out there and see how much food costs. Then you had the dealings with TRICARE saying ‘Well he doesn’t have a condition that warrants us to pay for his formula.’ I’ve had some pretty ugly conversations with people. The basic thing was is if he wasn’t tube fed you would have to feed him somehow. Well, of course. Well, [to them] that’s the same thing as buying formula. His supply of formula is around \$1300 a month. TRICARE said, ‘No, we’re not going to pay for it. We’re not obligated.’”

A Parent

“I’ve also been a parent that was referred out to civilian services and gotten over \$15,000 in bills.”

A Pediatrician and Parent

“[Finances,] that’s a huge issue with these families. The families really struggle and I don’t know how to help them out. I don’t think there is enough out there to help them. There is this financial weight put on them. A lot of our families even the E-3’s they don’t qualify for Social Security disability benefits for these children or Medicaid benefits because of something with their BAH [housing allowance] and it looks like they have more money. And we’ve met with people from Social Security to try and discuss these issues. So you have these people who have no money and they are still not getting services.”

A Discharge Planner

“My husband is like maybe you should get a second job. I am like, hello, he does not get it. He needs the education. He hasn’t been around. Finances are one thing, but I’m a stay at home mom. That’s my job. I’m my son’s nurse. Finances are a situation. Finances are a problem.”

A Parent

Theme summary statement:

There is a significant financial toll for families of children with life-threatening conditions, even with access to needed medical care through the TRICARE benefit. Items typically not covered by TRICARE or not fully covered include special formulas, diapers, home nursing, respite care, some equipment, home modifications, special clothing, special toys, and expenses of moving to get care. Families also need to pay for child care for other children during treatment, funerals, and other expenses. Some other funding sources are available (Medicaid, Supplemental Social Security Income, state and community resources, military relief societies), but these sources of funds are inconsistently available to military families.

Resources and limitations

Financial planning can be an area that is overlooked when a parent is caring for a child with a life-threatening condition. Although there is a universal healthcare benefit, there may be a co-payment, depending on the TRICARE option selected and the availability of an appropriate provider, vendor or service within the network. Medical treatment that is considered

experimental is not covered. Many services and some supplies and equipment are not considered “medical” and, therefore, are not covered by the TRICARE benefit, but they still result in substantial cost for families. Non-medical expenses and alternative therapies are not covered. Case managers and care coordinators, where available, help families obtain payment for all TRICARE-covered care and pursue other sources of funds for uncovered services if funds are available. Both families and care coordinators need education about existing resources for funding of care, services, supplies and equipment that are not covered by TRICARE.

The financial planning process can be complicated and may require the input of experts to assist with the legal and financial implications. Many healthcare professionals either lack the expertise to advise a family in the area of financial planning or may not know to address financial issues at all.

The Social Security and Supplemental Security Income disability programs are the largest of several Federal programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals, who have a disability and meet medical criteria, may qualify for benefits under either program. Most military families do not meet the criteria.

Gap statement

There are limited knowledge and resources available to families for either advice or support financially. Out-of-pocket expenses can be large when a child/family is emergently transferred to the continental United States for urgent treatment. Some items of equipment, supplies, special formulas, and some therapies can only be obtained by families if they pay out-of-pocket or find sources of payment in addition to TRICARE.

Options for addressing gaps:

1. Provide care coordinators based in military treatment facilities or military community organizations that can help families negotiate Social Security, Supplemental Security Income, Medicaid, Medicaid waiver programs, and other sources of funding.
2. Provide education for families and care coordinators about local state and community sources of funding for special healthcare needs.

Theme 11: Search for Meaning/Spiritual Care

“I love her, I would never have went back and change the situation. I never would have not wanted her to come. Just my beliefs have made a big difference. I think my support group with my church and my beliefs that this isn’t the end. She’s going to be okay. That has gotten me through a lot of knowing that it’s okay. That she is perfect and a real special spirit. I sense that from her. I enjoy. I find joy in being around her. Our family does too and anyone who meets her is just amazed at the feeling that they get from her. That’s really made a huge difference for me is my beliefs and knowing that it’s in God’s hands and that it’s going to be okay.”

A Parent

“[My son is] about 10. I still consider him a blessing. I don’t know why I’m saying this but I probably wouldn’t have it any other way. He has taught us a lot more and he is here for a reason and I’m thankful to be his mother that God has trusted me with this wonderful human being. That’s how I have to look at it to survive. It’s very hard.”

A Parent

“The chaplain service comes through and for individual patients that may be a big help but for the majority of patients they don’t count on our chaplain service, they count on their own ministers or religious people who help them with that.”

A Pediatric Sub-specialist

Theme summary statement:

Both children with life-threatening conditions and their parents need spiritual care and a chance to talk about spiritual issues and questions about the meaning of what is happening to them. Sometimes they want to talk with a nurse or other healthcare provider about these things.

Resources and limitations:

According to JCAHO hospital standards, a spiritual assessment should be conducted specifically for end-of-life situations, and the facility should provide access to pastoral care, if requested by family.⁷³ Families may not be aware that they should ask for this type of support. The TRICARE benefit authorizes counseling by a variety of providers, such as pastoral counselors, psychiatrists, psychologists, family therapists, and social workers, who may focus on meaning and the existential aspects of the family’s coping.

There are direct resources that assist families and children in addressing the positive meaning of the child’s condition that may include professional counseling and/or spiritual counseling. Professional counseling opportunities can be sought with assistance from Military OneSource or through the TRICARE network. These may include professional mental health counselors and licensed clinical social workers who can address difficult issues related to the end-of-life and the loss of a child.

⁷³ Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to RI 2.10, p. 142.

In addition, chaplain services may be available to address these very personal issues of loss or anticipation of loss. Professionals and others who support children with life-threatening conditions may also seek spiritual assistance within the general community, if a specific religious denomination is preferred by a family. However, not all professional clinical and pastoral counselors are qualified to provide counseling. They also may not have the expertise to address the issues related to a dying child. Further, not all families are comfortable with a traditional religious approach to the meaning of life

Some chaplains may be interested in pursuing clinical pastoral education with a focus on pediatric palliative care, or may want to participate in pediatric palliative care education as a member of a healthcare team.

Gap statement:

Not all professional clinical and pastoral counselors are qualified to provide counseling for parents under the extreme stress of the initial diagnosis of a life-threatening condition. They also may not have the expertise to address the issues related to a dying child.

Options for addressing gaps:

1. Identify chaplains who may have education in Clinical Pastoral Education who may also be interested in working with children with life-threatening conditions and their families, or with bereaved families.
2. Offer education to interested chaplains who would like to develop expertise in counseling bereaved families or children with life-threatening conditions and their families.
3. Identify non-medical counselors through Military OneSource who may be available to help families explore questions of meaning and purpose and coping when they have a child who may die.

THEME GROUP 4: Palliative Care and End-of-Life Care

Theme 12: Palliative Care

“They are now thinking that he is going to be on a 24 hour feeding instead of twice a day which is going to be very difficult because he is not on a wheelchair yet and he would be completely in his crib without moving. I’m having a hard time with that because he rolls. That’s the only thing that he does, he rolls. Even with that, he enjoys that and you can see the enjoyment in his face and that’s the only enjoyment that he has so taking that away is basically like taking my child away. I’m hoping and praying that they don’t do that so that he can have some kind of quality of his day.”

A Parent

“I just want to make whatever lifespan he has the best it can be physically, emotionally, spiritually, all of it. That’s my job; I’m his mom. So basically, that is it in a nutshell.”

A Parent

Theme summary statement:

Palliative care is a vital part of care for children with life-threatening conditions to improve both the child and the family’s quality of life and to help them begin to prepare for end-of-life care should it be the outcome. Parents focus on quality of life for their children, which usually means finding a way for children to be comfortable, to enjoy life in whatever way is important to them, and to help the child participate in family life, school, and typical activities to whatever degree is possible. Healthcare providers’ understanding of palliative care varies widely in the MHS.

Resources and limitations:

Currently there is no palliative care benefit within the TRICARE system. However, there are palliative care programs being implemented intermittently throughout the military healthcare system. To date, the programs are focused on adult palliative care and not on children. Some aspects of palliative care, usually more traditional pain or nausea control techniques, are available through the direct and purchased care system, if authorized as medically necessary care. Some types of palliative care that are effective for children may not be authorized, e.g., acupuncture, visual imagery, music therapy, massage therapy, art therapy. Support that addresses the quality of life of the child’s parents or family members is generally not covered by TRICARE. Education about palliative care is almost uniformly needed among healthcare providers

Policy and guidance is in place, typically following state regulations, which allow families to authorize DNR orders in the hospital, home, and school. Some healthcare providers in military treatment facilities have a special interest and/or special training in palliative care, but these healthcare providers are not available to all children with life-threatening conditions and their families.

Palliative care programs for children can be found in various healthcare models throughout the country. Some palliative care programs are not fully funded and, therefore, depend on the financial support of other flourishing programs. Children's Hospice International (CHI), with

technical assistance from experts in pediatrics, hospice and palliative care, and the Centers for Medicare and Medicaid Services (CMS), developed its CHI Program for All-Inclusive Care for Children and their Families® (CHI PACC®). CHI PACC® programs can only be available in states that actively pursue the CMS application process. To date, Florida and Colorado have been approved for the 1915 (c) waiver to deliver pediatric palliative/hospice care using Medicaid funding and the CHI PACC® model. Military families would need to be eligible for state Medicaid services to receive care through these programs.

Gap statement:

Although hospital- and community-based hospice programs are readily available throughout the country, there are relatively few formalized pediatric palliative care programs. In some areas of the country, children receive hospice-based services designed for the adult population.

Options for addressing gaps:

1. Enhance education about palliative care in military residencies for Pediatrics and Family Medicine.
2. Acquaint healthcare providers in the Military Health System with available local resources for palliative care at Children's Hospitals and in local hospice programs.

Theme 13: End-of-Life Care

“There is no doubt in my mind that it is avoided in pediatrics. It’s not avoided with older people, but in pediatrics it is a taboo topic. It is a we-are-not-going-to-discuss it topic. I think that when you have a pediatric patient who has a life-threatening incurable whatever, that needs to be part of the treatment plan. Because sooner or later it is going to come into play. Granted there are going to be other pediatric patients who are going to be in this situation all of a sudden but they need to have a plan of attack that they know. They need to know.”

A Parent

“At the end people, doctors nurses, everyone, social workers. Someone should come in and explain the process of death. And what it looks like. It doesn’t look like what they show you on TV.”

A Nurse

“One of the big needs when we got out there is that they just need to know what might happen. If they know like in the dying process that the extremities are going to get cool and that the respirations might get irregular and there might be the death rattle. If they understand all of that, that it might happen, they are okay with it. It’s that fear of the unknown.”

A Nurse

Theme summary statement:

Important, intense, and particular needs arise around end-of-life care, DNR discussions, and hospice care. Children and families need information, time, and support for making decisions, and a supportive environment for a child’s end-of-life care. The experience of healthcare providers in the MHS with end-of-life care varies widely, from none or nearly none to a great deal.

Resources and limitations:

Comfort and dignity are to be optimized during the end-of-life, according to JCAHO standards, and applicable to all “dying” patients within a hospital facility.⁷⁴ Hospitals should be addressing the wishes of the patients as they relate to end-of-life decisions. The hospital should have mechanisms to assist with the development of advanced directives and a responsibility to assist in honoring end-of-life wishes within the limits of the law and the hospital’s capability. For advanced directives, appropriate forms can be obtained from healthcare providers, legal offices, Offices on Aging, and state health departments. Some state social service agencies and local funeral providers may be approached to provide options to support funeral or burial resources.

TRICARE provides a hospice benefit when death is expected within 6 months, but this is an adult model of hospice and requires the family/child to forego disease-directed care. Many adult hospice programs lack providers with pediatric training and experience. In addition to hospice services, policy and guidance are in place, typically following state regulations, which allow

⁷⁴ Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to RI 2.80, p. 146.

families to authorize DNR orders in the hospital, home, and school as well as to assist with other end-of-life issues such as organ donation.

When DNR discussions do occur, staff physicians usually participate in these discussions with families. Pediatric and family practice residents have little exposure to the conduct of these discussions. Healthcare providers need education about specific end-of-life issues like DNR orders and how to ensure that families' wishes and decisions are recorded in all places necessary. Education about communication, decision making, palliative care, and community resources is also relevant to end-of-life care. When end-of-life care happens in the smaller military treatment facilities, the small size of the community sometimes makes it possible to provide support. If DNR discussions have not taken place, the result can be further suffering for the child and family as futile resuscitation measures are instituted.

Gap statement:

End-of-life care for children is inconsistent, rarely planned with a child and family, and can increase the child and family suffering.

Options for addressing gaps:

1. Provide education about end-of-life care.
2. Build stronger collaboration with children's hospitals and hospice programs that provide resources for end-of-life care for children.

THEME GROUP 5: Education

Theme 14: Education for Healthcare Providers and Families

“A lot of our physicians come into the army not really knowing much about the army, so possibly they need better exposure to the life of the regular enlisted, [that] would be helpful.”
A Resident

“Another part of it is administrative. Because the support is available and the regs keep changing. Regular updates from the TRICARE administrative level on here is the current procedure, here is what is covered, here is how this stuff is accessed. What do you do when the parent drops their copy of a denial letter off for services? That sort of thing. Because that keeps changing and I’m never sure from one month to the next. I have to run around and find someone who may or may not know. So regular updates of some sort would be helpful to me.”
A Resident

“My thing about end-of-life care and death and dying and hospice is that we don’t do a good job talking about it, we don’t do a good job training residents. Fortunately, we have very little exposure or sporadic exposure, which is fortunate for the patients, not so fortunate for the house staff who are going to graduate and become expert pediatricians and have no knowledge or experience in these areas.”
A Pediatrician

“Sometimes it’s literally with training you. They are training you to do central lines, care management. Sometimes it’s training and they are training you in your role. And as a parent, you can take pride in the fact that you are participating in health care, it’s really family-centered. You know how to do it and you do it well. That helps you in your viewpoint in your role.”
A Parent.

Theme summary statement:

Parents caring for a child with a life-threatening condition have a variety of education needs, including a clear, medically accurate understanding of their child’s medical diagnosis, specific treatment plan and prognosis, an understanding of how to address their child’s practical medical needs, and information about how to find needed support for their family. Healthcare providers need education about available care and services and how to help families access them, as well as about communication with children and families, palliative care, and end-of-life care.

Resources and limitations:

JCAHO standards for hospital care support the concept of education to meet the dying needs of patients. This support for education is intended for staff providers as well as families. In addition to the educational requirements for provider credentialing, hospital staff are expected to be educated about the unique needs of dying patients, their families, and caregivers. There are no specific education requirements for providers addressed in the benefit. For families, education and training to use medical equipment and to provide some therapies to their children, such as a

physical therapy home program, is a benefit. The patient and family should receive education and training in a way that is understandable and that accommodates various learning styles with the family's comprehension evaluated.⁷⁵

Education programs may be available within the major military medical centers as part of residency training and continuing medical education curricula. Several curricula oriented to the pediatric population have already been developed and are available for use by institutions seeking to educate providers on the principles of pediatric palliative care. One such curriculum is The Initiative for Pediatric Palliative Care (IPPC), developed by the Education Development Center, Inc. (EDC), an international non-profit educational research organization based in Newton, Massachusetts. IPPC is both an education and a quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve end-of-life care in the United States. These programs are less likely within smaller military treatment facilities and may require providers to seek external training programs at their own expense. The Uniformed Services University provides introductory education about palliative care for physicians who attend medical school there. Home visits are another valuable educational resource that has offered some healthcare providers in the MHS the opportunity to learn about chronic, complex care in a different, often more intimate environment than in-clinic appointments.

Other mechanisms for healthcare provider education in the MHS include Tri-Service required continuing education through computer modules and in-person education sessions, Pediatric and Family Medicine Consultants' service-wide email to distribute notices and documents world-wide, continuity clinics for residents, and required residency education.

Additional methods used for training include more informal venues that can occur in various healthcare settings. These efforts can focus on the education of staff, families, or providers. Some examples include the development and distribution of informational brochures, CD's, books or literature, facilitated discussions at staff lunch groups, small group lectures, resident/fellow rotations in a palliative care setting, child life internships, one-on-one training, grand rounds, or other special training events.

Gap statement:

Both providers and families lack sufficient knowledge about pediatric palliative care and how to identify and provide the support and services necessary for a comprehensive approach to care.

⁷⁵ Hospital Accreditation Standards 2006, Joint Commission on Accreditation of Healthcare Organizations, published by Joint Commission Resources, Inc., related to PC 6.30 (p.178) and PC 8.70 (p. 180).

Options for addressing gaps:

Please see the section on education findings for a thorough discussion of education regarding pediatric palliative care. (See Education Findings pages 57-61)

THEME GROUP 6: Military

Theme 15: Military Issues

“The military is our life and this is where we want people to hear us. They are the only ones that we have to hear us. So we want them to hear us.”

A Parent

“I think that the military should look into just leaving the families with high risk children in one place instead of moving them all over the place. ... Because that’s a pain to have to move from state to state and have to reestablish the benefits and everything else.”

A Parent

“It takes most services a month to get PCS orders. It would be nice to have something that was only available to order this family into medical transient status to the national capital region or a major U.S. city.”

A Pediatric Subspecialist

“So the cost to the military is, I think, we’ve got a whole lot of really stressed out families and that has to affect job performance and deployability and productivity of the serviceman. These families often feel trapped by the military to some degree as well. I think we have a huge unrecognized cost in decreased productivity and high stress levels in the soldier.”

A Pediatric Subspecialist

“With all the deployments, it not only affects the person being deployed it affects their whole family significantly, especially when they might be on their third deployment.”

A Pediatrician

Theme summary statement:

For most families, unique military administrative issues are a major determinant in the experience of a move between bases, air evacuation, or transfer to a higher level of medical care. For most, the experience of moving and settling into a new location, beyond being traumatic because of the child’s condition, is also confusing, lengthy, costly, and disrupts their ability to attend to their child. Disruption of the medical and social support system they had previously established contributes to their sense of powerlessness. Stress of frequent and lengthy deployments, both of the active duty member and the primary care physician for the child, adds another difficulty for families wherein the uncertainty associated with their child’s medical condition is exacerbated by the absence of trusted advisors and helpmates. Yet, many families emphasize their commitment to the military community and culture, and to the service of their country. They wish that their commitment and willingness to sacrifice was matched by a commitment on the part of the command to make their difficult transitions easier.

Resources and limitations:

Military medical providers are not necessarily familiar with or well trained in military issues and concerns for the active duty service member. This void becomes even more apparent when family members obtain care through non-military, network providers. There is no specific healthcare benefit under CHAMPUS that addresses this issue.

Education about military culture is important for healthcare providers who work with this population of children and families. Education about relevant regulations, provisions for special circumstances in military families, and resources available for support would be helpful for military administrative personnel and commands, as well.

The Exceptional Family Member Program (EFMP) is a military personnel function used during the assignment process to identify active duty service personnel whose family members have special needs. The purpose of early identification is to coordinate the assignment of the active duty service member with the medical and educational needs of their dependents. The program serves to ensure the availability of necessary medical services upon change of duty stations. MilitaryHOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services." Additionally, the Department of Defense contracts with Military OneSource, an Employee Assistance Program administered by Ceridian, to assist active military members and their families in locating resources and services to meet any needs a military family may identify. Although these resources support the logistical issues of deployment and relocation, the detailed needs related to the emotional and clinical aspects of care for a child with a life-threatening condition are not well addressed by the current system resources.

GAP STATEMENT

Military issues such as transfers and deployments create unique problems and added stress for these families. Additional care coordination and services are needed to support families before, during, and after deployments.

Options for addressing gaps:

1. Enhance care coordination at the time of transitions due to military moves, moves necessitated by a child's complex medical needs, and military deployments.
2. Provide education about military culture to healthcare providers in military residencies, military treatment facilities, and TRICARE network providers.
3. Provide education to administrative staff and commands about relevant military regulations, provisions, and support for children with special needs and their families.

RESULTS:

Summary of Expert Panel

A panel of experts in pediatric palliative care was assembled to meet with the Children's Hospice team. Each member of the panel represented one of the locations visited by members of the team as part of the site visit surveys. The purpose of the expert panel was to discuss and process with the Children's Hospice team key concepts and recommendations from their direct experience for the development of a PCC that could be incorporated into the MHS. An additional member of the panel was COL Carlos Parrado, an internist from Ft. Benning, GA, who identified a need for palliative care at his military treatment facility and began a program in 2001.

Dr. Parrado was invited to give a presentation on his adult palliative care program. His initial approach was to train 16 physicians in palliative care, using the established curriculum, Education on Palliative and End-of-life Care (EPEC). An additional 25 physicians were trained in 2005. Dr. Parrado discussed how elements of palliative care coincide with JCAHO standards and allow these standards to be met more efficiently. Dr. Parrado has maintained interest in palliative care at Ft. Benning by inviting experts in the field as guest speakers to his institution. He stressed that he did have "buy in" for a palliative care program by the chief of psychiatric services on his base, which appeared to be a critical factor in moving his project forward. While a funded palliative care team does not yet formally exist at Fort Benning, Dr. Parrado does have providers who serve as an interdisciplinary team with a focus on palliative care. This team is composed of an internist, family practice physician, medical residents, nurses, pharmacist, bereavement specialist, chaplain, and risk manager. Key elements that have been identified as lacking included physician communication skills with families, advanced care planning, and referral efficiency. Dr. Parrado and his team are continuing data collection on a variety of subjects, such as pain clinic referrals, admission of patients with debilitating diseases, frequent users of the Emergency Department, and use of narcotics in an effort to gain on-going support for palliative care services.

Key Implementation Strategies for Introducing Palliative Care into the Military Health Care System

The expert panel spent the remaining time discussing what they consider key implementation strategies for successful integration of pediatric palliative care into the military health care system. Several key themes were identified to include the need for a program champion, essential program elements and process elements, and the conduct of a site assessment.

First and foremost in moving this project forward is to identify key individuals within the military health care system that could be identified as **project champions** at each facility. This individual should be a respected person within the institution, who has the credibility of the commander. While it would be helpful for the individual to have had experience in palliative care, this is not necessarily critical. The individual, however, must have a passion for palliative care and be willing to learn about the field in depth. He or she must practice evidence based medicine and be willing to explain palliative care to colleagues as such even though palliative care is not always evidence based. The individual should have access to management and be

someone who would be willing to effect change at the institution regarding philosophy of care, perhaps even at a policy level. Data currently exists regarding cost savings to institutions when good care coordination and essential palliative care elements are in place and could be used as a justification for creating a pediatric palliative care program at the champion's facility. It was suggested that a questionnaire be sent out to each military health care facility to identify potential individuals who would be project champions.

The topic of **essential program elements** was discussed. There are clearly some basic services that a facility should have in place in order to offer good PPC. These would include access to an individual trained in pain and symptom management, social work services, spiritual/pastoral care, and bereavement. The panel recognized however that each military health facility may differ with respect to how extensive these services are at the facility. The child and family should also have access to an interdisciplinary care team that is family centered and focuses on their physical, social, psychological, and spiritual needs. The make up of this team will vary at each military treatment facility depending on the facility's resources, which means the project champion will need to be creative and flexible when assembling the team. Additional essential program elements include resources and support at end-of-life and advanced care planning (DNR documentation).

How the essential program elements are molded into a PPC program at each facility will depend on what **essential process elements** are in place at the facility. Once a project champion has been identified at a facility, he or she will need to define what constitutes the best possible PPC team for that institution. Care coordination is clearly an essential process element that will determine access to care. While it would be ideal to have an individual whose only job is care coordination, this may not be possible at many facilities. Creativity is the key and this role may need to be shared by an RN, social worker, etc. There will certainly need to be system wide education at each institution regarding pediatric palliative care. Patients and families must have an individualized plan of care that is reviewed on an ongoing basis and changed according to the level of service required. Ideally this plan would follow the patient and family at the time of a transfer to another facility. A framework for providing this continuity of care constitutes an essential program process. Finally quality assessment, outcomes, and research would allow for continued improvement in the delivery of PPC in the military. However, it must again be understood that these essential program processes may need to be added over time.

Finally there are several key elements that are critical for the **site assessment** that will need to take place at each facility with an interest in development of a pediatric palliative care program. Key will be the identification of a program champion from within each facility. That individual will be aware of the population of patients (types of diagnoses), who will receive PPC services at their facility. Existing services will need to be identified, such as personnel, who have an interest in pediatric palliative care, services available (social work, spiritual/pastoral care, mental health, care coordination), community resources within the military, and community resources acceptable to the military. A crucial piece of the site assessment is interest and support from the military treatment facility commander. Existing priorities of the facility will need to be identified to understand if a PPC program is feasible or not.

CONCLUSIONS

It is not feasible to implement the Children's Hospice International Program of All-inclusive Care for Children and their families (CHI PACC®) within the MHS. It is feasible to implement the principles of pediatric palliative care within the MHS as set out in the CHI PACC® core standards.

The CHI PACC® model consists of four core principles:

- Comprehensive care delivered by an interdisciplinary team
- Simultaneous curative and palliative care
- Care from point of diagnosis with single entry into system
- Ample and flexible funding.

The major barrier to implementing a CHI PACC model as promoted by CMS is the inability of the MHS to make use of the model waiver strategy which allows flexibility of the benefit with cost neutrality of prior expenditures for a particular population. Based on the nature of the military demographics, and the fact that the military system has national and international reach, there is no mechanism for the system to apply for a waiver as the system is beyond the boundaries of a particular state. In addition, the CHAMPUS authorization for military health care is determined by law and does not allow for deviation from or flexibility of the authorized benefit.

The additional requirements for families imposed by the nature of military life, such as frequent transitions, relocation away from extended family and other support groups, and deployments, add to the complexity of ensuring comprehensive, coordinated care with continuity of providers and services. The key aspects of palliative care, that can ensure that the rest of the palliative care principles are implemented, are education of all who provide care and services to children with life threatening conditions and their families and care coordination across all aspects of care throughout the entire course of the child's illness and in all settings of care.

RECOMMENDATIONS

Military treatment facilities commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population, MHS resources (authorized by CHAMPUS and accessible through TRICARE or the military treatment facilities) and non-medical community resources.

It is recommended that:

1. Education and information appropriate to the provision of pediatric palliative care and access to necessary resources and services be made available to all health care providers and families of children with life-threatening conditions.
2. Care coordination is made available to facilitate communication, promote continuity during transitions, and assist in identifying and obtaining necessary resources and services for all children, with life-threatening conditions, and their families.
3. TRICARE Management Activity establish an interdisciplinary process team on palliative and end-of-life care for children and adults to review options, make guidance available, and address challenges within the MHS.

OPTIONS and IMPLEMENTATION STRATEGIES

Consistent with Department of Defense (Health Affairs) policy, military treatment facilities commanders have the administrative flexibility to provide palliative care and care coordination to children with life-threatening conditions in their catchment area, using a variety of program designs as best fits their population, MHS resources, available medical resource authorized by CHAMPUS (and available through TRICARE and the military treatment facilities) as well as non-medical military and community resources. The only restriction is the commander may not authorize a service outside the military treatment facility that is not a TRICARE benefit. Therefore it is feasible to implement pediatric palliative care programs in this environment.

Palliative care models have been developed in a variety of settings, and it is important to understand that one size does not fit all. Program models vary across the nation in their structure, staffing and service delivery model. Models differ according to the needs of the children and families they serve as well as factors such as the availability and qualifications of staff, budget constraints, and the population density of children with life-threatening conditions in the area of consideration. Without exception, each program observed during site visits completed for this project demonstrated the importance of taking small yet consistent and deliberate steps to promote the development and advancement of palliative care. Education and the provision of coordinated care to the population were also key strategies for improvement in delivering palliative care. In some settings, staff roles were re-defined or slightly modified to address the needs of this population. Each program also found it necessary to create a cultural change in the way care is provided and viewed at the end-of-life. Collaboration of providers and services within an individual facility and the development of partnerships with existing community efforts were critical to promote the growth of a PPC program and improve the delivery of care for children and families.

Flexibility in the design of a program is of particular relevance to the military health care system. Variations in the size of the military treatment facilities, the geographic distribution of the targeted population of those children with life-threatening conditions, and the settings of the delivery of medical services across the military system do not support the development of one exclusive model for the delivery of palliative care.

Through the use of assignment coordination and compassionate reassignments, many families with significant medical requirements are relocated to and concentrated near major military medical centers. Those families at smaller facilities and in duty assignments remote from military communities are more dependent on civilian services through the TRICARE provider networks.

There are a variety of **program model design options** that could be considered. One approach is to focus on patient care, with a dedicated PPC team that provides care directly or acts in consultation with the primary care and subspecialty physicians, who do provide care for these children. This team concept could be implemented on a case-by-case basis or directed towards certain specialty clinics within the facility. The consultative team approach has been shown to

work in both the in-patient and out-patient settings (see the site visit report for The Children's Hospital, Denver, and Children's Mercy Hospital, Kansas City). The "team" could be as small as a single provider, as long as the plan of care addresses and implements all the domains of palliative care. The key is to identify an individual within the military treatment facilities, who is knowledgeable and passionate about PCC and who can serve as a **program champion**. The necessary attributes of this individual were described in the Expert Panel section (See pages 98-99).

Another approach to a PPC model is to concentrate on a single process such as education or care coordination. The provision of additional care coordination, education about pediatric palliative care for health care providers or education for parents of children with life-threatening conditions would go a long way to filling many of the gaps in continuity, coordination, and communication that families find lacking in their child's care.

Initiation of a pediatric palliative care program within a military treatment facility should begin with a local **site assessment** to understand the needs of the local population of children with life threatening conditions, the existing resources to support provision of palliative care in the specific locale, and the implications of implementing PCC on the existing staff. The following questions raise relevant issues that might be addressed in a site assessment:

1. What health care services are available for children with life-threatening conditions in our local military treatment facility, in the TRICARE network, and through community services in our area?
2. Who provides care coordination or case management for children in our military treatment facility, through the TRICARE contractor in our region, or through state and local programs for children with special needs?
3. What are the opportunities for providing continuity of relationships with physicians for children with complex medical needs in our military treatment facility? What resources are available to follow late-effects of treatment and address long-term needs of cancer survivors?
4. Which physicians and/or clinics provide a medical home for children with special needs in our facility? What opportunities do we have to organize the delivery of health care and care coordination so that more children with special needs could have a medical home?
5. What administrative challenges may create barriers to care for children with life-threatening conditions in our military treatment facility or with the TRICARE contractor in our region?
6. What education or support do parents of children with life-threatening conditions need in order to advocate effectively for their children in our healthcare system? Which healthcare providers in our military treatment facility are effective advocates for the children we serve?
7. What do the healthcare providers in our military treatment facility do well about communicating with children with complex medical needs and their families? What are the biggest challenges to good communication between healthcare providers and families? What processes do we have in place to facilitate communication between healthcare team members who provide care for a particular child?

8. What do the healthcare providers in our military treatment facility do to help parents make decisions about treatment for their children with life-threatening conditions? Do we use a communication tool or provide any particular approaches to education about options, risks and benefits of treatment
9. What sources of social and emotional support are available for families who have children with needs for complex health care? What programs in our area provide practical support such as respite care, child care for healthy siblings, transportation or temporary housing?
10. What sources of financial support for times of crisis are available in our local military and civilian communities? What state or local funding is available for military families through Medicaid, Social Security, or Supplemental Security Income, and how can we help military families apply for this assistance?
11. What local religious communities provide support for families who have children with special needs? What education can we provide for healthcare providers about talking with families about their spiritual needs and questions about the meaning of the difficult circumstances they face with their children?
12. What do we do to improve the quality of life of children with life-threatening conditions and their families?
13. How do we approach discussions about DNR decisions for children? What additional education do our providers need about having DNR conversations with families? What are the local resources for pediatric hospice care?
14. What education about pediatric palliative care have the healthcare providers in our military treatment facility received?
15. What are the education needs of the military commands on our installation regarding children with complex healthcare needs? Who are the local experts regarding military regulations and processes for compassionate re-assignment, medical evacuation, permissive TDY, the Exceptional Family Member Program and other provisions of the military services for families who have children with serious medical needs?

Identification of services already in place at a facility will influence what personnel will make up the team and what model of service delivery may work best. Using resources that are already in place, particularly if new staff cannot be added due to budget constraints, provides a place to begin. This might require redefining existing job descriptions to include responsibilities for palliative care and providing appropriate education in palliative care principles and approaches to care.

There are clearly some basic services that any program should have in order to offer good pediatric palliative care. **Essential program and process elements** encompass what the program will do, who will do it and how. Of primary importance is an interdisciplinary approach that is family centered and focuses on the family's physical, social, psychological, and spiritual needs. Additional important program elements include: an individualized written plan of care that reflects the family's needs and choices and is flexible as the child's status changes; some measures of quality of care and outcome; identified individuals who can assist families with care coordination. A care coordinator who understands PCC and has good knowledge of the available resources and services for this population can ensure implementation of the family's

individualized plan of care, and provide continuity across all venues. Education of providers not only on the principles of palliative care but also on the communication skills necessary to ensure they listen to families' needs and involve families in the decision-making process throughout the course of their child's illness.

The major **strategy for implementation** is to initiate education and training of the staff, adapt personnel resources through either the expansion or realignment of traditional roles, and address the impact on any budget considerations. Most military treatment facilities will probably start small and build a PPC care program gradually. It may work well to begin with a clinic or unit with a large population of children with life-threatening conditions whose staff may be more receptive to the concept of pediatric palliative care, such as the Pediatric Intensive Care Unit, Neonatal Intensive Care Unit, or Hematology/Oncology service. Efforts to identify "turf" issues early to avoid confrontation and consideration of first offering support as a consultant to the existing care team may help provide a successful beginning.



APPENDIX 1

CHI Program for All-Inclusive Care

for Children and Their Families[™] (CHI PACC[®])

CHI PACC[®] Standards of Care and Practice Guidelines

A CHI PACC[®] program provides a continuum of care for children and their families from the time that a child is diagnosed with a life-threatening condition, with hope for a cure, through the bereavement process, if cure is not attained. The CHI PACC[®] program's integrated, coordinated continuum of care is provided across all settings, 24 hours a day, 7 days a week.

May 2003

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Introduction

PURPOSE

The CHI PACC[®] Standards listed below outline basic essential model of care components for the development of local Programs of All-Inclusive Care for Children/Adolescents who are diagnosed with life-threatening conditions and the members of their families. The goal of CHI PACC[®] is to expand access to curative and palliative services beyond the scope of traditional hospice benefit.

The accompanying CHI PACC[®] Practice Guidelines represent best practices in the goal of providing optimal curative and palliative care to these children/adolescents and families. CHI PACC[®] programs are expected to continuously evaluate and improve the quality of the services and supports provided to program participants.

STATUS

CHI PACC[®] is an authorized demonstration program administered by Children's Hospice International in collaboration with the Centers for Medicare & Medicaid Services (CMS) and the United States Department of Defense. This program provides an opportunity to establish CHI PACC[®] projects with federal waivers or other mechanisms that remove existing regulatory barriers and redistribute funding.

PROGRAM EXPECTATIONS

The CHI PACC[®] Standards outline the components of the model of care. CHI expects that programs will establish plans by which the Standards will be implemented in an orderly, timely manner with timelines and measurable objectives.

The CHI PACC[®] Practice Guidelines outline the components of a fully developed CHI PACC[®] program. CHI expects that programs will establish plans by which the Practice Guidelines will be implemented in a manner that facilitates the provision of optimal care.

STANDARDS OF CHI PACC[®]

Implementing CHI PACC[®] Standards with their accompanying Practice Guidelines will assist CHI PACC[®] programs to establish health care systems which will help implement the new model of care. The following is a list of the core Standards of the CHI PACC[®] model, which must be adhered to in the development of any CHI PACC[®] program.

1. Creation of a continuum of care integrating provider organizations, community-based organizations, professionals and volunteers into one unified interdisciplinary team, providing any medical, nursing, psychosocial, or spiritual service needed for the child or

- family unit.
2. Integrations of a curative care with palliative care and community-based supportive services.
 3. Establishment of a system of comprehensive care with one point of entry providing a wide range of interdisciplinary services available from the time of diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation into an adult program of care, or if necessary, the provision of bereavement counseling.
 4. Redistribution of funding in order to increase the range of services available in the community and to ensure that the funds follow the child/family into the most appropriate treatment setting.

EXPECTED GENERAL CLINICAL OUTCOMES

The CHI PACC® Standards/Practice Guidelines establish a functional framework in which clinicians are not restricted by artificially limiting provider regulations and reimbursement. This model allows for the development of responsive client-based, client-determined, systems of clinical care with improved clinical outcomes and consumer satisfaction. These outcomes will address:

1. Early implementation of palliative care integrated with medical treatments of the life-threatening condition with the goal of addressing quality of life needs and issues through palliative care.
2. Expanded availability of home and community based services to reduce dependence on institutional care.
3. Enhanced support services to maintain family cohesion, sense of control, satisfaction with care, and informed decision making.
4. Facilitation of transitions from settings of care due to progression of condition.
5. Advanced preparation and support of families when end-of-life care becomes imminent.

EXPECTED FINANCIAL OUTCOMES FOR PAYERS CHI PACC®

The implementation of CHI PACC® programs will have a “cost neutral” impact upon the total expenditures of public and private payers. This will be achieved by cost-offsetting to fund expanded palliative care services through reducing expenditures in the following ways:

1. Preventing unnecessary Emergency Room and Hospital admissions.
2. Facilitating earlier discharges from hospitals into home care.
3. Performing some treatments and procedures, such as chemotherapy, at home.
4. Supporting families to provide end-of-life care at home rather than the hospital, as appropriate.
5. Providing “hospice in the hospital” when it is appropriate for a terminal admission.

TECHNICAL ASSISTANCE

CHI is available to answer any questions regarding the satisfaction or implementation of these Standards/Practice Guidelines. For assistance, please contact CHI at 800-2-4-CHILD, or at info@chionline.org.

DESCRIPTION OF KEY TERMS

All Settings of Care:	Describes any location in which services are provided, such as home, clinic, respite facility, hospital, etc.
Child/Adolescent:	Identifies anyone within program defined guidelines who is eligible for admission to a CHI PACC [®] program due to diagnosis of a life-threatening condition, regardless of chronological age, developmental stage, or gender.
Comprehensive Care:	Describes broad range of interdisciplinary services available in all settings of care to meet the medical, nursing, psychosocial, spiritual, and practical concerns and needs of those served by a CHI PACC [®] program.
Concurrent Care:	Care that integrates treatments aimed at cure or disease management with treatments aimed at managing symptoms through palliative care.
Continuity of Care:	Describes consistency in care and services across the entire continuum of care due to the portability of the plan of care and its goals in all settings of care, including ease of transitions from one setting to another.
Continuum of Care:	Describes the “seamless” array of services and providers available from the beginning of care at diagnosis, onset, or time of referral, through the attainment of cure/remission, the graduation to an adult program of care, or the completion of bereavement of care.
Diagnosis of Life-threatening Condition:	A formal evaluation made by a licensed physician indicating the existence of a condition that has the potential of limiting the life-expectancy of the child/adolescent.
Disease Treatment:	Medical interventions and procedures implemented by written orders of a licensed physician intended to treat the condition that is threatening the life-potential of a child/adolescent, whether the goal is the hope of eliminating the condition, achieving remission of the progression of the condition, or extending the life-potential of the child/adolescent without altering the basic underlying condition.
Family:	Identifies those persons who constitute the inner circle of physical, psychosocial, spiritual, and emotional relationships with the child/adolescent who is diagnosed with a life-threatening condition.
Children/Adolescents With Life-Threatening Categories:	Children/adolescents who fall into Conditions: <ol style="list-style-type: none">1. Children/adolescents for whom curative treatments are possible and likely to succeed, and who could benefit from palliative care.2. Children/adolescents for whom curative treatments are possible and fail, and who need palliative care.

3. Children/adolescents for whom extensive periods of curative or palliative treatment may extend their lives, even though death is likely.
4. Children/adolescents with chronic and/or progressive conditions for which there is no cure and whose treatment is primarily or exclusively palliative.
5. Children/adolescents with severe neurological disabilities causing susceptibility to complications which affect the child/adolescent's ability to function or quality of life, and symptoms causing discomfort.
6. Children/adolescents and families who are likely to experience a great deal of distress, disruption and suffering as a result of the condition.

Palliative Care:	An approach to provide total comprehensive comfort-oriented care for children/adolescents/families as a whole and whose purpose is to enhance quality of life, minimize suffering, relieve causes of distress, and provide emotional and spiritual support through interdisciplinary services and interventions.
Parent:	Identifies the individual(s) who have the legal or guardianship responsibility for the well-being and care of the child/adolescent diagnosed with a life-threatening condition.
Program of All-Inclusive Care:	Model of care providing enhanced services to children/adolescents with life-threatening conditions and their families.
CHI PACC [®] Program:	An organized program qualified to participate in the Children's Hospice International demonstration project for children/adolescents diagnosed with life-threatening conditions and the members of their families, abbreviated CHI PACC [®] .
Referral:	The point at which a physician, upon identification of a life-threatening condition, or symptoms of a life-threatening condition affecting the ability of a child/adolescent to function and/or have an acceptable quality of life, contacts the local CHI PACC [®] program for the child/adolescent to be considered for admission.

Principles of Care with Practice Guidelines

ACCESS TO CARE

Principle:

Children and adolescents diagnosed with life-threatening conditions and the members of their families have ease of access to a comprehensive, coordinated, competent continuum of care in their communities.

Practice:

- A.C.1. Outreach plans are implemented across all geographic areas in which CHI PACC[®] programs are available, in order to ensure eligible families, providers, and community organizations have adequate information to facilitate referral to the program. Programs must be comprised of adequate professional medical, social, and supportive staff to serve the needs of those eligible families in the program's service area.
- A.C.2. CHI PACC[®] services are culturally relevant, sensitive, and available to children/adolescents and families of the diverse cultures within the program's service area, and in language that is understandable.
- A.C.3. CHI PACC[®] program provides communication supports to assist children/adolescents and family members that are sensory or cognitively impaired.
- A.C.4. The CHI PACC[®] program provides organized outreach, ongoing education, accurate information about services, and timely resources to all potential referrers to the CHI PACC[®] palliative care program to enhance their ability to identify potentially appropriate children/adolescents and families for referral.
- A.C.5: Children/Adolescents in CHI PACC[®] Programs have access to treatments and therapies aimed at cure, condition modification or life extension concurrent with and integrated with treatments and services aimed at palliative care goals throughout the entire course of their care.

CHILD/ADOLESCENT/FAMILY AS UNIT OF CARE

Principle:

The CHI PACC[®] care continuum provides care that is consistently child/adolescent oriented and family-centered in its philosophy, values, practices and operation. All care seeks to support and enhance the life-experience and its quality for each child/adolescent/family unit as defined by their culture, values, beliefs, priorities, circumstances, choices and structure.

Practice:

- U.C.1. Care is provided to children/adolescents within the context of each one's age, developmental stage, level of understanding, communication ability, as well as severity of life-threatening condition and its symptomology. Each child/adolescent's own interest, hopes, fears, values, beliefs, and needs are solicited to ensure to the fullest degree possible the integration of the child/adolescent's own point of view and perspective in planning, implementing and evaluating services.
- U.C.2. Care is available to all members of the family according to assessed needs and individual choice, including siblings, parents, grandparents and/or other individuals significant to the family unit.
- U.C.3. Care affirms the uniqueness and distinctiveness of each family's own system of inter-relationships, roles, decision-making processes, and organizational structure.
- U.C.4. Care is implemented to encourage and assist each child/adolescent/family unit to live as normal as is possible under existing circumstances, continue in their customary roles and activities as much as possible and participate in the communities of which they are a part.
- U.C.5. Each family unit is assessed in order to establish a plan for meeting the ongoing family member's involvement in caregiving at home. Each family is provided education, training and support for its care giving activities and responsibilities. Careful attention is given to helping families be open to receiving additional support through volunteers, respite care, ancillary staff support, as well as assistance from others in the community.

ETHICS

Principle:

The CHI PACC[®] program operates its services for children/adolescents and family members according to generally accepted ethical standards.

Practice:

- E.1. CHI PACC[®] service staff respect and honor the individuality, uniqueness, and humanness of each child/adolescent and family member, ensuring their inclusion in decision-making to the full extent possible, and consistent with the beliefs and values of their culture, spirituality and family structure.
- E.2. CHI PACC[®] program staff ensures the appropriate, necessary, and responsible use of all information about each child/adolescent and family member, and protects the confidentiality of all communications, documents, records and materials from unauthorized exposure or use.
- E.3. CHI PACC[®] service staff ensures that each child/adolescent and family member receives information concerning the life-threatening conditions, diagnosis, condition trajectory, treatment options and their side effects, symptoms and their treatment options and side effects, and their quality of life implications in language understandable to them, and within a supportive respectful communication environment.
- E.4. CHI PACC[®] program staff ensures that its services are available and accessible to any child/adolescent diagnosed with any life-threatening condition and family members without discrimination for reason of age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program.
- E.5. The CHI PACC[®] service staff implements treatments and services whose intentions are designed to achieve the maximum beneficial child/adolescent and family outcomes possible with the least amount of negative impact possible on quality of life goals.
- E.6. The CHI PACC[®] program staff insures that its resources provide adequate support for the services provided and the continuing development of the program and an appropriate system of accountability is in place.
- E.7. The CHI PACC[®] program staff provides an ethics consultation and educational service to assist program personnel, family members and the child/adolescent living with a life-threatening condition when there are conflicts about choices for services and treatments.

MANAGEMENT AND OPERATIONS

Principle:

The CHI PACC[®] program is a comprehensive integrated continuum of services operating according to nationally recognized standards of care, evidence based treatments, and best practices. It is accountable to all appropriate licensure, regulatory and accreditation bodies and to the communities in which the families and children/adolescents live.

Practice:

- M.O.1. The CHI PACC[®] program establishes and maintains current, accurate, adequate and comprehensive management of all aspects of the program, provides all needed services, manages all personnel, coordinates all collaborative relationships, assures fiscal, clinical, and managerial accountability and ongoing evaluation and program improvement and development.
- M.O.2. The CHI PACC[®] program operates within the requirements all local, state and federal laws and regulations that govern the establishment and delivery of CHI PACC[®] services by various providers, as well as qualifications of professionals and volunteers delivering services.
- M.O.3. The CHI PACC[®] program provides a clear, accessible and responsive grievance procedure for children/adolescents and family members which outlines how to voice concerns or complaints about services and care without jeopardizing their relationship to the CHI PACC[®] program or access to needed services.
- M.O.4. The CHI PACC[®] program ensures that all personnel, including administrative, managerial, clinical, supportive and voluntary are qualified and oriented for their positions and responsibilities, operate with a current accurate job description, have a designated supervisor/administrator, have access to appropriate support and ongoing training and skills building, and are evaluated on a routine basis by criteria based on their job description and responsibilities.

INTERDISCIPLINARY TEAM

Principle:

Children/adolescents living with life-threatening conditions and the members of their families have a wide range and intensity of ongoing and changing stresses, needs, problems and hopes requiring care. This complex need for care requires the expertise and competence of many disciplines, perspectives and skills working together as an integrated, comprehensive, coordinated team to provide effective care.

Practice:

- I.T.1. The CHI PACC[®] core team is staffed by an appropriate and representative range of medical, nursing, psychosocial and spiritual professionals, ancillary and support personnel, and volunteers adequate to meet the need for care. The team incorporates and integrates members of many disciplines, and may include pediatricians, pediatric medical and nursing specialists, advance practice nurses, high tech nurses, physician specialists, physician assistants, nurse assistants, social workers, chaplains, home health aides, home makers, in-home respite workers, physical therapists, occupational therapists, speech and language therapists, nutritionists, art therapists, music therapists, play therapists, recreation therapists, pediatric psychiatrists and/or psychologists, massage therapists, and others according to their availability in the program service area.
- I.T.2. The CHI PACC[®] core team is responsible to provide ease of admission, comprehensive assessments, identification and clarification of goals of care, development and implementation of a current plan of care, facilitate continuity of care in all settings, provide effective symptom management, counseling and supportive services for those it serves, including end-of-life care as appropriate.
- I.T.3. The child/adolescent and family are included as members of the team assigned to their care, and encouraged to manage the care according to their desire and abilities.
- I.T.4. The CHI PACC[®] core team has a qualified medical director, nurse manager and psychosocial/spiritual care coordinator/supervisor, and a designated team coordinator.
- I.T.5. The CHI PACC[®] core team establishes and maintains an effective system to ensure timely sharing of information between all team members and the coordination of services.
- I.T.6. The CHI PACC[®] core team collaborates and coordinates care with the professionals in other settings.
- I.T.7. CHI PACC[®] core team members are qualified in their particular discipline, role and

responsibilities by training and/or experience, and certification and/or licensure when appropriate or required.

- I.T.8. CHI PACC[®] core team members receive educational, emotional and spiritual support appropriate to their roles and responsibilities, setting of care, and need.
- I.T.9. Essential medical, nursing, psychosocial and spiritual services are available to children/adolescents and family members 24 hours a day, each day, in all settings of care.
- I.T.10. In communities in which particular pediatric, medical or palliative care expertise is not available, the team has a documented plan and method to access that expertise.

ADMISSION PROCESS

Principle:

The CHI PACC[®] program maintains a barrier-free process which facilitates ease of entry into the program for children/adolescents and their families, timely response to initial and presenting needs and problems, and access to on-call care at the time of admission.

Practice:

- A.P.1. The CHI PACC[®] program provides ease of entry into its services for children/adolescents and their families and monitors the process of admission, recognizing that at the time of referral, many children/adolescents and families may be in crisis and need immediate care.
- A.P.2. An initial plan of care is established promptly after admission to guide care and services, (recognizing that it may take time to develop a trusting relationship between the child/adolescent and family and CHI PACC[®] staff) to assess the comprehensive needs of the child/adolescent and each family member, respond to presenting needs or problems, negotiate goals of care, receive, disseminate and evaluate all relevant and necessary information from the child's/adolescent's primary medical team and/or hospital.
- A.P.3. The CHI PACC[®] program acquires all necessary and needed demographic information, relevant medical history, and documentation about disease management and/or medical therapies at the time of referral and admission.
- A.P.4. Admission to the CHI PACC[®] program is made on the basis of the need for care and criteria for CHI PACC[®] eligibility without regard to age, gender, racial or ethnic origin, national origin, geographic location in service area, language, religion or

spirituality, sexual orientation, diagnosis, disability, family structure or status, ability to pay or potential cost of care to the program.

- A.P.5. CHI PACC[®] program eligibility criteria are available in language and terminology understandable to nonprofessionals, and family members and available in the primary languages spoken in the service area.
- A.P.6. Admission to CHI PACC[®] program is admission to the entire continuum of care and its comprehensive system of services.

COMPREHENSIVE ASSESSMENT PROCESS

Principle:

Comprehensive interdisciplinary assessment instruments are utilized by the CHI PACC[®] care team to insure that the goals of care and plan of care are based on needs identified as important to the child/adolescent and family. This assessment process is ongoing as needs, circumstances and hopes change during the course of care in response to the progression of the child/adolescent's life-threatening condition and its symptomology.

Practice:

- C.A.P.1. CHI PACC[®] interdisciplinary staff members assess the comprehensive ongoing physical, psychosocial, emotional, spiritual, practical and financial situations, circumstances, needs, hopes, concerns and goals of each child/adolescent and family member, from the time of admission and continuing throughout the entire course of care, including end-of-life care and bereavement.
- C.A.P.2. CHI PACC[®] team assessments take into consideration the child's/adolescent's developmental stage, spirituality, diagnosis, trajectory of life-threatening condition, treatment choices and protocols, and progressive symptomology, whether caused by the progression of the condition or its treatments.
- C.A.P.3. CHI PACC[®] team assessments are made within the understanding, language, culture, values, beliefs, hopes, family structure and social context of each child/adolescent and family.
- C.A.P.4. CHI PACC[®] team assessments are utilized to gather all the information needed for implementing services, and to provide a means for CHI PACC[®] staff members to build relationships with each child/adolescent and family, offer education and information about choices and options, and provide support.

GOALS OF CARE

Principle:

Consistent goals of care guide the establishment and implementation of all services in all care settings and by all providers of services. These goals reflect the culture, hopes, values, beliefs and quality of life needs of children/adolescents and their families in response to the assessed situation of the life-threatening condition. The goals are utilized to establish the integrated treatment of the disease or life-threatening condition along with the palliative care plan of care and array of services to be provided. All medical treatment goals and palliative goals are in response to the goals of the child/adolescent/family.

Practice:

- G.O.C.1. In order for children/adolescents/families to formulate reasonable, realistic goals of care within hope for cure, the most accurate truthful information is provided about the condition diagnosed, its symptomology, treatment options and their side effects and expectations, life expectancy, possible family burden, and opportunities for quality of life.
- G.O.C.2. The CHI PACC[®] Interdisciplinary Team collaborates with the primary care/disease management personnel and palliative care personnel to assess each child/adolescent's and family's life goals to offer best practices and supportive services to the child/adolescent and family within the context of these goals.
- G.O.C.3. The CHI PACC[®] Interdisciplinary Team establishes methods to evaluate, re-assess and adjust both the global and specific goals of care throughout the progress of the life-threatening condition and its care.
- G.O.C.4. The CHI PACC[®] Interdisciplinary Team utilizes the child/adolescent's and family's goals to frame discussions, education, and decision-making regarding the progression of the life-threatening condition, its symptomology, treatment options and achievable results.
- G.O.C.5. The CHI PACC[®] Interdisciplinary Team members who are directly responsible for the care of each child/adolescent and family unit, orient staff members in all settings of care to the child/adolescent and family's life goals, disease-treatment goals, and the palliative care goals as settings of care change.
- G.O.C.6. The CHI PACC[®] Interdisciplinary Team members responsible for the care of each child/adolescent/family unit ensure that discussions concerning the goals of care and their implications for services are conducted with language and vocabulary understandable to them, are done in a way that empowers the decision making choices of child/adolescent and family, and provides emotional and spiritual support.
- G.O.C.7. The CHI PACC[®] Interdisciplinary Team members responsible for the care of each child/adolescent/family unit recognize that there will be times and occasions in

which the child/adolescent and family members will experience ambiguity, conflict and/or unrealistic expectations regarding the goals of care, treatment therapies, and choices available to them, as well as potential differences about those choices, and their potential results. This ambiguity and/or conflict also may be present in the CHI PACC[®] team members and/or disease treatment professionals as well. Every effort is made to resolve the occasions through processes of mediation, consensus building, and provision of support, counseling and education.

- G.O.C.8. The CHI PACC[®] program provides support to and advocacy for the child/adolescent/family when there is a disconnect between the culture, values, and goals of the child/adolescent/family and those delivering services in any setting. A process of mediation and consensus building should be utilized to resolve occasions of conflict over the goals of care and their implications for services, procedures and treatments.

PLAN OF CARE

Principle:

An up-to-date comprehensive written plan of care is individualized to meet the specific needs, hopes and goals of each child/adolescent and family, addresses the medical, nursing, psychosocial, spiritual, and practical concerns and problems they have identified with achievable outcomes and results, and integrates the activity of the team implementing *medical* treatment services and the team implementing *palliative* services.

Practice:

- P.O.C.1. The CHI PACC[®] Interdisciplinary Team establishes a comprehensive plan of care appropriate for each child/adolescent and family based on comprehensive ongoing assessment of needs, hopes and goals identified by the child/adolescent and family unit.
- P.O.C.2. CHI PACC[®] Interdisciplinary Team members monitor the plan of care integrating treatment goals and procedures of the life-threatening condition and palliative care goals and services.
- P.O.C.3. The CHI PACC[®] Interdisciplinary Team ensures that each child/adolescent and family has direct input into the creation and establishment of the plan of care.
- P.O.C.4 The CHI PACC[®] plan of care identifies a family member and a CHI PACC[®] team member, as the point of contact for the coordination of services and care, and the resolution of problems.
- P.O.C.5. The CHI PACC[®] Interdisciplinary Team monitors, reviews and revises each plan of

care on a regular and ongoing basis as goals, needs and hope change and the disease and symptoms progress.

- P.O.C.6. The CHI PACC[®] Interdisciplinary Team establishes mechanisms to ensure the portability of the plan of care in all settings of care and communication with staff members of the plan of care when a change in the setting of care occurs.
- P.O.C.7. The CHI PACC[®] program ensures that appropriately signed consents are negotiated and documented for the initiation or withdrawal or withholding of treatment.

CONTINUITY OF CARE

Principle:

CHI PACC[®] service delivery is based on a therapeutic relationship between child/adolescent, family members, and CHI PACC[®] team members. It maintains an integrated coordinated continuum of community based home care, out patient services, respite care, supportive services, primary medical and inpatient care, end-of-life care, and community services. The CHI PACC[®] team ensures continuity and consistency of care, in any setting, is provided from the time of admission to the conclusion of bereavement services or discharges from the program and provides a system of care management to assist each child/adolescent/family unit. This continuity also extends to relationships important to the child/adolescent and family, such as school, religious affiliation, and community activities.

Practice:

- C.C.1. CHI PACC[®] medical, nursing, psychosocial and spiritual care is available on a consistent basis, 24 hours a day in all settings of care, to child/adolescent and family members.
- C.C.2. Appropriate members of the CHI PACC[®] program are available to children/adolescents and families at all times when the office is closed.
- C.C.3. The CHI PACC[®] program has a communication system that ensures the confidentiality and privacy of child/adolescent and family information, can be used to update team members about each child/adolescent's and family's status, and facilitates a timely response to changing needs and or problems.
- C.C.4. The CHI PACC[®] program has a functioning continuum of care that ensures the portability of goals of care and the plan of care, and access to needed services as settings of care change.
- C.C.5. The CHI PACC[®] program maintains all required and appropriate documents and clinical records, maintains their confidentiality, ensures their safety, and appropriate

clinical use.

- C.C.6. The CHI PACC[®] program has written policies and procedures for transitioning a child/adolescent who reaches adulthood and the family to the new legal status of the child/adolescent, which includes continuity with changes in providers, payer sources, status of legal documents, and treatment options and choices.

SYMPTOM MANAGEMENT

Principle:

The range and intensity of symptoms which cause distress to the child/adolescent and family are managed to achieve the most attainable quality of life for child/adolescent and family within the context of their culture, beliefs, values and goals. Children/adolescents and their families must have access to care which is both competent and compassionate.

Practice:

- S.M.1. The CHI PACC[®] Interdisciplinary Team assesses all symptoms which cause distress or discomfort, whether as the result of progression of the life-threatening condition or its treatment.
- S.M.2. The CHI PACC[®] Interdisciplinary Team identifies each distressing symptom, such as pain, dyspnea, fatigue, loss of appetite, loss of body image, constipation, diarrhea, vomiting, and loss of sleep and assesses each for its etiology, best practice evidence-based treatments, and range of choices for treatment.
- S.M.3. The CHI PACC[®] Interdisciplinary Team members discuss, evaluate and implement complementary, alternative and culturally relevant therapies and treatments important to children/adolescents and their families as appropriate to enhance the therapeutic environment.
- S.M.4. Members of the CHI PACC[®] Interdisciplinary Team provide clear, accurate information about evidence-based treatments and alternatives as objectively as possible to each child/adolescent and family to assist them in making the most appropriate choices for treatment options according to their own values, beliefs and goals.
- S.M.5. The CHI PACC[®] Interdisciplinary Team encourages consistency of symptom management services and treatments in all settings of care by all providers of care.
- S.M.6. The CHI PACC[®] program has clinical expertise through a competent medical and nursing staff to provide effective state-of-the-art symptom management, and access to specialists as may be required or needed.

COUNSELING AND SUPPORTIVE CARE

Principle:

The diagnosis of a child/adolescent at any age or stage of development with a life-threatening condition initiates a life-changing crisis within the family that turns their world, customary roles, activities, assumptions and expectations of each member “upside down.” These children/adolescents and family members must have access to a comprehensive, coordinated, competent continuum of counseling and supportive services to assist them with the physical, emotional and spiritual issues, interpersonal dynamics and psychosocial dimensions of their experience.

Practice:

- C.S.C.1. The CHI PACC[®] Interdisciplinary Team identifies the initial ongoing and changing physical, psychosocial, emotional and spiritual issues, concerns, conflicts, priorities and needs of each child/adolescent and family member, assesses and evaluates each for the most appropriate response, integrates this into the written goals and plan of care, and assigns appropriate team members to implement services.
- C.S.C.2. The CHI PACC[®] program does not require or advocate a “right way” for children/adolescent and a family member to believe, cope, make decisions, grieve, or die but recognizes the deeply personal and individual nature of this experience. CHI PACC[®] team members provide counseling and supporting services which build upon each family member’s own emotional and spiritual strengths, coping mechanisms, priorities, communication styles, belief and value systems, cultural and ethnic values, and social resources.
- C.S.C.3. The CHI PACC[®] program facilitates the provision of adequate counseling and supportive services in all settings of care.
- C.S.C.4. The CHI PACC[®] program has clinical expertise through competent counseling, social work and chaplain staff, as well as childlife and childcare specialists.

VOLUNTEER SERVICES

Principle:

Trained and screened volunteers provide an opportunity for members of the community, including children and adolescents, to become directly involved in the care of children/adolescents living with life-threatening conditions, their families and the bereaved, as well as to serve the CHI PACC[®] program in other supportive and organizational capacities.

Practice:

- V.S.1. The CHI PACC[®] program has a structured, organized and active volunteer program adequate to support the care needed by children/adolescents and their families, as well as to meet other needs within the CHI PACC[®] program for volunteer support.
- V.S.2. The CHI PACC[®] volunteer program is managed by a designated, qualified supervisor/coordinator that is a member of the CHI PACC[®] Interdisciplinary Team and meets regularly with them.
- V.S.3. CHI PACC[®] program volunteers are considered non-salaried staff members and are managed and supervised accordingly.
- V.S.4. All volunteers are appropriately recruited, screened, trained, assigned, supervised and evaluated on the basis of their roles and responsibilities.
- V.S.5. Volunteers may include children and adolescents.
- V.S.6. CHI PACC[®] volunteer services to children/adolescents and families are initiated according to the assessed need and consent of the child/adolescent and family.
- V.S.7. CHI PACC[®] volunteers have access to an organized program of ongoing education and support.
- V.S.8. CHI PACC[®] volunteer services are documented and reports provided on kinds of services provided, hours of services provided and other activities undertaken, as well as the financial value of these services to the program.

BEREAVEMENT PROGRAM

Principle:

Family members of children/adolescents who die may continue to need supportive and/or professional services following the child's/adolescent's death for a period of time that varies among families and family members. The overall goal of bereavement care is to assist family members to reintegrate themselves into the communities of which they are a part and to find their long-term support in their communities.

Practice:

- B.P.1. The CHI PACC[®] program has a structured, organized, adequate program of bereavement services for surviving family members and/or significant others, including linkage to support organizations and services in the community.
- B.P.2. The CHI PACC[®] bereavement program is managed by a designated, qualified supervisor/coordinator who is a functioning member of the CHI PACC[®] Interdisciplinary Team and meets regularly with them.
- B.P.3. The CHI PACC[®] bereavement program has professional and/or volunteer staff members adequate and competent to meet the range of services needed by family members, including siblings.
- B.P.4. The CHI PACC[®] Interdisciplinary Team members who were involved in the care of families before the child died provide an assessment of the level of risk and need for services of the bereavement program by family members.
- B.P.5. All CHI PACC[®] professional and volunteer staff members in other settings of care have access to bereavement services as needed.
- B.P.6. The CHI PACC[®] bereavement program establishes a written bereavement plan of care based on an assessment of needs for each family member receiving bereavement services until the person is discharged from the program.
- B.P.7. The CHI PACC[®] bereavement team members have access to an organized program of education, supervision, support and evaluation.
- B.P.8. CHI PACC[®] bereavement services are documented and reports provided on services and their utilization.

RESEARCH & EVALUATION

Principle:

The CHI PACC[®] care program acknowledges the importance of developing evidence to support the most effective care practices for children, families, providers, and health systems concerning comprehensive services for children diagnosed with life-threatening conditions and their families. CHI PACC[®] programs accept the responsibility to participate in a variety of research activities, including those that may have scientific value or others that may guide program improvements or meet reporting requirements. These diverse research activities will occur in community and clinical care settings, and shall extend to bereavement services as appropriate. While these research activities may vary in methodology and setting, they will all provide opportunities for patients, families and providers to assess the performance of programs and services in systematic, confidential, and valid ways. These research activities will share the general purposes of improving the quality of pediatric care and promoting optimum outcomes for patients, families, providers, and health systems. These research efforts will strive to be culturally competent and family-centered in their approach to conceptual and measurement issues. Because of the need to generate new knowledge in this area, CHI PACC[®] programs further accept the responsibility to protect the rights of patient privacy and to understand and guard against any potential harm, including psychological burden, to families and patients who participate in ongoing research and/or evaluation activities.

Practice:

- R.E.1. The CHI PACC[®] program has a defined and timely research agenda, plan, and structure for implementation.
- R.E.2. The CHI PACC[®] program staff at all levels is educated to the importance and necessity of research, its different approaches and methods, and requirements for the protection of human subjects. CHI PACC[®] program staff also is encouraged to initiate and/or participate in research activities.
- R.E.3. The CHI PACC[®] program provides resources to support the research activities it undertakes.
- R.E.4. THE CHI PACC[®] program encourages research collaborations locally and nationally to expedite the process of generating new knowledge and establishing clinical consensus.
- R.E.5. The CHI PACC[®] program has an organized and effective way to facilitate communication and sharing of tools and knowledge to others who are providing comprehensive pediatric care, including palliative and end-of-life care.
- R.E.6. The scope of outcomes that are relevant to the quality of care in pediatric services include outcomes across the care continuum and extend to bereavement care. The focus of outcomes are broad and span patient and family satisfaction, quality of life, provider satisfaction, cost-effectiveness, clinical performance, and health systems change.
- R.E.7. The CHI PACC[®] program participates in national cross-site type evaluation studies as

needed and supports the collection of nationally-based data, criteria, and evaluation information over and above information needed for program specific goals.

- R.E.8. The CHI PACC[®] program has methods and procedures for monitoring, evaluating and improving its performance in meeting its most fundamental assumptions of access to a continuum of integrated disease management and palliative care from the time of diagnosis, with hope of cure, until the time of discharge from the program, as well as consistency of care across all settings of care and cost effectiveness.
- R.E.9. The CHI PACC[®] program has an organized, effective and consistent way in which professional and volunteer staff members evaluate the effectiveness and adequacy of its policies and procedures, outreach, services, programs, management, and governance.
- R.E.10. The CHI PACC[®] program has an organized, effective method by which primary care pediatricians, professionals in disease and treatment, and key staff members in other collaborative settings and/or programs of care evaluate the effectiveness of the CHI PACC[®] program, its operation and services.
- R.E.11. The CHI PACC[®] program provides all reports, data and documentation required by funders and constituents in a timely, accurate manner.
- R.E.12. The CHI PACC[®] program participates in all required activities which foster the development and expansion of the national CHI PACC[®] model.
- R.E.13. The CHI PACC[®] program has an up-to-date written program for program improvement and utilization review.

GOVERNANCE AND ADMINISTRATION

Principle:

The governance and administration of, or for the CHI PACC[®] program, establishes, supports, and develops the program as a priority to meet the needs of children/adolescents and families in the community and/or region it serves. Governance may be achieved through an independent Board of Directors or an Advisory Board.

Practice:

- G.A.1. The governance structure for the CHI PACC[®] program insures that its mission, vision, general policies, and range of services implement the national CHI PACC[®] program standards to meet the needs of children/adolescents with life-threatening conditions and the members of their families in the program's service area.

- G.A.2. The governance structure of the CHI PACC[®] program includes a broad representation of its service area, including diverse community representatives, professional and/or industry representatives, and children/adolescents and family members, while protecting against incurring conflicts of interest.
- G.A.3. The governance structure of the CHI PACC[®] program insures the integrity and functioning of the CHI PACC[®] program by providing the level of resources necessary to provide the level of care, mix of services, and range of collaboration needed to meet the needs of children/adolescents and families throughout its service area.
- G.A.4. The CHI PACC[®] program director is accountable to an appropriate institutional administrator or governance structure.
- G.A.5. The administration and organizational structure of the CHI PACC[®] program is adequate and appropriate for its mission, principal functions, goals and objectives, requirements for services, and size of program.
- G.A.6. The CHI PACC[®] program has suitable, adequate, appropriate space, work and service environments, equipment, supplies, security and safety systems, communication systems, and other essential resources.
- G.A.7. The governance and administration of the CHI PACC[®] program participates in the ongoing development, refinement, and positioning of the CHI PACC[®] model and vision of care for children/adolescents and their families.

APPENDIX 2

CHI PACC® Needs Assessments for the DOD *m*Care Project Children's Hospice International – Z. Saunders July 15, 2004

CHI and the CHI PACC sites conducted a variety of needs assessments beginning in 1997 to identify problems in the current system of care for children with life-threatening conditions and their families and how best to address these to improve the quality and delivery of care.

Nationwide System and Structural Barriers

In 1997 CHI convened focus groups representing hospitals, home health and hospice agencies, public agencies, and professionals to identify system and structural barriers to optimal care for children with life threatening conditions that might be addressed in the design of the CHI PACC model

These barriers included:

- Admission to a hospice requires life expectancy of 6 months or less
- Admission to hospice means hope is abandoned
- Family must choose between hope for cure and supportive care
- Reimbursement is not available for respite, bereavement, expressive therapies
- Care is uncoordinated and there are gaps in the continuum of care
- Admission of pediatric cases is discouraged because of the expense

The system barriers lead to:

- Crisis driven and high cost care
- Institutional focus that results in ineffective and wasteful use of resources
- Disruption in family life, cohesion, resources that results in increased social cost
- Difficult access because of regulations and reimbursement restrictions
- Lack of early preparation for and access to end of life-care for the whole family.

Quality of Clinical Practice

Through a series of other meetings and discussions with similar groups, CHI identified problems in the current clinical practice for children with life-threatening conditions. These problems were addressed in the development of the CHI PACC Standards of Care and Practice Guidelines. The identified problems were organized as follows;

The Goals of Care:

- Plan of care specific to provider rather than consistent across all settings and providers.
- An almost exclusive focus on medical care in the acute care setting, while ignoring palliative care needs.
- Family and child often not included in care planning.

Integration of Disease Treatment and Symptom Management

- Unreliable and inconsistent assessments.
- Inadequate and ineffective symptom management and frequent failure to include family in decision making.
- Inconsistent availability of on-call medications in the community.

Advance Care Planning

- Discussions with parent and child on disease progression, treatment choices often do not occur.
- Child and parent choices are often ignored.
- Advance care planning often limited to signing a DNR form.

Coordination and Continuity of Care

- Medical records not available after hours.
- Long waits for urgent care.
- Difficult transfers in the last weeks of life including disruptions in medication.
- Care for multiple illnesses often fragmented.

Patient/Family Support

- Children/families feel alone, confused, and helpless.
- Care is not individualized.
- Cultural sensitivity is lacking.
- Children and families feel uncomfortable raising important concerns.
- Bereavement counseling and follow up is rare.
- Families must assume heavy financial burdens.

Care During the Time Near Death

- Contact with the care team is cut off after death.
- Family and child are not given realistic information about the disease trajectory.
- Symptoms near death are often endured rather than suppressed.
- Family and child's wishes regarding place and circumstances of death are often ignored.

State and Local Service Availability and Support

The CHI PACC sites also conducted needs assessments in their state and local areas in preparation for the design of their service and delivery package for children with life-threatening conditions. Although the primary focus of the CHI PACC programs is the Medicaid population, most of the needs assessments addressed a broader population including children covered under private insurance plans.

Utah conducted three different focus groups at two locations with parents of children who had died of a life-threatening condition within the past four years. Utah also conducted interviews with parents who were unable to attend the focus groups. The parents of 40 children were involved in the focus groups and interviews.

Kentucky contracted with another organization to conduct focus groups of parents who had children with life-threatening conditions, including those whose child had recently died. About 23 parents participated at five different locations.

In both Kentucky and Utah, parents were asked to discuss their experiences with the health care system from the point of diagnosis to bereavement including what was helpful and not helpful to them, and their suggestions for change. The major themes and concerns expressed by the parents in both Utah and Kentucky are summarized below.

Diagnosis/Information

- Families did not have adequate information about treatment options, the course of the disease and what to expect.
- Written and comprehensive information packets would have been helpful.
- Information and resources were more widely available to families whose child was diagnosed with cancer.
- Many parents sought and wanted to be linked to other parents who had experienced the same issues. Hospitals did not promote these linkages.
- Most indicated they wanted the physician to be frank and honest while maintaining a hopeful attitude.
- A number of parents expressed surprise that busy and important specialists took a personal interest in their child's welfare. Frequent calls, availability to answer questions, and support of the child and parent's choices demonstrated caring.

Care Coordination

- Families were often the primary coordinator of their child's care and none believed they received comprehensive case management that addressed medical, social, financial, and emotional aspects of their child's care. Care was often fragmented.
- Social workers who traditionally play this role were called in only when there was a crisis that the medical team did not want to address. Thus families felt no special rapport with the social worker, particularly in the hospital setting.
- Parents resented being asked the same questions over and over again, particularly when it seemed irrelevant or was already in the record.
- When multiple specialists were involved, it was difficult for parents to reconcile the different recommendations—"none of the doctors wants to take responsibility for the whole child."

- The child's pediatrician, who made the initial referral was usually out of the loop and was not necessarily interested in continuing to be involved.
- Coordinating with the child's school was often difficult and frustrating.
- Child and family in rural areas had the most difficulty accessing services and maintaining continuity of care.

Treatment – Hospital

- Medical practitioners ignored or failed to respect the parents' knowledge of his/her child.
- When treatment protocols were exhausted and child was considered terminal, the child and family felt abandoned by the medical team for there was often no further contact with this team.
- Families had difficulty generalizing about the quality of nursing care in the hospital because it was inconsistent and varied as much as the nurse on duty. Although some nurses were highly praised, parents felt they had to be vigilant to prevent medication and other errors.
- Rules in the newborn intensive care unit made it difficult for parents to care and bond with their infant.
- The family of the child who required frequent hospital visits experienced many hardships related to child care, transportation and lodging costs, missed work, etc. and there were few resources available to help them.
- Hospital had few accommodations for parents who wished to stay with their child.
- Although parents were trained to use equipment in the hospital, this equipment was not always the same equipment brought to their home.
- Many parents indicated they wanted to have more instruction in reading charts, vitals, labs, and pain symptoms so they could be more effective in monitoring their child's progress and care.
- Some parents felt their child was being treated as a guinea pig and they would have chosen to follow a different course had they been given more information.
- Families were frequently dissatisfied with care received in regional or community hospitals. Emergency room visits required long waits and staff was described as callous, inattentive, inexperienced, incompetent or arrogant.
- Parents recommended that medical staff including nurses receive sensitivity training.

- Almost all the families whose child had experience with child life specialists valued these contacts.

Home/Hospice Care

- Of all the services used during the course of their child's illness, families indicated the greatest satisfaction with home health or hospice care. This was the most critical service in helping them cope with their child's illness.
- Most families had no idea how much time and effort would be required to care for their child at home, including the performance of complex medical procedures. Training usually was begun at the hospital, just before discharge. Parents indicated they would have welcomed instruction earlier while their child was still in the hospital.
- The home health/hospice nurse was viewed as the "life line." They were often seen as a teacher, a surrogate parent to the parent, an advocate for the child, a shoulder to cry on, and the go between among all the other professionals who were involved. Since these individuals are pivotal in helping the family cope with the most painful experience of a life time, they must be exceptional. A positive relationship helps ease the pain for the child and all family members, while a negative relationship exacerbates the pain. Negative experience was more often encountered with agencies without pediatric expertise.
- Having to change home health or hospice provider because of a change in health insurance coverage, or other external circumstances usually resulted in a hardship for the child and family.
- All families needed some respite, but respite care was available to very few families. Many reluctantly relied on extended family to provide respite care. Employers who allowed parent to go on a flexible schedule were greatly appreciated.

Death/Bereavement

- Although the child's death was not unexpected, the timing of the child's death often was. Many parents felt they did not have adequate preparation or understanding of the dying process, even those with access to hospice.
- The opportunity to be close to their child and have other family members present, whether the death occurred at home or in the hospital was important for all families giving them a sense of control and closure.
- Many were overwhelmed by funeral arrangements, accommodating out-of-town family, calling the pharmacy and others involved in the child's care to notify them of the death.

- Many families relied on informal counseling provided through their church community to help them through bereavement, but often found this support inadequate though well meaning.
- Families did not value social workers who were sent in to provide counseling, after the fact, who were not part of the care team.
- Many families expressed appreciation for the doctor and nurse who acknowledged their child's death. When their child died, the support systems also vanished, magnifying the loss.
- Families who had access to the community and hospital-based bereavement newsletters, events, counseling found these helpful.
- Although grief counseling was available, it was not always accessible to other family members and siblings. Some indicated they needed counseling beyond the one-year deadline.
- All families attempted to make meaning of their loss from making donations to disease organization, to participating in memorial services, to writing about and sharing their experience, to joining support groups to help other families.
- Families with other children, expressed regret in not being able to meet the emotional needs of their other children during the illness. Marital problems and divorce occurred in some of the families.

Financial

- Health insurance generally covered most of the child's medical expenses, but some insurance carriers did not provide adequate coverage for home care.
- Some families were stretched financially or on the verge of bankruptcy, either because they gave up a job to qualify for Medicaid, to care for their child, or because of other expenses related to the illness.
- All families expressed frustration in dealing with insurance carriers. The companies seemed impenetrable and decisions seemed arbitrary. Navigating coverage issues, sorting incorrect claims, always with a different person was a full time job by itself. A few enlightened companies assigned a case manager, but this did not always help.

Services Needs and Gaps Assessment

Utah asked parents who attended the focus groups to rank the availability and adequacy of a list of services. The responses helped the Utah PACC program design its package of services.

RANKING OF SERVICES BY ALL RESPONDENTS

TIER	RANK	SERVICE	Availability Score (%)	Adequacy Score (%)
1	1	Insurance Coverage for Medical Services	100%	65%
2	2	Home Health / Nursing Care	91%	67%
	3	Medical Supplies and Equipment	95%	80%
	4	Case Management or Care Coordination	82%	53%
	5	Home Care Instruction for Parents	86%	74%
3	6	Pharmacy Services	90%	63%
	7	Pain and Symptom Management	81%	75%
	8	Spiritual Support	76%	87%
	9	Financial Information or Help	41%	36%
	10	Help in Navigating Insurance Coverage	23%	27%
	11	Information and Referral Services	76%	40%
	12	Bereavement Counseling	86%	67%
	13	Parent & Family Counseling & Support	77%	56%
	14	Parent-to-Parent Support	57%	29%
	15	Respite Care	53%	67%
	16	Home Therapy [e.g. Physical Therapy]	60%	67%
4	17	Housekeeping Help	23%	57%
	18	Play, Art & Music Therapy for the Child	53%	67%
	19	Child Care for Siblings	22%	14%
	20	Physician Home Visits	24%	38%
	21	Play, Art & Music Therapy for Siblings	40%	38%
	22	Transportation Assistance	6%	0%
	23	Home Modifications	19%	33%

New York State conducted their needs assessment through a web-based concept mapping system that provides a “more rigorous statistical basis for modeling needs.” In phase one, a group of advisory committee members participated in a brainstorming session to generate need statements. These were entered into the data base and then 12 advisory committee members were instructed to log on to the site and sort the items. Following the sorting, the importance was rated by the members on a scale of 1 to 5. This phase was then extended to colleagues who did the same.

The results of the brainstorming resulted in 74 unique needs statements contributed by 50 experts in pediatric palliative care. Children’s needs were placed in major clusters and ranked. The 10 highest-rated individual needs statements are shown in the cluster categories in the table below.

Major Clusters	10 Highest Cluster Ratings	Achievement Feasibility
Dignity-respect	2	*
Physical Support (Comfort)	4	*

Psychological Support	2	
Family Support		
System Access and Delivery	2	

A summary of conclusions from their report includes the following:

Dignity-respect – “dignity and respect deserve attention from program planners and evaluators as central aspects of a child’s life that should receive explicit attention in program planning and evaluation.”

Physical Comfort – The two highest ratings were “effective pain management” and “consistent pain assessment.”

Psychological Support – One third of the needs statements generated by experts reflected this item and include statements such as “love, access to peers, and fun.” They concluded “program planners may want to consider this as separate dimension in the assessment of child and family needs.”

Family Support Needs – This cluster varies with the individual family circumstances, geography, number of siblings, etc. ¹

Service System Access and Delivery – The top two items in this cluster included the barrier imposed by the 6-month limit on hospice and access to palliative care benefit from the time of diagnosis.

Survey of Utah Pediatricians

Utah also surveyed pediatricians at their annual meeting in Salt Lake City 2001 using an electronically administered survey to determine their training and information needs regarding children with terminal conditions. About 100 responded to the survey.

Results of Survey of Utah Pediatricians - June 2001

Questions	% Agree or Strongly Agree
1. I feel comfortable managing the terminal phase of my patient’s illness.	40%
2. I would benefit from additional training/education in pain and in the management of pain and other symptoms during the terminal phase of illness.	79%
3. I would find it helpful to have more information about existing	

¹ It is interesting to note that this cluster did not include any of the highest ratings. If parents and children had been included in the ratings, the results may be different. Although there had been plans to have parents and children participate in the web-based ratings, this has not occurred to date.

resources available to support families with a child with a life-threatening illness	90%
4. I am comfortable coordinating the communication between specialists and my patient when complex end-of-life issues arise.	58%
5. My patients with terminal illness and their families need better access to support services than they are generally able to access under our current system of health care delivery and financing.	66%

Other Parental Assessment of the Quality of Pediatric Palliative Care

Other researchers have attempted to assess parents experience regarding end of life care. Meyer² surveyed parents of 56 children who had died between 1994-1996 in the pediatric intensive care unit at two Boston hospitals. Contro³ interviewed 68 family members of 44 deceased children.

Meyer concludes “parents place the highest priorities on quality of life, likelihood of improvement, and perception of their child’s pain when considering withdrawal of life support. Parents make such decisions and garner psychosocial support in the context of a social network that changes over time and includes health care professionals, family, and friends.”

Recommendations include:

- Encouraging parents to share their views on withdrawal of life support to foster dialogue between parents and staff.
- Child’s quality of life, likelihood of getting better, perceived pain, and likelihood of survival need to be regular topics of discussion.
- Optimize the child’s pain management and educate parents about how pain is assessed and relieved.
- Educate parents about infrastructure of the health care team including who can best address their questions.
- Facilitate the involvement of community pediatricians, religious support persons, and palliative care programs during the hospitalization as a means to improve emotional support and continuity of care.

The Contro study identified several areas of unsatisfactory interactions with staff: “confusing, inadequate, uncaring communications regarding treatment or prognosis, preventable oversights in procedures or policies, failure to include or meet the needs of siblings and Spanish speaking family members, inconsistent bereavement follow-up.” The study also found a discrepancy between the high degree of pain and a perception that pain had been managed well.

Summary

CHI and the CHI PACC sites have used a variety of needs assessments including surveys, interviews, focus groups, and web-based and electronic surveys and mapping to help design system and program structure, scope of services, and identify training needs and approaches.

² E. Meyer et. al, “Parental perspectives on end- of- life care in the pediatric intensive care unit,” *Critical Care Medicine*, 2002, Vol 30. No. 1. pp 226-231.

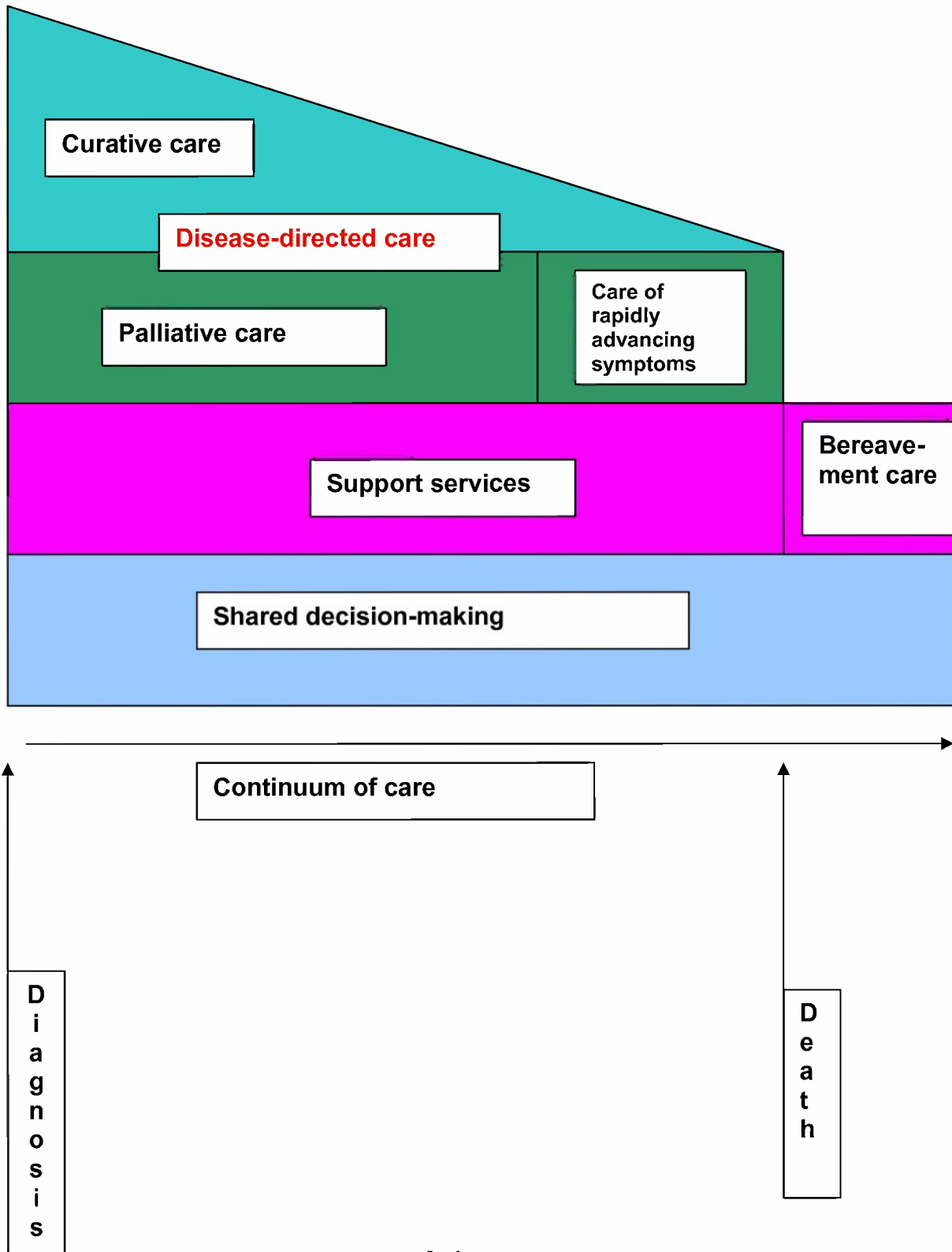
³ N Contro, et al, “Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics and Adolescent Medicine*,” Vol 156, No. 1, January 2002

Parents and professionals participated in these surveys and also helped develop and refine the instruments.

Obviously, the design and form of the instruments used by the *mCare* project will be driven by the purpose of the assessment. Although the results of the assessments done by CHI, the CHI PACC sites, and others have common themes, it will be important to articulate clearly how *mCare* plans to use the results and information learned before it determines how best to structure the assessment. It may use assessments to identify structural barriers in the military health system, service gaps, how information flows, professional training needs, etc. The results of similar assessments conducted by others will help inform the final design, but cannot substitute for assessing the needs of military families who have a child with a life-threatening condition.

APPENIDX 3

Tentative Schematic Diagram of Care



APPENDIX 4

PROPOSAL FOR A NEEDS ASSESSMENT FOR mCARE (MILITARY CHILDREN AT RISK— ENHANCING QUALITY OF LIFE) PHASE II

PRINCIPAL INVESTIGATOR : Janice L. Hanson, Ph.D., Ed.S.
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Proposal to collaborate in project submitted as USAMRMAA Proposal for Children's Hospice, Phase II, FY 04 funds

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Overall award to be administered by
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Abstract

Children with life-threatening illnesses and their families require a coordinated network of services involving health care, community resources and informal supports. For active duty and retired military families, this occurs in the context of the TRICARE benefit, resources and needs of the military community, and the various and changing civilian communities in which military families live.

This proposal describes Phase II of a needs assessment of military families with children with life-threatening illnesses, using a case study methodology. Phase I of the study (previously funded; both phases are described in the included protocol) includes case studies for the National Capital Area (NCA) and Wright-Patterson AFB. Phase II will include case studies of the areas surrounding the Madigan Army Medical Center, Naval Medical Center, San Diego Munson Army Health Clinic at Ft. Leavenworth, Kansas. Altogether, there will be case studies of the NCA, areas surrounding installations with major medical centers for the Army, Navy and Air Force, and the area surrounding a small installation with limited services available through the direct-care military health system. At each site, data collection will include interviews and/or focus groups with parents, interviews and focus groups with health care providers, and collection of TRICARE data regarding case management and utilization of care. Three existing surveys (the FACCT End-of-Life Survey, Medical Home Assessment Tools, and a survey of the quality of life of caregivers previously developed by the investigators with parent advisors), consultation with the mCARE project team and consultation with parent advisors will provide the basis for interview and focus group questions. Needs identified will be compared to the services available at each site and then to the services covered by the TRICARE benefit (as analyzed in Phase I of the needs assessment). In collaboration with other partners in the mCARE project, needs identified by parents of children with life-threatening illnesses and health care providers who provide care for them will be compared to services provided by the military health care system, the TRICARE benefit, and community resources. The assessment will also describe access and barriers to access for services from these three sources. Subsequently, the mCARE project team will propose a model of care for military children and their families that will provide a coordinated, comprehensive, family-centered approach to care from the time of diagnosis of a life-threatening illness through the time of bereavement of families.

This proposal also adds the following components to the needs assessment as described in the Phase I proposal: development of an advisory group of parents in the National Capitol Area, a collaboration with Family Medicine, adaptation to this population of a previously-developed measure of quality of life of caregivers, technical assistance in defining eligibility criteria, and participation in evaluation of program components piloted by other mCARE project team members (respite care and/or care coordination).

Budget Justification—Modification to Phase I Needs Assessment

USUHS Personnel

mCARE salaries:

	July 04-June 05	July 05-Dec 05	Jan 06-Dec 06	Oct 06-Dec 06 Additional time to produce reports and manuscripts
Phase I (already funded)	25% Hanson 20% Randall 35% Res Asst 20% Admin Asst	50% Hanson 20% Randall 35% Res Asst 25% Admin Asst		
Phase I modification (explained below)		25% Hanson		
Phase II (proposed here)			50% Hanson 20% Randall 35% Res Asst 20% Admin Asst	25% Hanson 20% Randall 40% Admin Asst

Principal Investigator

Dr. Hanson will devote 25% time to this project from July to December 2005, in addition to the 50% time budgeted and already funded in Phase I of the needs assessment (FY 03 dollars), totaling 75% of her time for this period. This will provide time to enhance the needs assessment as planned in Phase I (case studies in the National Capital Area and at Wright-Patterson Air Force Base) and also lay the foundation for the three case studies of Phase II. With this additional effort, the Phase II studies should be ready to begin early in 2006, as described in the following proposal. The additional time for Dr. Hanson will enable the USUHS researchers to accomplish the following:

- Complete the two initial case studies so as to provide timely input to the project as a whole. This will enable other mCARE partners to incorporate information from the needs assessment when they plan and develop project components such as curriculum materials and a guide to community resources.
- Participate in mCARE project team meetings.
- Submit applications to the IRBs at the three study sites for Phase II.
- Build a collaboration with Family Medicine.
- Develop an advisory group of parents in the National Capital Area to participate as research collaborators. They will participate in tasks such as developing interview and focus group questions, adapting a survey to measure the quality of life of caregivers, and interpreting data from a parents' perspective.
- Adapt a survey of the Quality of Life of Caregivers of Children with Special Needs for use with parents and other caregivers of children with life-threatening illnesses. This survey is needed as an outcome measure for other mCARE project activities.
- Participate in a working group to research eligibility criteria for mCARE/pediatric hospice services.
- Add to the case studies a description of the ways in which eligibility criteria may affect access to care and services under the TRICARE benefit.
- With the Maryland Coordinating Center, plan an evaluation of model program components.

Budget Justification—Phase II Needs Assessment, FY 04 Appropriation

USUHS Personnel

mCARE salaries:

	July 04-June 05	July 05-Dec 05	Jan 06-Dec 06	Oct 06-Dec 06 Additional time to produce reports and manuscripts
Phase I (already funded)	25% Hanson 20% Randall 35% Res Asst 20% Admin Asst	50% Hanson 20% Randall 35% Res Asst 25% Admin Asst		
Phase I modification (explained above)		25% Hanson		
Phase II (proposed here)			50% Hanson 20% Randall 35% Res Asst 20% Admin Asst	25% Hanson 20% Randall 40% Admin Asst

Principal Investigator and Co-Investigator

Dr. Janice Hanson will serve as Principal Investigator (PI) for this project at the Uniformed Services University of the Health Sciences (USUHS). She will oversee and participate in data collection and analysis, build collaborative activities with the Family Medicine faculty and Family Medicine physicians at the study sites, oversee submissions to the IRBs, attend team meetings with mCARE partners, and coordinate all mCARE activities in regard to the needs assessment.

For Phase II of the needs assessment, Dr. Hanson will devote 50% time to this project from January-December 2006. During the last three months of this period, the budget includes additional time for Dr. Hanson to produce reports and manuscripts (an additional 25% time for Dr. Hanson), totaling 75% of Dr. Hanson's time during this period.

As a co-investigator, Dr. Virginia Randall will devote 20% time to this project throughout 2006. She will assist with defining criteria for eligibility for this program and with data analysis, particularly in relation to the military health system and families' access to care. She will also attend team meetings with mCARE partners. During the last three months of this period, the budget includes additional time for Dr. Randall to produce reports and manuscripts (an additional 20% time for Dr. Randall).

Both Dr. Hanson and Dr. Randall have primary faculty appointments at USUHS in the Department of Pediatrics, and pending secondary appointments in the Department of Family Medicine. Dr. Randall also has a pending secondary appointment in the Department of Preventive Medicine and Biostatistics. Dr. Hanson's role as PI on this project encompasses activities in both Pediatrics (40% to 65% time) and Family Medicine (10% time).

Consultation with the Department of Preventive Medicine and Biometrics is available at the University as in-kind support to assist with health policy analysis. Faculty in the Departments of Pediatrics and Family Medicine at USUHS are available to provide contacts in Family Medicine at the study sites and to assist with interpretation of data and development of a model of care.

Research Associate

In addition, the Phase II budget includes funds for a research assistant 14 hours/week (35% time), hired as an administratively determined (AD) Research Associate. The Research Associate will assist with focus groups, interviews and other data collection activities of the needs assessment, as well as project organization.

Administrative Assistance

The budget covers one day per week, January through December 2006, of administrative assistance performed by a USUHS-hired GS employee funded by grant funds. Required assistance will include filing and organizing project materials, transcription, data entry and report preparation. In addition, for the last three months of the project (Oct.-Dec. 2006), during the time of preparation of final reports and manuscripts, the budget includes funds for two additional days per week of administrative assistance.

Fringe Benefits

Fringe benefits have been calculated at 26.9% for all four employees, who will be USUHS employees (AD or GS appointments).

Travel

The budget includes travel from Bethesda to San Diego, California, Tacoma, Washington (Madigan Army Medical Center), and Ft. Leavenworth, Kansas, for two researchers to facilitate focus groups of parents, residents, general pediatricians, family practitioners, pediatric subspecialists and other health care providers. These locations, which cover diverse geographical regions, have been chosen to supplement the Phase I studies in the National Capital Area and at the Wright-Patterson Air Force Base. Taken together, the sites include Army, Navy and Air Force medical centers, and both large and small military treatment facilities. This ensures that children and families in the various settings in the Military Health System will be represented in the needs assessment.

Estimating an average of \$1000 per trip (\$400 airfare, \$400 lodging, \$200 per diem for meals), the \$8000 budgeted for travel will cover one trip for one researcher to San Diego and Madigan to build liaisons and meet with the IRB (\$2000), and one trip for each of two researchers for data gathering at San Diego, Madigan and Ft. Leavenworth (\$6000). Since Ft. Leavenworth is much smaller, the pre-data gathering planning can be done by phone, email, fax and mail.

Materials, Supplies and Consumables

\$500 are included for general office supplies, \$500 for software for data analysis, \$500 for a black and white laser printer to produce reports, \$500 for cabinets with locks to store data, and \$2000 for a laptop computer to record data and notes and draft material for reports during site visits.

Other Expenses

The budget includes \$1030 for duplicating costs to produce reports, interview and focus group guides, and other research materials. It also includes \$6000 for honoraria for parents who participate in interviews, focus groups or the research advisory group (\$2100 + \$3900 as explained below).

In the National Capital Area, the researchers will assemble a group of parents to serve as research collaborators and advisors, to help write questions for focus groups and interviews, interpret data, and review draft reports. These parents will have experienced the death of a child or will have a child with a life-threatening illness. They will be parents who have collaborated with the researchers in this or other projects, and who have expertise to contribute that will inform the research plans and/or interpretation of data. This group is referred to as the "advisory group."

Funds are included for the advisory group for focus groups (\$50 honorarium for participating in each focus group), interviews (\$30 for participating in a one-to-one interview) and review of draft documents (\$30 per review). 7 to 8 parents per focus group x \$50/parent x 4 focus groups = \$1700, \$30/interview or document review x 20 = \$600, totals \$2100 for honoraria for the parent advisory group.

At each study site, funds are included for focus groups (\$50/parent x 14 parents = \$700), interviews (\$30 x 15 = \$450) and document review (\$30 x 5 = \$150). This totals \$3900 (\$1300 per site x 3 sites).

Indirect Costs

This project will be administered by the Henry M. Jackson Foundation. On-site indirect costs have been calculated at 50.6%.

Background and Significance

The 2000 National Home and Hospice Care Survey, a survey of home health agencies and hospices that included patients of all ages, found 64,000 patients under 18 years of age (4.7% of the population served) received home health and hospice services in 2000, representing a rate of 8.8 per 10,000 in the civilian population of the U.S. ¹ However, current insurance and delivery models are based on a Medicare model for adults, and few pediatric home and hospice care programs are available. A recent report from the Institute of Medicine emphasizes the importance of improving palliative and end-of-life care for children and families, and calls for research regarding models of care and ways to measure outcomes. ² Children with life-threatening illnesses and their families require a coordinated network of services involving health care, community resources and informal supports. For active duty and retired military families, this occurs in the context of the TRICARE benefit, resources and needs of the military community, and the various and changing civilian communities in which military families live. The current proposal sets forth the plan for Phase II of a needs assessment/feasibility study for the military population of children with life-threatening illnesses—a part of a larger Congressionally-funded feasibility study to develop an effective model of care within the Military Health System (MHS) and the TRICARE benefit, coordinated with available community services. The larger study is based on a partnership between Walter Reed Army Medical Center, the Uniformed Services University of the Health Sciences, Children's Hospice International (CHI) and the Maryland Coordinating Center (MCC) (the mCARE partners).

Phase I of the needs assessment addressed the following technical objectives:

Technical Objective 1:

Delineate the needs of children with life-threatening illnesses and their families who are eligible for care in the Military Health System (MHS).

Technical Objective 2:

Delineate the educational needs of pediatricians (pediatric residents, general pediatricians and pediatric subspecialists) that relate to providing and coordinating care for children with life-threatening illnesses and their families.

Technical Objective 3:

Analyze the TRICARE benefit and services provided by the MHS in relation to the needs of children with life-threatening illnesses and their families.

Technical Objective 4:

Develop recommendations for a program to provide health care and services to military children with life-threatening illnesses and their families.

This proposal is for Phase II of the needs assessment, which will be completed in collaboration with the mCARE partners. Phase II overall will address the following goals:

Goal 1: Expand the needs assessments of family members and providers to include additional off-site locations. Modify the needs assessment template developed from NCA and Wright-Patterson Air Force Medical Center findings based on experiences at the additional sites.

Since the original development of this plan, there have been major changes to the timelines of the various components of the project. Some of the changes are due, in part, to the length of time from conception and project design to the awarding of the contract and the subawards, approximately 1 year. Due to slippage of the timelines, there were changes in the availability of certain key personnel and associated increases in costs, necessitating a complete revamping of the USUHS budget. In addition, requirements for approval through

several institutional human use committees prior to conducting the focus groups dictated that the case studies be limited to those obtainable in the NCA and at Wright-Patterson Air Force Base. Therefore, plans for case studies at three other sites, and the integration of information from all 5 sites, have been moved to Phase II and are described in this proposal.

Goal 2: Define the eligibility criteria for the population of children to be served.

Although this was listed as a goal in the original proposal, it has become clear that a systematic method of identifying and classifying the population using objective criteria would provide the best framework for obtaining consistent and measurable outcome data, especially for cost.

Goal 3: Develop a framework for datasets to support the new model design.

Goal 4: Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.

Goal 5: Develop a plan for the education of families.

Goal 6: Design a new model of care with cost projections in preparation for implementation and cost analysis.

Goal 7: Develop implementation strategies for the new model design.

Goal 8: Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.

The research described in this proposal primarily falls under goal 1. The results of the research will be applied to the work of goals 2-8, with USUHS personnel participating in the ways described below.

Preliminary Studies

Phase I of the study includes case studies for the National Capital Area (NCA) and the Wright-Patterson Air Force Base. The data from these two case studies, and the needs assessment template designed for them, will inform Phase II case studies of the areas surrounding the Madigan Army Medical Center, the Naval Medical Center, San Diego Naval and Munson Army Medical Clinic at Ft. Leavenworth, Kansas. At each site, data collection will include interviews and/or focus groups with parents, interviews and focus groups with health care providers, and collection of TRICARE data regarding case management and utilization of care. Needs identified will be compared to the services available at each site, and then to the services covered by the TRICARE benefit (as analyzed in Phase I of the needs assessment). Other relevant preliminary studies of the principal investigator and co-investigator include the following:

- *Quality of Life of Caregivers of Children with Special Health Care Needs, A Survey Developed Collaboratively with Parents.*³ A copy of this survey appears in Appendix 2. A group of parents of children with special health care needs collaborated in determining the domains of the questions in this survey, as well as in writing the questions and descriptors.
- Focus groups with parents and patients about evidence-based medicine.⁴ These groups pursued a preliminary exploration of what parents and patients understand about medical evidence, and how they would like their doctors to communicate about evidence, with a consideration of what these findings mean for shared decision-making.

- Collaborative focus groups with patients and physicians which defined physician behaviors and patient/parent behaviors that facilitate shared decision-making.⁵
- A survey of parents to build an understanding of how they make decisions about whether to use alternative and complementary medicine, including whether they make decisions with their children's pediatricians. This survey was developed collaboratively with parents, and a focus group of parents assisted with interpretation of the data.⁶

The recent report from the Institute of Medicine, *When Children Die*,² emphasized the importance of developing ways to measure quality of life of children and caregivers, and of finding ways to develop genuine shared decision-making between parents and physicians when creating programs that will better meet the needs of children with life-threatening and advanced illness and their families. The quality of life survey has the potential to become an outcome measurement tool for this population, and developing strategies for shared decision-making is essential to providing care for these children and their families. Therefore, these preliminary studies will form a useful and relevant foundation for the work of this project.

Note: After phase I and II were funded, phases I and II were combined in one protocol presented below. Due to hurricane damage at Keesler AFB, Wright-Patterson AFB in Ohio was substituted for this site.

Research Design and Methods

Goal 1: Expand the needs assessments of family members and providers to include additional off-site locations. Modify the needs assessment template developed from NCA and Wright-Patterson Air Force Base findings based on experiences at the additional sites.

Activity: needs assessment at San Diego, Madigan and Ft. Leavenworth

Method: case studies with focus groups, interviews, surveys, and analysis of the MHS

Deliverables: report of parent focus groups and interviews; report of health care provider focus groups and interviews; case study reports for San Diego, Madigan and Ft. Leavenworth; integrated case study report; report of the MHS analysis; modified needs assessment template; journal article describing the needs assessment

Study Design

Dr. Hanson and Dr. Randall will conduct a needs assessment of children with life-threatening illnesses and their families who are MHS beneficiaries, using data gathered from families and health care providers at 3 additional military medical centers/clinics (the Madigan Army Medical Center, the Naval Medical Center, San Diego and the Munson Army Medical Clinic at Ft. Leavenworth, Kansas). The data will be summarized as case studies of each of these 3 sites,⁷ and integrated with the Phase I case study information from the National Capital Area (NCA) and the Wright-Patterson Air Force Base. Through the Department of Pediatrics and the Department of Family Medicine at USUHS, the researchers have contacts with residency program directors, clerkship site directors, and physicians at these sites. In addition, the researchers have discussed this proposal with the IRB at Wright-Patterson Air Force Base Medical Center, a developmental pediatrician at Madigan Army Medical Center, and the Exceptional Family Member Program director at Ft. Leavenworth. All are willing to assist with the project at those sites.

The inclusion of these sites will assure representative information reflecting the military population, as the sites represent major medical centers of the Army, Navy and Air Force and a

small installation far from a major military medical center. Children with complex medical needs at Ft. Leavenworth, Kansas receive care at 5 large civilian hospitals in that region.

At each of the 5 sites, the following data collection strategies will be employed to gather information about the needs of children and families, the services available to address those needs, and access and barriers to available services:

- Conducting focus groups and/or interviews of parents of children with life-threatening (both newly diagnosed and advanced) illnesses, or parents of children who have died in the previous two years.
- Conducting focus groups and interviews with pediatricians, pediatric residents, family medicine physicians and residents, and other health care providers that provide care for children with life-threatening illnesses.
- Assembling TRICARE data for the catchment areas represented by the 5 sites, from the TRICARE Management Activity. When possible, more detailed information will be requested from military lead agents and TRICARE contractors, including records of case management for a sample population.

Appendix 4 contains a tentative schematic diagram of care for children with life-threatening illnesses and their families. The diagram includes curative care, palliative care during all phases of disease, and a full array of support services, from the time of diagnosis through the time of bereavement. This model will guide the areas that will be explored with families and health care providers in the case studies, and will be modified after consultation with parents. This tentative model was adapted from Feudtner et al.¹⁰ and Hutton et al.¹¹

Sampling strategy

Parents and health care providers will be invited to participate in interviews, focus groups and/or surveys, with recruitment of participants continuing until the themes in their responses begin to repeat. Such repetition of themes will be an indication that the sample is adequate to represent the group being studied. Following are estimates of the numbers of participants:

- Interviews: 10 families in the National Capital Area; 3 families at each of 3 other sites with major military medical centers; 3 families at 1 small base with limited military medical resources (22 total) (Note: there could be 1-4 parents/step-parents per family)
- Surveys: 50 families (total, includes any TRICARE beneficiary family in any geographic location) (families completing surveys may also participate in an interview or focus group)
- Focus groups with parents: up to 25 families total at all sites if focus groups are needed in addition to in-home interviews
- Focus groups and interviews with residents, attending physicians, and other health care providers: 40 healthcare providers total
- Advisory group of parents: up to 10 additional parents (see below for description of advisory group)

Since the parents in this estimate are organized by families, and each family could have 1-4 parents, the maximum number of research participants would be 438, although most likely the actual number will be fewer.

Criteria for parents to participate in the study include the following:

- Having a child with a life-threatening illness or a child who has died (as interpreted by the parent)

- Being available for a focus group, interview, survey and/or review of written materials for this study

Criteria for health care providers to participate in the study include the following:

- Providing health care or care coordination for children with life-threatening illnesses and their families within the military health system (i.e., residents, staff physicians and other health care providers in pediatrics or family medicine)
- Being available for a focus group, interview, or survey for this study

In collaboration with Dr. Naulty, the Maryland Coordinating Center (MCC), and Children's Hospice International (CHI), the sampling strategy will be discussed. The following references are available to guide the sampling strategy.

- End-of-Life Survey developed by the Foundation for Accountability (FACCT)⁸ (see Appendix 1).
- Feudtner, C, Hays, RM, et al.¹²
- Reports from PACC projects funded by Congress to work within Medicaid to provide pediatric hospice services in the states.
- CHI's experience with other pediatric hospice projects
- ICF codes.^{13,14}

Consideration of this background information about children with life-threatening illnesses will enable the mCARE partners to ensure that the families who participate in interviews, surveys and focus groups represent circumstances similar to those described in the literature about children with life-threatening illnesses and encountered in other pediatric hospice programs. The mCARE partners will discuss a description of the families who consent to participate (absent any identifying information) to determine whether the sample adequately captures the population of children with life-threatening illnesses who may ultimately be served by a program developed with information from this project. If an interim description of the sample does not include families that adequately represent the population, additional families will be recruited. This process of discussion and review will add validity to the study by ensuring that the sample adequately captures the population. One outcome of the study will be the description of the needs of children with life-threatening illnesses and their families that emerges from the study group. This information may inform the development of eligibility criteria for a program to meet the needs of these children and families (see discussion of eligibility criteria below).

Advisory group of parents in the National Capital Area

An advisory group of research collaborators will be developed from a group of parents of children who have had, currently are ill with, or have died from chronic life-threatening illness. This group of parents, initially invited to participate from a group previously assembled under another project, will participate frequently in the work of Phase II by helping adapt a quality of life survey for caregivers, reviewing focus group and interview questions for parents and health care providers, assisting in interpretation of case study data, developing models, developing a program evaluation tool, and editing reports, with an eye toward whether data accurately reflect their experiences.^{15,16} Parents in the previously assembled group have agreed to be contacted about other study opportunities. As the mCARE project proceeds, some parents who participate in needs assessment focus groups and interviews may also be invited to join the advisory group. Advisory group members will be asked to participate in focus groups and interviews (see topic guides in appendix 11) and review of written materials.

Collaboration with Family Medicine

While the specialized medical care required by children with life-threatening and advanced illnesses will most often be provided by pediatric subspecialists, these children are often first identified through their primary care physicians in Pediatrics or Family Medicine. Other children in the family will most likely receive care from pediatricians or family medicine physicians, and parents of these children will very likely continue to receive their own care from the family practitioners from whom they were receiving care at the time of their children's diagnoses. Therefore, in order to obtain a thorough understanding of referral pathways for children and the needs of families for health care and support, it is important for the needs assessment to include family physicians as well as pediatricians in focus groups and interviews. While this partnership was not developed in the Phase I proposal of this project, it is important to establish it now.

The Principal Investigator will ensure that family medicine residents and physicians are involved in needs assessment focus groups and/or interviews at all study sites. The Department of Family Medicine at USUHS will assist with this through existing contacts with family physicians at different study sites, and the faculty will review focus group and interview plans to recommend questions from the family medicine perspective. In addition, the Department of Family Medicine is developing a National Capital Area research consortium with which the Principal Investigator can discuss study plans and issues that emerge during the project.

Focus group and interview plans

The following surveys are available to inform the development of questions and data collection strategies for focus groups and interviews, with guidance from the advisory group:

- The End-of-Life Survey developed by the Foundation for Accountability (FACCT)⁸ (Appendix 1) (integrated in questions for focus groups and interviews, with guidance from an advisory group of parents).
- The Quality of Life of Caregivers of Children with Special Health Care Needs survey developed by Dr. Randall and Dr. Hanson³ (Appendix 2) (integrated in questions for focus groups and interviews, with guidance from an advisory group of parents).
- The Medical Home Assessment Questionnaires and the Medical Home Index (family and provider versions),⁹ which are available from the American Academy of Pediatrics website (see Appendix 3).

During Phase I of the project, interview and focus group questions will be written in collaboration with the parents in the advisory group. After experience with the focus group and interview guides at the first study sites, the researchers will modify the questions (if necessary) for use at subsequent sites.

Adapted quality of life survey for caregivers

Dr. Randall, Dr. Hanson, and a group of parents of children with special needs have developed a survey of the quality of life of caregivers of children with special needs (Appendix 2). The survey has been tested statistically and is psychometrically sound. However, it was developed for use with parents of children with a wide variety of special needs, and requires adaptation for use with parents of children with life-threatening and advanced illness. Dr. Hanson and Dr. Randall will convene the advisory group of parents (described above) to review the survey and recommend changes to wording and/or additional items to address the needs of this group of parents. Collaborating with the advisory group to identify other domains to address in the survey will ensure face validity of the adapted survey, since the parents in this group have had experiences similar to those that the survey will target. When the adapted survey is complete, the questions will be integrated into focus groups and interviews. It will also provide a quality

assessment tool for use when planning evaluation of components of the model program that will be developed by the team of mCARE partners.

Parent focus groups and interviews

Parent focus groups and interviews will address the following broad topics: (1) how parents define the needs of children and families when a child has a life-threatening illness; (2) the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs; (3) the experience of children and families in finding and using services in their communities (both military and civilian communities); (4) education and information necessary to enable them to find and access the health care and services that they need; and (5) the degree to which the children's care has been coordinated and what the mechanisms of coordination have been. Focus groups and interviews will be audiotaped and transcribed. Parents will be offered both formats (focus groups and interviews), since the medical needs of their children may be complicated, and one format or the other may be more accessible for them. They may be asked to complete a survey in the context of a focus group or interview (see Appendices 1, 2 and 3). See Appendix 11 for focus group and interview topic guides and introductory scripts.

Health care provider focus groups and interviews

Health care provider focus groups will be held at each Military Treatment Facility (MTF) to discuss three broad topics: (1) how residents, pediatricians, family medicine physicians and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care; (2) participants' experiences with the MHS (direct care system and TRICARE) in meeting those needs; (3) education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families (mCARE).¹⁷ Interns/residents and staff physicians will participate in separate focus groups. Focus groups will be audiotaped and transcribed. Individual interviews may be conducted with health care providers who have specific knowledge and experience working with the families of children with life-threatening conditions. They may also be asked to complete a written survey regarding providing care for children with life-threatening illnesses within a Medical Home model⁹(see Appendix 3).

Military Health System Analysis

The Military Health System (MHS) analysis will include analysis of the military direct care system capability and capacity and the TRICARE benefit manual (available at <http://www.tricare.osd.mil/tricaremanuals/>). The following sources will be used to derive information:

- The TRICARE benefit manual.
- TRICARE reimbursement rates.
- Pending legislation for TRICARE.
- Policy makers at the TRICARE Management Activity.
- Case managers at lead agencies.
- Case managers at MTFs.
- Contract language.
- Contractor representatives.
- Medicare/Medicaid benefits and reimbursement rates.
- Pending legislation for Medicare/Medicaid.

From these sources, the researchers will derive descriptions of the following aspects of the MHS:

- Relevant covered care and services

- Definitions applicable to children with life-threatening illnesses
- History of care and services provided for children with life-threatening illnesses through the military direct care system and TRICARE (case examples, aggregate CPT and ICD-9 codes)
- Historical costs for this population of children
- Pending changes that may affect access to care and services for this population
- Policy makers', Lead Agents' and Contractors' interpretation of relevant benefits
- Explicitly-excluded care and services needed by children with life-threatening illnesses
- Current reimbursement rates for care and services through TRICARE and Medicaid.

Mapping

The needs assessment will delineate the needs of children and families from the perspectives of parents and health care providers, as well as the services these families use and the ease with which they can access those services. The MHS analysis will identify relevant aspects of the TRICARE benefit and the MHS. The Maryland Coordinating Center (MCC) will identify relevant resources in the community. Ultimately, the researchers will compare the needs of children and families with resources available through the MHS and civilian and military communities.

In the National Capital Area (NCA), it will be possible to create maps of the resources accessed, resources needed but not available, and resources available but not adequately accessed by the families in the study. There is software available to create geographic maps of families and available resources, and faculty members in the Department of Preventive Medicine and Biometrics at USUHS have experience using this software. The researchers will create maps with this software to portray and family locations in the NCA, using the results of the needs assessment and the community resource guide from the MCC. If this mapping produces helpful displays for analysis and planning, similar mapping will be done at the other study sites, and a plan for mapping will be developed as part of the needs assessment template.

Timeline

A task schedule for the above activities appears in Appendix 5.

Recruitment of Parents

Eligible parents will be informed of the study through posted flyers or by Military Healthcare System staff at each study site, including pediatricians, family medicine physicians, residents, nurses, and care coordinators. This identification will be based on knowledge of children's conditions known to the staff in their day-to-day duties in providing medical care and/or case management services. No new knowledge about children or parents will be learned by the staff telling parents about the study. A contact person (physician, nurse, or care coordinator) will be identified at each site to answer basic informational questions about the study. Interested parents may contact Dr. Hanson (PI at USUHS), Dr. Naulty (PI at WRAMC), or Dr. Randall (AI at USUHS) to ask further questions about the study. Children may be enrolled in TRICARE Prime and/or using TRICARE Extra, Standard, Medicaid, Medicare, other government programs or health insurance.

If a parent specifically expresses an interest in participating in the study, Military Healthcare System staff may forward the name, phone number, and brief description of each child's condition to Dr. Naulty (Principal Investigator at Walter Reed (WRAMC)), Dr. Hanson (Principal Investigator at the Uniformed Services University (USUHS)), Mr. Jason Cervenka

(Assistant Investigator at the Uniformed Services University (USUHS)) or Dr. Randall (Associate Investigator at the Uniformed Services University (USUHS)). One of them will call parents using the attached phone script (see Appendix 8) for the purpose of recruiting parents to the study. There will be no blind recruitment of parents. Parents will have the option of participating in an individual interview in their own home, a focus group, or both. Focus groups will take place at USUHS or WRAMC in the NCA or the military treatment facility at another site. Focus group participants will receive a \$50 subject fee. Parents will receive a \$30 subject fee paid for home interviews. Active duty parents must be on leave or off-duty hours to receive a subject fee. Military personnel stationed at USUHS cannot be paid. Written informed consent will be obtained from each parent before the home interview or focus group begins. See Appendix 7 for the text of the consent forms. Interviews and focus groups will be audiotaped with permission of the parents.

Flyers (see Appendix 9) will also be distributed in the clinics and hospital wards where such patients receive care within the MHS. Parents may self-identify through the information and contact phone number(s) provided in the flyer or through word-of-mouth from other families. If spouses of parent participants or step-parents of children of participants express an interest in participating, they may self-refer. All parents and step parents will read, receive an explanation of, and sign an ICD before engaging in study activities.

Recruitment of Health Care Providers

Eligible health care providers will be informed of the study through posted flyers at the military treatment facilities. Health care providers may self-identify through the information in the flyer. A contact person (physician, nurse, or care coordinator) will be identified at each site to answer basic informational questions about the study. Interested health care providers may contact Dr. Hanson (PI at USUHS), Dr. Naulty (PI at WRAMC), or Dr. Randall (AI at USUHS) to ask further questions about the study. One of them will return their call or email using the script in Appendix 12, and send the accompanying follow up letter. Health care providers may volunteer for a focus group, an individual interview, or both. Focus groups will take place at the site military treatment facility. Health care providers will not be compensated for their participation. Written informed consent will be obtained from each participating health care provider before a focus group or interview begins. Focus groups and interviews will be audiotaped with permission of the health care providers.

Data Analysis Plan

Data analysis will include both qualitative and quantitative analysis methods within a case study design, in which the cases studies are the 5 identified military treatment sites. For each study site, data analysis will include the following components:

Qualitative analysis

1. Parent focus groups and interviews
 - a. Gather field notes
 - b. Audiotape and transcribe focus group content
 - c. Audiotape and transcribe parent interviews
 - d. Identify themes using HyperResearch¹⁸ qualitative data analysis software.
Identify themes in these areas:
 - i. Child and family needs
 - ii. Resources used
 - iii. Resources needed but not accessible, available or adequate, and why
2. Health care provider focus groups and interviews
 - a. Gather field notes
 - b. Audiotape and transcribe focus group content
 - c. Record interview notes

- d. Identify themes using HyperResearch¹⁸ qualitative data analysis software. Identify themes in these areas:
 - i. Child and family needs
 - ii. Resources used
 - iii. Resources needed but not accessible, available or adequate, and why

Quantitative analysis

1. Summarize survey data
 - a. Gather selected End-of-life survey (FACCT)⁸ data during focus groups and parent interviews
 - b. Gather selected Quality of Life of Caregivers of Children with Special Health Care Needs survey³ data during focus groups and parent interviews
 - c. Gather selected Medical Home Assessment surveys⁹ data during focus groups and interviews
 - d. Tabulate data and portray graphically with Microsoft Excel¹⁹
2. Summarize resources used as reflected by available TRICARE data
 - a. Obtain available data from the TRICARE Lead Agent and contractor
 - b. Tabulate data and portray graphically with Microsoft Excel¹⁹

Summative analysis

1. Summarize qualitative and quantitative parent data in these areas:
 - a. Child and family needs
 - b. Resources used
 - c. Resources needed but not accessible, available or adequate, and why
2. Summarize qualitative and quantitative health care provider data in these areas:
 - a. Child and family needs
 - b. Resources used
 - c. Resources needed but not accessible, available or adequate, and why
3. Convene advisory focus groups in the National Capital Area to interpret data summaries
4. Develop concept maps with Decision Explorer²⁰ software
5. Develop a needs assessment template
 - a. Compile focus group and interview questions, surveys used, concept maps and any additional data collection strategies developed during the case study at site 1
 - b. Apply the needs assessment template from site 1 at sites 2, 3, 4 and 5; modify as necessary
 - c. Summarize needs assessment strategies used at all sites
6. Write a narrative summary for each site

Data analysis references

The overall approach to data analysis is described in by Pope and Ziebland²¹ and in volumes 5 of The Ethnographer's Toolkit, *Analyzing and Interpreting Ethnographic Data*.²²

Expected Results

Focus group and interview plans

Interview and focus group questions will be written in collaboration with the parents in the advisory group. After experience with the focus group and interview guides at the first study sites, the researchers will modify the questions (if necessary) for use at subsequent sites.

Needs assessment template

A needs assessment template will be developed in the NCA, and then modified for use at each subsequent study site. The template will include plans for focus groups and interviews with parents and health care providers, relevant surveys, a list of data to request from TRICARE lead agents and contractors, and a list of other data to gather in a community when assessing care and services for children with life-threatening illnesses and their families. When the Maryland Coordinating Center completes a guide to community resources, this will be incorporated in the needs assessment template as well. After a model of care is developed in this project, the needs assessment can be used when implementing the program in other communities where the Military Health System provides care and services.

Adapted quality of life survey for caregivers

One important product of this research will be an adapted survey to measure the quality of life of caregivers of children with life-threatening or advanced illness. Once complete, this survey will guide data collection during this project. It will also provide a quality assessment tool for use when planning evaluation of components of the model program that will be developed by the team of mCARE partners, as well as contributing to the larger literature about developing and assessing care and services for this group of children and their families.

Report of parent focus groups and interviews

This report will focus on these four facets of the needs assessment:

- Child and family needs as described by parents.
- Resources families use in the MHS and community.
- Resources needed but not accessible, available or adequate, and the barriers families experience when trying to obtain these resources.
- Families' needs for information and education regarding these needs, resources and gaps in services.

Report of health care provider focus groups and interviews

This report will focus on three facets of the needs assessment.

- How residents, pediatricians (both general pediatricians and subspecialists) and family medicine physicians, and other health care providers define the needs of the children and families for whom they provide care.
- Their experiences with the MHS (direct care and TRICARE benefit) and community services in meeting those needs.
- How residents, pediatricians, family medicine physicians, and other health care providers describe gaps in needed care and services.
- Education necessary to help physicians and other health care providers provide care in a Medical Home model for children with life-threatening illnesses and their families.

Case study reports

The researchers will produce a case study report for each study site (NCA, Wright-Patterson, Madigan, San Diego and Ft. Leavenworth), as well as an integrated report that will summarize the findings across sites. Each report will describe the needs of children and families,

the resources used, and the resources needed but not accessible, available or adequate, incorporating the perspectives of families and health care providers. The data delineated above will be used to map the networks of services and informal social support used by families in each geographic area, using concept maps and geographic maps as appropriate to show the locations of families and the services they access.²³ Gaps in services and support will be delineated, with policy recommendations for the military health system to address these gaps. The reports will also summarize relevant needs of families, physicians and other health care providers for education and information about care and services and how to access them.

Military Health System Analysis report

The MHS analysis report will contain:

- A description of the benefits and services routinely available to families and their children.
- A description of the benefits and services that are either not easily accessible or are not authorized. This description may include:
 - The legislative history of the omission of benefit authorization from the TRICARE manual.
 - A description of how the TRICARE contract language prevents families from accessing the benefit.
 - A description of how the TRICARE definitions prevent families from accessing the benefit.
- Alternatives for ensuring the families and children receive the necessary medical benefits will be provided. This may include new legislative language, new definitions, or new procedures for contractors or case managers/care coordinators/primary care providers.
- A description of implications for eligibility criteria for services within the TRICARE benefit.

Manuscripts for peer-reviewed journals

The needs assessment will also lead to research reports that will be submitted as manuscripts to peer-reviewed journals in the health care literature.

Human Subjects Protections

Phase I of this research has been approved by the Institutional Review Board at the Uniformed Services University (see Appendix 10). All additions to the research protocol that appear in this proposal have been submitted to the USUHS IRB as a modification and approved (see Appendix 10). The protocol will be submitted for required IRB approval at Walter Reed Army Medical Center, Malcolm Grow Air Force Medical Center and the National Naval Medical Center in the NCA, as well as to Ft. Detrick. The protocol will also be submitted as required to IRBs for Wright-Patterson Air Force Base Medical Center, Madigan Army Medical Center, the Naval Medical Center, San Diego, and Ft. Leavenworth.

Two categories of human subjects will be involved in the needs assessment:

1. parents of children with life-threatening illnesses or whose children have died and
2. health care providers who provide services for these children and their families.

When collecting data, the researchers will not actively seek sensitive information (e.g., drug and alcohol use, sexual practices, child or spousal abuse, or other information that could be criminal or damaging to one's financial or social standing, employability, insurability, or

psychological well-being) for either group of participants. However, participants may volunteer sensitive information during interviews or focus groups. Participants will not be asked directly about these topics. If sensitive information becomes available to a researcher, even though he or she did not seek that information, the researcher will discuss the situation with the family advocacy office on the relevant military base, and make the reports required to appropriate authorities as advised by the family advocacy office.

Parents will be involved in two ways, as participants in the needs assessment and as research collaborators in an advisory group. The advisory group will consist of 8-10 parents in the National Capital Area (NCA). They will be parents of children with life-threatening illnesses or of children who have died. Parents in the advisory group will have had some experience participating in research and/or medical education activities, either in the mCARE project or in other research and education projects with the Principal Investigator and Co-Investigator.

In addition to the advisory group, the number of participants in the needs assessment will be parents from up to 97 families and 40 healthcare providers, apportioned among the following study activities. The needs assessment will involve approximately half of the participants in each of the two phases of the study. Phase I has already been funded. Phase II is described in this proposal.

- Interviews: 10 families in the National Capital Area; 3 families at each of 3 other sites with major military medical centers; 3 families at 1 small base with limited military medical resources (22 total) (Note: there could be 1-4 parents/step-parents per family)
- Surveys: 50 families (total, includes any TRICARE beneficiary family in any geographic location) (families completing surveys may also participate in an interview or focus group)
- Focus groups with parents: up to 25 families total at all sites if focus groups are needed in addition to in-home interviews
- Focus groups and interviews with residents, attending physicians, and other health care providers: 40 healthcare providers total
- Advisory group of parents: up to 10 additional parents

Since the parents in this estimate are organized by families, and each family could have 1-4 parents, the maximum number of research participants would be 438, although most likely the actual number will be fewer.

Parents of children with life-threatening (both newly diagnosed and advanced) illnesses are being studied to determine the needs of these children and their families in the event of such an illness and to determine how well these needs are met by existing military medical, TRICARE, and community resources. The system of services available to military families with this circumstance will be analyzed for availability, accessibility and effectiveness, resulting in recommendations for changes to the TRICARE benefit and/or mechanisms by which families access TRICARE, military, and community resources. Participants will be invited to join the research on the basis of whether they are parents of children with life-threatening illnesses or children who have died or healthcare providers who provide services to children of this description. Families will be TRICARE beneficiaries, active duty or retired. Healthcare providers will be those who provide services to TRICARE beneficiaries.

The study participants will be adults (parents of children with life-threatening illnesses, parents of children who have died and residents, staff physicians, and other healthcare providers such as nurse and care coordinators). The study will include both male and female participants. Their physical and psychiatric conditions will not be identified. The researchers will seek participants from diverse racial and ethnic backgrounds.

For recruiting families in the National Capital Area, two contacts have been identified: Dr. Cheryl Naulty, Medical Director, Exceptional Family Member Program/Educational and Developmental Intervention Services, WRAMC/NARMC is Principal Investigator of the larger project of which this protocol is a part. Dr. Naulty has privileges at both Walter Reed Army Medical Center (WRAMC) and the National Naval Medical Center (NNMC). Deborah Wills, R.N., is a nurse in Pediatric Hematology/Oncology at WRAMC who works with families with children with life-threatening illnesses and will be one of the staff members working on this project. Dr. Naulty and Ms. Wills may explain the study to parents and healthcare providers, present the consent forms, and ask if they would like to participate in the study. They will also ask other healthcare providers to inform families about the opportunity to participate. At each study site, we will identify at least one physician or care coordinator who will post and distribute recruitment flyers and answer basic questions about the study. At WRAMC, we have identified Luzviminda Nazareno, RN and Linda Lucas-Clary, RN. At NNMC, we have identified Ellen M. Tierney, RN and Lisa M. Kaintoch (RNC). Physicians and nurses will inform families about the opportunity to participate. Families who are interested may contact Dr. Naulty, Ms. Wills, or Dr. Hanson (the PI for this needs assessment), or tell their physician or nurse they are interested in participating in the study and their name and phone number may be given to a study investigator who will call to explain the study in more detail and answer their questions so they can decide whether to participate.

Health care providers will be recruited according the process described above using the recruitment materials in Appendix 12. None of the project investigators supervises or influences the ratings of health care providers at the military treatment facilities. Participation in the study will be completely voluntary and by self-referral on the part of the health care providers.

At the other sites with major military treatment facilities (Madigan, San Diego and Wright-Patterson), the principal investigator will contact the site directors for the USUHS Pediatric and Family Medicine Clerkships, to establish contacts with the local IRB and residency programs and other necessary contacts to accomplish the project.

Possible risks and procedures to minimize them

For healthcare providers, there are no anticipated individual health or injury risks associated with this study. There are no anticipated risks to psychological health, although they may experience feelings of frustration, anger and sadness as they talk about children they have cared for or are caring for at the time. If they need immediate mental health support during a focus group or interview at a military treatment facility, the study staff will contact the mental health professional who is on call at that facility. In addition, they will receive the following information in their copy of the consent form:

"If after talking about your experience in providing services and securing resources for families with children who have life-threatening illnesses you feel worse than you normally do, you may wish to contact a health care provider in your area. If you are an active duty military service member, you can contact your primary care manager, call Health Net at 877-874-2273 or visit www.tricareonline.com to make a primary care appointment through TRICARE. Otherwise, consult your TRICARE Prime primary care manager or other regular doctor, call Health Net at 877-874-2273 or refer to listings under "physicians" in your local phone book, and ask for a referral to a mental health professional. You may also contact the American Psychological Association for a referral to a psychologist in their area by calling 1-800-964-2000. To determine what benefits are covered under TRICARE contact a Health Benefits Advisor at a military treatment facility or visit www.healthnetfederalservices.com. To find out which providers are in the TRICARE network, visit www.tricareonline.com or call Health Net at 877-874-2273."

Health care providers who participate in the study will be free to decline to answer any questions. They will also be free to withdraw from the study at any time. The research staff will not associate any identifiers with transcripts from interviews or focus groups in which health care providers participate or with a survey they may complete. Therefore, it will only be possible to

identify and destroy their data if they decide to withdraw before the end of an interview or focus group.

Comments made in a focus group will be heard by others in the focus group, some of whom may be their colleagues. Focus group guidelines will specify that comments made in the group are confidential. Staff physicians and residents will participate in separate focus groups, so residents will feel free to share their observations and concerns openly. Research staff will be trained to conduct interviews and focus groups with sensitivity and will complete training in the ethics of doing research with human participants. Consent forms will provide information about how to access mental health services through TRICARE and also how to get a referral to a provider through the American Psychological Association, should such services be needed. Confidentiality of the healthcare providers' information will be maintained. Any identifying information will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Access to information that could identify them will be restricted to members of the research team. The names of healthcare providers who participate will not appear in any published papers or presentations related to this study without their express written consent, and then only to acknowledge their contribution to the study. In addition to the study staff, files from this study may be reviewed by officials of the Uniformed Services University, U.S. Army Medical Research, and Material Command (USAMRMC) personnel, and/or other government officials as part of their responsibility to review research records and protect human subjects of research.

For parents, there are no anticipated individual health or injury risks associated with this study. There are anticipated risks to psychological health. They may experience feelings of sadness, unhappiness, anger and/or frustration as a result of discussing their children's condition or death. They may experience these same feelings as they discuss their experiences in looking for or finding resources and services. If they need immediate mental health support during a focus group or interview at a military treatment facility, the study staff will contact the mental health professional who is on call at that facility. They will also receive the following information in their copy of the consent form:

"If after talking about your child's illness and services you feel worse than you normally do, you may wish to contact a health care provider in your area. If you are an active duty military service member, contact your primary care manager, call Health Net at 877-874-2273 or visit www.tricareonline.com to make a primary care appointment through TRICARE. Otherwise, consult your TRICARE Prime primary care manager or other regular doctor, call Health Net at 877-874-2273 or refer to listings under "physicians" in your local phone book, and ask for a referral to a mental health professional. You may also contact the American Psychological Association for a referral to a psychologist in your area by calling 1-800-964-2000. To determine what benefits are covered under TRICARE contact a Health Benefits Advisor at a military treatment facility or visit www.healthnetfederalservices.com. To find out which providers are in the TRICARE network, visit www.tricareonline.com or call Health Net at 877-874-2273."

Parents who participate in the study are free to decline to answer any questions. They are also free to stop participating in the study at any time. If they withdraw from the study and they also want data collected from them to be removed from the study, it will be possible to identify and destroy information they provided in individual interviews or surveys. If they participate in a focus group discussion, it will not be possible to identify which participant made a particular statement. The research staff will keep those group transcripts, but the research staff will not know which of the sentences came from the individual. Research staff will be trained to conduct interviews and focus groups with sensitivity and will complete training in the ethics of doing research with human participants. Consent forms will provide information about how to access mental health services through TRICARE and also how to get a referral to a provider through the American Psychological Association, should such services be needed. Confidentiality of the parents' information will be maintained. Any identifying information will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Access to information that could identify them will be restricted to members of the research team. The names of parents who participate will not appear in any published papers or presentations related to this study without their express written consent, and then only to acknowledge their contribution to the study.

Confidentiality of Data

Confidentiality of information provided by parents and health care providers will be maintained. Their names will not appear in any published paper or presentation related to this study without their expressed written consent, and then only to acknowledge their contribution to the study. Participants' names will not be recorded on any survey or on typed transcripts of interviews or focus groups. A 3-digit identifier will be assigned to these surveys and transcripts. The master list linking the identifiers to participants' names will be stored in a separate locked drawer, not with the surveys and transcripts, for up to 10 years. Information that can be linked to participants will be stored in locked cabinets in the offices of the Principal Investigator on the premises of USUHS. Electronic data files with information about them will be password protected and access to these files will be restricted to members of the study staff. The computer that stores files with identifying information will not be connected to the internet, a network, or a phone line. The transcripts and surveys will be kept indefinitely and the master list with the participants' protected information will be destroyed after no longer than 10 years.

We will contact the TRICARE Management Activity and Lead Agents for TRICARE regions to request data reflecting use of services covered by the TRICARE benefit for patients who fit the criteria established in the project to determine eligibility as "a child with a life-threatening illness." No patient identifiers will be needed.

For survey, interview, and focus group data, the participants will be identifiable through the use of the 3-digit identifiers described above. The following procedures will be taken to assure confidentiality of the data:

- Surveys: Since the surveys will be used as a tool during interviews and focus groups as part of a comprehensive case study research methodology, the identities of parents will be known and recorded when they complete the survey. Participants' names will not be associated with survey data when it is analyzed or reported.
- Interviews: Since interviews will be conducted as part of a comprehensive case study research methodology, the identities of families and health care providers will be known and recorded at the time of the interviews. Interviews will be tape recorded and transcribed. Participants' names will not be associated with interview data when it is analyzed or reported.
- Focus groups with parents: Since focus groups will be conducted as part of a comprehensive case study research methodology, the identities of families will be known and recorded at the time of the groups. Interviews will be tape recorded and transcribed. Participants' names will not be associated with interview data when it is analyzed or reported.
- Focus groups of residents, attending physicians, and other healthcare providers: We will not associate identifiers with data collected in focus groups or interviews with healthcare providers. We will describe the disciplines of healthcare providers in the groups.

Modifications to the Protocol

As a multi-site protocol based at the Uniformed Services University of the Health Sciences (USUHS), this protocol will be reviewed and approved first by the USUHS Institutional

Review Board. USUHS is the home institution and this IRB of Record for the Principal Investigator for the mCARE needs assessment, Dr. Janice Hanson. Any local modifications to the protocol required by a site IRB will be submitted first to the USUHS IRB for approval and inclusions in the protocol, and then to the IRBs at all participating sites. This process will ensure standardization of protocol procedures across all participating institutions.

It is understood that site IRBs may require appropriate local modifications to the informed consent documents and HIPAA authorization forms. Local modifications to these forms will not require prior approval by the USU IRB. Final approved versions of site consent and HIPAA authorization documents will be submitted to the USU IRB for secondary review and inclusion in the protocol file.

Application of Research Results

Goal 2: Define the eligibility criteria for the population of children to be served.

Activity: participate in mCARE workgroup to define eligibility criteria

Method: review literature; review TRICARE benefit, policy and legislative history; consult with experts

Deliverable: contribution to workgroup, written summary of information reviewed

USUHS personnel will participate in a workgroup with other mCARE partners to define eligibility for an mCARE model program and eligibility for receipt of pediatric hospice and related services as part of the TRICARE benefit. Preparation for the workgroup will involve reviewing relevant literature and reviewing the TRICARE benefit, policy and legislative history. The analysis of the MHS described in the needs assessment will inform the definition of eligibility. Eligibility criteria will define the threshold of severity of illness or diagnosis necessary to receive mCARE services. The following sources will be reviewed for definitions that can inform these criteria:

- CHI PACC programs in the states.
- Hospice/palliative care programs based in hospitals that serve children (such as those at Dana Farber Cancer Institute in Boston and Johns Hopkins in Baltimore)
- Quality of life indicators such as those in the End-of-Life Survey developed by the Foundation for Accountability (FACCT)⁸ (see Appendix 1).
- Articles in the peer-reviewed literature, such as Feudtner et al.¹² and the American Academy of Pediatrics website on the Medical Home.⁹
- Published literature demonstrating ways of defining the potential population eligible for care by DRGs, numbers of hospitalizations/year, codes for diagnoses and severity, and estimates of burden of care on families.
- Examples of specific wording found in TRICARE programs (e.g., ECHO and PFPWD).
- TRICARE experience with the IMPC-PEC program (case management of expensive cases).
- Existing community-based care coordination centers that have experience with children who qualify for the Medicaid Waiver, such as the Maryland Coordinating Center.
- Criteria for the Medicaid Waiver.
- Recommendations in the the Institute of Medicine Report.²
- ICF codes that consider functional abilities, which are under development by Rune Simeonsson and colleagues.^{13,14}

Goal 3: Develop a framework for datasets to support the new model design.

Activity: develop a framework for datasets for the proposed model

Method: participate in mCARE team meetings

Deliverable: meeting participation

USUHS personnel will participate in mCARE team planning meetings where a framework for datasets will be discussed, contributing insights from the needs assessment and MHS analysis to development of a framework and descriptors of fields for datasets needed to coordinate information about children and families and relevant care and services in the model program. Themes from focus groups and interviews may inform the development of categories and descriptors for the framework. However, this activity will develop a proposal for a framework for a web-based database, not a prototype with research participants' personal data.

Goal 4: Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.

Activity: develop a plan for a flexible website for mCARE

Method: participate in mCARE team meetings

Deliverable: meeting participation, advisory group perspectives

USUHS researchers will participate in mCARE team planning meetings, contributing information from the needs assessment and MHS analysis to discussions about a website that will support the needs of the mCARE program. The advisory group of parents will be available to review website concepts, terminology and presentation as needed.

Goal 5: Develop a plan for the education of families.

Activity: develop a plan to educate families of children with life-threatening illnesses and MHS health care providers

Method: critique case studies, consult with advisory group of families, work with mCARE partners

Deliverable: draft of a plan for education of families in the mCARE model

The case study reports and other results of the needs assessment will provide information needed to develop an approach to education for families. Education will encompass MHS and civilian community resources and how to access them, building partnerships with health care providers and participating in shared decision-making. USUHS researchers will develop implications of the needs assessment for education of families and draft a plan for education. The plan will be discussed, revised and prepared for implementation in collaboration with other mCARE partners. The advisory group will be available to review and comment on draft plans. Children's Hospice International will develop curricula for healthcare providers, and the needs assessment results will inform the development of these educational materials.

Goal 6: Design new model of care with cost projections in preparation for implementation and cost analysis.

Goal 7: Develop implementation strategies for the new model design.

Activity: participate in development of the mCARE model of care and implementation strategies

Method: participate in mCARE team planning meetings and work groups, applying the results of the needs assessment

Deliverable: results of needs assessment and the associated tools and reports, meeting participation

USUHS researchers will participate with mCARE partners in team planning meetings and workgroups to develop a proposed model of care for children with life-threatening illnesses and

their families. The needs assessment reports and MHS analysis will provide crucial information to guide the development of this model.

Goal 8: Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.

Activity: program evaluation of pilot components of the proposed mCARE model

Method: work with mCARE partners to design program evaluation of components of the new model

Deliverable: survey of the quality of life of caregivers, adapted for parents of children with life-threatening illnesses; program evaluation design (developed collaboratively)

In collaboration with the advisory group of parents (described in the needs assessment plans), project researchers at USUHS will adapt a survey to measure quality of life of caregivers of children with special needs to families with children with life-threatening illnesses. See Appendix 2 for the current version of this survey. The IOM report *When Children Die*² cites quality of life of both children and caregivers as a key outcome measure of pediatric hospice programs, but the field is in need of valid ways to measure this dimension.

With mCARE partners, the USUHS researchers will participate in planning and implementing evaluation of components of the proposed mCARE model. The quality of life of caregivers survey will provide a valuable resource for measuring outcomes. Two components recommended for early evaluation are respite care and care coordination. The MCC has extensive experience implementing respite care (the Take a Break program) and care coordination, and can provide clear definitions and descriptions of these services, as well as existing data, to guide the development of solid program evaluation. The mCARE needs assessment will also provide a clear understanding of the outcome variables that are important to both families and health care providers. The advisory group will be available to review plans, data and interpretations from a parent perspective.

The proposed model will also comprise education of physicians and other health care providers. The needs assessment—particularly the report of focus groups and interviews with health care providers, will provide essential insight regarding the educational needs of health care providers in the MHS. The USUHS researchers will participate in plans to modify, implement and evaluate educational approaches for health care providers in the MHS.

Investigators' Qualifications

Please see the attached biographical sketches (Appendix 6).

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Appendix 1
End-of-Life Survey
(Foundation for Accountability)

Appendix 2
Quality of Life of Caregivers of Children with Special Needs
Survey
(Randall and Hanson)

Appendix 3
Medical Home Assessment Tools

GREENWOOD – July 15, 2002
 MEDICAL HOME ASSESSMENT QUESTIONNAIRE:
 HEALTH CARE PROFESSIONAL VERSION

Please read through these self-assessment questions and circle the response that best matches your level of ability.

Accessibility: Personal

This is not done well>>>This is done well

- | | | | | |
|--|---|---|---|---|
| 1. I acknowledge the family's sense of urgency by responding quickly to requests, such as for information & referrals. | 1 | 2 | 3 | 4 |
| 2. My schedule is flexible enough to individualize services for different family circumstances. | 1 | 2 | 3 | 4 |
| 3. My coworkers and I understand our responsibilities and how to respond appropriately to family needs. | 1 | 2 | 3 | 4 |
| 4. I educate families and professionals about how to contact our doctors. | 1 | 2 | 3 | 4 |
| 5. We schedule appointments at mutually convenient times for families. | 1 | 2 | 3 | 4 |
| 6. Our office has a plan to improve accessibility within the office. | 1 | 2 | 3 | 4 |

Accessibility: Geographic

- | | | | | |
|---|---|---|---|---|
| 7. I have information about where and when the following services are provided in my community: | | | | |
| a. Home health care and/or home nursing | 1 | 2 | 3 | 4 |
| b. Hospice care | 1 | 2 | 3 | 4 |
| c. Mental health services and support | 1 | 2 | 3 | 4 |
| d. School health care | 1 | 2 | 3 | 4 |
| e. Early intervention | 1 | 2 | 3 | 4 |
| f. Care coordination | 1 | 2 | 3 | 4 |
| g. Special education (from time of diagnosis to age 21) | 1 | 2 | 3 | 4 |
| h. Vocation, rehabilitation, and habilitation programs | 1 | 2 | 3 | 4 |
| i. Training for independent living | 1 | 2 | 3 | 4 |

j.	Hospital school programs including home tutoring	1	2	3	4
k.	Family resource libraries, centers, and programs	1	2	3	4
l.	Family-to-Family support and networking	1	2	3	4
m.	Sibling support	1	2	3	4
n.	Toy or equipment loan or exchange	1	2	3	4
o.	Playgrounds	1	2	3	4
p.	Respite care, child care, and baby sitting	1	2	3	4
q.	Transportation assistance	1	2	3	4
r.	Recreational programs and camps	1	2	3	4
s.	Legal services for estate planning,wills,&guardianships	1	2	3	4
t.	Spiritual support as the family desires	1	2	3	4
u.	Home adaptation for health or development equipment needs	1	2	3	4
8.	Our office is barrier-free (eg, wheelchair-accessible)	1	2	3	4
9.	When I suggest or prescribe services, I consider the demands they place on the family from the perspective of time, location, cost, and coordination	1	2	3	4

Accessibility: Financial

This is not done well>>>This is done well

10.	My coworkers and/or I are knowledgeable about resources (direct and indirect: eg, federal, state, local, foundations, clubs, non-governmental agencies) available to families.	1	2	3	4
11.	My coworkers and/or I encourage families to seek these resources.	1	2	3	4
12.	My coworkers and/or I are aware of the various health plans in which my patients may participate and how these plans treat special needs.	1	2	3	4
13.	My coworkers and/or I advocate for families when issues arise concerning their health care plan.	1	2	3	4
14.	My billing process is flexible enough to allow for various payment options or schedules.	1	2	3	4

CompassionateThis is not done well>>>This is done well

- | | | | | | |
|-----|--|---|---|---|---|
| 15. | I listen respectfully to the opinions of family members. | 1 | 2 | 3 | 4 |
| 16. | I work to create an environment in which families feel supported and comfortable enough to speak freely. | 1 | 2 | 3 | 4 |
| 17. | I believe that the family's perspective and opinion are as important as mine/ours as professionals | 1 | 2 | 3 | 4 |
| 18. | I set my values and preferences aside and operate from those of the family. | 1 | 2 | 3 | 4 |
| 19. | I take the time to learn about the child's family. | 1 | 2 | 3 | 4 |
| 20. | I ask families how they would like medical and other information provided to them. | 1 | 2 | 3 | 4 |
| 21. | I recognize the need for respite care and help families plan for it. | 1 | 2 | 3 | 4 |
| 22. | I accept that a child's health care needs are only one part of the family's priorities and that sometimes a family's needs and concerns may take precedence. | 1 | 2 | 3 | 4 |
| 23. | I value the competence of other care providers. | 1 | 2 | 3 | 4 |
| 24. | I talk with the family about the range of possibilities for a child's progress. | 1 | 2 | 3 | 4 |
| 25. | I take the time to ask about the needs, health, and other concerns of family caregivers. | 1 | 2 | 3 | 4 |

Comprehensive

- | | | | | | |
|-----|--|---|---|---|---|
| 26. | I and/or my coworkers make health care available 24 hours a day, 7 days a week. | 1 | 2 | 3 | 4 |
| 27. | My coworkers and/or I manage health promotion, injury prevention, acute and chronic illness, and the tertiary health care needs of our patients. | 1 | 2 | 3 | 4 |
| 28. | My coworkers and/or I provide children with special health care needs and their families anticipatory guidance and make referrals to community and tertiary resources when needed. | 1 | 2 | 3 | 4 |

Coordinated

- | | | | | | |
|-----|--|---|---|---|---|
| 29. | My coworkers and/or I freely share information with various providers to facilitate communication and collaboration. | 1 | 2 | 3 | 4 |
| 30. | My coworkers and/or I link families to all necessary providers | 1 | 2 | 3 | 4 |

and services to meet the needs of the child and family.

Family-centered Care

		This is <u>not</u> done well>>>This			
	is done well				
31.	My coworkers and/or I ask families to identify their strengths.	1	2	3	4
32.	My coworkers and/or I continuously and openly share information to families about their child's condition.	1	2	3	4
33.	My coworkers and/or I are supportive to families and help them adjust to the needs of their child.	1	2	3	4
34.	My coworkers and/or I work with families to identify needs during each visit.	1	2	3	4

Continuous

35.	I am aware of the variety of potential transitions that a child and family may experience.	1	2	3	4
36.	I provide support for families faced with upcoming transitions.	1	2	3	4
37.	I encourage families to learn necessary skills about how to manage their child's special needs at home.	1	2	3	4
38.	My coworkers and/or I make ourselves available to other professionals who are involved with the child's care during periods of transition.	1	2	3	4

Cultural Competence

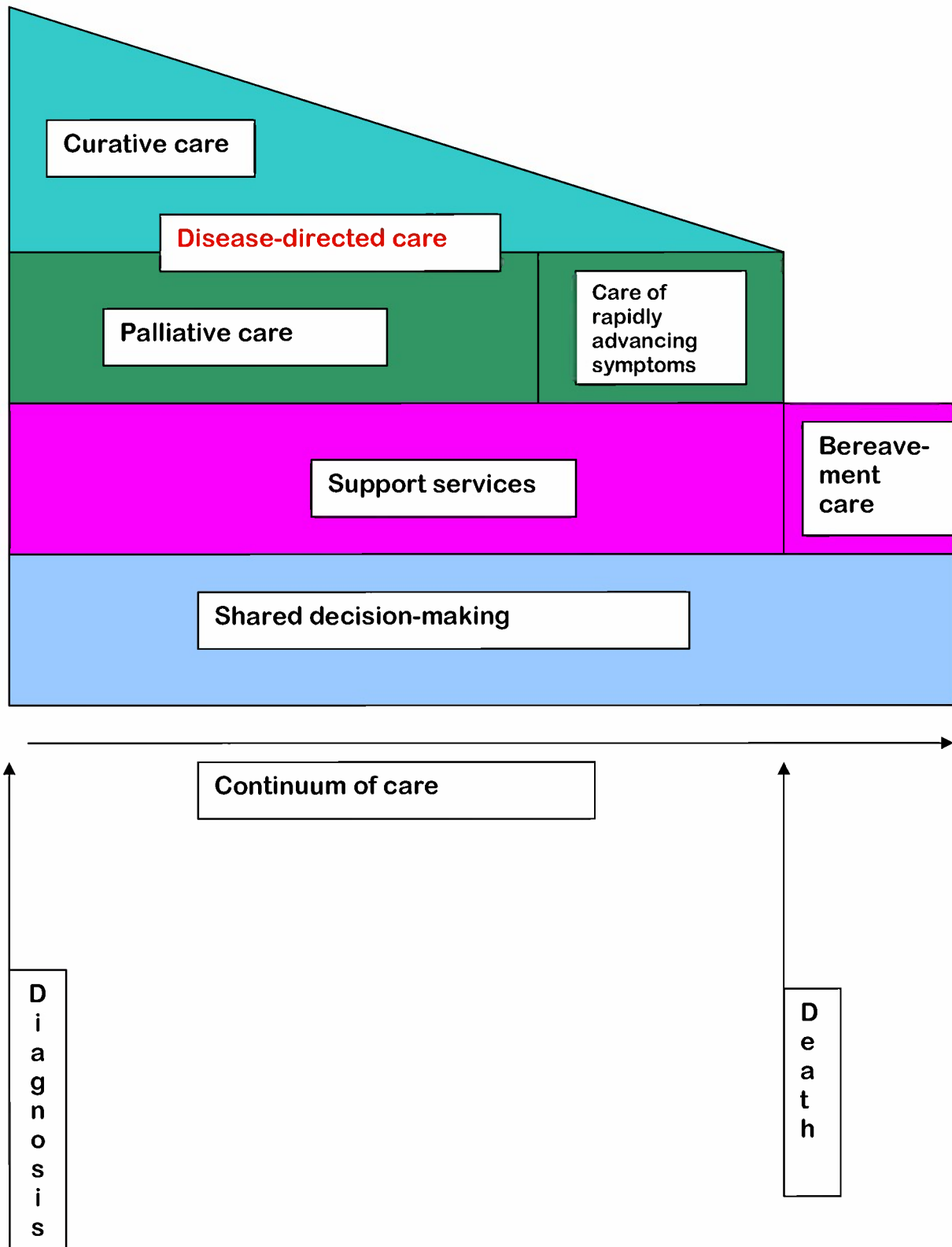
39.	My coworkers and/or I are trained in different ways of helping that are respectful of diversity in areas such as race and family structure.	1	2	3	4
40.	My coworkers and/or I are aware of and encourage families to seek out support of other families with similar backgrounds.	1	2	3	4
41.	My coworkers and/or I attempt to make information available to families in their first language.	1	2	3	4
42.	My coworkers and/or I are aware of the impact our background or presentation of self may have on the family and patient.	1	2	3	4
43.	We work to acquire the knowledge and skills needed to be sensitive to the primary culture group(s) that I serve.	1	2	3	4

ACTION PLAN:

Take a moment to look back at your responses. Look at the elements where more than half of your responses are circled 1 or 2. Create action steps to help improve these scores in the future. List 3 goals on which you would like to work:

Appendix 4
Schematic Diagram of Care

Tentative Schematic Diagram of Care



Appendix 5
Task Schedule for Needs Assessment

Task Schedule for Needs Assessment USUHS

Phase I Needs Assessment

	Jul/Aug/Sep/Oct 04	Nov/Dec 04	Jan/Feb/Mar 05	Apr/May/Jun 05	July/Aug/Sep/ 05	Oct/Nov/Dec 05
Focus groups, interviews and surveys	Identify contacts, recruit participants in NCA Focus groups and interviews in NCA	Write preliminary NCA case study	Focus groups and interviews at Wright-Patterson	NCA—focus groups to interpret data collected	Write preliminary Wright-Patterson case study Prepare needs assessment template for sites 3, 4, 5	
Data analysis		Input data	Interpret		Integrate 2 case studies and MHS analysis	Complete report of 2 case studies and MHS analysis
MHS analysis	Plan; request data from Lead Agent and Contractor	Define problem issues Review TRICARE benefit				
Develop publications				Two case studies, needs assessment template, MHS analysis and recommendations		
Team planning meetings	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners

Phase I Modification of Needs Assessment

	Jul/Aug/Sep/Oct 04	Nov/Dec 04	Jan/Feb/Mar 05	Apr/May/Jun 05	July/Aug/Sep/ 05	Oct/Nov/Dec 05
Focus groups, interviews and surveys	Build Family Medicine collaboration Identify contacts, recruit participants in NCA (pediatricians, pediatric residents, family medicine physicians and residents, case managers, therapists, other health care providers, TRICARE Management Activity representatives, TRICARE contractors, parents)	Identify contacts, recruit participants at Wright-Patterson Develop initial needs assessment template		Identify contacts at San Diego, Madigan and Ft. Leavenworth	Submit IRB applications to San Diego and Madigan Plan travel schedule for San Diego, Madigan and Ft. Leavenworth (sites 3, 4, 5)	Submit IRB application to Ft. Leavenworth
Advisory group	Establish advisory group	Adapt QOL of caregivers survey	Confer with advisory group as needed			
Data analysis						
MHS analysis		Research eligibility criteria and participate in working group			Describe access issues	
Program evaluation					Plan evaluation of program components with MCC	
Team planning meetings	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners

Phase II Needs Assessment

	Jan/Feb/Mar 06	Apr/May/Jun 06	Jul/Aug/Sep 06	Oct/Nov/Dec 06
Focus groups, interviews and surveys	<p>Focus groups and interviews in Ft. Leavenworth and Madigan</p> <p>Write preliminary Ft. Leavenworth case study</p> <p>Modify needs assessment template for sites 4 and 5 if necessary</p>	<p>Focus groups and interviews in San Diego</p> <p>Write preliminary Madigan and San Diego case studies</p>	<p>NCA—focus groups to interpret data collected and integrate all 5 case studies</p> <p>Complete report of case studies 3, 4, and 5</p>	
Advisory group	Confer with advisory group as needed			
Data analysis	Input data; Interpret data; Integrate case studies and MHS analysis			Summarize recommendations
MHS analysis	Request data from Lead Agents and Contractors for sites 3, 4, and 5			Summarize recommendations
MHS analysis		Research eligibility criteria and participate in working group		Describe access issues
Program evaluation		Plan evaluation of program components with MCC		
Develop publications	Ft. Leavenworth case study; Revised needs assessment template	Madigan and San Diego case studies	Integrated case study report	<p>Develop model with partners</p> <p>Complete evaluation of program components with MCC</p>
Team planning meetings	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners	Meet with mCARE partners

Appendix 6
Biographical Sketches

Janice Lynn Hanson, Ph.D.
Research Assistant Professor of Pediatrics

EDUCATION

2001		Johns Hopkins University, Curriculum Development Course (medical education)
1984	Ph.D.	University of Michigan, Ann Arbor, MI Education. Dissertation: <i>Effects of Developmental Evaluations on Parents of Infants and Young Children</i>
1979	Ed.S.	University of Michigan, Ann Arbor, MI Education and psychology
1978	M.A. Ed.	East Carolina University, Greenville, NC Special education: Learning disabilities
1974	B.A.	Western Michigan University, Kalamazoo, MI Special education: Orthopedic handicaps

RECENT PROFESSIONAL EXPERIENCE

May 1999-present	Research Assistant Professor of Pediatrics , Uniformed Services University of the Health Sciences, Bethesda, MD. (Adjunct Assistant Professor since 1997). Faculty Senator Jan. 2001-present; Chair, Comparability and Faculty Welfare Committee
1992-1999	Director for Research and Evaluation/Senior Policy and Program Specialist , Institute for Family-Centered Care, Bethesda, MD.
1993-1994	Principal Investigator , Sociometrics, Inc., Army Early Intervention Assessment and Planning Project, Silver Spring, MD.

RECENT FUNDED GRANTS

December 2003-	Principal Investigator at USUHS, <i>MCARE Needs Assessment</i> , component of Children's Hospice award on which Cheryl Naulty, M.D. is Principal Investigator at Walter Reed Army Medical Center. \$199,950, U. S. Army Medical Research and Materiel Command (USAMRMC)
December 2005	Principal Investigator, <i>Collaborative, Competency-based Medical Education</i> , \$471,556, Health Resources Services Administration (HRSA), U. S. Department. of Health and Human Services
July 2002-June 2005	Co-principal investigator with Dr. Virginia Randall, <i>Developing Competencies: Fostering Family-Centered Care in Medical Students</i> , \$548,472, Josiah Macy, Jr. Foundation for Medical Education
April 1999-June 2003	Project Manager and primary proposal author, <i>Families as Faculty and Advisors</i> , approximately \$500,000, contract between the Uniformed Services University of the Health Sciences and the Institute for Family-Centered Care, Bethesda, MD. COL Virginia Randall, M.D., Principal Investigator

SELECTED PUBLICATIONS

Jones, WS, **Hanson, JL** & Longacre, JL (in press) An Intentional Modeling Process to Teach Professional Behavior. *Teaching and Learning in Medicine*.

Randall, VF & **Hanson, JL**, (2003) "Frequently asked questions," chapter 4 in *Pediatric Clerkship Guide*, Jerold C. Woodhead, MD, Editor, Mosby/Elsevier.

Hanson, JL (2002) Sometimes I think in images. *Revista Eidon*, Journal of the Institute of Bioethics, Foundation for Health Sciences, Madrid, Spain. 11.

Randall, VF & **Hanson, JL** (2000) The Family Competency Project. *Academic Medicine*. 75(5), 529-530.

Hanson, JL, Randall, VF, & Colston, SS (1999) Parent advisors: Enhancing services for young children with special needs. *Infants and Young Children*. 12(1), 17-25.

Hanson, JL & Randall, VF (1999) Evaluating and improving the practice of family-centered care. *Pediatric Nursing*. 25(4), 445-449.

Hanson, JL, Jeppson, ES, Johnson, BH, & Thomas, J (1997) *Newborn Intensive Care: Resources for Family-Centered Care*. Bethesda, MD: Institute for Family-Centered Care.

Johnson, BH, **Hanson, JL** & Jeppson, ES (1997) *Maternity Care: Resources for Family-Centered Care*. Bethesda, MD: Institute for Family-Centered Care.

SELECTED PRESENTATIONS AT PROFESSIONAL MEETINGS

Hanson, JL & Randall, VF (2004) *Involving Parents as Research Collaborators*. Workshop, Pediatric Academic Societies, San Francisco, CA, May 1, 2004.

Smith, S, Beck, G, Christy, C, **Hanson, J**, Harris, M, Talib, N & Tewksbury, L (2004) *How Do we know what works? Finding the Best Evidence in Medical Education*. Workshop, COMSEP Annual Meeting, Panama City, FL, March 5-8, 2004.

Hanson, J, Randall, V & Sykora, W (2004) *Teaching Advocacy in the Family Medicine Clerkship: Evaluation Data Across 2 Years*. Society of Teachers of Family Medicine 30th Annual Predoctoral Education Conference, New Orleans, LA, Jan. 30-Feb. 1, 2004.

Sykora, W, Reamy, B & **Hanson, J** (2004) *Trial and Error: Trying to Create the Perfect Clerkship*. Society of Teachers of Family Medicine 30th Annual Predoctoral Education Conference, New Orleans, LA, Jan. 30-Feb. 1, 2004.

Hanson, J, Randall, V & Sykora, W (2004) *Involving Patients and Families in Medical Education*. Society of Teachers of Family Medicine 30th Annual Predoctoral Education Conference, New Orleans, LA, Jan. 30-Feb. 1, 2004.

Hanson, JL, Lackey, JN & Sykora, WS (2004) *Building an Elective on Spirituality and Medicine: Collaboration between Students, Patients and Faculty*. Society of Teachers of Family Medicine 30th Annual Predoctoral Education Conference, New Orleans, LA, Jan. 30-Feb. 1, 2004.

Jones WS, **Hanson JL**, Johnson CL, Randall VF, Vizcarrondo FE, Longacre JL. Student's Clinical Observations of Preceptors (SCOOP): A Process to Model Professionalism in Clinical Practice. *Pediatric Res*. 2003;53:4:510A. Platform Presentation at Pediatric Academic Societies Meeting, Seattle, May 3-6, 2003.

Randall, VF, Flake, EM, and **Hanson, JL**. *Parent Decision-Making About Complementary and Alternative Medicine*. Pediatric Academic Societies, May 2003.

Sykora, W & **Hanson, J** (2003) *Teaching Medical Students to Become Patient Advocates*. Society of Teachers of Family Medicine 29th Annual Predoctoral Education Conference, Austin, TX, Jan. 30-Feb.2, 2003.

Hanson, JL, Randall, VF, Jeppson, ES, Hawkins, R, Adamo, G. and Sykora, WS. (2002) *Teaching And Evaluating Advocacy Skills*, Council on Medical Student Education in Pediatrics (COMSEP), Nashville, Tennessee.

Hanson, JL, Randall, VF, and Jeppson, ES. (April 2001) *Utilizing a Pre/Post Self-Assessment Tool to Evaluate the Effectiveness of Teaching Physician Advocacy in the Family Practice Clerkship*. Poster presentation, Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Hanson, JL, Randall, VF, Hawkins, RE, Sykora, WS, Jeppson, ES, Adamo, G, Zanoni, AE and Lacy, TJ. (March 2001) *Advocating for Patients: Teaching Medical Students about Patient/Physician Communication and Effective Use of Health Care System Resources*. Workshop, Undergraduate Medical Education-21 (UME-21) Third Annual Meeting, Washington, DC.

Johnson, CL, **Hanson, JL**, Jones, WS, Randall, VF and Longacre, JL. (March 2001) *Utilizing a Matrix to Review Whether Clerkship Activities and Evaluation Tools Optimally Implement the COMSEP Curriculum*. Poster presentation, Council on Medical Student Education in Pediatrics (COMSEP), San Diego, CA and April 2001 Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Hanson, JL, Randall, VF, and Duque, E. (January 2001) *Health-Related Quality of Life of Caregivers of Children with Special Needs*. Ambulatory Pediatric Association Region IV Annual Meeting, Charlottesville, VA.

Hanson, JL, Randall, VF and Grotberg, E. (April 2000) *Promoting Resilience: Pediatric Clerks Gain Skills for Health Care Encounters*. Platform presentation, Council on Medical Student Education in Pediatrics Annual Meeting, Vancouver, British Columbia.

Randall, V and **Hanson, J**. (April 2000) *COMSEP Curriculum Review: Parent Focus Group*. Poster presentation, Council on Medical Student Education in Pediatrics Annual Meeting, Vancouver, British Columbia, , and March 2000 Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Christensen, K, **Hanson, J** and Bush, D. (April 2000) *Computer Generated Patient Education Handouts as Tools for Enhancing Medical Student Training in Ambulatory Care Settings*. Poster presentation, Council on Medical Student Education in Pediatrics Annual Meeting, Vancouver, British Columbia, and March 2000 Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Randall, VF and **Hanson, JL**. (October 1999) *Home Visits in Medical Education*. Poster presentation, Association of American Medical Colleges Annual Conference, Washington, DC.

Hanson, JL & Randall, VF. (April 1999) *Evaluating Impact on Medical Students: Home Visits in the Pediatric Clerkship*. Platform presentation, Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Randall, VF & **Hanson, JL**. (April 1999) *Families as Faculty and Advisors: Enhancing Medical Education and Health Care Service Delivery*. Poster presentation, Uniformed Services University of the Health Sciences Research Day, Bethesda, MD.

Hanson, JL & Randall, VF. (March 1999) *How We Do Home Visits*. Council on Medical Education in Pediatrics Annual Meeting, Galveston, TX.

Randall, VF & **Hanson, JL**. (June 1998) *Competencies Parents Expect from Physicians: How Do We Teach Them to Our Medical Students?* Sixteenth Annual Faculty Development Course, American Academy on Physician and Patient, Atlanta, GA.

Virginia F. Randall, MD, MPH
COL, USA, MC
Associate Professor of Pediatrics
164-34-9450

Local Address:

3804 Cherry Valley Drive, Olney, MD 20832
home phone: 301 924 8426

Duty Address:

Department of Pediatrics, Uniformed Services University of the Health Sciences,
4301 Jones Bridge Road, Bethesda, MD 20814
Duty phone: 301 295 3098
Duty email: vrandall@usuhs.mil

Education and Training:

1992: Johns Hopkins School of Hygiene and Public Health, Baltimore, MD
Masters of Public Health (Health Policy)
1982: Madigan Army Medical Center, Tacoma, WA
Fellowship in Developmental Pediatrics
1973: Medical College of Virginia, Richmond, VA
Internship and residency in pediatrics
1970: Jefferson Medical College, Philadelphia, PA
Doctor of Medicine
1966: Bridgewater College, Bridgewater, VA
Bachelor of Arts (Chemistry) *summa cum laude*

Board Certification:

Pediatrics, 1975
Recertified in Pediatrics, 2000

Medical License: Maryland D0061279

Military Assignment Record:

1995-present: Uniformed Services University of the Health Sciences
1986-1995: Policy analyst and Exceptional Family Member Program Manager,
Office of the Army Surgeon General
1984-1986: Staff, Developmental Pediatrics, Walter Reed Army Medical Center,
Washington, DC
1982-1984: Staff, Developmental Pediatrics, Madigan Army Medical Center,
Tacoma, WA
1980-1982: Fellowship in Developmental Pediatrics, Madigan Army Medical
Center, Tacoma, WA
1974-1980: Pediatric Clinic, General Pediatrics, Elmendorf Air Force Base,
Anchorage, AK

Academic Honors:

AOA: Jefferson Medical College

Military Honors:

Legion of Merit

Outstanding Service Medal

Meritorious Service Medal x 3

Army Commendation Medal x 2

Current Clinical Duty:

1995-present: Site director at Malcolm Grow Air Force Medical Center for third year medical student clerks in pediatrics. Provide one day/week of teaching in acute care clinic and one day/week of teaching in developmental pediatric clinic.

Pertinent Professional Committee Assignments:

1. Academy of Pediatric, Committee on Children with Disabilities, committee member, 1992-1996.
2. DoD/DHHS Committee on Children with Special Needs, co-chairman, 1991-1993.

Pertinent Administrative Experience:

1. Consultant to the Army Surgeon General on the Army Exceptional Family Member Program, The Individuals with Disabilities Education Act, Early Intervention
2. Author and COR on contract to develop early intervention program at Army installations in Germany, Panama, and Korea

Pertinent Presentations

a. Hanson, J.L, Randall, V. F., and Jeppson, E. S., Hawkins, R. Adamo, G., and Sykora, W. *Advocacy: Competency-Based Education In A Family Practice Clerkship*, Research Day, Uniformed Services University of the Health Sciences, May 2002.

b. Hanson, J.L. and Randall, V.F. "Collaborating with parents in challenging situations," workshop for Department of Defense early intervention providers (EDIS), April 16, 2002.

c. Hanson, J.L. and Randall, V.F. "Involving Parents as Research Collaborators," workshop for Pediatric Academic Societies Annual Meeting, May 1, 2004, San Francisco.

Appendix 7
Informed Consent Forms

Appendix 8
Recruitment Phone Script
and Follow-up Letter

mCARE Phone Recruitment Script

Principal Investigators and Associate Investigators will call parents to explain the study and request participation. The following script is provided for these calls:

“(Introduce self.) Is this a good time to call? I got your phone number because you (saw a flyer and said you might be interested in this project) (were referred by ____, who thought you might be interested). I’m calling to ask you to participate in a research project called mCARE. The purpose of mCARE is to find out about the needs of children with very serious, life threatening medical conditions, and the needs of their families. mCARE is interested in medical, psychological, social, educational, and spiritual needs, in fact, any need for services or equipment of any kind. mCARE is interested in the services that children and families have needed and received, as well as needs that have not been met very well. Eventually, mCARE will help DoD/TRICARE develop a service system that better meets the needs of children and families like yours, using resources of the health care system and the community.

“Would you be interested in coming to (name of military treatment facility) or the Uniformed Services University for a focus group? Would you be interested in inviting myself or another researcher to your home for an interview? In this (group or interview), we will ask you about all the needs of your child and family, what services you have found to meet these needs, and what services you wish you could find but you can’t find them or pay for them or get to them. We are especially interested in the efforts you have made to get services, whether or not these efforts were successful, and why.

(Then get contact information, and either schedule a home visit or time to attend a focus group, or say that you’ll be in touch to schedule at a later time. Give the parents a phone number to contact us. Follow up with written notice of the visit and contact information for the researchers.)

“Thank you for your time.”

mCARE Recruitment Follow-up Letter

Department of Pediatrics

(date)

Dear (parent(s)),

We are glad you have agreed to discuss your participation in the “mCARE” study with us. “mCARE” stands for “Military Children at Risk – Enhancing Quality of Life (mCARE) Needs Assessment.” As we discussed on the phone, this study will collect information from you about your experiences with your child’s illness. With this information, and with your help and the help of other parents who have children with life-threatening illnesses, we will make recommendations for changes in TRICARE benefits or other mechanisms that will help military families access resources they need.

We will soon be (visiting you in your home on (date) at (time)) (meeting in a focus group at USUHS with other parents on (date) at (time) in (room)) to thoroughly describe and discuss this study, answer any questions you may have about the study, and ask you to sign consent forms. (If meeting in a focus group, a map of USUHS with the meeting room marked, parking information and a parking pass if needed will be included.) We will then begin to talk about your child and family and the services you’ve used or wished were available.

Please call me at 301 295 9726 if you have questions and to confirm that the (home visit) (focus group time and location) will work for you.

Sincerely,

Janice L. Hanson, Ph.D.
Principal Investigator

Appendix 9
Sample Recruitment Flyer

mCARE
Military Children At Risk – Enhancing Quality of Life

***DO YOU HAVE A CHILD WITH A VERY
SERIOUS, LIFE-THREATENING MEDICAL
CONDITION?***

***You can help the military healthcare system to
meet the needs of families like yours***

You are invited to participate in a research study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in obtaining the services you and your child need. The project team will interview you in your home or invite you to group discussions. Sharing your experience will help us plan for better services for children and families.

Information that you share about you or your child will be held as confidential.

For more information, contact
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhhs.mil)

Appendix 10
IRB Approval Letters from the Uniformed Services
University of the Health Sciences

Appendix 11
Focus Group and Interview Topic Guides
and Introductory Scripts

Focus Group Topic Guide and Introductory Script

Parent Advisory Group

Focus Group and Interview Questions

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to review focus group and interview questions for parents and health care providers.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ FACCT End-of-Life Survey (appendix 1)
- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2)
- ❖ Medical Home Assessment Tools (appendix 3)
- ❖ Tentative Schematic Diagram of Care (appendix 4)
- ❖ Topic Guides for focus groups and interviews (appendix 11)

Topics for discussion

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for health care provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews
- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

Focus Group Topic Guide and Introductory Script

Parent Advisory Group

Quality of Life Survey

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2)
- ❖ Tentative Schematic Diagram of Care (appendix 4)

Topics for discussion

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey
- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses
- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisors think should be added to the survey

Focus Group Topic Guide and Introductory Script

Parent Advisory Group

Assistance with Data Interpretation and Needs Assessment Template

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care (appendix 4)

Topics for discussion

- ❖ Review tentative themes and discuss clarity of descriptions of the themes
- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

Focus Group Topic Guide and Introductory Script

Parent Advisory Group

Editing Study Reports and Making Recommendations for a Model of Care

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Draft study reports as ready
 - Report of parent focus groups and interviews
 - Report of health care provider focus groups and interviews
 - Case study reports
 - Military Health System Analysis report
 - Research reports for submission to journals
- ❖ Tentative schematic diagram of care (appendix 4)

Topics for discussion

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits
- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care

Interview Topic Guide and Introductory Script

Parent Advisory Group

Focus Group and Interview Questions

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to review focus group and interview questions for parents and health care providers.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ FACCT End-of-Life Survey (appendix 1)
- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2)
- ❖ Medical Home Assessment Tools (appendix 3)
- ❖ Tentative Schematic Diagram of Care (appendix 4)
- ❖ Topic Guides for focus groups and interviews (appendix 11)

Topics for discussion

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for health care provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews
- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

Interview Group Topic Guide and Introductory Script

Parent Advisory Group

Quality of Life Survey

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2)
- ❖ Tentative Schematic Diagram of Care (appendix 4)

Topics for discussion

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey
- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses
- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisor thinks should be added to the survey

Interview Group Topic Guide and Introductory Script

Parent Advisory Group

Assistance with Data Interpretation and Needs Assessment Template

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care (appendix 4)

Topics for discussion

- ❖ Review tentative themes and discuss clarity of descriptions of the themes
- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

Interview Group Topic Guide and Introductory Script

Parent Advisory Group

Editing Study Reports and Making Recommendations for a Model of Care

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Draft study reports as ready
 - Report of parent focus groups and interviews
 - Report of health care provider focus groups and interviews
 - Case study reports
 - Military Health System Analysis report
 - Research reports for submission to journals
- ❖ Tentative schematic diagram of care (appendix 4)

Topics for discussion

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits
- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care

Focus Group Topic Guide and Introductory Script

Parents

Explanation of Background Information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials needed

- ❖ FACCT End-of-Life Survey (appendix 1)
- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2) as adapted by advisory group
- ❖ Medical Home Family Index (appendix 3)
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

Topics for discussion

- ❖ how parents define the needs of children and families when a child has a life-threatening illness
- ❖ the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ the experience of children and families in finding and using services in their communities (both military and civilian communities)
- ❖ education and information necessary to enable them to find and access the health care and services that they need
- ❖ the degree to which the children’s care has been coordinated and what the mechanisms of coordination have been.

Focus Group Topic Guide and Introductory Script

Health Care Providers

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group to gather your perspectives as a health care provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain mCARE consent form (and HIPAA form) for health care providers.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and health care providers present.
 - “This group meeting will last about 1 hour. It will be audiotaped and later transcribed.”

Materials needed

- ❖ Medical Home Index (appendix 3)
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version (appendix 3)

Topics for discussion

- ❖ how residents, pediatricians, family medicine physicians and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families (mCARE).

Interview Topic Guide and Introductory Script

Parents

Explanation of Background Information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (2 hours). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials needed

- ❖ FACCT End-of-Life Survey (appendix 1)
- ❖ Quality of Life of Caregivers of Children with Special Needs survey (appendix 2) as adapted by advisory group
- ❖ Medical Home Family Index (appendix 3)
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

Topics for discussion

- ❖ how parents define the needs of children and families when a child has a life-threatening illness
- ❖ the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ the experience of children and families in finding and using services in their communities (both military and civilian communities)
- ❖ education and information necessary to enable them to find and access the health care and services that they need
- ❖ the degree to which the children’s care has been coordinated and what the mechanisms of coordination have been.

Interview Topic Guide and Introductory Script

Health Care Providers

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality-of-life for DoD children with life-threatening conditions and their families. This information will help project staff understand how physicians and other health care providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to gather your perspectives as a health care provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain mCARE consent form (and HIPAA form) for health care providers.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”

Materials needed

- ❖ Medical Home Index (appendix 3)
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version (appendix 3)

Topics for discussion

- ❖ how residents, pediatricians, family medicine physicians and other health care providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families (mCARE).

Appendix 12
Health Care Provider Recruitment Materials

mCARE Needs Assessment Phone and Email Recruitment Script for Health Care Providers

Principal Investigators and Associate Investigators will call or email health care providers to explain the study and request participation. The following script is provided for these calls and email messages:

“(Introduce self.) (Is this a good time to call?) I got your (phone number or email address) because you (saw a flyer and said you might be interested in this project) (were referred by ___, who thought you might be interested). I’m (calling or writing) to ask you to participate in a research project called *mCARE*, which stands for Military Children at Risk- Enhancing Quality of Life. The purpose of *mCARE* is to learn about the needs of children with very serious, life-threatening medical conditions and the needs of their families. We are interested in medical, psychological, social, educational, and spiritual needs, in fact, any need for services or equipment of any kind. We plan to describe the services that children and families have needed and received, as well as needs that have not been addressed very well. Eventually, *mCARE* will make recommendations to DoD/TRICARE about developing a service system that better meets the needs of children and families, using resources of the health care system and the community.

“We will be talking with parents of children with life-threatening medical conditions, and we also want to know what you as a health care provider understand about the concerns, needs and services for these children and their families. We would also like to talk with you about what education might equip you to address their needs more effectively, since one of the goals of *mCARE* is to recommend an educational plan for health care providers that deals specifically with children with life-threatening illness and their families.

“Would you be interested in meeting at a specified location at (Malcolm Grow Medical Center) for a focus group? Or would you be interested in meeting with me or another researcher for an individual interview? In this (focus group or interview), we will ask you about all the needs of any of your patients who have a life-threatening illness and their families. In addition, we will ask about what services you have found to meet these needs, what services you wish you could help the families find but you can’t, and what problems the families have had with accessing services and/or payment. We are especially interested in the efforts you have made to help families get services, whether or not these efforts were successful, and why.

(Then request contact information, and schedule either an interview or a time to attend a focus group, or say that you’ll be in touch to schedule at a later time. Give the health care provider a phone number to contact us. Follow up with written notice of the visit and contact information for the researchers.)

“Thank you for your time.”

mCARE Needs Assessment Recruitment Follow-up Letter for Health Care Providers

Department of Pediatrics

(date)

Dear (health care provider),

We are glad you have agreed to discuss your participation in the “mCARE” study with us. “mCARE” stands for “Military Children at Risk – Enhancing Quality of Life (mCARE) Needs Assessment.” As we discussed on the phone, this study will collect information from you about your experiences with your patients’ life-threatening medical conditions. With this information, and with your help and the help of parents and other healthcare providers who care for children with life-threatening illnesses and their families, we will make recommendations for changes in TRICARE benefits or other mechanisms that will help military families access resources they need.

We will soon be [(meeting with you for an individual interview)(meeting in a focus group at Malcolm Grow Medical Center with other health care providers on (date) at (time) in (room)))] to thoroughly describe and discuss this study, answer any questions you may have about the study, and ask you to sign consent forms. We will then begin to talk about your patients and families, the services you’ve recommended or wished were available and any barriers you encountered in accessing these services for your families.

Please call me at (301) 295-9726 if you have questions and to confirm that the (individual interview time and location) (focus group time and location) will work for you.

Sincerely,

Janice L. Hanson, Ph.D., Ed.S.
Principal Investigator
Research Assistant Professor of Pediatrics
Assistant Professor of Family Medicine

mCARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a research study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at Malcolm Grow Medical Center. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(naulty.cheryl@wramc.na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at Walter Reed Army Medical Center. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at the National Naval Medical Center. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at Wright-Patterson Medical Center. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at Madigan Army Medical Center. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at the Naval Medical Center, San Diego. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at Munson Army Health Clinic, Ft. Leavenworth. Sharing your experience will help us plan for better services for children and families.

For more information, contact
Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

*m*CARE
Military Children At Risk – Enhancing Quality of Life
Needs Assessment

***Do You Provide Care to Children with Life-
Threatening Medical Conditions
and Their Families?***

PLEASE READ THIS

You are invited to participate in a study designed to help the Military Healthcare System to determine the needs (met and unmet) of children with very serious, life-threatening medical conditions and their families. The goal is to improve access to services through TRICARE and community coordination.

Please share your knowledge and experience in providing care to children with life-threatening medical conditions and their families at group discussions and/or in individual interviews at [LOCAL INSTITUTION]. Sharing your experience will help us plan for better services for children and families.

For more information, contact
[SITE PI/COORDINATOR CONTACT INFORMATION]

Dr. Janice Hanson, (301) 295-9726
(jhanson@usuhs.mil)
Dr. Cheryl Naulty, (202) 782-4185
(cheryl.naulty@na.amedd.army.mil)

APPENDIX 5

Demographics for Research Participants

	Healthcare Provider Participants	Parent Participants
National Capital Area Total	31	19
<i>USUHS</i>	6	15
<i>WRAMC</i>	8	2
<i>NNMC</i>	6	1
<i>MGMC</i>	11	1
Madigan AMC	28	35
NMC San Diego	24	24
Wright Patterson AFMC	17	15
<i>TOTAL</i>	<i>100</i>	<i>93</i>

Parents

Active Duty Army	23
Active Duty Navy	12
Active Duty Marine Corps	3
Active Duty Air Force	18
Retired (all)	15
Active Duty, but branch unknown	15
Completely unknown service	7
<i>Total</i>	<i>93</i>

	<u>National Capital Area</u>	<u>Madigan AMC</u>	<u>NMC San Diego</u>	<u>Wright Patterson AFMC</u>
Officer – Ret	0	1	0	1
Officer – Active Duty	0	6	3	5
Officer – unknown	0	0	0	0

*Madigan AMC also has 1 senior enlisted

Healthcare Providers

Gender

	Males	Females	Total
National Capital Area			
<i>USUHS</i>	<i>5</i>	<i>1</i>	<i>6</i>
<i>WRAMC</i>	<i>4</i>	<i>4</i>	<i>8</i>
<i>NNMC</i>	<i>1</i>	<i>5</i>	<i>6</i>
<i>MGMC</i>	<i>4</i>	<i>7</i>	<i>11</i>
National Capital Area Total	14	17	31
Madigan AMC	18	10	28
NMC San Diego	12	12	24
Wright Patterson AFMC	7	10	17
Total Healthcare Providers	51	49	100

Specialties

	<u>National Capital Area</u>	<u>Madigan AMC</u>	<u>NMC San Diego</u>	<u>Wright-Patterson AFMC</u>	<i>TOTAL</i>
General Pediatricians	4	2	7	3	16
Pediatric NICU Fellows	2				2
Pediatric Interns/Residents		9	9	8	26
Developmental Fellow		1			1
Medical Students			2		2
Family Medicine Physicians	3		1		4
Family Medicine Residents	9	3			12
Nurses, Care Coordinators, Case Managers, Social Workers, Palliative Care Managers	8	3	3	4	18
Psychologist	1				1
Pediatric Psychiatrist		1			1
Internal Medicine Physician	1				1
Pediatric Intensivist	1				1
Pediatric Cardiologist	1	1	1		3
Pediatric Neurologist		1			1
Developmental Pediatrician		2	1		3
Pediatric Oncologist	1	1			2
Pediatric Infectious Disease Specialist		1			1
Adolescent Medicine		1			1

Pediatric Endocrinologist		1		1	2
Pediatric Dysmorphologist		1			1
Pediatric Gastroenterologist				1	1
<i>TOTAL</i>	<i>31</i>	<i>28</i>	<i>24</i>	<i>17</i>	<i>100</i>

Ethnicity

	White	African American	Pacific Islander	Native American	Hispanic	Other
National Capital Area						
<i>USUHS</i>						
<i>WRAMC</i>						
<i>NNMC</i>						
<i>MGMC</i>						
National Capital Area Total						
Madigan AMC						
NMC San Diego	10	0	1	0	2	11
Wright Patterson AFMC	15	0	0	0	0	1
Total Healthcare Providers	10	0	1	0	2	11

Specialties

NATIONAL CAPITAL AREA*	<p><u>Overall:</u></p> <ul style="list-style-type: none"> • 7 Pediatricians or Pediatric Subspecialists • 2 Pediatric Residents or Fellows • 2 Family Medicine Physicians • 9 Family Medicine Residents • 8 Nurses, Care Coordinators, Case Managers, Social Workers, Palliative Care Managers • 1 Psychologist • 1 Internal Medicine Physician <p><u>Specifics:</u></p> <ul style="list-style-type: none"> • Social Worker • Pediatric Fellow • Family Practice Residents (9-10) • Nurse Case Manager/Clinical Nurse
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	<p>Specialist (2)</p> <ul style="list-style-type: none"> • Clinical Nurse Specialist • RN Pediatric Case Manager • NICU staff nurse discharge planner • Palliative Care Coordinator • Family Medicine Physician (2) • Internal Medicine • Pediatric Cardiologist
Madigan AMC	<p><u>Overall:</u></p> <ul style="list-style-type: none"> • 11 Pediatricians or Pediatric Subspecialists • 10 Pediatric Residents or Fellows • 3 Family Medicine Residents • 3 Nurse Practitioners, Nurse Case Managers, Social Workers • 1 Psychiatrist <p><u>Specifics:</u></p> <ul style="list-style-type: none"> • Nurse Case Manager • Nurse Practitioner • Dysmorphologist • Psychiatrist • Clinical Social Worker • Pediatrician (3) • Pediatric Neurologist • Pediatric Cardiologist • Developmental Pediatrician • Oncologist • Infectious Disease Specialist • Adolescent Medicine • Endocrinologist • Developmental Pediatric Fellow (1) • Pediatric Residents (9) • Family Medicine Residents (3)
NMC San Diego	<p><u>Overall:</u></p> <ul style="list-style-type: none"> • 9 Pediatricians or Pediatric Subspecialists • 11 Pediatric Residents, Interns, or Students • 3 Nurse Case Managers, Social Workers, or Clinic Coordinators • 1 Family Medicine Physician <p><u>Specifics:</u></p> <ul style="list-style-type: none"> • Nurse Case Manager • Coordinator of Developmental Clinic • NICU Social Worker

	<ul style="list-style-type: none"> • Pediatrician (7) • Pediatric Cardiologist • Developmental Pediatrician • Family Medicine • Pediatric Residents (5) • Pediatric Interns (4) • Medical Students (2)
Wright Patterson AFMC	<u>Specifics:</u> <ul style="list-style-type: none"> • Pediatric Case Manager (2) • General Pediatrician (3) • Chief Pediatric Resident • Pediatric Clinical Nurse • Nurse Practitioner • Pediatric Gastroenterologist • Endocrinologist • Pediatric Residents (7)

*All healthcare provider interviews were grouped together for the National Capital Area so it is unknown which specialties came from which specific site within the National Capital Area.

Parent Participants

Uniformed Services University

Male Parents: 4 Female Parents: 11 Total: 15

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>State of Residence</u>
8	Oligohydroamniosis	Army – Retired	Minnesota
14	Leukemia	Air Force – Retired	MD
Died at 15	Heart condition	Navy	VA
11 (died later at 12)	Cerebral Palsy, Quadriplegic	Marine	VA
Died at 14	Cerebral Palsy, Quadriplegic	Army – Retired	MD
15	Rhett's Syndrome	Air Force – Retired (2 parents)	MD
14	Cerebral Palsy	Air Force	MD
7	Leukodystrophy (possibly)	Air Force	MD
?	Leukemia	Army	MD
Died at 20	Cystic Fibrosis	Army	VA
Died at 14	Brain cancer	Navy	VA
18	Cerebral Palsy	Army Active Duty (2 parents)	MD

Walter Reed Army Medical Center

Male Parent: 0 Female Parent: 2 Total: 2

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>State of Residence</u>
4	DiGeorge Syndrome	Army	MD
17	Cerebral Palsy	Army	MD

National Naval Medical Center

Male Parent: 0 Female Parent: 1 Total: 1

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>State of Residence</u>
14 mo	Hypoplastic Lung	?	MD

Malcom Grow Air Force Medical Center

Male Parent: 0 Female Parent: 1 Total: 1

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>State of Residence</u>
Died at 1 or 2	Seizure disorder	Air Force	MD

Madigan Army Medical Center*Male Parents: 8**Female Parents: 27**Total: 35*

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>Ethnicity</u>
11	thalamic AVM with a dilation of the vena Galen	Active Duty Army (husband was Army too but got out)	
(over 2)	son with cerebral palsy, he's a twin	wife of Active Duty husband (both husband and wife participated)	
13	diagnosed with muscular dystrophy at 2, has bad scoliosis	ex-husband Active Duty Air Force and retiring soon but kids will be covered under his new wife who is still Active Duty	
4	neonatal seizures, sub-arachnoid hemorrhaging, prenatal strokes, alopecia universalis (hair loss disease)	husband is Active Duty, came from Ft. Hood	
4	Diagnosed before birth. bilateral periventricular nodular heterotopia, lissencephaly, microcephaly with simplified gyri, intrauterine growth restriction, failure to thrive, a seizure disorder, cortical blindness	husband is Active Duty Army	
20	diagnosed with severe cerebral palsy at 3 mo old	ex-husband is retired Army she gets privileges	
8	diagnosed with Duchenne muscular dystrophy at 5 yrs old	Active Duty enlisted Air Force	
16	Had eye surgery for strabismus at 3 mo; seizures started at 6 mo	husband Active Duty enlisted Army, PV1	
17; 9	both with genetic immune deficiency (x-linked hyper IgM); oldest son has cancer too	Active Duty Army officer (wife and husband participated)	
3	severe cerebral palsy, seizure disorder	Active Duty enlisted Air Force	wife is German
5	Rhett syndrome	Active Duty Army officer (husband and wife participated)	
?	leukemia	husband is Active Duty enlisted	
8	cerebral palsy, Quadriplegic	husband Active Duty Navy enlisted	
7	baby shake syndrome, seizures	daughter is Active Duty officer, her son is sick (child is participant's grandson)	
?	severe cerebral palsy, brain damage, needs risky heart surgery	husband Active Duty Army enlisted	

3	diagnosed with spina bifida at 16 wks, has has hydrocephalus with a shunt, chiari-II malformation which is where the brainstem gets pulled into the spinal cord	Active Duty enlisted Air Force, hubby quit job to stay home with kids	
7 ; 2	cystic fibrosis (7 yr old); hydrocephalous and severe delays (2 yr old)	Active Duty Army officer, has been in 5 yrs (husband and wife participated)	
?	leukemia, relapsed 4 months before finishing treatment	husband Army senior enlisted, retiring in 1 week	
32	cerebral palsy, severely mentally retarded	husband retired Army officer, retired after 27 yrs	
4	congenital heart defect, discovered at 20 weeks, has had several open-heart surgeries	husband Active Duty Army warrant officer, she is a nurse	
17	cerebral palsy	husband Active Duty, has been away from home for military since 1999	
21 mo	born without an anus and stomach exploded b/c of it, has pulmonary stenosis, slight cerebral palsy	husband Active Duty	
7	diagnosed with infantile spasms at 4 mo, has cerebral palsy	husband Active Duty	
4	Rhett Syndrome, seizures	Husband is 0-3, mom is a nursing student (husband and wife participated),	
2	hydroencephaly	husband Active Duty E3 Air Force	
5	diagnosed with leukemia at 3 yrs old, it has reached to his spinal cord and brain	Active Duty E6 Army	
2	Joubert Syndrome (basically poor muscle tone)	Husband Active Duty (Army?)	
4	4.5 mo preemie, severe Cerebral Palsy, non-verbal, blind	Husband Active Duty	
Died at 7	astrocytoma brain tumor	husband is Active Duty in Navy, retiring in 3 years	
6	in remission for ALL, diagnosed at 3	husband is E6 (Army? Stationed at Ft Lewis)	
5	cyst on the corpus collosum, has seizures and cerebral palsy	Army, active duty	

Naval Medical Center, San Diego

*This data is not as thorough, as transcripts have not yet been individually analyzed

Male Parent: 7

Female Parent: 17

Total: 24

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>Ethnicity</u>
?	Oldest autistic with behavioral problems; youngest (of 4) with autism and recent brain surgery	Husband Active Duty officer	white
?	multiple disabilities, ventilator-dependent	Active Duty Marine Corps	African American
?	1 with diabetes; 1 with asthma; youngest with undiagnosed collection of difficulties	Husband Active Duty Navy enlisted	white
?	in remission from ALL	Active Duty but soon to retire	African American
2 sons, 3 yrs old	Autism	Husband retired Navy	White
?	Tuberousclerosis	Former Active Duty (husband and wife there)	White (both)
?	Rhett Syndrome	Active Duty	White
8	Sturgis Webber Syndrome	Active Duty	African American
2	Med-evaced from Triplet to Bethesda, aspirated, pneumonia, reflux	Active Duty	African American
3	Autism	Active Duty Navy officer	White
7 mo	Preemie needing oxygen and G-tube, failure to thrive	Active Duty Navy enlisted	Filipino
3	JMAL (?) a rare type of leukemia; in remission but relapse is common	?	Other
?	Nephritic syndrome, kidney failure, multiple medical problems	?	African American
5	Encephalitis that recurred, non-responsive to sight, touch, sound	Active Duty Navy enlisted	Filipino
?	Preemie, G-tube, trach that was removed, born with grade 4 bleed, coded 3 times at house, now doing better	Husband in Army reserves, was in Navy	African American
?	Two children with autism	Recently retired	Hispanic
*	Autism	Husband Active Duty	?
About 5	Cerebral Palsy	Active Duty Navy enlisted; single mother	White

3	Metabolic storage disease	Active Duty Navy	White
17	Cerebral Palsy	Husband Active Duty Navy, nearing retirement	White
20	Brain aneurism at 14 improving slowly	Active Duty Marine Corps	White
*	Diabetes	?	White
?	?	Husband Active Duty officer; at Camp Pendleton	African American

*Said very little, doesn't fit Himelstein descriptions

Wright Patterson Air Force Medical Center

*This data is not as thorough, as transcripts have not yet been individually analyzed

Male Parent: 13 Female Parent: 2 Total: 15

<u>Age of Child</u>	<u>Diagnosis</u>	<u>Military Service</u>	<u>Ethnicity</u>
?	Anoplastic Wilms Tumor	Husband Active Duty Air Force intelligence officer	White
6	Noonan's and Crohn's Disease	Husband Active Duty Air Force executive officer	White
8	Spastic Quadriplegia	Husband Active Duty Air Force enlisted	White
13	MMA (methylmionic academia)	Husband retired Air Force (was officer at end of career)	White
3	Chromoso micro-deletion on chromosome 9	Active Duty enlisted Air Force	White
6	Asthma, nut allergy, didn't fit	Husband Active Duty Air Force?	White
18 mo	Congenital Myopathy (suspected multiminicort/congenital myopathy hypotonia)	Husband Active Duty Air Force enlisted Senior Airman	White
6	Crouzan's Disease and Turner's Syndrome	Husband Active Duty officer	White
9	Cerebral Palsy	Husband retired Air Force	White
21 mo	?	Active Duty Air Force	White
4	Cerebral Palsy and Seizure Disorder	Husband Active Duty Air Force officer (Lt Col or Major)	White
4;2	Reflux as infant; Cerebral Palsy	Husband Active Duty Air Force non-commissioned officer (?)	White (both parents there)
18; other died 2 yrs ago at 17	Ataxia-Telangectasia (both children)	Husband retired Air Force	White (both parents there)

APPENDIX 6

Focus Group and Interview Topic Guides and Introductory Scripts

Focus Group Topic Guide and Introductory Script Parent Advisory Group Focus Group and Interview Questions

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to review focus group and interview questions for parents and healthcare providers.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Medical Home Assessment Tools

- ❖ Tentative Schematic Diagram of Care
- ❖ Topic Guides for focus groups and interviews

Topics for discussion

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for healthcare provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews
- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

Focus Group Topic Guide and Introductory Script
Parent Advisory Group
Quality of Life Survey

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Tentative Schematic Diagram of Care

Topics for discussion

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey

- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses
- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisors think should be added to the survey

Focus Group Topic Guide and Introductory Script
Parent Advisory Group
Assistance with Data Interpretation and Needs Assessment Template

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care

Topics for discussion

- ❖ Review tentative themes and discuss clarity of descriptions of the themes

- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

Focus Group Topic Guide and Introductory Script
Parent Advisory Group
Editing Study Reports and Making Recommendations for a Model of Care

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials available for review

- ❖ Draft study reports as ready
 - Report of parent focus groups and interviews
 - Report of healthcare provider focus groups and interviews
 - Case study reports
 - Military Health System Analysis report
 - Research reports for submission to journals
- ❖ Tentative schematic diagram of care

Topics for discussion

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits
- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care

Interview Topic Guide and Introductory Script
Parent Advisory Group
Focus Group and Interview Questions

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to review focus group and interview questions for parents and healthcare providers.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Medical Home Assessment Tools
- ❖ Tentative Schematic Diagram of Care
- ❖ Topic Guides for focus groups and interviews

Topics for discussion

- ❖ Review topic guides for parent focus groups and interviews
- ❖ Review topic guides for healthcare provider focus groups and interviews
- ❖ Discuss ways to be sensitive to parent participants in future focus groups and interviews
- ❖ Obtain suggested wording for focus group and interview questions
- ❖ Discuss suggestions for incorporating surveys listed above in focus groups and interviews

- ❖ Review tentative schematic diagram of care
- ❖ Determine whether additional topics need to be added to focus group and interview guides

Interview Group Topic Guide and Introductory Script
Parent Advisory Group
Quality of Life Survey

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to adapt a survey about Quality of Life for Caregivers of Children with Special Needs, so that it will effectively address the needs of parents of children with life-threatening illnesses.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Tentative Schematic Diagram of Care

Topics for discussion

- ❖ Review current version of Quality of Life of Caregivers of Children with Special Needs survey
- ❖ Review categories of questions in the survey
- ❖ Discuss the categories of questions in the survey, whether any categories should be eliminated, and whether additional categories of questions are needed to address the circumstances of children with life-threatening illnesses

- ❖ Discuss whether the wording of existing questions should be changed for this group of parents
- ❖ Draft wording for any questions that the advisor thinks should be added to the survey

Interview Group Topic Guide and Introductory Script
Parent Advisory Group
Assistance with Data Interpretation and Needs Assessment Template

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to assist with interpretation of data for the needs assessment and to develop or modify a needs assessment template.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Tentative themes from focus groups and interviews completed to date (no identifying information)
- ❖ Summary presentations of survey data (no identifying information)
- ❖ List of items for a needs assessment template
- ❖ Tentative schematic diagram of care

Topics for discussion

- ❖ Review tentative themes and discuss clarity of descriptions of the themes
- ❖ Review available survey data and discuss clarity of its presentation
- ❖ Discuss additional information that needs to be collected
- ❖ Discuss implications of themes and survey results to date
- ❖ Edit needs assessment template as needed
- ❖ Review tentative schematic diagram of care and modify as needed to reflect data to date

Interview Group Topic Guide and Introductory Script
Parent Advisory Group
Editing Study Reports and Making Recommendations for a Model of Care

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to edit one or more draft study reports and make recommendations for a proposed model of care.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials available for review

- ❖ Draft study reports as ready
 - Report of parent focus groups and interviews
 - Report of healthcare provider focus groups and interviews
 - Case study reports
 - Military Health System Analysis report
 - Research reports for submission to journals
- ❖ Tentative schematic diagram of care

Topics for discussion

- ❖ Review one draft report
- ❖ Discuss recommended editing of that report
- ❖ Repeat for one or more additional reports if available and time permits

- ❖ Discuss recommended editing of additional report(s)
- ❖ Review tentative schematic diagram of care and modify as needed to reflect information in reports
- ❖ Discuss implications of reviewed reports for a recommended model of care

Focus Group Topic Guide and Introductory Script Parents

Explanation of Background Information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person or his or her family. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and advisors present.
 - “This group meeting will last about 2 hours. It will be audiotaped and later transcribed.”
 - “Please sign this sheet in order to receive the fee for participating as described in the consent form.”
 - Explain parking, restrooms, food as relevant to this group.

Materials needed

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey as adapted by advisory group
- ❖ Medical Home Family Index
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

Topics for discussion

- ❖ Discuss how parents define the needs of children and families when a child has a life-threatening illness

- ❖ Discuss the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ Discuss the experience of children and families in finding and using services in their communities (both military and civilian communities)
- ❖ Discuss education and information necessary to enable them to find and access the health care and services that they need
- ❖ Discuss the degree to which the children's care has been coordinated and what the mechanisms of coordination have been.

Focus Group Topic Guide and Introductory Script Healthcare Providers

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s group is to gather your perspectives as a healthcare provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
 - “Before beginning the group, we will go over the informed consent form and ask each of you who has not previously signed this form to do so before participating in the group.”
 - Present and explain the consent form (and HIPAA form) for healthcare providers.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form) for each group participant who has not previously consented.
- ❖ Confidentiality
 - “The information discussed in this group is confidential. Outside of this group, please do not discuss any information shared by anyone else in the group in any way that would enable anyone else to identify that person. Please keep this information in this room.”
- ❖ Practical information about the group
 - Introduce project staff and healthcare providers present.
 - “This group meeting will last about 1 hour. It will be audiotaped and later transcribed.”

Materials needed

- ❖ Medical Home Index
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version

Topics for discussion

- ❖ Discuss how residents, pediatricians, family medicine physicians and other healthcare providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ Discuss participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ Discuss education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families.

Interview Topic Guide and Introductory Script Parents

Explanation of Background Information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to learn about your child’s needs, your family’s needs, and your experiences in seeking, finding and using services to meet those needs.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for parent advisors.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you or your family.”
- ❖ Practical information about the interview
 - “This interview will last about (2 hours). It will be audiotaped and later transcribed.”
 - “If applicable to you, you will receive the fee for participating as described in the consent form.”

Materials needed

- ❖ FACCT End-of-Life Survey
- ❖ Quality of Life of Caregivers of Children with Special Needs survey as adapted by advisory group
- ❖ Medical Home Family Index
- ❖ Topic guide for parent focus groups and interviews as adapted by advisory group

Topics for discussion

- ❖ Discuss how parents define the needs of children and families when a child has a life-threatening illness
- ❖ Discuss the experience of children and families with the MHS (direct care system and TRICARE) in meeting those needs
- ❖ Discuss the experience of children and families in finding and using services in their communities (both military and civilian communities)

- ❖ Discuss education and information necessary to enable them to find and access the health care and services that they need
- ❖ Discuss the degree to which the children's care has been coordinated and what the mechanisms of coordination have been.

Interview Topic Guide and Introductory Script Healthcare Providers

Explanation of background information

- ❖ Purposes
 - “The purpose of this study is to do a needs assessment to gather information that will help develop a model of care coordination that enhances the quality of life for Department of Defense children with life-threatening conditions and their families. This information will help project staff understand how physicians and other healthcare providers and the Military Health System can better meet the needs of children with life-threatening illnesses and their families. It will help us plan for better care for families with children like yours.”
 - “The purpose of today’s interview is to gather your perspectives as a healthcare provider about the needs of children with life-threatening illnesses and their families, the care and services available to address those needs, and your need for education about these topics.”
- ❖ Informed consent
 - “Before beginning the interview, we will go over the informed consent form and I will ask you to sign it.” (if this participant has not previously signed this form)
 - Present and explain the consent form (and HIPAA form) for healthcare providers.
 - Answer any questions.
 - Obtain signed consent form (and HIPAA form).
- ❖ Confidentiality
 - “The information discussed in this interview is confidential. I will not share any information outside of this interview in any way that would identify you”
- ❖ Practical information about the interview
 - “This interview will last about (1 hour). It will be audiotaped and later transcribed.”

Materials needed

- ❖ Medical Home Index
- ❖ Medical Home Assessment Questionnaire—Health Care Professional version

Topics for discussion

- ❖ Discuss how residents, pediatricians, family medicine physicians and other healthcare providers define the needs of the children with life-threatening conditions and their families for whom they provide care
- ❖ Discuss participants’ experiences with the Military Health System (direct care system and TRICARE) in meeting those needs
- ❖ Discuss education and information necessary to help them provide comprehensive care in a Medical Home model for children with life-threatening illnesses and their families.

APPENDIX 7

Focus Group and Interview Questions for Parents and Healthcare Providers

Parent Focus Group and Interview Questions

1. (show the Himmelstein definition of children with life-threatening illnesses) Where do you see your child in relation to this definition? Does (s)he fit one or more of these 4 categories? How?
2. How would you describe the needs of your child and family?
3. What services have you received to address these needs?
4. What needs remain unmet?
5. What has been your experience in finding the services you need through the Military Health System (MHS), through both the military treatment facilities and services provided in the civilian community through TRICARE?
6. What has been your experience in finding services you need in the military community (not including the MHS)?
7. What has been your experience in finding services you need in the civilian community?
8. What education and information have you needed to find the health care and other services that your child and family need?
9. How has your child's care been coordinated? Who has provided care coordination?
10. What has worked especially well in meeting the needs of your child and family?
11. How has your experience with your child been affected by the military? How has being in the military affected your experience with your child? How has the military career in your family been affected?

Specifics to explore if time:

Care coordination

Palliative care

Counseling/support

Respite care

Idea of physician/parent/care coordinator team, written plan of care, and a specific benefit for eligible children with life-threatening conditions

Healthcare Provider Focus Group and Interview Questions

1. How would you describe the needs of the children with life-threatening conditions for whom you provide care?
2. How would you describe the needs of their families?
3. Please describe your experience and observations about meeting the needs of these children and families in military treatment facilities.
4. Please describe your experience and observations about meeting the needs of these children and their families through civilian care and services paid for by TRICARE.
5. How would you describe the concept of a medical home?
6. What education and information do you think is needed to help residents, staff physicians, nurses and others in the military health system provide comprehensive care in a medical home model for children with life-threatening illnesses and their families?
7. Have you ever had training in pain management or palliative care? Enough? Please describe it and what additional training you need?
8. What services do you see that families need beyond health care? Which of these services do you provide or actively link families with through the military treatment facility?

APPENDIX 8



Military Health System Analysis Report: Care for Children with Life-Threatening Conditions

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Military Health System Analysis Report: Care for Children with Life-Threatening Conditions

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This Military Health System (MHS) report will discuss aspects of the MHS as it pertains to care for children with life-threatening conditions (LTC), including a discussion of the availability and accessibility of services found in a comprehensive pediatric palliative care and hospice program. It was developed by the Uniformed Services University of the Health Sciences under contract #W81XWH-04-C-0064 for the U.S. Army Medical Research and Materiel Command through the Henry M. Jackson Foundation for the Advancement of Military Medicine.

The contract requires that the following topics are addressed in the report:

- ✓ A description of the healthcare benefits available to children with LTC and their families.
- ✓ A description of benefits and services that are either not easily accessible or are not authorized.
- ✓ Alternatives for ensuring children with LTC and their families receive necessary medical benefits.
- ✓ A description of implications of eligibility criteria for a comprehensive pediatric palliative care and hospice program as a CHAMPUS benefit.

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Summary

Children with life-threatening conditions (LTC) who are entitled to services from the Military Health System (MHS) do not receive care in the comprehensive pediatric palliative care and hospice model called for by the Institute of Medicine¹, Medicaid², the Children's Hospice International³, and the National Quality Forum⁴. This model is rapidly becoming the standard-of-care for dying children. Children with LTC include those who have irreversible progressive conditions in which treatment is exclusively palliative from diagnosis to death; conditions requiring long periods of intensive treatment aimed at prolonging and improving quality-of-life; conditions for which curative treatment is possible but may fail; and, conditions with severe, non-progressive disability causing extreme vulnerability to health complications and death.⁵

An estimated 4000 children with LTC are eligible for medical care through the MHS each year. Approximately 400 of these children die each year. MHS costs to serve this population are rising rapidly (an increase of 64% from FY01/02 to FY 04/05.) An independent government cost estimate of a comprehensive palliative and hospice program for children, however, demonstrates that a net cost savings would be obtained by the MHS within a few years of implementing such a program.⁶

The Institute of Medicine recommends "insurers should restructure hospice benefits for children to ... eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care [and] reimburse bereavement services for parents and surviving siblings of children who die."⁷ These key features of a pediatric palliative care and hospice program are not available to most children with LTC in the MHS. CHAMPUS/TRICARE authorizes extended home health care *only* to children who meet a high threshold of disability and who are dependents of active duty service members.⁸ Hospice is authorized as a benefit *only* when it meets Medicaid criteria (begins within six months of expected death, patient must forgo disease-directed care).⁹ Bereavement counseling is *explicitly excluded* as a benefit under CHAMPUS/TRICARE unless the beneficiary meets a definition of mental illness¹⁰.

Options for providing medically appropriate care to children with LTC include a new CHAMPUS program to provide robust home-based health care, individualized care coordination, respite care and bereavement counseling to parents and siblings as a "wrap-around" to traditional medical and palliative care services delivered through the direct care system or purchased through TRICARE. This proposal would provide medically appropriate care and result in a net savings in dollars to the MHS. Alternately, the "hospice" program benefit in CHAMPUS/TRICARE could be redefined for children to authorize the Medicaid/CHI-PACC program benefits.

¹ Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, pp 1-16.

² Children's Health Services, Home and Community Waiver, Center for Medicaid and Medicare Services
³ <http://www.chionline.org/programs/> Last accessed 6/20/2006

⁴ www.nationalconsensusproject.org/guideline.pdf Last accessed 1/05/2006.

⁵ Association for Children with Life-Threatening Conditions and Their Families (ACT) *A Guide To The Development Of Children's Palliative Care Services 2nd ed*; London, 2003.

⁶ Kennell and Associates, Inc. Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center, February 28, 2006.

⁷ Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, pp 1-16.

⁸ Title 32, CHAMPUS, Part 199.5 - TRICARE Extended Care Health Option

⁹ Title 32, CHAMPUS, Part 199.4.- Basic Program

¹⁰ Title 32, CHAMPUS, Part 199.4.- Basic Program

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¹¹ Children who died or disenrolled from the MHS during FY01 are included using their FY01 age, all others using their FY02 age. These departures add roughly 250,000 children to the total vs a midpoint population count.

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¹² Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center (Task Order 3001-088). See Appendix G.

1.

Definitions

Life-Threatening Condition (LTC)

A life-threatening condition (LTC) is a medical condition that has a substantial likelihood of leading to the death of an individual before the age of 24 yrs. This term includes children born with lethal conditions as well as those who develop a life-threatening illness. As used in this report, it does not include children who die soon after birth, an injury, or a sudden illness.

Care Coordination

Care coordination is “a collaborative process of assessment, planning, facilitation, and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality, cost-effective outcomes.”¹³ In this report, care coordination also addresses the needs of the family, is proactive (especially in obtaining palliative care and integrating palliative care with disease-directed care), and ensures that the family obtains the support they need while planning for the peaceful and meaningful death of their child and that the family receives needed bereavement support following the death of the child.

Care coordination is a component of medical management, which also includes utilization management, case management, and disease management, as directed by the TRICARE Management Activity Department of Defense Instruction (DoDI 6025.20) and in the *Medical Management Guide*.¹⁴ The DoD TRICARE Management Activity defines care coordination as clinical case management or individually-based case management when provided by a clinical case manager rather than another member of the health care team, and recommends clinical case management be available across the entire health care continuum.¹⁵

CHAMPUS

Title 10, USC, which defines the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) now known as TRICARE. It outlines the healthcare benefits to which uniformed service members and their dependents are entitled.

Disease-Directed Care

Disease-directed care is medical care that is intended to cure or slow the progression of a medical condition.

Military Health System (MHS)

¹³ Case Management Society of America, *Standards at a Glance, Accreditation Program Guide for Case Management Standards*; version 2.0, URAC, 2002.

¹⁴ DoD TRICARE Management Activity, *Medical Management Guide*; January 2006.

¹⁵ DoD TRICARE Management Activity, *Population Health Improvement Plan and Guide*, December 2001.

The MHS provides medical care for active duty and retired service members and their dependents. The direct care component includes 70 hospitals and 411 medical clinics in the U.S. and throughout the world. Medically necessary care is also purchased from the civilian sector as described in CHAMPUS and implemented by TRICARE.

Palliative Care

Palliative care is defined by the Institute of Medicine as distinct from end-of-life care. It is “care that seeks to prevent, relieve, reduce, or soothe the symptoms produced by serious medical conditions or their treatments and to maintain patients’ quality of life. The benefits of such care are not limited to people thought to be dying or those enrolled in hospice programs.”¹⁶ Symptoms addressed in palliative care include pain, dyspnea, nausea, itching, fatigue, and mental, emotional, and spiritual suffering.

TRICARE

TRICARE is the managed healthcare program that is established by the Secretary of Defense under authority of chapter 55 of title 10, United States Code, principally section 1097 of such title, and includes the competitive selection of contractors to financially underwrite the delivery of health care services under the Civilian Health and Medical Program of the Uniformed Services.¹⁷ TRICARE uses military healthcare as the main delivery system augmented by a civilian network of providers and facilities. TRICARE contractors oversee the purchase of care from the civilian sector, ensure that it is medically necessary and appropriate, and adjudicate payment of the provider and/or reimbursement of the service member.

¹⁶ Institute of Medicine. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. The National Academies Press: Washington, DC 2003, pp 33-34.

¹⁷ USC Title 10, Section 712© Public Law 104-201, September 23, 1996.

2.

Numbers of Children with Life-Threatening Conditions Who Are Entitled to Care in the Military Health System

Methods are available for estimating the numbers of children with “special health care needs” in a population. However, methods to estimate the numbers of children with life-threatening conditions (LTC) are not readily generalizable to our population and depend upon the definition of LTC and the purpose for which the estimate is being done. A method was sought to estimate the numbers of children with life-threatening conditions in our population. This number will be substantially smaller than the numbers of children with special health care needs. Several methods of defining cases of children with life-threatening conditions (LTC) were examined:

1. *Based on pre-determined ICD-9 codes.* The ICD-9 codes proposed by Kentucky for eligibility criteria for a Medicaid waiver pediatric hospice program were reviewed and the frequency of specific ICD-9 codes appearing in records of children who were seriously ill and enrolled in a case management program in the MHS were tabulated. Redundant coding for the same patient and omissions in coding made this method of defining children unreliable for data retrieval for the purpose of program design or planning.

2. *Based on cost data.* At least one state calculated costs for hospice and related services paid for children through Medicaid and then constructed a way of identifying children that they could serve for the same amount of money but providing different services. In the DoD, the difficulty of accounting for direct care costs makes this method unreliable. Further, conceptually, cost does not always correlate with the presence of an LTC, at least in the years prior to the year of death.

3. *Based on characteristics of the condition.* The descriptive definition of “Conditions Appropriate for Pediatric Palliative Care,” proposed by ACT¹⁸ in 1997 and endorsed by Himmelstein, Hilden and Boldt¹⁹ in 2004 is widely used by pediatric hospice policy makers. We offer it here as the definition of eligibility for medically necessary pediatric hospice services in the MHS. The Himmelstein definitions of conditions requiring pediatric hospice care describe a different death trajectory for each condition. In *When Children Die*²⁰ the Institute of Medicine describes different patterns of death in children, ranging from death moments after birth or trauma, to death months and years after a diagnosis of a LTC with the utilization of health care services varying from intermittent to continual. A case definition based on characteristics of conditions therefore has implications for program design, service delivery, and costs, making this a reasonable definition to use for retrieval data on numbers of children and costs. ICD-9 codes were selected for each condition that would account for the majority of children with that condition and would be a reasonable search string in the DoD medical database.

¹⁸ ACT/RCPCH. *A Guide to the Development of Children’s Palliative Care Services: Report of the Joint Working Party.* ACT/RCPCH; London, 1997.

¹⁹ Himmelstein B, Hilden J, Boldt A, et al. Medical progress: pediatric palliative care. *N Eng J Med* 2004; 350:1752-62.

²⁰ Institute of Medicine, *When Children Die: Improving Palliative and End-of-life Care for Children and Their Families.* The National Academies Press, Washington, DC. 2003, pp 41-71.

The following table (Table 1), based on the work of ACT and Himmelstein, displays the case definition and the ICD-9 codes used for the searches:

Table 1
Life-Threatening Conditions in Children

Designation for data retrieval purposes	Description of condition	Examples chosen for this study	ICD-9 codes used to search databases
<i>“incurable”</i>	Progressive conditions in which treatment is exclusively palliative from diagnosis.	Spinal muscular atrophy, trisomy 13 or 18, severe infantile asphyxia	335.0, 335.10, 335.11, 758.1, 758.2, 758.3, 768.0, 768.1, 768.2, 768.5
<i>“manageable”</i>	Conditions requiring long periods of intensive treatment aimed at prolonging life and improving quality-of-life.	Cystic fibrosis, muscular dystrophy	277.00, 277.01, 359.1
<i>“curable”</i>	Conditions for which curative treatment is possible but may fail.	Any childhood malignancy	191.x, 204.xx, 206.xx, 207.xx, 208.xx, 209.xx
<i>“co-morbid”</i>	Conditions with severe, non-progressive disability causing extreme vulnerability to health complications.	Spastic quadriplegia, presence of a tracheostomy with any diagnosis	343.2, V55.0

Methods

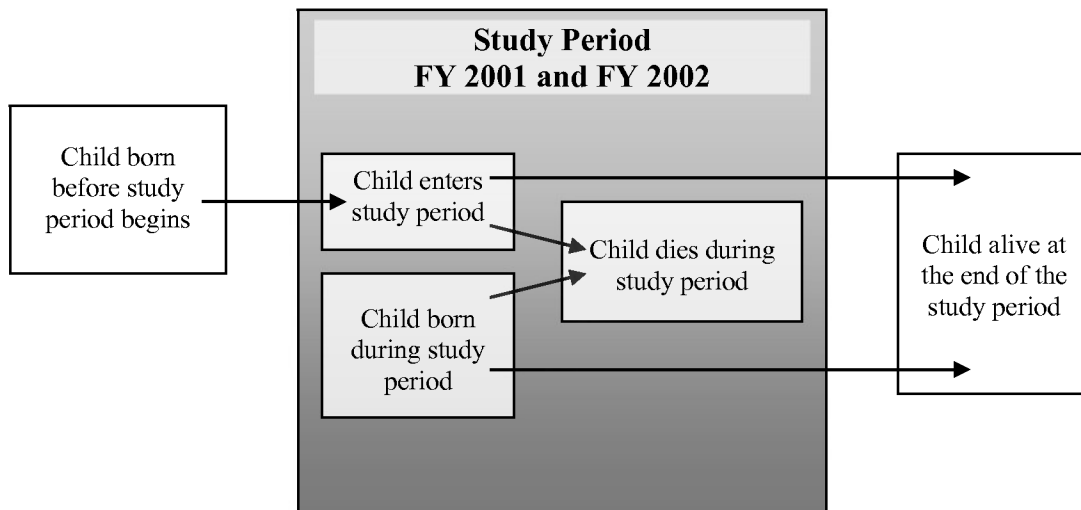
We extracted data from the Military Health System (MHS) Master Data Repository (MDR), which contains administrative inpatient and outpatient records for all care provided in MHS facilities as well as care from other sources that has been purchased by the MHS. For each inpatient discharge or outpatient encounter, data were available on diagnoses, procedures, associated costs or payments, and certain patient demographics. The data existed in separate tables (military facility inpatient, military facility outpatient, non-military [purchased] inpatient, and non-military outpatient and special services [e.g., home health]), by both year and record source, but linkable by a unique patient identifier field across all tables. These data were subsetted and combined as follows.

All inpatient and outpatient records for dependent children, aged 24 years and below, from FY2001-FY2002 were selected from the original tables. Any child with LTC alive during the study period was included (see Table 2). Deaths were identified based on either a Defense Eligibility and Enrollment Record System (DEERS) record date of death within the two years in question or by a clinical record having a disposition code indicating death. Records for both years were combined, creating a non-duplicate record analytic data set for the period under examination.

Using the previously published Himmelstein “criteria” (see Table 1 above for definitions), four trajectories of patients were selected from the data: those with incurable disease,

manageable disease, curable disease, or those with significant co-morbidities that are often associated with hospitalization and death. For each of the four categories, total encounters, inpatient admissions, use of special services, and associated costs were tabulated separately by whether or not the patient had died during the two-year period of observation. All data manipulations and tabulations were conducted using SAS software version 9.1.²¹

Table 2
Children Included in the Study Population



Numbers of Child Beneficiaries with LTC in the MHS

Two methods were used to determine the approximate number of children who meet the case definition for LTC who are entitled to care in the MHS.

1. *An estimate* was made based on the numbers of children registered in DEERS, and to which prevalence rates from the United Kingdom were applied. The numbers of children in DEERS by age groupings were tabulated as follows (Table 3):

²¹ SAS Institute, Inc. Base SAS Software; Cary, NC, 2003.

Table 3
Numbers of TRICARE-Eligible Children in DEERS
During FY 01/02 by Age Group²²

Age Group	Numbers of Children
<1 yr	180,909
1-4 yrs	471,752
5-9 yrs	584,566
10-14 yrs	591,247
15-19 yrs	579,227
20-24 yrs ²³	233,853
Total	2,641,554

A search of the literature found three reports of prevalence data for children with LTC that were judged appropriate for our purposes because: (1) the definition of LTC closely matched our own, (2) data came from actual counts of records, and (3) the purpose of the studies was for program planning. The prevalence rates found are:

1:1000 (0.1%)^{24, 25},
1.2:1000 (0.12%)^{26, 27},
1.72:1000 (0.17%)^{28, 29},

Applying these prevalence rates to the numbers of children in DEERS (see Table 3) provides an estimate of from 2,642 to 4,543 children entitled to care in the MHS during FY01/02 who have a life-threatening condition.

2. *A count* based on the ICD-9 codes chosen for each case-definition. One of the authors (DA) executed the data searches of the DEERS, SIDR (inpatient direct care), SADR (outpatient direct care), HCSR (institutional purchased care) and HSCRN (non-

²² Children who died or disenrolled from the MHS during FY01 are included using their FY01 age, all others using their FY02 age. These departures add roughly 250,000 children to the total vs a midpoint population count.

²³ Includes only children still entitled to care, i.e., those with permanent dependency and those in college. Does not include spouses in this age range.

²⁴ Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*. 2nd ed, London; 2003.

²⁵ Davies RE. Mortality in all children in South Glamorgan. *Welsh Paed J*, 2001

²⁶ Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*, 2nd ed, London; 2003.

²⁷ Lenton et al. Prevalence and morbidity associated with non-malignant life threatening conditions in childhood. *Child Care, Health and Development*. 2001, 27(5), 389-398.

²⁸ Association for Children with Life-Threatening Conditions and their Families (ACT). *A Guide to the Development of Children's Palliative Care Services*. 2nd ed, Longon; 2003.

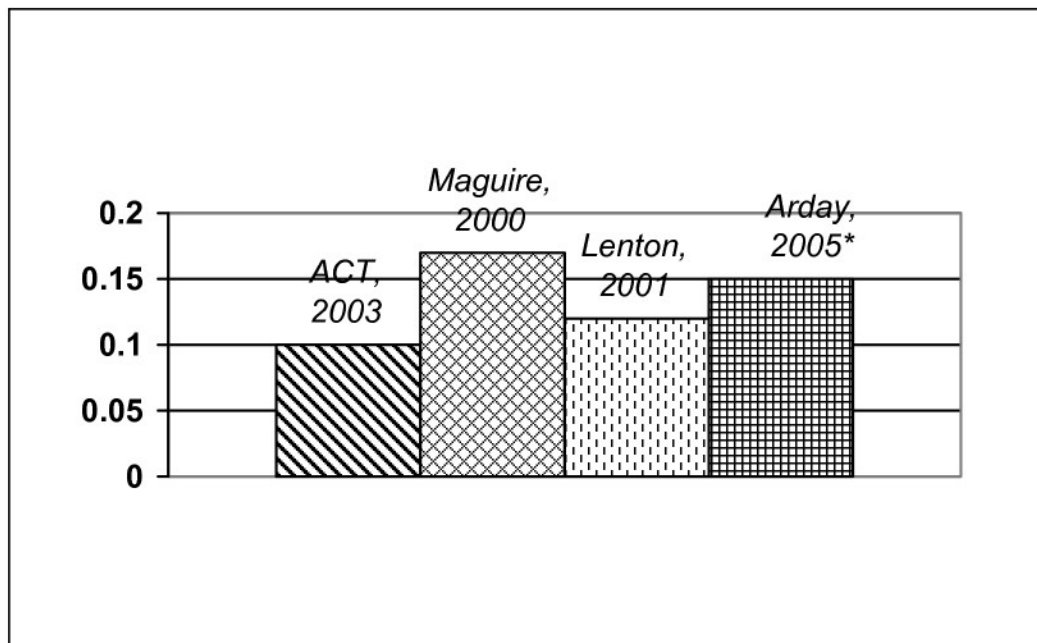
²⁹ Maguire H. *Assessment of the need of children with life-limited children in Northern Ireland*. Northern Ireland Children's Service, 2000.

institutional purchased care) records described above and collaborated in interpreting the results. The counts determined for FY 2001 through FY 2002 were as follows (Table 4):

Table 4
Counts of Children with Life-Threatening Conditions
in the MHS (by Condition), FY01/02

Designation for this condition	Description of condition	Numbers of children alive at any point in study period FY 01/02
<i>“incurable”</i>	Progressive decline to death	728
<i>“manageable”</i>	Intermittent periods of intensive care to maintain quality-of-life	964
<i>“curable”</i>	Curative treatment is possible but may fail	1239
<i>“co-morbid”</i>	Severe, non-progressive with extreme vulnerability	940
<i>Total</i>		<i>3,871</i>

Table 5
Percent of Children with Life-Threatening Conditions
in Four Studies



* This study.

The prevalence rates of children with LTC found in the literature (0.1%, 0.12%, 0.17%) and that determined in this study (0.15%) are in close agreement and provide reassurance that our method of counting cases of LTC in our population is appropriate (see Table 5).

3.

Numbers of Children who Die from Life-Threatening Conditions Who are Entitled to Care in the Military Health System

To estimate the numbers of deaths per year among the population of children with LTC, we extrapolated from data provided in the Institute of Medicine, *When Children Die*, pp 41-71; 2003 “Deaths: Leading Causes for 1999” from NCHS, 2001 data³⁰ and applied these rates to the total number of children in DEERS in each age category.

Table 6
Estimated Number of Children Dying
From Complex Chronic Conditions in the MHS per Year

	<1 yr old	1-4 yrs old	5-9 yrs old	10-14 yrs old	15-19 yrs old	Totals
Rate (all causes/yr)	705.6/ 100,000	34.7/ 100,000	17.4/ 100,000	21.1/ 100,000	69.8/ 100,000	
Rate not related to trauma or immediate newborn	“1/4 th of all infant deaths due to complex chronic conditions” Feudtner 2001 or rate of 176.4/ 100,000	19.6/ 100,000	9.2/ 100,000	11.5/ 100,000	17.1/ 100,000	
# of children in MHS	181,000	472,000	585,000	591,000	579,000	2,408,000
Estimated # children dying from complex chronic conditions/year	319	93	54	68	99	633

This estimate of 633 child deaths/yr from LTC was compared to a count obtained by a search for deaths in the FY01/02 DEERS and M2 database using the ICD-9 codes in each case definition. The number of deaths counted was 105. These data were a known undercount because the M2 database did not record children who died at home and missed some children who died in civilian institutions.

Furthermore, the rate estimated from the NCHS data may include children whose diagnosis does not fit our definition and method of counting LTC. Thus, while 105 is

³⁰ Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, 41-71.

likely an undercount, an estimate of 633 from NCHS “Causes of Death” data may be an overcount.

A thorough search of the literature found one study deriving a death rate from LTC as 10% of those with children identified with LTC³¹. Using this rate would estimate 400 deaths per year among DoD children with LTC.

We chose to use 400 deaths as a reasonable estimate of the numbers of DoD children who die from LTC each year (see Table 7).

Table 7
Summary of Numbers of Children Suggested for Program Planning

	Estimate based on 2,408,000 children ages 0-19 yrs and prevalence of life-threatening illness of 0.17% (Britain) with 10% deaths/year	Based on projections from IOM death rate tables	Counted from study period FY01/02 in DEERS and M2 databases	Numbers Suggested for Program Planning
Non-trauma deaths per year in MHS	400	633	105	400
Numbers of children with life-threatening conditions in MHS	4093	n/a	3976	4000

³¹ Davies RE. Mortality in all children in South Glamorgan. *Welsh Paed J*. 15:31-36; 2001.

4.

Costs of Providing Healthcare to Children with Life-Threatening Conditions in the Military Health System

We queried the database for the total cost of care for the population of children by type of condition. Total cost of care includes that provided by the direct care system of military treatment facilities and that purchased from civilian providers and billed to TRICARE, the military third party payer. It does not include care billed to Medicaid or private insurance. Total cost to the DoD for care of children with life-threatening illness during the study period excluding outpatient pharmacy costs was \$166.9 millions, with \$20.1 millions of that spent during the study period for children who died. Costs have likely increased in the five years since the study period. (See Tables 8 and 9.)

Table 8
Cost Data for Children Who Were Living at the End of the Study Period FY01/02

Condition	Numbers of children who were alive at the end of the study period.	Total cost for the study period for this population of children.	Average cost per child for the study period.
<i>“incurable”</i>	728	\$23,537,844	\$32,332
<i>“manageable”</i>	964	\$24,587,596	\$25,505
<i>“curable”</i>	1239	\$50,589,106	\$40,830
<i>“co-morbid”</i>	940	\$48,137,604	\$51,210
<i>Total</i>	<i>3871</i>	<i>\$146.9M</i>	<i>\$37,936</i>

Table 9
Cost Data for Children with LTC Identified as Having Died During the Study Period FY01/02 (Excludes Children Who Died at Home)

Condition	Numbers of children identified as having died during the study period.	Total cost for the study period for this population of children.	Average cost per child for the study period.
<i>“incurable”</i>	25	\$3,593,185	\$143,727
<i>“manageable”</i>	8	\$637,264	\$79,658
<i>“curable”</i>	54	\$14,257,364	\$264,025
<i>“co-morbid”</i>	18	\$1,594,814	\$88,600
<i>Total</i>	<i>105</i>	<i>\$20.1M</i>	<i>\$191,263</i>

The average cost per child was substantially higher if the child died during the study period and the highest average cost per child for those who died was for the children with potentially curable conditions, i.e., those with leukemia or cancer. In contrast, the highest average cost per child for children who were alive at the end of the study period was for children with severe non-progressive conditions that present extreme vulnerability to lethal health complications, i.e., those with spastic quadriplegia or tracheostomies.

Because the highest average costs occurred during the child's terminal illness, we examined the distribution of those costs more closely.

Table 10
Hospitalizations Distribution for a Child Identified as Having Died During the Study Period FY01/02
(Excludes Children Who Died at Home)

Condition	Number of children identified as having died	Total hospitalizations	Average number of hospitalizations	Average length of stay	Total bed days
<i>“incurable”</i>	25	80	3.2	23.5	1880
<i>“manageable”</i>	8	31	3.9	10	310
<i>“curable”</i>	54	449	8.3	15.5	6960
<i>“co-morbid”</i>	18	78	4.3	48.3	3767
<i>Total/ Average</i>	<i>105</i>	<i>638</i>	<i>6.1</i>	<i>20.2</i>	<i>12,917</i>

Table 11
Average Costs by Source of Care for a Child Identified as Having Died During the Study Period FY01/02
(Excludes Children Who Died at Home)

Condition	Direct care system (military treatment facilities including hospitals and clinics)	Purchased care (TRICARE) at civilian hospitals and clinics
<i>“incurable”</i>	\$7,319	\$136,408
<i>“manageable”</i>	\$8,081	\$71,571
<i>“curable”</i>	\$70,372	\$193,653
<i>“co-morbid”</i>	\$12,040	\$76,561

5.

Healthcare Benefits Authorized in CHAMPUS/TRICARE, Gaps in Coverage, and Challenges to Access

CHAMPUS/TRICARE COVERAGE OF MEDICALLY NECESSARY SERVICES FOR CHILDREN WITH LIFE-THREATENING CONDITIONS

Medical services needed to serve children with life-threatening conditions and their families may include:

- Medical care
- Occupational, physical, and speech therapy
- Respite care
- Home health care
- Custodial care
- Homemaker services
- Skilled nursing facility care
- Prescription drugs
- Dental care
- Counseling services including pre-bereavement and bereavement care
- Care coordination/case management
- Hospice program
- Expressive therapies (music, art, play)
- Durable equipment
- Durable medical equipment
- Structural alterations to dwelling
- Transportation by other than an ambulance

Most of these services are provided to all TRICARE eligibles under the Basic Program or to family members of active duty service members under the Extended Care Health Option (ECHO) Program. Some of these services are not available under CHAMPUS/TRICARE to any beneficiary.

The ECHO Program.

1. The ECHO Program is available only to family members of active duty service members and has the following eligibility criteria: mental retardation, serious physical disability, extraordinary physical or psychological condition, infant/toddler with serious disability, multiple disabilities. The patient's condition must qualify under one of these definitions for the ECHO Program to be applicable.

2. ECHO includes Extended Home Health Care (EHHC) that provides benefits to patients who (i) meet ECHO definitions and (ii) who are homebound and (iii) require medically necessary skills services that exceed the Basic Program home health care benefit, or (iv) require frequent interventions such that respite care is necessary.

3. Pre-authorized ECHO/EHHC services are paid for by the government up to \$2500 per month. There is a monthly co-pay based on rank of sponsor.

4. Family members receiving services under ECHO cannot receive those same services under the Basic Program, but can receive other services under the Basic Program such as prescription drugs, acute care visits, and medically necessary hospital care.

Hospice.

There is currently no unique TRICARE-defined hospice benefit; rather, the Basic Program authorizes hospice care in a Medicare-approved hospice with its eligibility criteria for life expectancy of less than six months and the requirement to forgo disease-directed care. Most available Medicare-approved hospices care for adults, and skilled care for children may not be available. The services, however, are interdisciplinary, delivered under a plan of care, include intermittent skilled nursing as well as health aide and homemaker services, and provide counseling to beneficiary and family members prior to the death.

Table 12
Summary of Benefits

Benefit	Beneficiary of Active Duty Service member Eligible for ECHO/EHHC	Beneficiary of Retired Service member <i>OR</i> Active Duty using Basic Program and Not Eligible for ECHO or in addition to ECHO
<i>Respite care</i>	16 hrs per month under ECHO 8 hr/day, 5 day/wk under EHHC (available only if receiving some form of ECHO/EHHC services)	Not covered.
<i>Home health care</i>	Not limited to part-time or intermittent. Cost may not exceed Medicare cost for care in a SNF. (Skilled nursing facility)	Part-time or intermittent, same as Medicare.
<i>Custodial care</i>	Provided as part of plan of care under home health care services.	Not covered.
<i>Homemaker</i>		Available when enrolled in Medicare-approved hospice.
<i>Skilled nursing facility</i>		Available in Medicare-approved facility, no limit on days, provided as long as medically necessary and appropriate.
<i>Prescription drugs</i>		Available through authorized physician signature.
<i>Dental care</i>		Care is covered when necessary to treat a medical condition such as treatment of oral cancer.
<i>Counseling services prior to patient's death</i>		Available for those diagnosed with a mental disorder, i.e., depression.
<i>Bereavement counseling for family after patient's death</i>		Available for those diagnosed with a mental disorder, i.e., depression.
<i>Care</i>	Care plans are required under ECHO and	Care in a SNF or in a hospice requires a

<i>coordination/ case management</i>	EHHC.	care plan.
<i>Hospice program</i>		Care authorized in a Medicare-approved hospice (limited to patients with a prognosis of death within six months and require the patient to forgo disease-directed or life-prolonging care).
<i>Expressive therapies (music, art, play)</i>	Not covered.	Not covered.
<i>Durable equipment</i>	Covered.	Not covered.
<i>Durable medical equipment</i>		Covered if ordered by a physician, specific to medical condition, and can only be used by patient.
<i>Structural alterations to dwelling</i>	Not covered.	Not covered.
<i>Transportation by other than an ambulance</i>	Mileage to and from therapy services reimbursed for those in ECHO.	Not covered.

A more extensive analysis of the benefit is at Appendix B.

6.

Comparison of Benefits/Services Available in the MHS to Children with LTC vs Services

Recommended by:

The Institute of Medicine, The Children's Hospice International, and the National Consensus Project's *National Framework for Palliative and Hospice Care Quality Measurement and Reporting*

The Institute of Medicine

There are significant gaps in services available to children with LTC and their families when the Institute of Medicine (IOM) recommendations for pediatric palliative care and hospice services are addressed. Specifically, the IOM recommended that "Public and private insurers should restructure hospice benefits for children to ... eliminate eligibility restrictions related to life expectancy, substitute criteria based on diagnosis and severity of illness, and drop rules requiring children to forgo curative or life-prolonging care (possibly in a case management framework.)"³² The IOM report also calls on policy to "reimburse bereavement services for parents and surviving siblings of children who die."³³ These benefits are unavailable through the CHAMPUS/TRICARE benefit structure.

The IOM also recommends specific clinical care practices. Many of these aspects of clinical care could be delivered (and in some cases are being delivered) to children with LTC if staff are available with the time, training, and experience in the MHS direct care system.

Appendix C outlines the IOM recommendations and the ability of the MHS to meet these recommendations.

The Children's Hospice International

The Children's Hospice International has developed a model Program for All Inclusive Care for Children and Their Families (CHI-PACC) in coordination with the Centers for Medicare and Medicaid Services. The CHI-PACC Implementation Manual³⁴ provides a list of core domains for clinical care. The clinical care called for is only

³² Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, pp 290

³³ Institute of Medicine of the National Academies. *When Children Die*. The National Academies Press: Washington, DC; 2003, pp 291

³⁴ Zarbock S, *Children's Hospice International Program for All-Inclusive Care for Children and Their Families: CHI-PACC Implementation Manual*, 2003.

available in the MHS where adequately trained and experienced staff are available and have time to provide it, either through the direct care system or through purchased care. If using purchased care, the following care and service listed in the CHI-PACC core domains cannot be reimbursed: care coordination, respite care, flexible home health care, and bereavement counseling. Furthermore, bereavement counseling, however, an important component of clinical care, is explicitly excluded as a benefit under TRICARE/CHAMPUS. Appendix D discusses the availability of this clinical care through the MHS.

National Consensus Project's: A National Framework for Palliative and Hospice Care Quality Measurement and Reporting

The National Consensus Project represents a consortium of five leading national organizations (American Academy of Hospice and Palliative Care, Center to Advance Palliative Care, Hospice and Palliative Care Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization). The project has compiled a list of preferred practices for palliative and hospice services that are based on evidence of effectiveness, unique to palliative/hospice care, and endorsed by these professional organizations.³⁵ For these reasons, these preferred practices are used as one standard against which to measure the benefits and services available through CHAMPUS/TRICARE for children with LTC. Appendix E lists the preferred practices vs the benefits and services available to children in the MHS.

³⁵ www.nationalconsensusproject.org/guideline.pdf. Last accessed January 5, 2006.

7.

Analysis of Options for Providing Comprehensive Pediatric Palliative Care and Hospice Program Services to Military Health System Beneficiaries

Many options exist for programmatic means to ensure the children with LTC and their families in the MHS receive the services available through a comprehensive pediatric palliative care and hospice program. Services not currently delivered consistently are care coordination, respite care, flexible home health care, and bereavement counseling. Care coordination is the key service that will ensure the needs of the child with LTC and the family are identified and met.

One option is to create a new program within the Basic Benefit of CHAMPUS that would entitle all children who meet the case definition of life-threatening condition to receive services commensurate with the Institute of Medicine recommendations, Children's Hospice International hospice program model and the National Quality Forum Palliative Care Quality Measurement. Although the most ambitious legislatively and administratively, according to the government cost estimate by Kennel and Associates, this option would be cost neutral and/or provide a cost savings over the current system of providing services to children with LTC. Care coordination at the individual case level would be provided and would be the major mechanism for cost savings, as unnecessary hospitalizations would be avoided and home health care flexibility would be introduced.

A second option would authorize children who meet the eligibility definition to be cared for in children's hospices, without a restriction for forgoing disease-directed care, without a restriction on time-limit until death, and including bereavement services.

Another several options involve placing dedicated care coordinators at various levels of the MHS to ensure children and families are receiving all the community services they need and have access to other federal and state programs that provide medical care. Care coordinators could be placed at the local clinic level, the hospital, the TRICARE contractor, the TRICARE Management Activity in Aurora, CO and/or at the TRICARE Management Activity in the Office of the Chief Medical Officer. At each level, care coordinators would contribute important planning and advocacy, whether for individual children and families or for the population. To address the needs of the population of children with LTCs, these care coordinators would coordinate across the direct care system, purchased care and community resources and would be available to all pediatric beneficiaries with LTCs (PRIME enrollees, Standard beneficiaries, children of both active duty and retired members). The creation of a cadre of care coordinators who move problems and solutions up and down the chain of responsibility and command and would not involve new legislation.

A fourth option is to provide information to hospital commanders as they seek to re-capture and manage healthcare costs from TRICARE and to align system cost incentives to make it possible for the commanders to plan programs to address the needs of children with LTCs. Providing them with the data regarding numbers of children in their regions with LTC, numbers of children dying from LTC, estimated cost per child, and estimated utilization of resources per child would enable the commander to design a

more cost-effective system that more efficiently meets the needs of the child with LTC and family. (See Table 13 for a summary of policy options.)

Table 13
Analysis of Options for Providing Comprehensive Pediatric Palliative Care and Hospice Services to Military Health Systems Beneficiaries

	Political Feasibility	Administrative Feasibility	Cost	Impact on quality of care provided	Impact on child and family
<i>1. Create a new program within the Basic CHAMPUS benefit for a pediatric palliative care and hospice program that includes care coordination.</i>	Least feasible at this time.	Would require contractors to develop means of administering and adjudating; however, once established, would be straightforward benefit.	According to government cost estimate, would save money after several years.	Great improvement.	Substantial positive impact.
<i>2. Authorize care in a children's hospice by modifying the definition of hospice in Basic Champus.</i>	May be feasible.	Would require contractors to develop means of administering and adjudating; however, once established, would be straightforward benefit.	May or may not provide cost savings.	Improvement, although integration with direct care system may not be smooth. Depends on availability of TRICARE-authorized pediatric hospice services in communities.	Substantial positive impact.
<i>3. Increase availability of trained care coordinators for this population.</i>	May be feasible.	Dollars/civilian slots would need to be diverted from other programs and/or new dollars/civilian slots requested.	Would provide a cost savings.	Improvement especially in use of resources in civilian community.	Positive impact.
<i>4. Encourage hospital commanders to develop programs by providing information and assistance.</i>	Is feasible.	Varies with commitment of commander.	Probable cost savings especially if care coordination is included.	Improvement especially in use of resources in civilian community.	Positive impact.

8.

Proposal for a new CHAMPUS Program to Deliver Comprehensive Pediatric Palliative and Hospice Care to Children with Life-Threatening Conditions

Essential components of a comprehensive pediatric palliative program and hospice care were listed from the following sources:

- ✓ The Institute of Medicine report recommendations
- ✓ The CHI-PACC model
- ✓ The National Quality Forum Domains of Care and Preferred Practices

These components were compared with their authorization and accessibility under CHAMPUS/TRICARE and the following were identified as unavailable or difficult to obtain:

- ✓ Care coordination as a separate, individualized, proactive service that works across the direct care system, purchased care, and military and civilian resources for all children with LTCs
- ✓ Respite care
- ✓ Home health care at level needed (administrative flexibility in authorizing/funding)
- ✓ Pre-bereavement and bereavement counseling

A draft proposal for a new program in CHAMPUS was developed to explicitly incorporate these unauthorized or difficult to obtain services and is Attachment F. It includes a definition for eligibility based on the definitions of life-threatening conditions used in this report.

9. Numbers of Children with Life-Threatening Conditions in Selected Catchment Areas

For program planning, it is important to estimate the numbers of children with LTC who might be served in any given catchment area. Resources and staff can then be planned to meet the need. Numbers of children available were either total population in catchment area or those enrolled as Prime to the MTF. We chose to apply the rate of 0.17% to the number available to us, realizing that the total number of children in a catchment area would be greater than that estimated based on Prime enrollees. (See Table 14.)

Table 14
Estimated Numbers of Children with Life-Threatening
Conditions in Defined Catchment Areas

	National Capital Area	Naval Medical Center San Diego	Madigan Army Medical Center	Wright- Patterson Air Force Medical Center
Total population of children	145,166		45,117	
Children enrolled to the MTF		26,600		10,801
Numbers of children with LTC (0.17%)	247	45	77	18
Numbers of children who die each year of LTC (10% of those with LTC)	25	5	8	2

We chose to examine the population data for a geographically defined area served by three military medical centers with a single pediatric health care delivery system, i.e., the National Capital Area (NCA). Pediatric health care in the NCA is undergoing a reorganization as required by the Base Realignment and Closure (BRAC) report and may represent an opportunity for initiating some or all the components of a pediatric hospice program. Prior to the BRAC report, pediatric inpatient care and training of pediatric

residents was consolidated within the region. Of the 2,641,554 children eligible for care in the MHS, 145,166 or 5.5% live within the National Capital Area.

Search of the DoD DEERS and M2 database-identified 268 children who had LTC living in the NCA during FY01/02 with six deaths. The total cost of care for these 268 children during the study period was \$14.6 millions. (See Table 15.)

Table 15
Children with LTC in the NCA during the Study Period
FY01/02 and Their Costs of Care

Condition	Number counted of children who were alive during study period	Number of children who were identified as having died during study period	Total cost of care for all children with LTC in FY01/02
<i>“incurable”</i>	33	0	\$1,559,150
<i>“manageable”</i>	48	0	\$971,874
<i>“curable”</i>	114	4	\$5,750,474
<i>“co-morbid”</i>	67	2	\$6,364,663
<i>Total</i>	262	6	<i>\$14,646,161</i>

Healthcare providers in the NCA can recall more deaths than those counted in this study. This may reflect the difficulty in counting deaths that occurred outside a military hospital or the selection of ICD-9 codes for cases may have been overly restrictive, especially for a referral center such as the NCA.

The estimate based on the IOM death rates is 43, and based on 10% of children with LTC, the number estimated is 25. The number used for planning purposes will be 25.

Because it appears the total number of children who died was not found for analysis in this study, the cost data are offered with that caveat in Tables 16, 18 and 19.).

Table 16
Average Cost of Care by Source for Children with LTC
in NCA Surviving at the End of the Study Period FY01/02

Condition	Average cost per patient for inpatient direct care (SIDR)	Average cost per patient for outpatient direct care (SADR)	Average cost per patient for institutional purchased care (HCSRI)	Average cost per patient for noninstitutional purchased care (HSCRN)
<i>“incurable”</i>	\$8,142	\$6,815	\$14,848	\$17,442
<i>“manageable”</i>	\$5,515	\$6468	\$1,871	\$6,394
<i>“curable”</i>	\$25,688	\$12,032	\$2,752	\$3,744
<i>“co-morbid”</i>	\$13,745	\$11,263	\$11,731	\$57,142

Table 17
Hospitalizations for Children with LTC
Who Were Alive at the End of the Study Period FY01/02 in the NCA

Condition	Number of children alive	Total hospitalizations	Average number of hospitalizations	Average length of stay (days)	Total bed days
<i>“incurable”</i>	33	48	1.5	21	1010
<i>“manageable”</i>	48	42	0.9	5.8	243
<i>“curable”</i>	114	282	2.8	5.3	1487
<i>“co-morbid”</i>	67	145	2.2	31.4	4554

Table 18
Hospitalizations for a Child with LTC
Who Were Identified as Having Died During the Study Period FY01/02 in the NCA

Condition	Identified children who died	Total hospitalizations	Average number of hospitalizations	Average length of stay	Total bed days
<i>“incurable”</i>	0	n/a	n/a	n/a	n/a
<i>“manageable”</i>	0	n/a	n/a	n/a	n/a
<i>“curable”</i>	4	49	12.3	9.4	463
<i>“co-morbid”</i>	2	4	2	3.3	13

Table 19
Average Costs by Source of Care for a Child with LTC Who was Identified as Having Died During the Study Period FY01/02 in The NCA

Condition	Average cost per patient for all care	Direct care system (military treatment facilities including hospitals and clinics)	Purchased care (TRICARE) at civilian hospitals and clinics
<i>“incurable”</i>	n/a	n/a	n/a
<i>“manageable”</i>	n/a	n/a	n/a
<i>“curable”</i>	\$266,293	\$142,552	\$123,741
<i>“co-morbid”</i>	\$26,370	\$9,634	\$16,737

Table 20
Average Costs by Source of Care for a Child with LTC
Living at the End of the Study Period FY01/02 in the NCA

Condition	Average cost per patient for all care	Average cost for direct care system (military treatment facilities including hospitals and clinics)	Average cost of purchased care (TRICARE) at civilian hospitals and clinics
<i>“incurable”</i>	\$47,247	\$14,957	\$32,290
<i>“manageable”</i>	\$20,247	\$11,983	\$8,262
<i>“curable”</i>	\$41,099	\$34,603	\$6,496
<i>“co-morbid”</i>	\$94,208	\$25,335	\$68,873

Table 21
Utilization of Home Health Care and Infusion Services by Children with LTC in the NCA During the Study Period FY01/02

Condition	Total cost for those who were alive at end of study period	Total cost for those who were identified as having died during study period (excludes children who died at home)
<i>“incurable”</i>	\$161,922	n/a
<i>“manageable”</i>	\$20,282	n/a
<i>“curable”</i>	\$44,070	\$18,435
<i>“co-morbid”</i>	\$2,246,886	0
<i>Total</i>	\$2,454,724	\$18,435

Table 22
Comparison of Average Cost/Child in Total MHS Population and The NCA for Those Children Alive at the End of the Study Period

Condition	Total Population	NCA
<i>“incurable”</i>	\$32,332	\$47,247
<i>“manageable”</i>	\$25,505	\$20,247
<i>“curable”</i>	\$40,830	\$41,099
<i>“co-morbid”</i>	\$51,210	\$94,208

Costs for children with co-morbid conditions, i.e. severe cerebral palsy and/or tracheostomies are significantly higher in the NCA than the MHS average cost for children with similar diagnoses. (See Table 22.)

Because this geographic area includes three major military medical centers that are medical referral centers, we were interested to determine the prevalence of children with LTC living in this geographic area vs children living outside this area. The NCA has 5.5% of all the children in the MHS living in its catchment area..

Table 23
Percent of Children with Various Types of
Life-Threatening Conditions in the NCA vs Total in MHS

Condition	% of total MHS children in the NCA
<i>“incurable”</i>	4.5
<i>“manageable”</i>	5.0
<i>“curable”</i>	9.5
<i>“co-morbid”</i>	7.3

Children with “curable” conditions requiring intermittent intensive care (cancer), and to a less extent, children with “co-morbid” severe, non-progressive conditions with extreme vulnerability are over-represented in this geographic area. (See Table 23.) At least two factors may have contributed to this distribution: (1) the military medical centers within this geographic area are major referral centers with pediatric hematology-oncology expertise and a fellowship program and (2) the military assignment system can move families of children with complex conditions (such as “co-morbid”) to locations where the child’s medical needs can be met and the military service member has a military-relevant assignment.

10.
Independent Government Cost Estimate for Pediatric mCare
Pilot Project at Walter Reed Army Medical Center
(Task Order 3001-088)
Kennell and Associates, Inc.
February 28, 2006

In November 2005, The Office of the Chief Medical Officer, TRICARE Management Activity, requested Kennell and Associates, Inc. to provide an independent government cost estimate of the implementation of a pilot project in the National Capital Area (NCA) to provide palliative and end-of-life care to children with life-threatening conditions (LTC). (See Appendix G for the complete report.) The Kennell report based its findings on the same case definitions (ICD9 codes) as previously discussed in this paper and as used by Dr. Arday in the FY01/02 analysis when determining the numbers of children and the associated costs. The Kennell report analyzed the additional cost of providing care coordination, home health care, respite care, and bereavement counseling to the families, as these services were identified as the “missing” services in a comprehensive pediatric palliative care and hospice program.

The Kennell report, based on FY04/05 data in the DEERS and M2 database, also had the advantage of the recent establishment of the DEERS Death File in its data analysis. The Kennell report presents a closer approximation to the numbers and costs of children in a pilot or demonstration program in the NCA were one to be implemented in the near future. The Arday report provides more detailed information about expenditures for children with LTC in the NCA and provides data about the entire population of children in the MHS. The two reports complement one another and reinforce the utility of the methods developed in this report of estimating children with LTC in the MHS and within a given catchment area in the MHS.

Table 24
Number of Unique Pediatric Beneficiaries with LTC
in the NCA During Two Study Periods

	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
<i>FY 01/02</i>					
Lived	33	48	114	67	262
Died	0	0	4	2	6
Total	33	48	118	69	268
<i>FY 04/05</i>					
Lived	40	58	130	78	306
Died	0	1	8	6	15
Total	40	59	138	84	321

The percentage distribution of cases by diagnosis in FY 04/05 was almost identical to that in FY 01/02, although the total number of cases found was about 20% higher.

Costs to provide and/or purchase care for the population of children with LTC in the NCA were \$15 million higher over the two year study period in FY04/05 than in FY01/02 in which the costs were \$14.6 million for the two year study period (an increase of 100% in health care costs). Some of this increase (20%) is due to the increased number of patients served, but 70% of the increase was estimated to be due to increased health care costs per child. (See Table 25.)

Table 25
FY 04/05 Direct Care and Purchased Care Costs for Children with LTC in NCA

	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
Total Direct and Purchased Care Costs					
Lived	\$2,175,280	\$3,639,386	\$15,377,666	\$6,405,625	\$27,597,957
Died	n/a	\$86,859	\$1,042,216	\$877,821	\$2,006,896
Total	\$2,175,280	\$3,726,244	\$16,419,882	\$7,283,447	\$29,604,853
Costs per Child					
Lived	\$54,382	\$62,748	\$118,290	\$82,123	\$90,189
Died	n/a	\$86,856	\$130,227	\$146,304	\$133,793
Total	\$54,382	\$63,157	\$118,985	\$86,708	\$92,227
Inpatient Days per Child					
Lived	8.5	9.1	16.1	16.1	13.8
Died	n/a	20.0	27.8	46.5	34.7
Total	8.5	9.3	16.8	18.3	14.8

Table 26
Average Cost per Child with LTC in the NCA FY 01/02 Compared to FY 04/05

	FY 01/02	FY 04/05
Total Costs	\$14,646,161	\$29,604,853
Total Number of Children with LTC	268	321
Average Cost per Child	\$56,081	\$92,227

The average cost per child increased from \$56,081 to \$92,227 (increase of 64%) from the two year study period FY 01/02 to FY 04/05. (See Table 26.) The highest average cost per child for each study period was for a child who died during the study period, and the highest among these was children who had “curable” or “comorbid” conditions. From study period FY 01/02 to study period FY 04/05, however, the cost per child who died with a “curable” condition in the NCA actually decreased from \$266,293 to \$130,227.

Major Cost Savings. The Kennell Report estimated the cost per year of providing the “missing services” (i.e., care coordination, home health care including care by personal attendants, respite care and bereavement counseling) to the population of children with LTC living in the NCA and to those with LTC who died. Kennell’s report is based on several assumptions: (1) services were provided to 15 children per year who died and to 225 who survived the year. (2) The combination of family support and education by care coordinators and the increased availability of a robust home health care program is assumed to allow 11 children to move from inpatient care during their terminal illness to home, saving \$30,844 per child per year, or \$346,998 for the NCA MHS per year. (3) Care coordination also generates savings by using telephone triage and parent education to increase the efficiency of use of medical resources, estimated to provide an annual savings of \$275,000 to \$550,000. (4) Care coordination further saves physician time that can then be used to re-capture purchased care patient visits at a potential cost savings of \$430,000.

Major Program Costs. The estimated salary costs/year of six care coordinators and one administrative staff member is \$619,365. Costs of respite care (1 weekend per month/family) is \$313,200. Bereavement counseling costs are estimated at \$15,000.

Kennell estimates a net cost savings per year of \$111,000 - \$388,000 several years after the program reaches a “steady-state” and families/staff are confident in their roles and in the resources available to them (see Table 27).

Table 27
Summary of the mCARE Pilot Project Estimated Savings
at WRAMC for the National Capital Area in FY 06³⁶

Added Costs for Pediatric Palliative Care Program in the MTF	
Care coordination based at the MTF	\$619,000
Respite care provided for families at home or in the hospital	\$313,000
Bereavement counseling for parents and families after the death of a child	\$15,000
Savings Produced by Providing Suggested Care	
Substituting home care for severely ill children instead of hospital care	\$347,000
Freeing physician time through quality care coordination	\$435,000
Providing some triage and parent education over the phone rather than during visits	\$277,000 – \$554,000
Net Program Savings in FY 06	\$111,000 – \$388,000

³⁶ Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center (Task Order 3001-088). See Appendix G.

Appendix A

Data from DEERS and M2 Database Study Period FY01/02 (on CD to the Jackson Foundation with this report and to others upon request.)

Appendix B

Benefits Available in TRICARE/CHAMPUS for Children with Life-Threatening Conditions and Their Families

Respite Care

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Respite care</i>	TRICARE Extended Care Health Option (ECHO). Final Rule/FR Vol 69, No 144, Jul 28, 2004	(c)(7) Respite care. ECHO beneficiaries are eligible for 16 hours of respite care per month in any month during which the qualified beneficiary otherwise receives an ECHO benefit(s). Respite care is defined in Sec. 199.2. Respite care services will be provided by a TRICARE-authorized home health agency and will be designed to provide health care services for the covered beneficiary, and not baby-sitting or child-care services for other members of the family. The benefit will not be cumulative, that is, any respite care hours not used in one month will not be carried over or banked for use on another occasion.	<p><i>Pending signature and contract modifications.</i></p> <p>Part 199.2 Definitions (b) Specific definitions. <u>Mental retardation</u> = A diagnosis of moderate or severe mental retardation make in accordance with the criteria of the current edition of the “Diagnostic and Statistical Manual of Mental Disorders” published by the American Psychiatric Association. <u>Serious physical disability</u> = Any physiological disorder or condition or anatomical loss affecting one or more body systems which has lasted, or with reasonable certainty is expected to last, for minimum period of 12 contiguous months, and which precludes the person with the disorder, condition or anatomical loss from unaided performance of at least one Major Life Activity as defined in this section. <u>Extraordinary condition</u> = A complex clinical condition, which resulted, or is expected to result, in extraordinary TRICARE/CHAMPUS costs or utilization, based on thresholds established by the Director, OCHAMPUS, or designee. <u>Extraordinary physical or psychological condition</u> = A complex physical or psychological clinical condition of such severity which results in the beneficiary being homebound as defined in this section. <u>Homebound</u> = A beneficiary’s condition is such that there exists a normal inability to leave home and, consequently, leaving home would require considerable and taxing effort....Absences...for the purpose of</p>	<p>Available only for TRICARE-eligible family members of active duty service members.</p> <p>Network inadequate.</p>

Benefit	Citation	Description of Benefit	Comments	Gap
			<p>attending an educational program...shall not negate the beneficiary's homebound status.</p> <p><u>Major Life Activity</u> = Breathing, cognition, hearing, seeing, and age-appropriate ability essential to bathing, eating, grooming, speaking, stair use, toilet use, transferring, and walking.</p> <p><u>Respite care</u> = Respite care is short-term care for a patient in order to provide rest and change for those who have been caring for the patient at home, usually the patient's family.</p> <p>Government cost-share maximum monthly benefit of \$2,500.</p>	
	<p>Part 199.5 – TRICARE Extended Care Health Option (ECHO), Jul 28, 2004. (e)ECHO Home Health Care (EHHC).</p>	<p>(e)(2) EHHC beneficiaries whose plan of care includes frequent interventions by the primary caregiver(s) are eligible for respite care services in lieu of the ECHO general respite care benefit. For the purposes of this section, the term “frequent” means “more than two interventions during the eight-hour period per day that the primary caregiver would normally be sleeping.” The services provided...are those that can be performed ...by the average non-medical person...after has been trained by appropriate medical personnel. EHHC beneficiaries in this situation are eligible for a maximum of eight hours per day, 5 days per week, or respite care by a TRICARE-authorized home health agency.</p>	<p>(e)(3) EHHC eligibility. Beneficiaries meet all ECHO eligibility requirements and who: (i) are homebound; (ii) require medically necessary skilled services that exceed the level of coverage provided under the Basic Program's home health care benefit; or (iii) require frequent interventions by the primary care giver(s) such that respite care services are necessary to allow primary caregiver(s) the opportunity to rest, and are case-managed to include reassessment at least every 90 days and receive services as outlined in a written plan of care; and (iv) receive all home healthcare services from a TRICARE-authorized home health agency as described in Sec 199.6(b)(4)(xv), in the beneficiary's primary residence.</p> <p>(e)(4) EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided, and support the professional level of the provider.</p>	

Home Health Care

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Home health care</i>	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	<p>(e)(1) ECHO Home Health Care (EHC). Home health care. Covered ECHO home health care services are the same as, and provided under the same conditions as those services described in Sec 199.4, except that they are not limited to part-time or intermittent services.</p> <p>(f)(3)(ii) ECHO home health care. The maximum annual Government cost-share for ECHO home health care, including EHC respite care may not exceed the local wage-adjusted highest Medicare Resource Utilization Group (RUG-III) category cost for care in a TRICARE-authorized skilled nursing facility.</p>	Basic Program. 199.4(e)(21)(1) Home health services. Home health services are covered when furnished by, or under arrangement with, a home health agency (HHA) that participates in the TRICARE program and provides care on a visiting basis in the beneficiary's home. Covered HHA services are the same as those provided under Medicare under section 1861(m) of the Social Security Act. ...Benefit coverage...part-time or intermittent skilled nursing care, physical therapy, speech-language pathology, and occupational therapy, medical social services, part-time or intermittent services of a home health aide, medical supplies, a covered osteoporosis drug, and durable medical equipment, services at hospitals, SNFs or rehabilitation centers.	Adequate numbers of qualified providers are not available in the network.

Custodial Care

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Custodial Care</i>	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	(e)(1)...Custodial care services, as defined in Sec. 199.2, may be provided to the extent such services are provided in conjunction with authorized ECHO home health care services, including the EHHC respite care benefit.	Custodial care services may be provided only as specifically set out in ECHO.	

Counseling Services

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Bereavement care</i>			Excluded in hospice care through Basic Program.	
<i>Counseling for child</i>	Part 199.4 – Basic Program	(ix) Treatment of mental disorders....the patient must be diagnosed by a CHAMPUS-authorized ...mental health professional to be suffering from a mental disorder...in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.		

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Counseling for family members before child's death</i>	Part 199.4 – Basic Program	(ix) Treatment of mental disorders....the patient must be diagnosed by a CHAMPUS-authorized ...mental health professional to be suffering from a mental disorder...in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.		

Care Management/Care Coordination Services

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Care coordination</i>				
<i>Nursing case management</i>				

Hospice

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Hospice</i>	Part 199.4 – Basic Program	(19) Hospice Care. Hospice care is a program which provides an integrated set of services and supplies designed to care for the terminally ill. This type of care emphasizes palliative care and supportive services, such as pain control and home care, rather than cure-oriented services provide in institutions that are otherwise the primary focus under CHAMPUS. The benefit provides coverage for a humane and sensible approach to care during the last days of life for some terminally ill patients. (i) Benefit coverage. CHAMPUS beneficiaries who are terminally ill (that is, a life expectancy of six months or less if the disease runs its normal course) will be eligible for the following services and supplies in lieu of most other CHAMPUS benefits: (A) Physician services. (B) Nursing care. (C) Medical social services ... (1) Assessment of social and emotional factors ... (2) Assessment of relationship between ... requirements and availability of community resources. (3) Appropriate action to obtain available community	Part 199.6 Authorized providers. Hospice programs. Hospice programs must be Medicare-approved and meet all Medicare conditions of participation (42 CFR part 418) in relation to CHAMPUS patients in order to receive payment under the CHAMPUS program.... May be either a public agency or private organization which: (A) is primarily engaged in providing care and services described under Sec 199.4(e)(19) and makes such services available on a 24-hour basis. (B) Provides bereavement counseling for the immediate family or terminally ill individuals. (C) Provides for such care and services in individuals' homes, on an outpatient basis, and on a short term inpatient basis, (4) Have an interdisciplinary group composed of (i) physician; (ii) registered professional nurse; (iii) social worker; (iv) pastoral or other counselor. (5) Maintains central clinical records on all patients. (7) The hospice and all hospice employees must be licensed in accordance with applicable Federal, state and local laws and regulations.	Must meet Medicaid definition of hospice care.

Benefit	Citation	Description of Benefit	Comments	Gap
		resources to assist in resolving the beneficiary's problem. (4) Counseling services that are required by the beneficiary. (D) Counseling services provided to the terminally ill individual and the family member or other persons caring for the individual at home...Bereavement counseling is not reimbursable. (E) Home health aide services ... and homemaker services.		

Additional Services

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Child life services at home</i>				Unavailable.
<i>Massage therapy</i>				Unavailable.
<i>Music therapy</i>				Unavailable.
<i>Acupuncture</i>				Unavailable.

Equipment and Structural Alterations

Benefit	Citation	Description of Benefit	Comments	Gap
<i>Durable equipment and durable medical equipment</i>	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	<p>(g)(2) Equipment (i) The TRICARE allowable amount for durable equipment and durable medical equipment shall be calculated in the same manner as durable medical equipment allowable through Sec. 199.4.</p> <p>(ii) Allocating equipment expense. The ECHO beneficiary...may, only at the time of the request for authorization of equipment, specify how the allowable cost of the equipment is to be allocated as an ECHO benefit. The entire allowable cost...may be allocated in the month of purchase...or may be prorated.</p> <p>(c)(7)(ii) Equipment adaptation. The allowable equipment purchase shall include such services and modifications to the equipment as necessary to make the equipment usable for a particular ECHO beneficiary.</p> <p>(iii) Equipment maintenance. Reasonable repairs and maintenance of beneficiary owned or rented durable equipment or durable medical equipment provided by this section shall be allowed while a</p>	Part 199.2 –Definitions. <u>Durable equipment</u> . A device or apparatus which does not qualify as durable medical equipment and which is essential to the efficient arrest or reduction of functional loss resulting from, or the disabling effects of a qualifying condition. <u>Durable medical equipment</u> . Equipment for which the allowable charge is over \$100 and which: (1) is medically necessary for the treatment of a covered illness or injury; (2) improves the function of a malformed, diseased, or injured body part, or retards further deterioration of a patient's physical condition; (3) is primarily and customarily designed and intended to serve a medical purpose rather than primarily for transportation, comfort or convenience; (4) provides the medically-appropriate level of performance and quality for the medical condition present.	

Benefit	Citation	Description of Benefit	Comments	Gap
		beneficiary is registered in ECHO.		
<i>Structural alterations to dwelling</i>	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	(d)(3) Structural alterations. Alterations to living space and permanent fixtures attached thereto, including alterations necessary to accommodate installation of equipment or to facilitate entrance or exit, are excluded.		

Appendix C

MHS Benefits and Services vs the Institute of Medicine Recommendations

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented

Recommendations	Availability in the MHS
<p>1. Pediatric professionals, children's hospitals, hospices, home health agencies, professional societies, family advocacy groups, government agencies, and others should work together to develop and implement clinical practice guidelines and institutional protocols and procedures for palliative, end-of-life, and bereavement care that meet the needs of children and families for:</p> <ul style="list-style-type: none"> - complete, timely, understandable information about diagnosis, prognosis, treatments (including their potential benefits and burdens), and palliative care options. - early and continuing discussion of goals and preferences for care that will be honored wherever care is provided. - effective and timely prevention, assessment, and treatment of physical and psychological symptoms and other distress, whatever the goals of care and wherever care is provided. - competent, fair, and compassionate clinical management of end-of-life decisions about such interventions as resuscitation and mechanical ventilation. 	<p>Services are only provided in areas where experienced staff are available and it is done without an explicit program/plan, is highly variable and inconsistent.</p>
<p>2. Children's hospitals, hospices, home health agencies, and other organizations that care for seriously ill or injured children should collaborate to assign specific responsibilities for implementing clinical and administrative protocols and procedures for palliative, end-of-life, and bereavement care. In addition to supporting competent clinical services, protocols should promote the coordination and continuity of care and the timely flow of information among caregivers and within and among care sites including hospitals, family homes, residential care facilities, and injury scenes.</p>	<p>Services are provided based on availability, training, and experience of staff. Further limitations on bereavement care</p>
<p>3. Children's hospitals, hospices with established pediatric programs, and other institutions that care for children with fatal or potentially fatal medical conditions should work with professional societies, state agencies, and other organizations to develop regional information programs and other resources to assist clinicians and families in local and outlying communities and rural areas. These resources should include the following:</p>	<p>Services are provided based on availability, training, and experience of staff.</p>

<ul style="list-style-type: none"> - consultative services to advise a child's primary physician or local hospice staff on all aspects of care for the child and family from diagnosis through death and bereavement; - clinical, organizational, and other guides and information resources to help families to advocate for appropriate care for their children and themselves; and - professional education and other programs to support palliative, end-of-life, and bereavement care that is competent, continuous, and coordinated across settings, among providers, and over time (regardless of duration of illness). 	
<p>4. Children's hospitals, hospices, and other institutions that care for seriously ill or injured children should work with physicians, parents, child patients, psychologists, and other relevant experts to create policies and procedures for involving children in discussions and decisions about their medical condition and its treatment. These policies and procedures – and their application – should be sensitive to children's' intellectual and emotional maturity and preferences and to families' cultural backgrounds and values.</p>	<p>Services are provided based on availability, training, and experience of staff.</p>
<p>5. Children's hospitals and other hospitals that care for children who die should work with hospices and other relevant community organizations to develop and implement protocols and procedures for</p> <ul style="list-style-type: none"> - identifying and coordinating culturally sensitive bereavement services for parents, siblings, and other survivors, whether the child dies after a prolonged illness or after a sudden event; - defining bereavement support roles for hospital-based and out-of-hospital personnel, including emergency medical services, law enforcement officers, hospital pathologists, and staff in medical examiners' offices; and - responding to the bereavement needs and stresses of professionals, including emergency services and law enforcement personnel, who assist dying children and their families. 	<p>Services are provided based on availability, training, and experience of staff. Further limitations on bereavement care</p>
<p>6. Public and private insurers should restructure hospice benefits for children to</p> <ul style="list-style-type: none"> - add hospice care to the services required by Congress in Medicaid and other public insurance programs for children and to the services covered for children under private health plans; - eliminate eligibility restrictions related to life expectancy, substitute criteria based on a child's diagnosis and severity of illness, and drop rules requiring children forgo curative or life-prolonging care (possibly in a case management framework); and - include outlier payments for exceptionally costly hospice patients. 	<p>The DoD third party payer (TRICARE, CHAMPUS), although not specifically referenced in this recommendation, does not provide for an appropriate children's hospice program as recommended</p>
<p>7. In addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting benefits for other palliative services related to a child's life-threatening medical conditions. Such modifications should</p> <ul style="list-style-type: none"> - reimburse the time necessary for fully informing and 	<p>The DoD third party payer (TRICARE, CHAMPUS), although not specifically referenced in this</p>

<p>counseling parents (whether or not the child is present) about their child's (1) diagnosis and prognosis, (2) options for care, including potential benefits and harms, and (3) plan of care, including end-of-life decisions and care for which the family is responsible;</p> <ul style="list-style-type: none"> - make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations; - reimburse bereavement services for parents and surviving siblings of children who die; - specify coverage and eligibility criteria for palliative inpatient, home health, and professional services based on diagnosis (and, for certain services, severity of illness) to guide specialized case managers and others involved in administering the benefits; and - provide for the Centers for Medicare and Medicaid Services to develop estimates of the potential cost of implementing these modifications for Medicaid. 	<p>recommendation, does not provide for an appropriate children's hospice program as recommended. Bereavement services are explicitly excluded as a coverable benefit.</p>
<p>8. Federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to (1) define diagnosis and, as appropriate, severity criteria for eligibility for expanded benefits for palliative, hospice, and bereavement services; (2) examine the appropriateness for reimbursing pediatric palliative and end-of-life care of diagnostic, procedure, and other classification systems that were developed for reimbursement of adult services; and (3) develop guidance for practitioners and administrative staff about accurate, consistent coding and documenting of palliative, end-of-life, and bereavement services.</p>	<p>Not yet accomplished in the DoD.</p>
<p>9. Medical, nursing, and other health professions schools or programs should collaborate with professional societies to improve the care provided to seriously ill and injured children by creating and testing curricula and experiences that</p> <ul style="list-style-type: none"> - prepare all health professionals who work with children and families to have relevant basic competence in palliative, end-of-life, and bereavement care; - prepare specialists, subspecialists, and others who routinely care for children with life-threatening conditions to have advanced competence in the technical and psychosocial aspects of palliative, end-of-life, and bereavement care in their respective fields; and - prepare a group of pediatric palliative care specialists to take lead responsibility for acting as clinical role models, educating other professionals, and conducting research that extends the knowledge base for palliative, end-of-life, and bereavement care. 	<p>The Uniformed Services University is providing an introduction to end-of-life care for medical students. At some tertiary care institutions, groups of pediatric palliative care specialists are forming.</p>
<p>10. To provide instruction and experiences appropriate for all health care professionals who care for children, experts in general and specialty fields of pediatric health care and education should collaborate with experts in adult and pediatric palliative care and education to develop and implement</p> <ul style="list-style-type: none"> - model curricula that provide a basic foundation of knowledge 	<p>Military pediatric residency programs provide the required training in end-of-life care. No military fellowships in</p>

<p>about palliative, end-of-life, and bereavement care that is appropriate for undergraduate health professions education in areas including but not limited to medicine, nursing, social work, psychology, and pastoral care;</p> <ul style="list-style-type: none"> - residency program requirements that provide more extensive preparations as appropriate for each category of pediatric specialists and subspecialists who care for children with life-threatening medical conditions; - pediatric palliative care fellowships and similar training opportunities; - introductory and advanced continuing education programs and requirements for both generalist and specialist pediatric professionals; and - practical, fundable strategies to evaluate selected techniques or tools for educating health professionals in palliative, end-of-life, and bereavement care. 	<p>pediatric palliative care.</p>
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Appendix D

MHS Benefits and Services vs the CHI-PACC Core Domains of Clinical Care

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented.

Core Domain of Clinical Care	Availability in the MHS
1. <i>Goals of care.</i> Consistent goals of care in all settings that reflect the values, hopes, religious beliefs, and needs of children/ adolescents and their families.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
2. <i>Integration of Disease Management and Symptom Control.</i> An approach that brings the best evidence-based care for managing disease progress, and symptoms of disease and treatments to maintain quality-of-life needs of children/adolescents and families.	Available, but implementation highly dependent on interest, training, and caseload of health care providers. Disease management not available in hospice care.
3. <i>Advance Care Planning.</i> An ongoing process of identification and implementation wishes for care, treatments, and services that is understood by providers not as an “event” but as an on-going process that anticipates what may be next in terms of the progression of the illness and medical conditions of the child/ adolescent.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
4. <i>Patient and family education.</i> Each child/adolescent at his/her developmental level and all members of the family, not just parents/legal guardians, have all the information they need and want about the disease, treatments, symptoms, services, and choices throughout the entire course of disease.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
5. <i>Comprehensive, coordination and continuity of care.</i> A functional, inter-related, inter-dependent system of care to support children/adolescents and families across the entire trajectory of the illness.	Available, but implementation highly dependent on interest, training, and caseload of health care providers. Very limited coordination across direct care system, purchased care, and community resources and for patients not enrolled to PRIME.
6. <i>Patient and Family Support.</i> Children/adolescents and the members of their families do not experience abandonment but have a consistent safety net of support from	Available, but implementation highly dependent on interest, training, and caseload of health care providers.

both providers and within their community.	
7. <i>End-of-life Care.</i> The ending of life is prepared for, goals of the child/adolescent and family are met for closure, and all family members have access to appropriate bereavement care.	Bereavement counseling specifically excluded as a TRICARE benefit, but may be available on a limited basis through the direct care system

Appendix E

MHS Benefits and Services for Children with Life-Threatening Conditions vs The National Quality Forum Domains of Care and Preferred Practices for Quality Palliative and Hospice Care³⁷

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented

Domain and Definition	Preferred Practice	MHS
1. 1 Structures of Care. <i>To provide patients and their families care that addresses their multi-faceted needs, palliative and hospice programs should establish the organizational components that ensure that the provision of this complex care can be achieved. These structural elements provide the foundation that enables the program to achieve their aims.</i>		
	1. Provide palliative care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, chaplains and others who collaborate with primary healthcare professional(s).	This team could be developed at any location that elected to do so. Components of these teams are available at a tertiary care centers, usually centered in the pediatric hematology/oncology service.
	2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, seven days a week.	Available for selected pediatric oncology patients.
	3. Provide continuing education to both primary care practitioners as well as specialized palliative care professionals, on the domains of palliative care and hospice care.	Sites with pediatric residency programs and hematology/oncology fellowships are providing this training, although to a limited degree.
	4. Provide adequate training and clinical support to assure that professional staff is confident in its ability to provide palliative care for patients.	Varies widely with interest, training, and available time of staff.
	5. Hospice and specialized palliative care professionals should be appropriately trained,	Most healthcare providers for children with LTC do not have specialized training in palliative care.

³⁷ www.nationalconsensusproject.org/guideline.pdf. Last accessed January 5, 2006.

	credentialed, and/or certified in their area of expertise.	
<u>1.2 General Processes of Care.</u> <i>Providing high-quality palliative and hospice family-centered care requires the institution of formal processes that often transcend the requirements of routine medical practice. Implementing such processes permits proactive management of the symptom and end-of-life needs of patients cared for by these programs.</i>		
	6. Formulate, utilize and regularly review a care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family.	Varies widely with interest, training, and available time of staff.
	7. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising, and reintroduce option as patient declines.	Varies widely with interest, training, and available time of staff.
	8. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.	Routinely provided by pediatric hematology/oncology service.
	9. Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.	Varies widely with interest, training, and available time of staff.
<u>2. Physical Aspects of Care.</u> <i>The amelioration of physical symptoms such as pain, fatigue, nausea and vomiting is an essential component of the improvement of quality of life for palliative care and hospice patients.</i>		
	10. Measure and document pain, dyspnea, and other symptoms using available standardized scales.	Pain routinely assessed.
	11. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.	Goal of pediatric hematology/oncology services. Varies with interest, training and available time of staff.
<u>3. Psychological and Psychiatric Aspects of Care.</u> <i>The presence of physical symptoms or entry into the end-of-life phase of an illness engenders a variety of emotional responses that must be dealt with if quality of life is to be preserved. This care ranges from emotional support appropriate to all patients to specific management of psychological disorder.</i>		
	12. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.	Varies widely with interest, training, and available time of staff.
	13. Manage anxiety, depression,	Varies widely with interest, training, and

	delirium, behavioral disturbances, and other common psychological symptoms in a timely, safe, and effective manner to a level acceptable to the patient and family.	available time of staff.
	14. Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss (including stress, anticipatory grief and coping), in a regular ongoing fashion.	Varies widely with interest, training, and available time of staff.
	15. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after death of the patient.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit.
<p><u>4. Social Aspects of Care.</u> <i>The impact of disabling symptoms and entry into the terminal phase of an illness has important ramifications on all aspects of family life, ranging from childcare to work conditions to financial coping. The palliative care team and hospice must be able to assess these problems and either provide resources or make the appropriate referrals to alleviate these burdens.</i></p>		
	16. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care and advanced care planning, and offer support.	Varies widely with interest, training, and available time of staff.
	17. Develop and implement a comprehensive social care plan which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decision-making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, access to medicines and equipment.	Varies widely with interest, training, and available time of staff.
<p><u>5. Spiritual, Religious, and Existential Aspects of Care.</u> <i>Under the stressful conditions of the palliative care setting, the patient's and family's concerns about religious and spiritual matters could become of paramount importance. Programs must be able to assess these needs and provide appropriate resources to meet them.</i></p>		
	18. Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate into the palliative care	Varies widely with interest, training, and available time of staff.

	plan.	
	19. Provide information about the availability of pastoral/spiritual care services and make pastoral/spiritual care available either through organizational pastoral counseling or through the patient's own clergy relationships.	A hospital chaplain is available at all military hospitals.
	20. Specialized palliative and hospice care teams should include pastoral care professionals appropriately trained and credentialed in palliative care.	A hospital chaplain is available at all military hospitals.
	21. Specialized palliative and hospice pastoral care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care.	Varies widely with interest, training, and available time of staff.
<u>6. Cultural Aspects of Care.</u> <i>Patient and family reactions to symptoms and entry into the last stages of life are conditioned in part by their cultural beliefs and values. Palliative care and hospice programs must be able to recognize these diverse approaches and tailor their interventions to accommodate them.</i>		
	22. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision-making, truth telling and decision-making, dietary preferences, language, family communication, perspectives on death, suffering and grieving and funeral/burial rituals.	Varies widely with interest, training, and available time of staff.
	23. Provide professional interpreter services and materials in the patient's and family's preferred language.	Available for most non-English speaking families served by the MHS
<u>7. Care of the Imminently Dying Patient.</u> <i>When a patient's death becomes imminent, a host of unique needs – both patient-centered and family-centered – must be addressed. These unique needs require unique programmatic components to help the patient achieve a "good death."</i>		
	24. Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.	Varies widely with interest, training, and available time of staff.
	25. The family is educated regarding signs and symptoms of imminent death in a developmentally, age and culturally-appropriate manner.	Varies widely with interest, training, and available time of staff.
	26. Ascertain and document patient	Varies widely with interest, training, and

	and family wishes about the care setting for site of death, and fulfill patient and family preferences when possible.	available time of staff.
	27. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns such as fear of analgesics hastening death.	Varies widely with interest, training, and available time of staff.
	28. Treat the body post-death with respect according to the cultural and religious practices of the family.	Routinely provided by nursing services.
	29. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when the family becomes the focus of care.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit
<i>8. Ethical and Legal Aspects of Care. To ensure that all patient and family rights are protected and preserved, systematic processes and procedures must be implemented and disseminated.</i>		
	30. Document the designated surrogate/decision-maker in a state-specific legal document for every patient in primary, acute, and long-term care and in palliative and hospice care.	Routinely provided at MTFs for adults, not discussed with child.
	31. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.	Varies widely with interest, training, and available time of staff.
	32. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, such as the Physicians Orders for Life-Sustaining Treatments – POLST Paradigm Program.	Varies widely with interest, training, and available time of staff.
	33. Make advance directives and surrogacy designations available across care settings, e.g., by internet-based registries or electronic personal health records.	Potentially available in electronic personal health record.
	34. Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g.,	Varies widely with interest, training, and available time of staff.

	Respecting Choices, Community Conversations on Compassionate Care.	
	35. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end-of-life.	Available at tertiary care centers.
	36. For minors with decision-making capability, document the child's views and preferences for medical care, including assent for treatment, and give appropriate weight in decision-making. Make appropriate professional staff members available when the child's wishes differ from those of the adult decision-maker.	Varies widely with interest, training, and available time of staff.

Appendix F

Proposed Plan:

mCARE

Integrated Palliative Care Program For Children With Life-Threatening Illnesses

(a) General. (1) The TRICARE mCARE is a supplement to the Basic Program and is a voluntary program. It does not provide acute care or benefits available through TRICARE Basic Program or the ECHO Program. mCARE benefits are available to children of active duty and retired sponsors. There is no cost-share liability to the sponsor or a maximum monthly government liability.

(2) The purpose of mCARE is to provide a mechanism to coordinate and integrate palliative care, disease-directed care, and support for children with life-threatening illnesses and their families from diagnosis through treatment with hope for a cure to bereavement care if a cure is not obtained. Care provided through the mCARE program will be continuous, comprehensive, coordinated, family-centered, culturally-competent, and medically-appropriate. It expands the benefits available to a child with a life-threatening illness and their family to include services defined in a Medicaid-approved pediatric hospice program.

(b) Eligibility. (1) The following categories of TRICARE/CHAMPUS PRIME beneficiaries with a qualifying condition are eligible for mCARE benefits.

(i) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) of a member or one of the Uniformed Services; or

(ii) An abused dependent child as described in Section 199.3(b)(2)(iii); or

(iii) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) of a member of one of the Uniformed Services who dies while on active duty. In such case the child remains eligible for benefits under the mCARE program for a period of three years from the date the active duty sponsor dies; or

(iv) A child (as described in 10 U.S.C. 1072(2)(A),(D), or (I)) or a deceased member of one of the Uniformed Services, who, at the time of death was eligible for receipt of hostile-fire pay, or died as a result of disease or injury incurred while eligible for such pay. In such case, the child remains eligible through midnight of the beneficiary's twenty-first birthday.

(2) Qualifying condition. Children will be determined to have a life-threatening qualifying condition by their primary care physician in coordination with their parents. The following are examples of qualifying conditions:

- (i) Children with diseases for whom treatment is available, but may not be successful.
- (ii) Children for whom aggressive treatment is available that may result in a good quality of life, but who, nevertheless, will die prematurely.
- (iii) Children with progressive diseases who may live for prolonged periods of time.
- (iv) Children with severe disabilities that are not progressive, but will likely lead to complications and premature death.

(3) Loss of mCARE eligibility. Upon death or separation from the service.

(c) mCARE benefit. Services that the Director, TRICARE Management Activity, or designee has determined are capable of ensuring the provision of an integrated program of palliative care, disease-directed care, and support as determined appropriate by the child's primary care physician and the family, includes, but are not limited to:

(1) Care coordination. Care coordination will be provided by a pediatric palliative care coordinator and will implement a comprehensive plan of care. Care coordination may be provided by the MTF or purchased from a TRICARE-approved home health agency or agency that coordinates care for CMS MEDICAID waiver programs and that has pediatric-trained and experienced staff. Care coordination is necessary to receive other benefits under this program.

(i) A written comprehensive plan of care will be developed within two weeks of referral to the mCARE program. The plan of care will include all services, durable medical equipment, and durable equipment necessary to address medical, social, educational, spiritual needs of the child, and support services for the family, although not all these services or equipment are necessarily purchased or provided through the MHS unless provided for below. The plan of care will be reviewed at least every three months and updated as needed. The written comprehensive plan of care will be developed by a team including the care coordinator, the parents, the child if appropriate, and the child's primary care physician and appropriate specialty care physicians.

(ii) A copy of the plan of care will be placed in the child's medical record, a copy provided to the parents, and a copy forwarded to the mCARE program manager at the MTF.

(iii) The plan of care will specify an emergency plan of action for the parents or school.

(iv) The plan of care will address the support a family requires when two or more family members have special needs.

(v) Parents and physicians will have access to educational materials preparing them for their role on the care coordination team.

(2) Respite care. Two consecutive 24-hour periods per month may be provided by a TRICARE-approved home health agency. The level of training required by the respite care provider will be specified in the plan of care.

(3) Pre-bereavement and bereavement counseling. Counseling will be provided to the child and family as defined in the plan of care. A diagnosis of mental illness is not necessary for the child or any family member in order to qualify for this service. The level of training of the counselor will be specified in the plan of care. The provider must be TRICARE-approved for reimbursement.

(4) Home health care. Home health care will be provided as described in the plan of care. The level of training of the provider will be specified in the plan of care and may include any or all of the following: registered nurse, licensed practical nurse, personal attendant. Services are not limited to part-time or intermittent. The services of a registered nurse are not necessary to receive this benefit. If home health care is provided by a family member, that family member will be reimbursed for up to 40 hours per week at the same rate as a personal care attendant in a local TRICARE-approved home health agency.

(5) Custodial care. Custodial care is authorized under mCARE. If custodial care is provided by a family member, that family member will be reimbursed for up to 40 hours per week at the same rate as a personal care attendant in a local TRICARE-approved home health agency.

(6) Inpatient pediatric hospice services. Inpatient pediatric hospice services may be purchased when provided in a TRICARE-approved hospice program or a MEDICAID-approved pediatric custodial care facility. A written plan of care is required and bereavement counseling services must be provided.

(7) Durable medical equipment and durable equipment. Durable medical equipment specified in the plan of care will be purchased by the MHS as provided for in the Basic Program. Durable equipment will be purchased under this program.

(8) Transportation. Specialized medical transportation (ambulance or taxi accommodating wheelchairs) will be purchased by the MHS when specified in the plan of care and necessary for the child to travel to and from the hospital or clinic.

(9) Structural alterations. As specified in the plan of care, up to \$1000 per child may be reimbursed to the family by the MHS for structural alterations necessary to provide care to the child in the family home.

(10) Coordination during PCS moves and deployments. The written plan of care will address the increased need for support a family faces during PCS moves or deployments when caring for a child with a life-threatening illness. The plan of care will provide for a seamless transition to the gaining medical facility.

(11) Expressive therapies. As defined in the written plan of care, expressive therapies such as music therapy, art therapy, and play therapy are authorized when provided by licensed or registered therapist.

(d) mCARE Exclusions. Benefits provided under the TRICARE Basic Program and the Extended Care Health Option (ECHO) will not be provided through mCARE. These benefits will, however, be specified and coordinated in the written plan of care.

Appendix G

February 28, 2006

Memorandum

TO: Pamela Cunningham

FROM: Dave Kennell
Arnie Brooks

CC: Tim Napora

SUBJECT: Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center (Task Order 3001-088)

You requested that we estimate the potential costs and savings related to a proposed pilot program which would provide palliative care and other services to children with life-threatening conditions. This document contains our estimate of the costs and savings for a pilot program for children in the NCA.

The following presents our IGCE for the mCare pilot project at WRAMC. After discussing our understanding of the pilot program, we discuss how we identified the target population in the NCA. We then discuss how we defined the mCare benefit for eligible participants. We then examine the potential for health care savings, the expected costs of the program, and net program costs. We end with a discussion of the critical assumptions underlying our savings and cost estimates.

Introduction and Background

Children's Hospice International (CHI) is a non-profit organization for the promotion of hospice care for the pediatric population. With the technical assistance of

CMS, CHI developed the CHI Program for All-Inclusive Care for Children and their Families (CHI-PACC) to address care for children with life-threatening conditions. In FY 2003, Congress allocated funding to study the feasibility of developing a similar program for eligible children and their families in the MHS.

DoD is considering a pilot demonstration project, targeting a selected population of eligible pediatric dependents of active duty and retired service members in the National Capitol Area (NCA). This pilot would evaluate the feasibility of CHI PACC approach to care in the DoD. This pilot project will be run out of Walter Reed Army Medical Center (WRAMC).

The name mCare (Military Children at Risk—Enhancing Quality of Life) has been designated for the military CHI-PACC program. The mCare working group team has asked that we provide an IGCE of the cost of providing the following CHI-PACC benefits (not currently covered through TRICARE) through the WRAMC pilot demonstration:

- Care Coordination
- Home health care
- Respite care
- Bereavement counseling

Participation in the pilot program would be voluntary based upon the decision of the patient's family and the program participant would not give up access to standard curative care at any time (unlike Medicare's hospice program).

The mCare working group has chosen to use the four groupings of life-threatening pediatric (up to age 24) conditions proposed by Himmelstein in his 2004 paper as

qualifying criteria for the NCA demonstration.³⁸ The working group has operationalized Himmelstein’s approach and we have used these definitions to identify the relevant pediatric population in the NCA as indicated in Table 1 below.

Table 1 Life Threatening Conditions in Pediatric Cases			
Himmelstein’s Description of Conditions	Working Group Designation for These Conditions	Examples	ICD-9 Diagnosis Codes Used to Create Database
Progressive conditions in which treatment is exclusively palliative from diagnosis	“Incurable”	Spinal muscular atrophy, trisomy 13 or 18, severe infantile asphyxia	335.0, 335.10, 335.11, 758.1, 758.2, 758.3, 768.0, 768.1, 768.2, 768.5
Conditions requiring long periods of intensive treatment aimed at prolonging quality of life	“Manageable”	Cystic fibrosis, muscular dystrophy	277.00, 277.01, 359.1
Conditions for which curative treatment is possible but may fail	“Curable”	Any childhood leukemia or malignancy	191.x, 204.xx, 206.xx, 207.xx, 208.xx, 209.xx
Conditions with severe, non-progressive disability causing extreme vulnerability to health complications	“Co-morbid”	Spastic quadriplegia, presence of tracheotomy with any diagnosis	343.2, V55.0

This IGCE is based upon our review of the literature as well as conversations with many professionals in the field of providing palliative care to children with life-threatening illnesses. Outside of the mCare working group, our contacts have been with professionals at CMS, the state Medicaid demonstration programs (CO, UT, NY), independent programs within states (University of MN Department of Pediatrics USK Program, Children’s Hospital Regional Medical Center of Seattle Washington Pediatric Palliative Care Project, and St. John’s Hospital Pediatric Palliative Care Committee Project in Detroit, MI), and associated professionals in the National Capital Area (Respite Services of Montgomery County, MD and the Child Welfare League of America).

Target NCA Pediatric Population

³⁸ Himmelstein B., Hilden J., Boldt A., et al., “Medical progress: Pediatric palliative Care,” *New England Journal of Medicine*, 2004, Vol. 350, pages 1752-62.

To determine the size of the relevant pediatric population with life-threatening illnesses in the NCA catchment area, we used DEERS and M2 data to determine the number of unique (unduplicated) beneficiaries with claims in either the direct care or purchased health care systems during FY 04 and FY 05. Unique users had to have at least one claim with any diagnosis code indicated in Table 1 and be younger than age 25 throughout the end of FY 2005. Once unique users were identified, we used the DEERS Death File to determine if they had died during FY 04 or FY 05. We believe that the resulting number of deaths will be underreported using this approach because not all deaths are reported to DEERS in a timely manner.

The results of our analysis of the unique user counts are presented in Table 2 by diagnosis. We compared these results with the results obtained by Dr. Arday using similar data in FY 01 and FY 02.

Table 2					
Number of Unique Pediatric Beneficiaries With Life Threatening Illnesses Within the NCA					
	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
Kennell Analysis of Unique Beneficiaries in FY 04/FY 05					
Lived	40	58	130	78	306
Died	0	1	8	6	15
Total	40	59	138	84	321
% Distn by Diagnosis	12%	18%	43%	26%	100%
Arday Analysis of Unique Beneficiaries in FY 01/FY 02					
Lived	33	48	114	67	262
Died	0	0	4	2	6
Total	33	48	118	69	268
% Distn by Diagnosis	12%	18%	44%	26%	100%

Our analysis of direct and purchased care claims found that there were 321 pediatric beneficiaries with life-threatening illnesses in the NCA during FY 04/FY05. The largest concentration of beneficiaries is in the curable category (leukemia at 43

percent), followed by comorbid (quadriplegia/trach at 26 percent), manageable (CF/MD at 18 percent) and then incurable (SMA/trisomy at 12 percent). The percentage distribution of cases by diagnosis in FY04/05 is almost identical to the percentage distribution of cases found in Arday's analysis of FY 01/FY 02 data, although we note that we found about 20 percent more cases than Arday did. We found that only 15 beneficiaries died during the two year period FY 04 through FY 05. As discussed above, we believe that this is an under-estimate of the actual number of deaths because of DEERS under-reporting. The working group also believes that there are about 25 deaths per year based upon observations at WRAMC.

We found that the government spent \$29.6 million direct and purchased care health care costs for pediatric beneficiaries with life threatening illnesses in the NCA in the two-year FY 04/FY 05 period. This spending level is significantly higher than the level found by Arday for FY01/FY02 (in FY01/02 combined expenditures were \$14.6 million). While about 20 percent of this increase can be explained by an increase in the number of pediatric cases with the diagnoses, about 70 percent is due to an increase in costs per case. The vast majority of health care expenditures were for beneficiaries with curable (\$16.4 million) and comorbid (\$7.2 million) diagnoses. On an average cost per beneficiary basis, we found that costs are nearly 50 percent higher for those beneficiaries that die (\$133,793) compared with those that live (\$90,189) over the two year period due to the fact that dying beneficiaries use more hospital services. On average, pediatric patients that die have 2.5 times the number of hospital days than those that live (34.7 for those that die versus 13.8 for those that live).

Table 3 FY 04/FY 05 Direct Care and Purchased Care Health Care Cost for NCA Pediatric Beneficiaries With Life Threatening Illnesses					
	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
Total Direct and Purchased Care Costs					
Lived	\$2,175,280	\$3,639,386	\$15,377,666	\$6,405,625	\$27,597,957
Died	NA	\$86,859	\$1,042,216	\$877,821	\$2,006,896
Total	\$2,175,280	\$3,726,244	\$16,419,882	\$7,283,447	\$29,604,853
Costs Per Beneficiary					
Lived	\$54,382	\$62,748	\$118,290	\$82,123	\$90,189
Died	NA	\$86,859	\$130,227	\$146,304	\$133,793
Total	\$54,382	\$63,157	\$118,985	\$86,708	\$92,227
Inpatient Days Per Beneficiary					
Lived	8.5	9.1	16.1	16.1	13.8
Died	NA	20.0	27.8	46.5	34.7
Total	8.5	9.3	16.8	18.3	14.8

The mCare Benefit

From discussions with the working group it is our understanding that the mCare pilot demonstration will provide a system of integrated medical and palliative care and support to the pediatric beneficiary as determined by the child's primary care physician and family. As noted above, the four primary elements of the program are care coordination, home health care at appropriate levels, bereavement counseling, and respite care.

Care coordination would be provided by pediatric care coordinators based at WRAMC. Coordinators would be experienced pediatric professionals that are RNs or pediatric social workers/psychologists. Family acceptance of care coordination is a necessary condition for beneficiary participation in the program. A written comprehensive plan of care would be developed once the family has decided to participate in the mCare program. The plan of care would include all services necessary to address medical, social, educational, spiritual needs of the child, and support services for the family. The written comprehensive plan of care would be developed by a team including the care coordinator, the parents, the child if appropriate, and the child's primary care physician and appropriate specialty care physicians. The developed plan would attempt to empower the care coordinator to take on a very large share of the non-medical care coordination responsibilities currently being performed by the patient's primary care physician. The care coordinator would also be responsible for ongoing coordination of care by ensuring that the multiple appointments each child has are scheduled at convenient times for the family, properly sequenced with recommended

testing, and coordinated with other visits when possible to reduce overlap and redundancy. The coordinator would also act as a central hub for information flow.

Care coordinators would also be responsible for telephone triage and parent/patient education. Both are intended to result in a more efficient use of medical resources and to economize time and energy expended by the patient and family. Whenever possible, illnesses would be addressed over the telephone by a care coordinator. Addressing illnesses promptly would aim to avoid delays in implementing treatments, potentially avoid more severe illnesses, and ultimately reduce the number of emergency room visits and hospitalizations.

Another function of the pilot demonstration would be the education and support of families to build their confidence as they learn to manage their child's care at home with less dependence upon the resources of the MHS. Based on our research, the key to this program function is the development of customized, recurrent-illness plans. These plans have the benefit of earlier identification of problems by the family and health care providers, earlier implementation of effective treatments, and reduction in unplanned emergency room visits and hospitalizations.

Home health care would also be provided as described in the plan of care. This would be particularly important for end-of-life patients. The level of training of the provider would be specified in the plan of care and might include registered nurses, licensed practical nurses, or personal attendants that would be available through the purchased care system.

Participating mCare families would also be eligible for respite care. The level of training required by the respite care provider would be specified in the plan of care.

Respite care could be provided at a respite care center or at home by a registered nurses, licensed practical nurses, or personal attendant. It is our understanding that respite care would be limited to one weekend per month per family.

Bereavement counseling would also be provided to the family as defined in the plan of care. A diagnosis of mental illness would not be necessary for the child or any family member in order to qualify for this service. The level of training of the counselor would be specified in the plan of care. This service would be available for a period of one year following the death of the child.

Approach to Estimating Pilot Program Savings and Costs

We built a simple spreadsheet model to estimate the pilot program's health care costs and savings. The model uses findings from our analysis of NCA claims as well as assumptions based upon our research and interviews with knowledgeable health care professionals (see Appendix A for the detailed spreadsheet model). The three major sources of health care cost savings are:

- substitution of less expensive home care for hospital care in the case of terminal patients,
- care coordinators freeing-up the time of MTF primary care physicians, and
- the use of telephone triage and parent education.

There are three sources of additional program costs:

- hiring care coordinators,
- respite care, and
- bereavement counseling.

Based upon the observations of the working group at WRAMC, we assumed that approximately 25 pediatric patients in the NCA with life-threatening diseases will die annually. Based upon our analysis of FY 04/05 direct care and purchased care claims, we also estimate that there are roughly 300 patients annually with life threatening illnesses in the NCA who survive each year.

We assumed that about 60 percent of dying patients would participate in the pilot program (based upon Milliman USA's review of the New York State Medicaid Essential Care Program Demonstration). A second key participation assumption was that 75 percent of the surviving patients with life threatening illnesses would participate in the

pilot program because of the added benefits of the program with no additional costs to the families of the patients. This assumption was based upon the judgement of the working group. These assumptions are summarized in Table 4 below.

Table 4 Basic Input Assumptions for Number of Patients and Program Participation Rates in the NCA Pilot Program for Pediatric Patients With Life Threatening Illnesses			
	Dying in Year	Surviving	Total
<i>Annual Patients</i>	25 ^{1/}	300 ^{2/}	325
<i>Estimated Participation Rate</i>	60% ^{3/}	75% ^{4/}	74%
<i>Estimated Participating Children</i>	15	225	240

1/ Assumption based upon working group observations at WRAMC.

2/ Based upon Kennell claims analysis of FY 04/05 direct and purchased care data in the NCA.

3/ Based upon Milliman USA evaluation of New York State Medicaid Demonstration (Essential Care Program) for dying patients.

4/ Working group assumption.

Estimated Program Savings

Research and interviews with program experts indicate that program savings can be achieved from the three following program elements:

- substitution of less expensive home care for hospital care in the case of terminal patients,
- care coordinators freeing-up the time of MTF primary care physicians, and
- the use of telephone triage and parent education.

We discuss each of these below.

Substantial savings on a per patient basis can be achieved by moving pediatric patients that are at a terminal stage from the hospital setting to the community or home setting during the last days of life. As discussed above, we estimate that approximately 15 dying children would participate in the NCA pilot project annually. We found that approximately 75 percent of the children with life-threatening illnesses who die in a

given year do so in hospitals (versus the community setting) and that the average length of a terminal hospital stay is about 10 days. Our analysis of claims data also indicates that the average FY 06 healthcare costs of a child during the final 10 days of life is about \$3,410 per day or about \$34,100 per patient.

We estimate that if each hospitalized child who dies had spent his or her final ten days at home, they would have incurred home care costs of approximately \$325 per day or about \$3,250 per patient in total. Thus, we estimate that each patient who shifts from dying in hospital to dying at home would save the government about \$30,850. Thus, the 11 patients in the pilot program would save the government about \$347,000 in FY 06 as noted in Table 5 below.

Table 5 Potential FY 06 Health Care Cost Savings from Home Care			
	Hospitalization	Home Care	Home Care Savings
<i>Number of Dying Children</i>	25	25	
<i>Program Participation Rate</i>	60%	60%	
<i>Estimated Participating Children</i>	15	15	
<i>Adjustment for Children Already Dying at Home</i>	75%	75%	
<i>Net Number of Patients Participating</i>	11	11	
<i>Terminal Hospital Days/Patient</i>	10	10	
<i>Cost Per Day</i>	\$3,410	\$326	\$3,084
<i>Total Costs Per Patient</i>	\$34,104	\$3,260	\$30,844
<i>Total Costs</i>	\$383,673	\$36,675	\$346,998

For detailed information on sources see Appendix A.

Pediatric patients with life threatening illnesses require health and social services well beyond the level required by other children. Physicians who care for such patients can spend a substantial number of hours providing care coordination for their patients. Physician time can be spent coordinating care with different health care providers in different health care organizations and subspecialties, third-party payers, organizations,

schools, and agencies funded by a variety of sources. The lack of a single entry point linking systems of health care, social services, education, public health services, and home services makes coordination of care complicated. Thus, substantial government cost savings could potentially be achieved by using non-physicians to perform care coordination tasks. Based upon the working group's observations at WRAMC, the group has estimated that MTF physicians on average spend approximately 10-12 hours per year for each pediatric patient with life-threatening illness. Assuming that 10 hours per patient per year could be saved, with a total of 240 children participating (see Table 4), we estimate that a total of 2,400 hours of physician time could be saved each year by using care coordinators. Assuming that each physician would be able to see three additional patients for each hour of time saved, we estimate that as a result of care coordination, an additional 7,200 visits could occur as a result of care coordination through the pilot program. We estimate the value of one recaptured civilian visit from the purchased care sector to be \$60 based on a volume weighted average CMAC for CPT codes 99213 and 99214 (the highest volume established patient office visit codes). Thus, we estimate that care coordination has the potential to save more than \$430,000 (7,200 visits x \$60 per visit) annually as a result of care coordinators freeing up physicians' time for more productive uses.

Telephone triage and patient education are expected to be essential components of the pilot program under mCare. When possible, the program would provide telephone management for each of a child's multiple problems, particularly for illness symptoms. Many illnesses will be addressed over the telephone which, in theory, should avoid delays in implementing treatments and potentially avoiding more severe illnesses. It

would also reduce the number of ER visits and hospitalizations. Another function of the pilot program will be to educate and build the confidence of the support families to learn how to manage their child's care at home.

The amount of savings from telephone triage and patient education is uncertain because no controlled studies have been completed on this topic. As a result, we provide a range of estimated savings. First, as discussed above, we estimate that there are 225 surviving patients with life threatening illnesses that will participate in the program. Second, based upon our analysis of claims data, we estimate that these surviving children cost the government about \$49,200 in non-pharmacy medical costs per patient per year in FY 06. Third, based upon discussions with experts in the field, we estimate that only about half of the families could actually benefit from telephone triage and education.³⁹ Fourth, we estimate the percent of savings that could be achieved from telephone triage and education.

While no controlled studies or published estimates are available, our conversations with experts lead us to estimate that it is possible to achieve between 5 and 10 percent of annual inpatient and outpatient medical cost savings as a result of more efficient use of medical resources as a result of telephone triage and parent education. These assumptions imply annual savings of between \$275,000 and \$550,000 for telephone triage and parent education in FY 06.⁴⁰ These savings represent steady-state program savings once the program is fully operational and the care coordinators have a working relationship with the patients and families. Savings in the early years of the program in this area are likely to be much smaller.

³⁹ The other 50 percent are not likely to want to use these types of services.

⁴⁰ Fifty percent of the 225 patients multiplied by 5% of the \$49,200 in average expenditures per patient equals \$277,000. If the savings were 10 percent the savings would be \$554,000.

Estimated Program Costs

We believe pilot program costs will result from the following program elements:

- employing care coordinators at WRAMC,
- providing the respite care benefit, and
- providing the bereavement counseling benefit.

The most significant cost component of the mCare pilot program will be the cost of hiring care coordinators. For the purposes of this IGCE and at the direction of the working group, we have assumed that excess space will be available at WRAMC and thus we assume that there will be no additional overhead costs for the care coordinators that are hired as a result of the demonstration. Based upon our interviews of professionals in the field and the results of the “2005 Case Management Salary Survey,” we estimate that the project will have to hire one care coordinator for every 45 surviving children who participate. We also assumed that each child would need intermittent care coordination at least once a quarter. Because we estimate there will be 225 surviving participants, this implies that 5 care coordinators would need to be hired. Additionally, because dying children need more coordinated care contact, we estimate that the 25 dying children would need one dedicated care coordinator. Thus, we estimate that a total of 6 care coordinators would be needed for the project.

The care coordinators would primarily be RNs with possibly one or two psychologists (MSWs). The working group believes that the average salary for this group will be at the GS-12 step 5 level implying a total annual wage and benefits (28 percent) package of \$94,362 per care coordinator in FY 06. Thus, total costs for the six care coordinators would be \$566,169 (6x\$94,362). By adding in a clerk for filing, word

processing, and telephone coordination at \$53,196 (GS-7 step 5 with 28 percent benefits) we estimate total care coordination costs of \$619,365 (\$566,169 + \$53,196).

Estimating the cost of the respite care benefit is difficult. We have contacted the coordinators of state-run Medicaid programs and also private programs regarding the utilization of respite care. However, the programs are either in the formative process (CO, NY, and UT) or have not had enough experience with their program that is currently in place (FL and WA). Based upon these conversations, we think that it is reasonable to assume that about 25 percent of the 240 participating families (see Table 1) would use these services about one weekend each month. Additionally, we know that about 25 percent of the children in the analysis of FY 04/05 claims have conditions that already qualify them for the respite care benefit under TRICARE's ECHO program. Thus, we estimate that about 45 families will use the new respite care benefit under the mCare pilot program once a month.⁴¹ Based upon our review of respite services in Montgomery County, MD, two workable options are available: care at a respite care

⁴¹ $240 \times .25 \times (1-.25) = 45$

center or respite care at home. Based upon our conversations with Karen Patterson of Respite Services of Montgomery County, the overnight daily rate for care center services averages approximately \$200 per night and varies depending upon the severity of the patient's illness. For the IGCE we assumed that each patient whose family uses respite care would have 12 two-night stays each year; this implies \$4,800 per patient ($12 \times 2 \times \200) or total program costs of \$216,000 ($45 \times \$4,800$). Ms. Patterson also indicated that costs for in-home nursing services in Montgomery County are between \$40 and \$55 per hour based upon the provider skill level. For the IGCE we assumed two 8 hour shifts per weekend 12 times per year which implies \$9,120 per patient or total program costs of \$410,400.⁴² To estimate total program costs for respite care, we assume that ultimately services will be equally weighted between care center and in-home providers which yields estimated total respite care costs of \$313,200 (the average of \$216,000 and \$410,400).

Bereavement counseling is an integral part of the mCare pilot program. Based upon our conversations with program officials, we estimate two to three months of bereavement counseling would occur for families that participate in the program and have lost a child as a result of their illness. Thus, for the 15 participating families with dying children, we estimate 10 counseling sessions at a cost of \$100 per session resulting in costs of approximately \$1,000 per family ($10 \times \100) and total program costs of approximately \$15,000 ($15 \times \$1,000$).

Net Program Savings

⁴² $12 \times 2 \times 8 \times (\$40 + \$55)/2 = \$9,120$. $45 \times \$9,120 = \$410,400$.

On an annual basis and once the program is fully implemented, we anticipate that the mCare Pilot Project could result in gross health care cost savings of about \$1.1 to \$1.3 million per year. A large part of these gross savings would depend upon the success of the telephone triage and parent education program. We also expect that the program would result in additional costs of more than \$0.9 million annually resulting. Thus, the net program savings would be roughly \$100,000 to \$400,000 annually once the program is fully implemented (see Table 6 below). As discussed above, there are likely to be little or no savings in the first year or two because the telephone triage savings are not likely to occur until families develop confidence in their care coordinator.

Table 6 Summary of Estimated mCare Pilot Project Steady-State Savings at WRAMC for the National Capital Area in FY 06 (\$in thousands)	
Savings	\$1,058 - \$1,335
Substitution of Home Care for Hospital Care for Terminal Patients	\$347
Freeing Up MTF Physician Time	\$435
Steady-State Telephone Triage and Parent Education	\$277 - \$554
Added Costs	\$948
Coordinated Care	\$619
Respite Care	\$313
Bereavement Counseling	\$15
Total Net Program Savings	\$111 - \$388

Critical Assumptions

There are no controlled studies regarding the actual savings from CHI-PACC type pilot projects. The literature about relevant studies is sparse because new ground is just now being broken in the palliative treatment of pediatric cases. Only the Florida CHI-PACC demonstration is currently running and it will be six months to one year before any preliminary data are available.

As a result, in order to estimate costs and savings for this IGCE, we have had to rely on the judgments of researchers and persons who are implementing similar programs, as well as the expert opinions of the mCare working group members. There are four assumptions that are particularly critical and that could affect whether there are net savings or costs from this type of pilot program. First, for telephone triage and parent education savings, we assumed that the WRAMC care coordinators' efforts would result in saving 5 to 10 percent of total health care costs for those that could benefit from assistance. While savings could be potentially greater, it is also possible that no savings would be forthcoming. Dr. Anne Kelly (Program Director for U Special Kids at the University of MN) cautions that such savings are virtually non-existent until the care coordinators become very familiar with each patient and their parents and the parents feel empowered to take an active role in caring for their children. Additionally, until the care coordinators are confident they know the families well, they are very reluctant to recommend not coming to the emergency room. It is not until such relationships are solidified that a recommended "wait-and-see approach" will result in avoided ER visits or hospitalizations.

Second, based upon working group staff observations at WRAMC, the IGCE assumes that approximately 10 hours per year per patient will be saved for each participating patient as a result of the new care coordinators taking on the work of the care coordination tasks of MTF physicians and nurses. Although the working group believes that the MTF physicians at WRAMC seem to take on a great deal of this burden, this burden is significantly higher than what has been estimated to apply in the civilian

sector.⁴³ Because this assumption results in gross savings of over \$400,000 and because the net savings are only \$100,000 - \$400,000, if the actual savings in physician time achieved at WRAMC are only at the level found by Antonelli in the civilian sector, then the net savings would be reduced or eliminated.

Third, based upon the recommendations of the working group, we have assumed that there would be no marginal costs associated with office space or equipment because these services would have already been supplied by WRAMC. If such resources were not available, we estimate that approximately \$200,000 or more would need to be spent to pay for office space and associated supplies. Although this is a good assumption for FY06, it may not be true when WRAMC changes its location in a few years.

⁴³ Antonelli, RC, et al., "Providing a Medical Home: The Costs of Care Coordination Services in a Community-Based, General Pediatric Practice," *Pediatrics*, Vol. 113, No. 5, May 2004. This study indicates that physicians and nurses spend 1.1 hours per patient per year on care coordination.

Finally, the IGCE assumes that there would be no additional administrative costs associated with coordination of services provided through the civilian sector by the current TNEX contractor (HealthNet). However, approximately half of the government expenditures for children with life-threatening illnesses are in the civilian sector in the NCA. Based upon our experience, it is certainly possible that HealthNet will ask for some administrative costs associated with coordinating care and paying special claims for relevant civilian sector cases. On the other hand, this pilot could also relieve HealthNet from the task of care coordination for these patients.

Appendix H

Detailed Spreadsheet Model to Estimate WRAMC Pilot mCare Annual Costs in FY

06

Table 1

Basic Input Assumptions

	Dying in Year	Surviving	Total
Annual Pediatric Patients	25 1/	300 2/	325
Program Participation Rate	60% 3/	75% 4/	74%
Participating Children	15	225	240

1/ Working group assumption based upon WRAMC history.

2/ Based on Kennell claims analysis of FY 04/FY 05 direct and purchased care data.

3/ Milliman USA New York State Medicaid Demonstration.

4/ Working Group Assumption

Table 2

FY 06 Potential Savings From Substitution of Home Care for Hospital Care for Terminal Patients

Children who die and need intensive care (working group assumption)	25
Program participation rate	1/ 60%
Estimated dying children who participate	15

Hospitalization Cost Savings (From NCA)		
Terminal Hospitalization Cost/Patient		
FY04&FY05 Total Hospital Costs/Day (Dying Patient in NCA)	2/	\$3,125
Months From FY 04/05 to FY 06		18
Average Annual Inflation Rate		6%
Estimated FY 06 Total Hospital Costs/Day (Dying Patient in NCA)		\$3,410
Terminal Hospital Days per Patient	2/	10
Estimated FY 06 Terminal Hospital Cost Per Patient		\$34,104
Adjustment for those already dying at home	3/	75%
Potential Hospitalization Savings Per Patient		\$25,578
Number of Patients		15
Potential Gross Savings		\$383,673

Added Costs of Home Care		
Terminal Days Per patient	2/	10
Home Health Care Cost/Day @ 8 hours/day @ \$41/hour	4/	\$326
Adjustment for those already dying at home		75%
Potential Added Home Health Cost/Patient		\$2,445
Number of Patients		15
Potential Added Gross Costs		\$36,675

Net Savings	\$346,998
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1/ Milliman USA New York State Medicaid Demonstration (Essential Care Program) study on palliative care for children with life limiting illnesses in 2003.

2/ Estimate based on Kennell analysis of the final-stay inpatient claims of 13 pediatric patients who died in the NCA during FY 04/FY05. Examining the final hospitalizations prior to death, we found a total of 129 days at total cost of \$403,085. This implies an average length of stay of 10 days and average cost of \$3,125 per day.

3/ Kennell Analysis of FY 04/FY05 claims of pediatric patients indicates that 10 of 13 patients (77%) died while in the hospital.

4/ Hours vary by condition, rates vary by RN vs LPN, assumptions and sources are as follows:

	Curable	Comorbid	Total
number of children	12.5	12.5	25
hour/day at home			weighted avg
Carol Marsiglia	4	16	10
Pam Jennings	2	10	6
average	3	13	8
	RN	LPN	
RN/LPN weight	25%	75%	
cost/hour			
Carol Marsiglia	\$46.00	\$35.00	\$37.75
Karen Patterson	\$55.00	\$40.00	\$43.75

01/05/06 e-mail from Carol Marsiglia to Virginia Randall
conversation with Pamela Jennings, MSN, RN, PNP, St. John Hospital, Detroit, MI

conversation with Pamela Jennings, MSN, RN, PNP, St. John Hospital, Detroit, MI

01/05/06 e-mail from Carol Marsiglia to Virginia Randall
conversation with Karen Patterson, Respite Services Montgomery County.

Table 3

FY 06 Savings From Freeing Up MTF Physician Time

Children Participating 1/ and care coordination at least once/week	240
Hours of Physician Time Saved Per Patient/Year 2/	10.0
Estimated Physician Hours Saved	2,400
Additional MTF Visits Per Hour Saved 3/	3
Recaptured Civilian Visits	7,200
Value of One Recaptured Civilian Visit 4/	\$60
Annual Value of Physican Hours Saved	\$434,550

1/ See input assumptions page.

2/ Working group assumption based upon WRAMC observations.
It should be noted that these savings are nearly 10 times those
from the Antonelli Study, *Pediatrics*, May 5, 2004 that finds 1.1 hours
saved per patient per year: 482 hours saved for 444 patients.

3/ Estimate of 3 per hour based upon 20 minute visit.

4/ Weighted average CMACs for 99213 & 99214.

Table 4

Telephone Triage & Parent Education Savings

Telephone triage can result in less ER/office visits and hospitalizations. The same arguments can be made for care coordinator education of parents in being able to more efficiently care for their children. A preliminary evaluation of the U Special Kids program (U of Minn) indicates the program has demonstrated that its care coordination services are associated with lower hospital admissions for acute illnesses. Conversations with Dr. Ross Hays and Pam Collier of Children's Hospital and Regional Medical Center of Seattle Washington and Dr. Brian Greffee the Colorado Butterfly Program indicate that substantial savings can be achieved as a result telephone triage and parent education, although these savings have not been quantified using a controlled methodological approach.

It is important to note below that the saving below represent long-term steady state savings achieved only after care coordinators know and trust patients. The estimates below assume that the pilot project will be able to set up a telephone triage program and will integrate parent education into the coordinated care process.

	Low End	High End
Estimated Telephone Triage & Parent Education Savings		
FY 04&FY 05 NCA IP and OP Annual Costs Per Living Patient 1/	\$45,095	\$45,095
Months From FY 04/05 to FY 06	18	18
Average Annual Inflation Rate	6%	6%
Estimated FY 06 NCA IP and OP Annual Costs Per Living Patient	\$49,213	\$49,213
Participating children who need intermittent care and contact 2/	225	225
Estimated percent who can benefit from telephone triage and education 3/	50%	50%
Estimated savings rate in outpatient cost from triage and education 4/	5%	10%
Estimated annual savings from triage and education	\$276,825	\$553,649

1/ Based upon Kennell analysis of surviving patients in the NCA in FY 04/FY05.

2/ See Assumptions page.

3/ Based upon our conversation with Pam Collier of the Pediatric Palliative Care Project in Seattle Washington, many parents have already self-educated and have learned by necessity how to be efficient consumers of health care services.

4/ No estimates are available--we conservatively estimate a range of 5 to 10 percent.

Table 5

FY 06 NCA Care Coordination Costs

Children who die	25
Program Participation Rate 1/	60%
Dying Children Who Participate	15
Care Coordinators Needed (1 per 25 patients)	1
Care Coordinator Salary & Benefits & Overhead 2/	\$94,362
Care Coordinator Cost	\$94,362
Children who need intermittent care coordination and contact once/quarter 3/	300
Program Participation Rate	75%
Non-Dying Children Who Participate	225
Care Coordinators Needed (1 per 45 patients) 4/	5
Care Coordinator Salary and Benefits 2/	\$94,362
Care Coordinator Cost	\$471,808
Clerk for filing and phone calls 5/	\$53,196
Total Care Coordinator Cost	\$619,365
Existing Care Coordinators Available	3
Existing Costs	\$283,085
Marginal Cost of New Program	\$336,280

1/ Essential Care Program in NY from Milliman USA study.

2/ GS-12 Step 5 including 28 percent benefits and **no overhead** multiplier for rent, office equipment, supplies and communication.

3/ Kennell updated NCA analysis for FY 04.

4/ 2005 Case Management Salary Survey Results. Utah's CHI-PACC has a 1 to 40 ratio and Utah's Tech Kids program has a 1 to 55 ratio.

5/ GS-7 Step 5 including 28 percent benefits and **no overhead** multiplier for rent, office equipment, supplies and communication.

Table 6

FY 06 Bereavement Counseling Costs

Children who die	25
Program Participation Rate 1/	60%
Dying Children Whose Families Participate	15
Counseling Sessions/Family 1/	10
Cost Per Session 2/	\$100
Total Cost/Patient	\$1,002
Total Program Costs	\$15,028

1/ Essential Care Program of NY analysis by Milliman is 5, we assume 10.

2/ Weighted CMAC for 90847.

Table 7

FY 06 Respite Care Costs

	Low End	High End
	Respite at Center	Respite at Home
Total Children Participating	240	240
Respite Care Participation Rate 1/	25%	25%
Children Who Participate	60	60
% Who Already Get Respite Care in ECHO 2/	25%	25%
Net Children Who Will Participate	45	45
Number of Weekends Per Year	12	12
Hourly or Daily Rate 3/	\$200	\$47.50
Hours or Days Per Weekend	2	16
Total Cost/Patient/Year	\$4,800	\$9,120
Total Program Costs	\$216,000	\$410,400

average \$313,200

1/ Seems reasonable to assume that 25 percent will participate but this is uncertain.

2/ 25 percent of children are in the comorbid category (i.e. spastic quadriplegia, and already qualify for respite care under ECHO).

3/ Costs provided by Karen Patterson of Respite Services of Montgomery County. Costs are between \$40 and \$55 per hour for in-home services and \$150 and \$250 per day for institutional services based on level of need.
Child Welfare League of America study (Susan Dougherty) indicates far lower average hourly rates of \$10 to \$15 per hour.

Note that Lisa Morris of Utah's CHI-PACC indicates that costs can be cut substantially if non-skilled staff can be used in the home. In Utah, non-skilled staff is usually used for all non-high-tech kids. Utah allows employment of relatives and neighbors as non-skilled labor. Dr. Anne Kelley of U Special Kids Program indicates that she believes that respite care is cost effective in that it results in parents being willing to provide more hours of home care rather than paid staff.

Table 8

Summary of PACC Pilot Project Steady-State Savings at Walter Reed AMC for National Capital Area Savings Estimated for FY 06

Savings

Savings from Substitution of Home Care for Hospital Care for Terminal Patients	\$346,998		
Savings From Freeing Up MTF Physician Time 1/	\$434,550		
Steady-State Telephone Triage & Parent Education Savings 2/	\$276,825	to	\$553,649
Subtotal Savings	\$1,058,373	to	\$1,335,197

Added Costs

Coordinated Care 3/	\$619,365
Bereavement Counseling	\$15,028
Respite Care	\$313,200
Subtotal Added Costs	\$947,593

Total Net Program Savings	\$110,780	to	\$387,605
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1/ Based upon observations at WRAMC, this estimate assumes that 10 hours per patient of physician time can be saved through care coordination. It should be noted that these savings are nearly 10 times greater than the savings from the Antonelli study, *Pediatrics*, May 5, 2004 that finds 1.1 hours saved per patient per year: 482 hours saved for 444 patients.

2/ Range of savings based upon 5 percent to 10 percent of total health care costs. Savings cited here are steady-state savings that may become available after care coordinators have gotten to know patients and their families and feel confident in giving advice over the telephone and being able to advise a "wait-and-see" approach prior to advising an office or ER visit.

3/ Includes care cost for three existing care coordinators plus three new care coordinators and one administrative staff assistant for filing and answering phone calls. It should be noted that no overhead costs are assumed in this estimate for rent, office equipment, supplies or communication.

Note: does not include any costs for coordination with TNEX contractors.

APPENDIX 9

BENEFITS AVAILABLE IN TRICARE/CHAMPUS FOR CHILDREN WITH LIFE THREATENING ILLNESSES AND THEIR FAMILIES

Respite Care

BENEFIT	CITATION	DESCRIPTION OF BENEFIT	COMMENTS	GAP
Respite care	TRICARE Extended Care Health Option (ECHO). Final Rule/FR Vol 69, No 144, Jul 28, 2004	(c)(7) Respite care. ECHO beneficiaries are eligible for 16 hours of respite care per month in any month during which the qualified beneficiary otherwise receives an ECHO benefit(s). Respite care is defined in Sec. 199.2. Respite care services will be provided by a TRICARE-authorized home health agency and will be designed to provide health care services for the covered beneficiary, and not baby-sitting or child-care services for other members of the family. The benefit will not be	<i>Pending signature and contract modifications.</i> Part 199.2 Definitions (b) Specific definitions. <u>Mental retardation</u> = A diagnosis of moderate or severe mental retardation make in accordance with the criteria of the current edition of the “Diagnostic and Statistical Manual of Mental Disorders” published by the American Psychiatric Association. <u>Serious physical disability</u> = Any physiological disorder or condition or anatomical loss affecting one or more body systems which has lasted, or with reasonable certainty is expected to last, for minimum period of 12 contiguous months, and which precludes the person with the disorder, condition or anatomical loss from unaided performance of at least one Major Life Activity as defined in this section. <u>Extraordinary condition</u> = A complex clinical condition, which resulted, or is expected to result, in extraordinary TRICARE/CHAMPUS costs or utilization, based on thresholds established by the Director, OCHAMPUS, or designee.	Available only for TRICARE-eligible family members of active duty service members. Network inadequate.

		<p>cumulative, that is, any respite care hours not used in one month will not be carried over or banked for use on another occasion.</p>	<p><u>Extraordinary physical or psychological condition</u> = A complex physical or psychological clinical condition of such severity which results in the beneficiary being homebound as defined in this section.</p> <p><u>Homebound</u> = A beneficiary's condition is such that there exists a normal inability to leave home and, consequently, leaving home would require considerable and taxing effort....Absences...for the purpose of attending an educational program...shall not negate the beneficiary's homebound status.</p> <p><u>Major Life Activity</u> = Breathing, cognition, hearing, seeing, and age appropriate ability essential to bathing, eating, grooming, speaking, stair use, toilet use, transferring, and walking.</p> <p><u>Respite care</u> = Respite care is short-term care for a patient in order to provide rest and change for those who have been caring for the patient at home, usually the patient's family.</p> <p>Government cost-share maximum monthly benefit of \$2,500.</p>	
	<p>Part 199.5 – TRICARE Extended Care Health Option (ECHO), Jul 28, 2004. (e)ECHO Home Health</p>	<p>(e)(2) EHHC beneficiaries whose plan of care includes frequent interventions by the primary caregiver(s) are eligible for respite care services in lieu of the ECHO general respite care benefit. For the purposes of</p>	<p>(e)(3) EHHC eligibility. Beneficiaries meet all ECHO eligibility requirements and who: (ii) are homebound; (iii) require medically necessary skilled services that exceed the level of coverage provided under the Basic Program's home health care benefit; (iv) or require frequent interventions by the primary care giver(s) such that respite care services are necessary to allow primary caregiver(s) the opportunity to rest, and are case managed to include reassessment at least every 90 days and receive services as</p>	

	<p>Care (EHHC).</p>	<p>this section, the term “frequent” means “more than two interventions during the eight-hour period per day that the primary caregiver would normally be sleeping.” The services provided...are those that can be performed ...by the average non-medical person...after has been trained by appropriate medical personnel. EHHC beneficiaries in this situation are eligible for a maximum of eight hours per day, 5 days per week, or respite care by a TRICARE-authorized home health agency.</p>	<p>outlined in a written plan of care; and (vi) receive all home healthcare services from a TRICARE-authorized home health agency as described in Sec 199.6(b)(4)(xv), in the beneficiary’s primary residence.</p> <p>(e)(4) EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided and support the professional level of the provider.</p>	
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Home Health Care

Home health care	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	<p>(e)(1) ECHO Home Health Care (EHHC). Home health care. Covered ECHO home health care services are the same as, and provided under the same conditions as those services described in Sec 199.4, except that they are not limited to part-time or intermittent services.</p> <p>(f)(3)(ii) ECHO home health care. The maximum annual Government cost-share for ECHO home health care, including EHHC respite care may not exceed the local wage-adjusted highest Medicare Resource Utilization Group (RUG-III) category cost for care in a TRICARE-authorized skilled nursing facility.</p>	Network inadequate.
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	Part 199.4 – Basic Program Benefits	<p>(e)(12)(ii)(B)One hour per day of nursing care may be authorized if patient is determined to be receiving custodial care.</p> <p>(e)(21)(1) Home health services. Home health services are covered when furnished by, or under arrangement with, a home health agency (HHA) that participates in the TRICARE program and provides care on a visiting basis in the beneficiary's home. Covered HHA services are the same as those provided under Medicare under section 1861(m) of the Social Security Act. ...Benefit coverage...part-time or intermittent skilled nursing care, physical therapy, speech-language pathology, and occupational therapy, medical social services, part-time or intermittent services of a home health</p>	<p>May be authorized when physician certifies need for home health services, services provided under a plan of care established and approved by a physician, plan of care contains all pertinent diagnoses,...type of services...Beneficiary must need skilled nursing care on an intermittent basis or physical or speech language pathology services, or have a continued need for occupational therapy after the need for skilled nursing care, physical therapy, or speech-language pathology services has ceased....Incorporates the current version of the Outcome and Assessment Information Set (OASIS).</p>	
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		<p>aide, medical supplies, a covered osteoporosis drug, and durable medical equipment, services at hospitals, SNFs or rehabilitation centers.</p>		
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Custodial Care

Custodial care	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	(e)(1)...Custodial care services, as defined in Sec. 199.2, may be provided to the extent such services are provided in conjunction with authorized ECHO home health care services, including the EHC respite care benefit.	Custodial care services may be provided only as specifically set out in ECHO.	
	Part 199.4 – Basic Program Benefits	(e)(12) Custodial care. The statute under which CHAMPUS operates specifically excludes custodial care....CHAMPUS benefits are not available for services related to a custodial care case, with the following specific exceptions: (A) Prescription drugs and medicines, medical supplies and durable medical equipment. (B) Nursing services, limited.		

		Recognizing that even though the care being received is determined primarily to be custodial, an occasional specific skills nursing service may be required. When it is determined such skilled nursing services are needed, benefits may be extended for one hour of nursing care per day.		
Home-maker			Home maker services available under Medicaid hospice and in Basic Program hospice.	

Skilled Nursing Facility

Skilled nursing facility	Part 199.4 – Basic Program	(b)(3)(xiv) Covered services in SNFs are the same as provided under Medicare...except that the Medicare limitation on the number of days of coverage...shall not be applicable under TRICARE. Skilled nursing facility care for each spell of illness shall continue to be provided for as long as necessary and appropriate. ...Extended care services...include...nursing care, bed and board, physical or occupational therapy and speech language pathology, medical social services, drugs, supplies, appliances, and equipment.		
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Prescription Drugs

Prescription drugs and medicines	Part 199.4 – Basic Program Benefits	(d)(vi) Prescription drugs and medicines that by U.S. law require a physician’s or other authorized individual professional providers ...in connection with an otherwise covered condition or treatment.		
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Dental Care and Oral Surgery

Dental care	Part 199.4 – Basic Program Benefits	<p>(e)(10)Dental care which is medically necessary in the treatment of an otherwise covered medical (not dental) condition, is an integral part of the treatment of such medical condition and is essential to the control of the primary medical condition. ...list of conditions...(1) Intraoral abscesses with extend beyond the dental alveolus. (2) Extraoral abscesses....(iv) covered oral surgery (A) Excision of tumors and cysts of jaws, cheeks, lips, tongue and roof and floor of mouth...(C) Treatment of facial or oral cancer.</p>		
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Counseling Services

Bereave- ment care			Excluded in hospice care through Basic Program. Available in Medicaid hospice program.	
Counseling for child	Part 199.4 – Basic Program	(c)(ix) Treatment of mental disorders....the patient must be diagnosed by a CHAMPUS-authorized ...mental health professional to be suffering from a mental disorder...in order for treatment of a mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.		
Counseling for family members before child's death	Part 199.4 – Basic Program	(ix) Treatment of mental disorders....the patient must be diagnosed by a CHAMPUS-authorized ...mental health professional to be suffering from a mental disorder...in order for treatment of a		

		<p>mental disorder to be medically or psychologically necessary, the patient must, as a result of a diagnosed mental disorder, be experiencing both physical or psychological distress and an impairment in his or her ability to function in appropriate occupational, education, or social roles.</p>		
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Care Management/Care Coordination Services

Care co-ordination	<p>Part 199.5 – Extended Care Health Option (e)(4)</p> <p>Part 199.4 – Basic Program (e)(19)</p> <p>Part 199.4 – Basic Program (b)(3)(ivx)</p>		<p>EHHC plan of care. A written plan of care is required prior to authorizing ECHO home health care. The plan must include the type, frequency, scope and duration of the care provided and support the professional level of the provider.</p> <p>Hospice Care requires a care plan.</p> <p>Hospitalization in skilled nursing facility requires a care plan.</p>	
Nursing case management				

Hospice

Hospice	Part 199.4 – Basic Program	<p>(e)(19) Hospice Care. Hospice care is a program which provides an integrated set of services and supplies designed to care for the terminally ill. This type of care emphasizes palliative care and supportive services, such as pain control and home care, rather than cure-oriented services provide in institutions that are otherwise the primary focus under CHAMPUS. The benefit provides coverage for a humane and sensible approach to care during the last days of life for some terminally ill patients. (i) Benefit coverage. CHAMPUS beneficiaries who are terminally ill (that is, a life expectancy of six months or less if the disease runs its normal course) will be eligible for the following services and supplies in</p>	<p>Part 199.6 Authorized providers. Hospice programs. Hospice programs must be Medicare approved and meet all Medicare conditions of participation (42 CFR part 418) in relation to CHAMPUS patients in order to receive payment under the CHAMPUS program....May be either a public agency or private organization which: (A) is primarily engaged in providing care and services described under Sec 199.4(e)(19) and makes such services available on a 24-hour basis. (B) Provides bereavement counseling for the immediate family or terminally ill individuals. (C) Provides for such care and services in individuals' homes, on an outpatient basis, and on a short term inpatient basis,(4) Have an interdisciplinary group composed of (i) physician; (ii) registered professional nurse; (iii) social worker; (iv) pastoral or other counselor. (5) Maintains central clinical records on all patients. (7) The hospice and all hospice employees must be licensed in accordance with applicable Federal, state and local laws and regulations.</p>	Must meet Medicaid definition of hospice care.
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		<p>lieu of most other CHAMPUS benefits: (A) Physician services. (B) Nursing care. (C) Medical social services ... (1) Assessment of social and emotional factors ... (2) Assessment of relationship between ... requirements and availability of community resources. (3) Appropriate action to obtain available community resources to assist in resolving the beneficiary's problem. (4) Counseling services that are required by the beneficiary. (D) Counseling services provided to the terminally ill individual and the family member or other persons caring for the individual at home... Bereavement counseling is not reimbursable. (E) Home health aide services ... and homemaker services.</p>		
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Additional Services

Child life services at home				
Massage therapy				
Music therapy				
Acu- puncture				

Equipment and Structural Alterations

Durable equipment and durable medical equipment	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004	<p>(g)(2) Equipment (i) The TRICARE allowable amount for durable equipment and durable medical equipment shall be calculated in the same manner as durable medical equipment allowable through Sec. 199.4. (ii) Allocating equipment expense. The ECHO beneficiary...may, only at the time of the request for authorization of equipment, specify how the allowable cost of the equipment is to be allocated as an ECHO benefit. The entire allowable cost...may be allocated in the month of purchase...or may be prorated.</p> <p>(c)(7)(ii) Equipment adaptation. The allowable equipment purchase shall include such services and modifications to the equipment as necessary to</p>	<p>Part 199.2 –Definitions. <u>Durable equipment.</u> A device or apparatus which does not qualify as durable medical equipment and which is essential to the efficient arrest or reduction of functional loss resulting from, or the disabling effects of a qualifying condition. <u>Durable medical equipment.</u> Equipment for which the allowable charge is over \$100 and which: (1) Is medically necessary for the treatment of a covered illness or injury; (2) Improves the function of a malformed, diseased, or injured body part, or retards further deterioration of a patient’s physical condition; (3) Is primarily and customarily designed and intended to serve a medical purpose rather than primarily for transportation, comfort or convenience; (5) Provides the medically appropriate level of performance and quality for the medical condition present.</p>	
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	Part 199.4 – Basic Program	<p>make the equipment usable for a particular ECHO beneficiary. (iii) Equipment maintenance. Reasonable repairs and maintenance of beneficiary owned or rented durable equipment or durable medical equipment provide by this section shall be allowed while a beneficiary is registered in ECHO.</p> <p>(d)(3)(ii) Durable medical equipment. Ordered by a physician for the specific use of the beneficiary, and which complies with the definition of Durable medical equipment in sec 199.2 and which is not otherwise excluded by this regulation qualifies as a Basic Program benefit.</p> <p>(iii) Medical supplies and dressings (consumables). Such items must be related directly to an appropriate and verified covered medical condition of the</p>		
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		beneficiary. (iv) Oxygen. Oxygen and equipment for its administration are covered.		
Structural alterations to dwelling	Part 199.5 – TRICARE Extended Care Health Option (ECHO) July 28, 2004 Part 199.4 – Basic Program Benefits	(d)(3) Structural alterations. Alterations to living space and permanent fixtures attached thereto, including alterations necessary to accommodate installation of equipment or to facilitate entrance or exit, are excluded. (g)(54) Excluded...Elevators or chair lifts.		

Transportation

Transportation by other than ambulance	Part 199.4 – Basic Program Benefits	(g)(67) Excluded ... All transportation except by ambulance ...except as authorized in paragraph (e)(5) of this section.	(d)(v)(B) Vehicles such as medicabs or ambicabs function primarily as public passenger conveyances transporting patients to and from their medical appointments. No actual medical care is provided to the patients in transit. These types of vehicles do not qualify for benefits for the purpose of CHAMPUS payment.	

MEDICAID HOSPICE PROGRAM

Eligibility – Eligible for Part A Medicaid, physician certifies terminally ill and probably less than 6 mos to live, sign agreement for hospice care foregoing disease directed care, use Medicaid approved hospice.

Services – physician, nursing care, medical equipment, medical supplies, drugs for pain and symptom control, short term stay in hospital (including respite care for 5 days at a time with no limit on the number of stays per year), home health aid, homemaker, physical and occupational therapy, speech therapy, social work, dietary counseling, grief counseling for patient and family.

Costs - \$5 per Rx, \$5 per hospital day

APPENDIX 10

Table 12
Summary of Benefits

Benefit	Beneficiary of Active Duty Service member Eligible for ECHO/EHHC	Beneficiary of Retired Service member <u>OR</u> Active Duty using Basic Program and Not Eligible for ECHO or in addition to ECHO
<i>Respite care</i>	16 hrs per month under ECHO 8 hr/day, 5 day/wk under EHHC (available only if receiving some form of ECHO/EHHC services)	Not covered.
<i>Home health care</i>	Not limited to part-time or intermittent. Cost may not exceed Medicare cost for care in a SNF. (Skilled nursing facility)	Part-time or intermittent, same as Medicare.
<i>Custodial care</i>	Provided as part of plan of care under home health care services.	Not covered.
<i>Homemaker</i>		Available when enrolled in Medicare-approved hospice.
<i>Skilled nursing facility</i>		Available in Medicare-approved facility, no limit on days, provided as long as medically necessary and appropriate.
<i>Prescription drugs</i>		Available through authorized physician signature.
<i>Dental care</i>		Care is covered when necessary to treat a medical condition such as treatment of oral cancer.
<i>Counseling services prior to patient's death</i>		Available for those diagnosed with a mental disorder, i.e., depression.
<i>Bereavement counseling for family after patient's death</i>		Available for those diagnosed with a mental disorder, i.e., depression.
<i>Care coordination/case management</i>	Care plans are required under ECHO and EHHC.	Care in a SNF or in a hospice requires a care plan.
<i>Hospice program</i>		Care authorized in a Medicare-approved hospice (limited to patients with a prognosis of death within six months and require the patient to forgo disease-directed or life-prolonging care).

<i>Expressive therapies (music, art, play)</i>	Not covered.	Not covered.
<i>Durable equipment</i>	Covered.	Not covered.
<i>Durable medical equipment</i>		Covered if ordered by a physician, specific to medical condition, and can only be used by patient.
<i>Structural alterations to dwelling</i>	Not covered.	Not covered.
<i>Transportation by other than an ambulance</i>	Mileage to and from therapy services reimbursed for those in ECHO.	Not covered.

APPENDIX 11

MHS Benefits and Services vs the Institute of Medicine Recommendations

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented

Recommendations	Availability in the MHS
<p>1. Pediatric professionals, children's hospitals, hospices, home health agencies, professional societies, family advocacy groups, government agencies, and others should work together to develop and implement clinical practice guidelines and institutional protocols and procedures for palliative, end-of-life, and bereavement care that meet the needs of children and families for:</p> <ul style="list-style-type: none"> - complete, timely, understandable information about diagnosis, prognosis, treatments (including their potential benefits and burdens), and palliative care options. - early and continuing discussion of goals and preferences for care that will be honored wherever care is provided. - effective and timely prevention, assessment, and treatment of physical and psychological symptoms and other distress, whatever the goals of care and wherever care is provided. - competent, fair, and compassionate clinical management of end-of-life decisions about such interventions as resuscitation and mechanical ventilation. 	<p>Services are only provided in areas where experienced staff are available and it is done without an explicit program/plan, is highly variable and inconsistent.</p>
<p>2. Children's hospitals, hospices, home health agencies, and other organizations that care for seriously ill or injured children should collaborate to assign specific responsibilities for implementing clinical and administrative protocols and procedures for palliative, end-of-life, and bereavement care. In addition to supporting competent clinical services, protocols should promote the coordination and continuity of care and the timely flow of information among caregivers and within and among care sites including hospitals, family homes, residential care facilities, and injury scenes.</p>	<p>Services are provided based on availability, training and experience of staff. Further limitations on bereavement care</p>
<p>3. Children's hospitals, hospices with established pediatric programs, and other institutions that care for children with</p>	<p>Services are provided based on</p>

<p>fatal or potentially fatal medical conditions should work with professional societies, state agencies, and other organizations to develop regional information programs and other resources to assist clinicians and families in local and outlying communities and rural areas. These resources should include the following:</p> <ul style="list-style-type: none"> - consultative services to advise a child's primary physician or local hospice staff on all aspects of care for the child and family from diagnosis through death and bereavement; - clinical, organizational, and other guides and information resources to help families to advocate for appropriate care for their children and themselves; and - professional education and other programs to support palliative, end-of-life, and bereavement care that is competent, continuous, and coordinated across settings, among providers, and over time (regardless of duration of illness). 	<p>availability, training, and experience of staff.</p>
<p>4. Children's hospitals, hospices, and other institutions that care for seriously ill or injured children should work with physicians, parents, child patients, psychologists, and other relevant experts to create policies and procedures for involving children in discussions and decisions about their medical condition and its treatment. These policies and procedures – and their application – should be sensitive to children's' intellectual and emotional maturity and preferences and to families' cultural backgrounds and values.</p>	<p>Services are provided based on availability, training, and experience of staff.</p>
<p>5. Children's hospitals and other hospitals that care for children who die should work with hospices and other relevant community organizations to develop and implement protocols and procedures for</p> <ul style="list-style-type: none"> - identifying and coordinating culturally sensitive bereavement services for parents, siblings, and other survivors, whether the child dies after a prolonged illness or after a sudden event; - defining bereavement support roles for hospital-based and out-of-hospital personnel, including emergency medical services, law enforcement officers, hospital pathologists, and staff in medical examiners' offices; and - responding to the bereavement needs and stresses of professionals, including emergency services and law enforcement personnel, who assist dying children and their families. 	<p>Services are provided based on availability, training, and experience of staff. Further limitations on bereavement care.</p>
<p>6. Public and private insurers should restructure hospice benefits for children to</p> <ul style="list-style-type: none"> - add hospice care to the services required by Congress in 	<p>The DoD third party payer (TRICARE CHAMPUS).</p>

<p>Medicaid and other public insurance programs for children and to the services covered for children under private health plans;</p> <ul style="list-style-type: none"> - eliminate eligibility restrictions related to life expectancy, substitute criteria based on a child's diagnosis and severity of illness, and drop rules requiring children forgo curative or life-prolonging care (possibly in a case management framework); and - include outlier payments for exceptionally costly hospice patients. 	<p>although not specifically referenced in this recommendation does not provide for an appropriate children's hospice program as recommended</p>
<p>7. In addition to modifying hospice benefits, Medicaid and private insurers should modify policies restricting benefits for other palliative services related to a child's life-threatening medical conditions. Such modifications should</p> <ul style="list-style-type: none"> - reimburse the time necessary for fully informing and counseling parents (whether or not the child is present) about their child's (1) diagnosis and prognosis, (2) options for care, including potential benefits and harms, and (3) plan of care, including end-of-life decisions and care for which the family is responsible; - make the expertise of palliative care experts and hospice personnel more widely available by covering palliative care consultations; - reimburse bereavement services for parents and surviving siblings of children who die; - specify coverage and eligibility criteria for palliative inpatient, home health, and professional services based on diagnosis (and, for certain services, severity of illness) to guide specialized case managers and others involved in administering the benefits; and - provide for the Centers for Medicare and Medicaid Services to develop estimates of the potential cost of implementing these modifications for Medicaid. 	<p>The DoD third party payer (TRICARE CHAMPUS), although not specifically referenced in this recommendation does not provide for an appropriate children's hospice program as recommended. Bereavement services are explicitly excluded as a coverable benefit.</p>
<p>8. Federal and state Medicaid agencies, pediatric organizations, and private insurers should cooperate to (1) define diagnosis and, as appropriate, severity criteria for eligibility for expanded benefits for palliative, hospice, and bereavement services; (2) examine the appropriateness for reimbursing pediatric palliative and end-of-life care of diagnostic, procedure, and other classification systems that were developed for reimbursement of adult services; and (3) develop guidance for practitioners and administrative staff about accurate, consistent coding and documenting of palliative, end-of-life, and bereavement services.</p>	<p>Not yet accomplished in the DoD.</p>
<p>9. Medical, nursing, and other health professions schools or programs should collaborate with professional societies to</p>	<p>The Uniformed Services University</p>

<p>improve the care provided to seriously ill and injured children by creating and testing curricula and experiences that</p> <ul style="list-style-type: none"> - prepare all health professionals who work with children and families to have relevant basic competence in palliative, end-of-life, and bereavement care; - prepare specialists, subspecialists, and others who routinely care for children with life-threatening conditions to have advanced competence in the technical and psychosocial aspects of palliative, end-of-life, and bereavement care in their respective fields; and - prepare a group of pediatric palliative care specialists to take lead responsibility for acting as clinical role models, educating other professionals, and conducting research that extends the knowledge base for palliative, end-of-life, and bereavement care. 	<p>is providing an introduction to end-of-life care for medical students. At some tertiary care institutions, groups of pediatric palliative care specialists are forming.</p>
<p>10. To provide instruction and experiences appropriate for all health care professionals who care for children, experts in general and specialty fields of pediatric health care and education should collaborate with experts in adult and pediatric palliative care and education to develop and implement</p> <ul style="list-style-type: none"> - model curricula that provide a basic foundation of knowledge about palliative, end-of-life, and bereavement care that is appropriate for undergraduate health professions education in areas including but not limited to medicine, nursing, social work, psychology, and pastoral care; - residency program requirements that provide more extensive preparations as appropriate for each category of pediatric specialists and subspecialists who care for children with life-threatening medical conditions; - pediatric palliative care fellowships and similar training opportunities; - introductory and advanced continuing education programs and requirements for both generalist and specialist pediatric professionals; and - practical, fundable strategies to evaluate selected techniques or tools for educating health professionals in palliative, end-of-life, and bereavement care. 	<p>Military pediatric residency programs provide the required training in end-of-life care. No military fellowships in pediatric palliative care.</p>



APPENDIX 12

CHILDREN'S HOSPICE INTERNATIONAL

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MEMORANDUM

Date: August 17, 2004

To: mCare Planning Team

From: Zohreh Saunders
Deborah Kurnik

Subject: "Services/Resources Proposed in Developing CHI PACC® Models" Chart

The attached comparison chart is one method of looking at the range of services that may be covered by Medicaid under a waiver or through the Medicaid State Plan benefit. However, the state-by-state comparison may be misleading for the following reasons:

1. **To date none of the CHI PACC states included in the list have received CMS approval to implement their Medicaid waiver program.** Florida did receive approval to offer a modified CHI PACC program to the SCHIP (State Child Health Insurance Program). They are currently serving about 6 children in this program.
2. The CHI PACC states were originally encouraged to develop Section 1115 proposals (research and demonstration models) that would enable them to restructure service delivery, add new services, and request waivers of other aspects of the Medicaid program for the target population in order to serve them more effectively. Florida and Utah submitted their proposals in 2001 and 2002, respectively, to the Centers for Medicare & Medicaid Services (CMS.) Dennis Smith, the Director of the Medicaid Section of CMS, recently suggested that **the states use another vehicle, such as a home and community-based waiver to obtain approval for the addition of services not currently available to the target population.** Florida and Utah are returning to the drawing board to determine how best to accomplish their goals for the CHI PACC program using another type of Medicaid waiver. Kentucky, Colorado, and New York are also reconsidering their options.
3. Although the chart reflects the information currently available from the CHI PACC states, **only Florida, Utah, and Kentucky have completed the design of their service package.** The services were designed to be included in their 1115 proposals. As they will have to use another type of proposal—most likely a home and community-based waiver or a freedom-of-choice waiver-- to obtain approval from CMS for the addition of new services, it is unlikely

the states will be able to use Medicaid dollars to fund bereavement services, since the service is directed toward the parents or other family members and not the child. Nevertheless, most of the other services in the original design will likely be covered under the new waiver proposals. Since bereavement services are an essential component of CHI PACC programs, the programs will look to other sources of funding for bereavement services.

4. The national CHI PACC program recommends that the following services should be available to the target population:

- I. An integrated coordinated continuum of care involving:
 - Home care
 - Outpatient care
 - Community-based care
 - Respite care
 - Social and supportive services
 - Acute care
 - End-of-life care
 - Bereavement follow up care
- II. An interdisciplinary team involving and coordinating the following services:
 - Pediatric palliative care physicians
 - Pediatric physician specialists
 - Nurses
 - Social Workers
 - Chaplains
 - Pediatric Therapist Specialists (Music, Art, Play, etc.)
 - Psychologists
 - Allied Therapists (PT, OT, Speech, Dietary, etc)
 - Home health aides, home makers
 - Volunteers
 - Laboratory
 - Medications and biologicals
 - Durable Medical Equipment
 - Medical Supplies
 - Communication supports (translators, telemedicine)
 - Complementary therapies (massage, acupuncture, guided imagery, etc.)
 - Anything else to sustain presence in the community
- III. Specific pediatric family support services including:
 - Day care
 - In-house/community-based respite care
 - Caregiver support
 - Family support (for traditional and non-traditional families, for long distance care giving needs)
 - Community services to prevent unnecessary institutionalization and enhance quality of life
 - Care for siblings
 - Coordination with schools
 - On-call system
- IV. Essential services accessible 24 hours a day, 7 days a week.

The comparison chart lists some, but not all of these services and methods of delivery.

Neither the chart nor the above list of comprehensive CHI PACC services differentiates between the services that are available through the state's regular Medicaid program or the child's health insurance benefit. Furthermore, the two lists do not differentiate service and place of service.

The Medicaid program is structured such that each state must offer/provide mandatory services to mandatory coverage groups. The state may also offer optional services to the mandatory coverage group, and persons in optional coverage groups. Through various waivers directed to a specified target group, the state may offer additional services. The federal government provides matching funds for the mandatory services and the optional services covered in the Medicaid approved State Plan and the waiver services as approved by the federal government.

Many of the services on the comparison chart are the additional services that would be offered to the CHI PACC target population through an approved waiver.

It is also important to know that children under 18 who are covered by Medicaid have a special dispensation through the EPSDT (Early Periodic Screening, Diagnosis, and Treatment services). The state must provide any medically necessary services that may be offered under Medicaid as an optional or mandatory service, even if the state does not specifically cover that service in its State Plan. It is left to the state to define what is medically necessary and the approval process for the service.

Thus **the comparison chart as labeled may not reflect all the services that a child with a life-threatening condition would be able to receive under the state's Medicaid program** (see page 4 of this memo). It might be better to list on the chart only the new services that will be added to the Medicaid program to meet the unique needs of the target population, which are primarily offered as an alternative to institutional-based care.

5. The labeling of services in the first column of the state-by-state comparison chart can be confusing because **similar services may be named or defined differently**. For instance, "Social Work/Counseling" may be intended to encompass family, caregiver, individual, group, and bereavement counseling or it may only mean counseling for some of those categories.

Medicaid Services

Mandatory Services (42CFR 440.10 to 440.50)

- Inpatient hospital Services (other than an institution for mental illness)
- Outpatient hospital services and rural health clinic services
- Laboratory and X-ray services
- Nursing facility services for individuals age 21 or older (other than an institution for mental illness)
- EPSDT (early and periodic screening and diagnosis and treatment)
- Family planning services and supplies
- Physician services and surgical services of a dentist

Optional Services (42CFR 440.60 to 440.170, 440.185)

- Medical care or other remedial care provided by licensed practitioners (chiropractors)
- Home health services (nursing, home health aide, medical supplies & equipment, PT, OT, speech, audiology, etc.)
- Medical rehabilitation facility
- Private duty nursing services
- Clinic services
- Dental services
- Physical therapy, occupational therapy, services for speech, hearing and language disorders)
- Prescribed drugs, dentures, prosthetic devices, and eyeglasses
- Diagnostic, screening, preventive and rehabilitative services
- Inpatient hospital and nursing facility services for individuals age 65 or over in an institution for mental disease
- Intermediate care facility services for the mentally retarded (ICF/MR)
- Nursing facility other than in institutions for mental diseases.
- Inpatient psychiatric services for individuals under age 21.
- Nurse midwife services
- Nurse practitioner services
- Personal care services
- Targeted Case Management
- Respiratory care for ventilator dependent individuals
- Any other medical care or remedial care recognized under state law and specified by the Secretary
 - Transportation and travel expenses (meals, lodging, attendant)
 - Services furnished in a religious non medical health care institution
 - Skilled nursing facility services for individuals under age 21
 - Emergency hospital services
 - Critical access hospital
 - Hospice

Home and Community-Based Waiver Services (1915c) (including but not limited to)

- Case management
- Home maker
- Home health aide
- Personal care
- Adult day health
- Habilitation
- Respite Care
- Day treatment
- Expanded habilitation

Freedom of Choice Waivers (1915b)

May offer all or some of the mandatory and optional services covered under the State Plan through a specified delivery system such as managed care or primary care physician program. The waiver allows a state to limit the client's choice of providers to those of the specified delivery system.

Services/Resources Proposed in Developing CHI PACC® Models

Service Type	Utah	Kentucky	Florida	Colorado	New York	mCare
State Medicaid Services	X	X	X	X	X	
Respite	X (includes family choice)	X	X		X	
Family/Caregiver Counseling	X	X	X			
Individual Counseling	X	X	X			
Group Counseling		X	X			
Bereavement Counseling	X	X	X	X	X	
Pain and Symptom control/Palliative Care	X	X	X	X		
Support Therapies	X (Expressive Therapies)		X		X (Creative Arts and Therapies)	
Hospice in Home Nursing	X		X			
Hospice in Home Personal Care			X			
Volunteer Support			X	X		
Collaborative Care Planning (Coordinator)	X	X	X	X	X	
Patient Medical Management		X				
Direct Nursing Services	X	X		X		
Transportation	X	X				
Pharmacy	X	X		X		
Plan of Care	X				X	
Family/Child Education					X	
Social Work/Counseling		X		X	X	
Spiritual Care		X		X	X	

(Chaplain Services)						
Advocacy for Child/Family Needs					X	
Standards of Care					X	
Provider Education	X	X	X	X	X	
Tricare Health Benefits						X
Dietary Support		X (Nutritional Support)		X		
Physical Therapy		X		X		
Speech Therapy		X				
Respiratory Therapy		X				
Occupational Therapy		X		X		
Medical Director				X		
Insurance Navigator	X					
Resource Coordinator		X				
Disposable Supplies	X	X				
Durable Equipment	X	X				
Food and Lodging Vouchers		X				

References

- Florida -** 1115 Waiver Request for PACC, Section F, p. 15.
CHI 3rd Technical Assistance Conference, Florida *Partners in Care* Model Outline, May 2004
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CHI 3rd Technical Assistance Conference, Promoting HOPE for Utah Children Abstract, May 2004
- Colorado -** CHI 3rd Technical Assistance Conference, Colorado PACC – The Butterfly Program description, May 2004
CHI Program Implementation Manual, 2nd ed., Chapter 12, p. 122-124.

APPENDIX 13

MHS Benefits and Services vs the CHI-PACC Core Domains of Clinical Care

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented

Core Domain of Clinical Care	Availability in the MHS
1. <i>Goals of care.</i> Consistent goals of care in all settings that reflect the values, hopes, religious beliefs, and needs of children/adolescents and their families.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
2. <i>Integration of Disease Management and Symptom Control.</i> An approach that brings the best evidence-based care for managing disease progress, and symptoms of disease and treatments to maintain quality-of-life needs of children/adolescents and families.	Available, but implementation highly dependent on interest, training, and caseload of health care providers. Disease management not available in hospice care.
3. <i>Advance Care Planning.</i> An ongoing process of identification and implementation wishes for care, treatments, and services that is understood by providers not as an “event” but as an on-going process that anticipates what may be next in terms of the progression of the illness and medical conditions of the child/adolescent.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
4. <i>Patient and family education.</i> Each child/adolescent at his/her developmental level and all members of the family, not just parents/legal guardians, have all the information they need and want about the disease, treatments, symptoms, services, and choices throughout the entire course of disease.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
5. <i>Comprehensive, coordination and continuity of care.</i> A functional, inter-related, inter-dependent system of care to support children/adolescents and families across the entire trajectory of the illness.	Available, but implementation highly dependent on interest, training, and caseload of health care providers. Very limited coordination across direct care system, purchased care, and community

	resources and for patients not enrolled to PRIME.
6. <i>Patient and Family Support.</i> Children/adolescents and the members of their families do not experience abandonment but have a consistent safety net of support from both providers and within their community.	Available, but implementation highly dependent on interest, training, and caseload of health care providers.
7. <i>End-of-life Care.</i> The ending of life is prepared for, goals of the child/adolescent and family are met for closure, and all family members have access to appropriate bereavement care.	Bereavement counseling specifically excluded as a TRICARE benefit, but may be available on a limited basis through the direct care system.

APPENDIX 14

MHS Benefits and Services for Children with Life-Threatening Conditions vs The National Quality Forum Domains of Care and Preferred Practices for Quality Palliative and Hospice Care¹

Service or Process is widely available.

Service or process is partially implemented.

Service or process is not available/not implemented.

Domain and Definition	Preferred Practice	MHS
<u>1.1 Structures of Care.</u> <i>To provide patients and their families care that addresses their multi-faceted needs, palliative and hospice programs should establish the organizational components that ensure that the provision of this complex care can be achieved. These structural elements provide the foundation that enables the program to achieve their aims.</i>		
	1. Provide palliative care by an interdisciplinary team of skilled palliative care professionals, including, for example, physicians, nurses, social workers, chaplains and others who collaborate with primary healthcare professional(s).	This team could be developed at any location that elected to do so. Components of these teams are available at a tertiary care centers, usually centered in the pediatric hematology/oncology service.
	2. Provide access to palliative and hospice care that is responsive to the patient and family 24 hours a day, seven days a week.	Available for selected pediatric oncology patients.
	3. Provide continuing education to both primary care practitioners as well as specialized palliative care professionals, on the domains of palliative care and hospice care.	Sites with pediatric residency programs and hematology/oncology fellowships are providing this training, although to a limited degree.
	4. Provide adequate training and clinical support to assure that professional staff is confident in its ability to provide palliative care for patients.	Varies widely with interest, training, and available time of staff.
	5. Hospice and specialized palliative care professionals should be appropriately trained, credentialed, and/or certified in their area of expertise.	Most healthcare providers for children with TC do not have specialized training in palliative care.

¹ www.nationalconsensusproject.org/guideline.pdf. Last accessed January 5, 2006.

<p><u>1.2 General Processes of Care.</u> <i>Providing high-quality palliative and hospice family-centered care requires the institution of formal processes that often transcend the requirements of routine medical practice. Implementing such processes permits proactive management of the symptom and end-of-life needs of patients cared for by these programs.</i></p>		
	6. Formulate, utilize and regularly review a care plan based on a comprehensive interdisciplinary assessment of the values, preferences, goals and needs of the patient and family.	Varies widely with interest, training, and available time of staff.
	7. Healthcare professionals should present hospice as an option to all patients and families when death within a year would not be surprising, and reintroduce option as patient declines.	Varies widely with interest, training, and available time of staff.
	8. Enable patients to make informed decisions about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.	Routinely provided by pediatric hematology/oncology service.
	9. Provide education and support to families and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.	Varies widely with interest, training, and available time of staff.
<p><u>2. Physical Aspects of Care.</u> <i>The amelioration of physical symptoms such as pain, fatigue, nausea and vomiting is an essential component of the improvement of quality of life for palliative care and hospice patients.</i></p>		
	10. Measure and document pain, dyspnea, and other symptoms using available standardized scales.	Pain routinely assessed.
	11. Assess and manage symptoms and side effects in a timely, safe, and effective manner to a level acceptable to the patient and family.	Goal of pediatric hematology/oncology services. Varies with interest, training and available time of staff.
<p><u>3. Psychological and Psychiatric Aspects of Care.</u> <i>The presence of physical symptoms or entry into the end-of-life phase of an illness engenders a variety of emotional responses that must be dealt with if quality of life is to be preserved. This care ranges from emotional support appropriate to all patients to specific management of psychological disorder.</i></p>		
	12. Measure and document anxiety, depression, delirium, behavioral disturbances, and other common psychological symptoms using available standardized scales.	Varies widely with interest, training, and available time of staff.
	13. Manage anxiety, depression, delirium, behavioral disturbances, and other common psychological	Varies widely with interest, training, and available time of staff.

	symptoms in a timely, safe, and effective manner to a level acceptable to the patient and family.	
	14. Assess and manage psychological reactions of patients and families to address emotional and functional impairment and loss (including stress, anticipatory grief and coping), in a regular ongoing fashion.	Varies widely with interest, training, and available time of staff.
	15. Develop and offer a grief and bereavement care plan to provide services to patients and families prior to and for at least 13 months after death of the patient.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit.
<p><u>4. Social Aspects of Care.</u> <i>The impact of disabling symptoms and entry into the terminal phase of an illness has important ramifications on all aspects of family life, ranging from childcare to work conditions to financial coping. The palliative care team and hospice must be able to assess these problems and either provide resources or make the appropriate referrals to alleviate these burdens.</i></p>		
	16. Conduct regular patient and family care conferences with physicians and other appropriate members of the interdisciplinary team to provide information, discuss goals of care and advanced care planning, and offer support.	Varies widely with interest, training, and available time of staff.
	17. Develop and implement a comprehensive social care plan which addresses the social, practical and legal needs of the patient and caregivers, including but not limited to: relationships, communication, existing social and cultural networks, decision-making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, access to medicines and equipment.	Varies widely with interest, training, and available time of staff.
<p><u>5. Spiritual, Religious, and Existential Aspects of Care.</u> <i>Under the stressful conditions of the palliative care setting, the patient's and family's concerns about religious and spiritual matters could become of paramount importance. Programs must be able to assess these needs and provide appropriate resources to meet them.</i></p>		
	18. Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate into the palliative care plan.	Varies widely with interest, training, and available time of staff.
	19. Provide information about the	A hospital chaplain is available at all military

	availability of pastoral/spiritual care services and make pastoral/spiritual care available either through organizational pastoral counseling or through the patient's own clergy relationships.	hospitals.
	20. Specialized palliative and hospice care teams should include pastoral care professionals appropriately trained and credentialed in palliative care.	A hospital chaplain is available at all military hospitals.
	21. Specialized palliative and hospice pastoral care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care.	Varies widely with interest, training, and available time of staff.
<u>6. Cultural Aspects of Care.</u> <i>Patient and family reactions to symptoms and entry into the last stages of life are conditioned in part by their cultural beliefs and values. Palliative care and hospice programs must be able to recognize these diverse approaches and tailor their interventions to accommodate them.</i>		
	22. Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to: locus of decision-making, truth telling and decision-making, dietary preferences, language, family communication, perspectives on death, suffering and grieving and funeral/burial rituals.	Varies widely with interest, training, and available time of staff.
	23. Provide professional interpreter services and materials in the patient's and family's preferred language.	Available for most non-English speaking families served by the MHS
<u>7. Care of the Imminently Dying Patient.</u> <i>When a patient's death becomes imminent, a host of unique needs – both patient-centered and family-centered – must be addressed. These unique needs require unique programmatic components to help the patient achieve a "good death."</i>		
	24. Recognize and document the transition to the active dying phase and communicate to the patient, family, and staff the expectation of imminent death.	Varies widely with interest, training, and available time of staff.
	25. The family is educated regarding signs and symptoms of imminent death in a developmentally, age and culturally-appropriate manner.	Varies widely with interest, training, and available time of staff.
	26. Ascertain and document patient and family wishes about the care setting for site of death, and fulfill	Varies widely with interest, training, and available time of staff.

	patient and family preferences when possible.	
	27. Provide adequate dosage of analgesics and sedatives as appropriate to achieve patient comfort during the active dying phase and address concerns such as fear of analgesics hastening death.	Varies widely with interest, training, and available time of staff.
	28. Treat the body post-death with respect according to the cultural and religious practices of the family.	Routinely provided by nursing services.
	29. Facilitate effective grieving by implementing in a timely manner a bereavement care plan after the patient's death when the family becomes the focus of care.	Bereavement counseling purchased through TRICARE is specifically excluded as a benefit.
<i>8. Ethical and Legal Aspects of Care. To ensure that all patient and family rights are protected and preserved, systematic processes and procedures must be implemented and disseminated.</i>		
	30. Document the designated surrogate/decision-maker in a state-specific legal document for every patient in primary, acute, and long-term care and in palliative and hospice care.	Routinely provided at MTFs for adults, not discussed with child.
	31. Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.	Varies widely with interest, training, and available time of staff.
	32. Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, such as the Physicians Orders for Life-Sustaining Treatments – POLST Paradigm Program.	Varies widely with interest, training, and available time of staff.
	33. Make advance directives and surrogacy designations available across care settings, e.g., by internet-based registries or electronic personal health records.	Potentially available in electronic personal health record.
	34. Develop healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate	Varies widely with interest, training, and available time of staff.

	Care.	
	35. Establish or have access to ethics committees or ethics consultation across care settings to address ethical conflicts at the end-of-life.	Available at tertiary care centers.
	36. For minors with decision-making capability, document the child's views and preferences for medical care, including assent for treatment, and give appropriate weight in decision-making. Make appropriate professional staff members available when the child's wishes differ from those of the adult decision-maker.	Varies widely with interest, training, and available time of staff.

APPENDIX 15

Comparison of ICD-9 Diagnostic Codes Used to Identify Children with Life-Threatening or Life-Limiting or Complex Chronic Conditions By Five CHI PACC Programs and Chris Feudtner (July 6, 2004)

ICD-9 Category	ICD-9 Description	ICD-9 Diagnosis Codes					
		Feudtner	Utah	New York	Kentucky	Virginia	Florida
Infectious	Human Immunodeficiency virus (HIV) disease	042	042		042	042	x
Neoplasms	Neoplasms/malignancy	140.0-239.9		140.0-239.9			x
Malignancy	Malignant neoplasm of digestive organs & peritoneum				150.0-150.9		
	Malignant neoplasm of colon					153.9	
	Malignant neoplasm of liver and intrahepatic bile ducts		155.0 -155.2			155.0	
	Malignant neoplasm of pancreas		157.0 -157.9				
	Malignant neoplasm of retroperitoneum and peritoneum		158.0 - 158.8				
	Malignant neoplasm other & ill defined sites in digestive orgs.		159.0 - 159.9				
	Malignant neoplasm of trachea, bronchus, and lung		162.0-162.9			162.9	
	Malignant neoplasm of thymus, heart and mediastinum		164.0 -164.9				
	Malignant neoplasm of other & ill defined sites in respiratory...		165.0 -165.9				
	Malignant neoplasm of bone and articular cartilage		170.0 - 170.9		170.0-176.9	170.9	
	Malignant neoplasm of connective and other soft tissue		171.0 - 171.9			171.9	
	Malignant neoplasm of testis		186.0 -186.9				
	Malignant neoplasm of kidney & other unspecified urinary organs		189.0 - 189.9			189.0	
	Malignant neoplasm of eye		190.0 - 190.9		190.0-199.1		
						191.0; 191.6;	
	Malignant neoplasm of brain		191.0 - 191.9			191.7; 191.9	
	Malignant neoplasm other & unspecified parts of nervous sy..		192.0 - 192.9			192.0; 192.1	
	Malignant neoplasm of thyroid gland		193				
	Malignant neoplasm other endocrine glands & related struct.		194.0 - 194.9			194.0; 194.4	
	Malignant neoplasm of other ill-defined sites		195.0 -195.8				
	Malignant neoplasm without specification of site		199.0 - 199.1			199.1 201.9; 202.8; 204.0; 205.0; 205.1;	
	Malignant neoplasm of lymphatic & hematopoietic tissue		200.0 - 208.9		200.0-208.9	208.0; 208.9	
	Hemangioma and lymphangioma, any site					228.0	

	Neoplasms of brain and spinal cord	237.5			237.0; 237.7; 238.0	
	Neoplasms of unspecified nature				239.6; 239.7	
Endocrine Metabolic	Diabetes melitus			250.0-250.93	250.0; 250.1	
	Dwarfism/bone & joint anomalies	259.4			259.4	
	Amino acid metabolism	270-270.9			270.6; 270.7	x
	Carbohydrate metabolism	271.0-271.9			271.0	x
	Lipid metabolism	272.0-272.9	272.0-272.9		272.7	x
	Lipidoses		272.7			x
	Disorders of mineral metabolism	275.0-275.3	-			x
Endocrine Metabolic (continued)	Cystic fibrosis	277.0			277.0	x
	Other metabolic disorders	277.2-277.6			277.5	x
					277.6; 277.8 - 277.9	
	Mucopolysaccharidosis., etc.	277.8-277.9	277.5 - 277.9	277.0-277.9		x
	Hereditary immunodeficiency	279.0-279.9				
	Deficiency of cell-mediated immunity		279.1 - 279.19		279.1; 279.2	
	Combined immunity deficiency		279.2			
	Unspecified immunity deficiency		279.3		279.3	
Blood Hematology & Immuno- deficiency	Hereditary anemias	282.0-282.4			282.3; 282.6	x
	Sickle-cell anemia	282.5-282.6	282.60-282.69			x
	Aplastic anemia		284.0 - 284.9		284.9 286.0; 286.6; 286.9	
	Coagulation defects		286.0 -286.3			
	Hereditary immunodeficiency (diseases of white blood cells)	288.1-288.2				x
Nervous Neuromuscular	Mental retardation	318.0-319.0				
	Central nervous system degeneration & disease	330.0-337.9		330.0-337.9	331.0-331.9	330.0; 330.1; 330.8; 331.4; 331.8
						x
	Other cerebral degenerations		330.1			
	Anterior horn cell disease		335.0 - 335.9	335.0-335.9	335.0; 335.1	
	Infantile cerebral palsy - Quadriplegic	343.0-343.9	343.2	343.2		x
	Infantile cerebral palsy - unspecified		343.9	343.9	343.9	x
	Epilepsy	345.0-345.9				x

	Other unspecified conditions of nervous system		348.2 - 348.4		348.0-348.9	348.1; 348.3 - 348.5; 348.8; 348.9; 349.8	
	Muscular dystrophies & brain myopathies —	359.0-359.3	359.0-359.1			359.0 - 359.2	x
Circulatory Cardiovascular	Unspecified hypertensive heart disease				402.9		
	Acute myocarestial infarction				410		
	Cornary atherosclerosis				414.0		
	Chronic ischemic heart disease, NOS				414.9		
	Chronic pulmonary hypertension					416.0	
	Chronic pulmonary heart disease					416.9	
						425.3;	
	Cardiomyopathy	425.0-425.4	425.0 - 425.4		425.0-425.9	425.4; 425.9	x
						426.0;	
	Conduction disorders	426.0-427.4				426.8; 427.4	x
	Dysrhythmias	427.6-427.9			427.5-427.9	427.9	
Circulatory Cardiovascular (continued)	Congestive heart disease				428.0		
						429.0;	
	Myocarditis, unspecified	429.1	429.0 - 429.9		429.0-429.9	429.1; 429.3; 429.9	
	Intracerebral Hemorrhage					431	
	Cerebvrovascular (acute)				436		
	Unspecified cardiovascular disease/lesion				437.9		
	General and unspecified arteriosclerosis				440.9		
	Acute febrile mucocutaneous lymph node syndrome	446.1					
Respiratory	Asthma				493.0-493.9		
	Chronic airway obstruction, not elsewhere classified				496		
	Chronic respiratory failure						518.8
	Other diseases of the respiratory system					519.1	
Digestive	Diaphragmatic hernia	553.3				553.3	
	Inflammatory bowel disease	555.0-556.9					x
	Chronic liver disease and cirrhosis	571.4-571.9	571.4 - 571.9				x
Genitourinary	Acute renal failure					571.5; 571.8	
	Chronic renal failure	585	585			585	
	Renal failure unspecified		586		586	586	

	Curvature of spine	740.0-742.9	740.0 - 740.2	740.0-742.9	740.0-740.2	373.3 740.0; 740.2; 741.0; 741.9; 742.0 - 742.4; 742.8; 742.9	
	Brain& spinal cord malformations						
	Anencephalus						
	Spina bifida		741.0 - 741.9				
	Other congenital anomalies of nervous system				742.0-742.9		
	Heart & great vessel malformations	745.0-747.4		745.0-747.4		745.1; 745.2 745.3; 745.5; 745.6	x
Congenital	Bulbus cordis anomalies & cardiac septal closure		745.0-745.3		745.0-745.9	746.1 - 746.4	
	Other congenital anomalies of the heart						
	Hypoplastic left heart syndrome		746.7		746.0-746.9	746.7-746.9	
	Other specified anomalies of the heart		746.85-746.86 747.41			747.0 - 747.4; 747.6; 747.7	
	Other congenital anomalies of the circulatory system				747.0-747.8		x
		748.0-748.9		748.0-748.9		748.3; 748.5; 748.6	x
	Respiratory malformations				748.0-748.9		x
	Other congenital anomalies respiratory sys.-		748.3-748.5				x
	Congenital anomalies - gastrointestinal	750.3					x
	Other congenital anomalies digestive sys.-	751.1-751.3	751.1-751.2		751.0-751.9	751.3	x
	Congenital anomalies - gastrointestinal	751.6-751.9				751.6	x
	Congenital anomalies -renal	753.0-753.9					x
	Congenital anomalies of urinary system—		753.0-753.1		753.0-753.9	753.1; 753.9	x
	Congenital musculoskeletal	756.0-756.5			756.1-756.9	756.0; 756.1; 756.5 - 756.8	x
	Osteogenesis imperfecta		756.51				x
	Anomalies of diaphragm	756.6	756.6				x
Congenital	Anomalies of abdominal wall	756.7	756.7- 756.71				x
(continued)	Down's syndrome / chromosomal anomalies	758.0-758.9	758	758.0-758.9	758.0-758.9		x
	Patau's syndrome		758.1			758.1 758.2; 753.3; 758.5; 758.9	
	Edward's syndrome [and other chromosomal abnormalities]		758.2				
	Multiple congenital anomalies,	759.7	759.7	759.7-759.9	759.7	759.7	x
	Other specified anomalies				759.81- 759.89	759.8	x
	Fragile X Syndrome		759.83				
	Congenital anomaly, unspecified	759.9	759.9			759.9	x
Perinatal	Other maternal specified conditions affecting fetus/newborn				760.0-760.8		

	Fetus/newborn affected by maternal complications of pregnancy			761.0-761.9		
	Extreme immaturity	765		765.0-765.9	765.0	
	Other preterm infants	765.1		765.10-765.19	765.1	
	Birth asphyxiation			768.5-768.9		
	Respiratory distress syndrome in newborn			769	769	
	Chronic respiratory disease arising in perinatal period	770.7	770.7	770.0-770.9	770.7	x
	Other infections specific to the perinatal period			771.8		
	NEC and intestinal perforation			777.5-777.6		
Injury & Poisoning	Asphyxiation & strangulation			994.7		
	Child maltreatment syndrome			995.50-995.59		
	Shaken infant syndrome			995.55		
	Complications of transplanted bone marrow			996.85		
External Injury	Accidental drowning or submersion			E910		

Codes in bold for Utah and Florida indicate that in addition to diagnosis, other factors such as hospitalization or utilization of other services, co-morbidity, etc. are required to identify the child as having a life-threatening condition.

Sources: FEUDTNER, Chris, et.al, "Deaths Attributed to Pediatric Complex Chronic Conditions: National Trends and Implications for Supportive Care Services. *Pediatrics*, Vol.107 No 6, June 2001, p107.

UTAH - "State of Utah Application for a Section 1115 Research and Demonstration Program Promoting HOPE for Utah Children, A CHI PACC Project," February 12, 2003

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KENTUCKY - "PACC Diagnosis Codes for Potential Program Candidates," PACC Diagnosis Severity Index January 2004.

FLORIDA - Partners in Care -Agency for Health Care Administration, Florida Department of Health, Florida Hospice and Palliative Care, Inc., "An 1115 Waiver Request, Program for All-Inclusive Care for Children, Florida," October 24, 2002.

VIRGINIA - From "ICD-9 Diagnoses that Will Define the VAPACC Target Population." From a list of child deaths in Virginia between 1992-1998 in order of frequency, this chart includes only those diagnoses with at least 2 deaths occurring during the 6-year period.

APPENDIX 16

Estimating the Size of the Population of Children Served by the U.S. Military Life-Threatening Conditions					
Who Might Benefit from CHI PACC Services					
August 10, 2004 - Prepared by Zohreh Saunders for Children's Hospice International					
	Source	United States	Percentage	Military Health System	Tri-Care Prime
Demographics					
Total U.S. population	US 2000 Census	281,421,906			
U.S. Population 0-18	US 2000 Census	72,325,430		2,000,000	1,200,000
U.S. Population 0-6	US 2000 Census	19,136,690	0.068		
Percent of U.S. population in metro areas	2001 Kaiser Health Facts	227,951,744	0.810		
Percent of population in non-metro areas	2001 Kaiser Health Facts	53,470,162	0.190		
Persons per household	US 2000 Census	2.59			
Households with children	Kids Count??	38,022,155			
Median household income	USA Quick Facts (1999)	\$41,994			
U.S. population below poverty	USA Quick Facts (1999)	34,896,316	0.124		
Children below poverty (\$14,600 per 3 person household in 2001)	2001 Kaiser Health Facts	15,043,689	0.208		
U.S. population non-white	US 2000 Census	70,074,055	0.249		
Children without health insurance	2001 Kaiser Health Facts	9,237,000	0.120		
Total U.S. population enrolled in Medicaid (monthly)	Kaiser Health Facts (2002)	39,604,366	0.141		
Medicaid population enrolled in managed care	Kaiser Health Facts (1998)	22,732,906	0.574		
Unduplicated children enrolled in Medicaid	2000 CMS-416 EPSDT	16,915,680	0.234		
SCHIP Enrollment	2001 CMS/HHS	4,601,098	0.064		
Deaths					
Children 0-19 who die annually	(1999) IOM p.49	54,559	0.00075	1,509	905
Children under age 1 who die annually	Kaiser Health Facts 2001	27,568	0.00038	762	457
Estimated number of children who die annually of complex chronic conditions	Feudtner 2000	15,000	0.00021	415	249
Estimated number of children who die annually of designated life-threatening diagnosis	extrapolated from Utah Vital Statistics 1990-1999	18,204	0.00025	503	302
Chronic Conditions					
Estimated number of children (0-17) with severe chronic illness who would benefit from palliative	NACHRI	1,374,183	0.01900	38,000	22,800
Estimated number of children with a severe chronic condition	1989 GAO report	1,000,000	0.01383	27,653	16,592
Estimated number of children with a designated ICD-9 code indicating a life-threatening condition	Extrapolated from Utah Medicaid FFS claims data	1,223,746	0.01692	33,840	20,304

Prevalence of selected serious conditions among Utah children	<i>Extrapolated from national/Utah prevalence rates (C. Norlin, Utah)</i>	1,114,300	0.01541	30,814	18,488
CSHCN Conditions among TriCare 0-18 enrollees	<i>Williams, Pediatrics 2004</i>	16,634,849	0.23000	460,000	276,000
CSHSN With Functional Limitation 0-18	<i>Williams, Pediatrics 2004</i>	3,941,736	0.05450	109,000	65,400
Life-Threatening/Life Limiting Conditions					
Estimated number of children with chronic life-limiting conditions	<i>ChiPPs paper, March 2001</i>	446,000	0.00617	12,333	7,400
Annual hospital discharge cases for children with a designated life-threatening diagnosis	<i>Extrapolated from Utah hospital discharge data</i>	218,200	0.00302	6,034	3,620
Children who live with chronic life-limiting conditions	<i>UK estimates 10:10,000</i>	72,235	0.00100	1,997	1,198
Children not expected to survive childhood because of a life-threatening condition	<i>Extrapolated from survey of Utah pediatric specialists</i>	60,266	0.00083	1,667	1,000
Children not expected to survive childhood because of a life-threatening condition as defined	<i>Extrapolated from Utah Medicaid claims and Utah</i>	75,869	0.00105	2,098	1,259
		139,081	0.00192	3,846	2,308
Life-Threatening Conditions - Dally Census					
Estimated number of children who would benefit from palliative care	<i>ChiPPs paper, March 2001</i>	6,000	0.00008	166	100
		8,000	0.00011	221	133
Estimated number of children within 6 months of death with complex chronic conditions.	<i>Feudtner, et. Al</i>	5000	0.00007	138	83

Estimating the Size of the Population of Children in Massachusetts with Life-Threatening Conditions								
Who Might Benefit from CHI PACC Program Services								
March 11, 2004 - Prepared by Zohreh Saunders for Children's Hospice International								
<i>Numbers in italic are derived or extrapolated from U.S. data estimates. Extrapolations for Massachusetts are based on US 2000 census data that MA has 2.1% of U.S. child population. Extrapolations for MA Medicaid based on assumption that in 2000, 29.7% of MA children were on Medicaid.</i>								
	Source	United States	Massachusetts	Massachusetts Medicaid				
Demographics								
Total population	<i>US 2000 Census</i>	281,421,908	6,349,097	963,251				
Population of children 0-5	<i>US 2000 Census</i>	19,136,690	31,745	163,672				
Population of children 0-18	<i>US 2000 Census</i>	72,325,430	1,498,387	445,049				
Percent of total population under 18 years	<i>US 2000 Census</i>	25.7%	23.6%	46.2%				
Percent of child population under 5 years	<i>US 2000 Census</i>	6.8%	0.5%	17.0%				
Percent of US population 0-18 child	<i>derived US 2000 Census</i>	100%	2.1%	n/a				
Percent of population in metro areas	<i>2001 Kaiser Health Facts</i>	81.0%	95%	?				
Percent of population in non-metro areas	<i>2001 Kaiser Health Facts</i>	19.0%	0.5%	?				
Persons per household	<i>US 2000 Census</i>	2.59	2.51	?				
Households with children	<i>Kids Count??</i>	38,022,155	804,940	?				
Median household income	<i>USA Quick Facts (1999)</i>	\$41,994	\$50,502	n/a				
Percent of population below poverty	<i>USA Quick Facts (1999)</i>	12.4%	9.3%	n/a				
Percent of children below poverty (\$14,600 per 3 person household in 2001)	<i>2001 Kaiser Health Facts</i>	20.8%	16%	n/a				
Percent population non-white	<i>US 2000 Census</i>	24.9%	15.5%					
Number of children without health insurance	<i>2001 Kaiser Health Facts</i>	9,237,000	87,940	n/a				
Percent of children without health insurance	<i>2001 Kaiser Health Facts</i>	12.0%	5.9%	n/a				
Population enrolled in Medicaid (monthly)	<i>Kaiser Health Facts (2002)</i>	39,604,366		963,251				
Percent of total population enrolled in Medicaid (monthly)	<i>derived from Kaiser Health Fa</i>	14.1%	15.2%	n/a				
Percent of Medicaid population enrolled in managed care	<i>Kaiser Health Facts (1998)</i>	57.4%		63.8%				
State & federal Medicaid spending per enrollee	<i>Kaiser Health Fact (1998)</i>	\$3,822	\$5,352	\$5,352				
Total state and federal spending for Medicaid	<i>Kaiser Health Fact (2002)</i>	\$248.7 Billion	\$7.9 Billion	\$7.9 Billion				
Federal Matching Rate (FMAP) for services	<i>Kaiser Health Fact (2002)</i>		53%	53%				
Percent of total 0-18 population enrolled in Medicaid	<i>derived from 416 EPSDT</i>	23.0%	29.7%	29.7%				
Unduplicated children enrolled in Medicaid	<i>2000 CMS-416 EPSDT</i>	16,915,680	445,049	445,049				
Percent of children enrolled in SCHIP	<i>derived from 2001 CMS/HHS</i>	6.4%	7.0%					
SCHIP Enrollment	<i>2001 CMS/HHS</i>	4,601,098	105,072					
Deaths								
Children 0-19 who die annually	<i>(1999) IOM p.49</i>	54,559	1,146	340				
Children under age 1 who die annually	<i>Kaiser Health Facts 2001</i>	27,568	405	120				
Estimated number of children who die annually of complex chronic conditions	<i>Feudtner 2000</i>	15,000	315	94				
Estimated number of children who die annually of designated life-threatening diagnosis	<i>extrapolated from Utah Vital Statistics 1990-1999</i>	18,204	382	114				
Chronic Conditions								
Estimated number of children (0-17) with severe chronic illness who would benefit from palliative	<i>NACHRI</i>	1,374,183	28,858	8,571				

	Source	United States	Massachusetts	Massachusetts Medicaid			
Estimated number of children with a severe chronic condition	1989 GAO report	1,000,000	21,000	6,237			
Estimated number of children with a designated ICD-9 code indicating a life-threatening condition	Extrapolated from Utah Medicaid FFS claims data	1,223,746	25,699	7,633			
Prevalence of selected serious conditions among Utah children	Extrapolated from national/Utah prevalence rates (C. Norlin, Utah)	1,114,300	23,400	6,950		139081	75869
Life-Threatening/Life Limiting Conditions						0,021	0,021
Estimated number of children with chronic life-limiting conditions	ChiPPs paper, March 2001	446,000	9,366	2,782		2920.701	1593.249
Annual hospital discharge cases for children with a designated life-threatening diagnosis	Extrapolated from Utah hospital discharge data	218,200	4,582	1,361		0.297	0.297
Children who live with chronic life-limiting conditions	UK estimates 10:10,000	72,235	1,517	451		867.4482	473.195
Children not expected to survive childhood because of a life-threatening condition	Extrapolated from survey of Utah pediatric specialists	60,266	1,266	376			
Children not expected to survive childhood because of a life-threatening condition as defined in the Utah Algorithm including technology dependent	Extrapolated from Utah Medicaid claims and Utah Algorithm	139,081 to 75,869	2,921-1,593	867-473			
Life-Threatening Conditions - Dally Census							
Estimated number of children who would benefit from palliative care	ChiPPs paper, March 2001	6000-6000	126-168	37 to 50			
Estimated number of children within 6 months of death with complex chronic conditions.	Feudtner, et. Al	5000	105	31			

APPENDIX 17

Data Gathering Recommendations for the DOD mCare Project

Children's Hospice International – Z. Saunders

July 15, 2004

In conducting a feasibility study to determine how best the CHI PACC model of care can be implemented for the children and family of military members, it is important to (1) identify the potential target group, (2) estimate its numbers, and (3) estimate how this group has historically used the available medical and support services. Lastly, it will be important to know (4) the average monthly cost of these services to Walter Reed Hospital, Tri-Care, and the families themselves. (Items 3 and 4 will be addressed at a later time).

Identifying the Potential Target Population

The CHI PACC model is intended to serve children with life-threatening conditions and their families from diagnosis to bereavement, if cure is not attained. There are currently no universal definitions of children with life-threatening conditions. A number of the CHI PACC grantee programs have attempted to define the group in a broad way for admission criteria, and through more specific diagnostic criteria to compile historical costs and characteristics of a proxy population.

State/Region	Eligibility Criteria
Colorado	Under development
Florida	Children with life-threatening conditions in the Children's Medical Services Network (CMSN) referred to the program by primary care physician
Kentucky	Medicaid-eligible children certified by a physician to have a diagnosis of a life-threatening illness/condition
New York	Children eligible for 1915 (c) home and community-based services waiver (Long Term Home Health Program waiver)
Utah	Determination by treating physician that the child has a medical condition so serious it is likely the child will not live beyond age 18. <i>Child who might benefit may have a diagnosis</i> <ul style="list-style-type: none">- <i>for which a cure is possible, but not certain (e.g. Cancer);</i>- <i>for which there is no known cure, but treatment may increase life-expectancy and quality (e.g. cystic fibrosis, muscular dystrophy, HIV);</i>- <i>for which treatment is palliative from the beginning (e.g. neurodegenerative disorders, Batten's Tay-Sachs);</i>- <i>which is not progressive but may cause life-limiting complications (e.g. severe cerebral palsy, brain trauma or damage).</i>
Virginia	Under development
New England	Under development

The 2003 Institute of Medicine report, *When Children Die*, defines life-threatening conditions as those that "(1) carry a substantial probability of death in childhood, although treatment may succeed in curing the condition or substantially prolonging life,

and (2) are perceived as potentially having a fatal outcome.”¹ (IOM p. 37). Some use the term life-limiting which can connote that there may be limitations on the quality of life and daily living, but not necessarily premature death. There are also terms such as life-shortening or fatal medical conditions which may seem clear to clinicians, but not parents.

Himmelstein² identifies “conditions appropriate for pediatric palliative care” as follows:

Conditions for which curative treatment is possible but may fail

Advanced or progressive cancer or cancer with a poor prognosis

Complex and severe congenital or acquired heart disease

Conditions requiring intensive long-term treatment aimed at maintaining the quality of life

Human immunodeficiency virus infection

Cystic fibrosis

Severe gastrointestinal disorders or malformations such as gastrochisis

Severe epidermolysis bullosa

Severe immunodeficiencies

Renal failure in which dialysis, transplantation, or both are not available or indicated

Chronic or severe respiratory failure

Muscular dystrophy

Progressive conditions in which treatment is exclusively palliative after diagnosis

Progressive metabolic disorders

Certain chromosomal abnormalities such as trisomy 13 or 18

Severe forms of osteogenesis imperfecta

Conditions involving severe, nonprogressive disability, causing extreme vulnerability to health complications

Severe cerebral palsy with recurrent infection or difficult-to-control symptoms

Extreme prematurity

Severe neurologic sequelae of infectious disease

Hypoxic or anoxic brain injury

Holoprosencephaly or other severe brain malformations

Estimating the Numbers in the Potential Target Population

Just as there are no uniform definitions of children with life-threatening conditions, the number of children with such conditions in the United States varies. Estimated numbers

¹ Institute of Medicine, *When Children Die, Improving Palliative and End-of-Life Care for Children and their Families*, Institute of Medicine of the National Academies, 2003 p. 37.

² B. Himmelstein, J. Hilden, A. Boldt, D. Weissman, “Medical Progress Pediatric Palliative Care,” *New England Journal of Medicine*, 350:17, April 2004.

range significantly. On the high end is a count of 1.3 million based on the National Association of Children's Hospitals and Related Institutions' (NACHRI) estimate that 1.9% of children under age 17 have a severe chronic illness. On the low end, estimates from the United Kingdom indicate that 10:10,000 children can benefit from hospice care, which translates to about 72,000 children in the U.S. based on the 2000 census. This number is based on utilization in the U.K. which has more widespread access to freestanding hospice.

According to a 1989 report of the General Accounting Office (GAO), 10-15% of all children have chronic health conditions and "about 10% of them—or 1 million children—have a severe form of it."³ Although the report does not define chronic health conditions, it surveyed families whose children had the following diagnoses: juvenile-onset diabetes, asthma, spina bifida, cleft palate/craniofacial anomaly, congenital heart disease, leukemia, end-stage renal disease, sickle cell anemia, cystic fibrosis, muscular dystrophy, and other. This list indicates the GAO definition of chronic health conditions is broader than what the CHI PACC programs have proposed as it includes conditions that are not necessarily life-threatening such as cleft palate and asthma.

The ChiPPS group, a subcommittee of the National Hospice and Palliative Care Organization, estimates 500,000 children in the U.S. have chronic life-limiting conditions. This number includes children who may not face premature death, but whose quality of life is impaired by their condition.

Feudtner⁴ takes a different approach by defining the group of infants, children, and young adults that may benefit from palliative care supportive services, as those who have "complex chronic conditions. In this analysis, he estimates that 15,000 infants, children, adolescents, and young adults (includes those up to age 24) die each year from conditions that would benefit from pediatric supportive care services. This is based on a review of death certificates among 0-24 age group in the period 1979-1997 where the cause of death is within specified ICD-9 diagnosis codes classified as complex chronic conditions.

At the same time, he attempts to estimate the average number of children with complex, chronic conditions who would be eligible for hospice care. "Because most infant deaths occur within hours to days of birth, infants who die because of CCCs spend few days alive in the 6-month period of time during which they would have been eligible for hospice insurance benefits."⁵ Thus, there are more adolescents and young adults who might benefit from supportive care than infants or children. Feudtner estimates that based on deaths in 1997, on any given day 5,000 are living within the last 6 months of life. This translates to approximately 20,000 individuals 0-24 who in the course of a year might be eligible for hospice services because they are within 6 months of death. This number may be slightly inflated for use by the CHI PACC projects as most of the CHI PACC projects intend to serve the age group up to age 18 or in some cases to age 21.

³ GAO, "Home Care Experiences of Families with Chronically Ill Children, GAO/HRD89-73, June 1989.

⁴ C. Feudtner, "Deaths Attributed to Pediatric Complex Chronic Conditions: National Trends and Implications for Supportive Services. *Pediatrics*, Vol 107, No. 6, June 2001.

⁵ Ibid.

Because the intent of the CHI PACC projects is to reach children and families earlier than the 6-month period before death, Feudtner estimates are likely too low as there are many children who might benefit from palliative care and support services much earlier in the trajectory of their disease.

Feudtner Estimates of Number of 0-24 year olds Eligible for Hospice at a Point in Time

	Infants	Children	Adolescents/Young Adults	Total
Cancer	47	541	1139	1727
Non Cancer	1050	873	1409	3332
Total	1097	1414	2548	5059

In summary, the estimates of the number of children 0 to age 21 in the U.S. who may be potential candidates for participation in a CHI PACC program, from the point of diagnosis probably falls within the low estimate of 20,000 by Feudtner and the high estimate of 400,000 by the ChiPPS group.

Feudtner's list of ICD-9 diagnosis codes was published just as the CHI PACC states were developing their own lists and his list was studied and utilized in part by all the CHI PACC states. Before the publication of Feudtner's article, Utah compiled a similar list of diagnostic codes based on the records of a home health/hospice agency that served this group of children and an analysis of nine years of vital statistics data for the State of Utah. Utah compiled the number of children under the age of one and those age one to 18 who died between 1990-1998 whose underlying cause of death based on ICD-9 codes was included in the range of life-threatening conditions in the table on the following page. Utah identified an average of 181 child deaths per year from these conditions. About 66 percent of the deaths occurred among those under age one and 34 percent for age one to eighteen.

This list of diagnosis (See Table 1) codes was then run against the Medicaid claims data for CY2000 to identify the number of children 0 -18 who had a paid claim for a Medicaid service with one of the identified diagnosis codes in one year. This run identified 1680 unduplicated children with one of these diagnoses on a fee-for-service claim which represents 1.3% of the children on Medicaid. This number appeared much higher than would be expected based on Utah hospital discharge data, a survey of pediatric specialists, the number of deaths of children due to a life-threatening condition, and an extrapolation of Feudtner's data regarding the number of children within six months of death. Therefore, we concluded that diagnosis alone is not sufficient to identify the potential number of children in the Medicaid program who might be classified as having a life-threatening condition.

Table: A Sample of Life Threatening Illnesses in Children by ICD - 9 Codes and Frequency of Mortality in Utah 1990 - 1998 by Age Group (Revised 6/27/01)

Illness	ICD - 9	Mortality Frequency	
		Under 1	Age 1 - 18
Infectious and Parasitic Diseases			
Human Immunodeficiency Virus, Type 2	042	0	3
Subtotal		0	3
Neoplasms			
Malignant Neoplasm of lip, oral cavity, pharynx	140.0 - 149.9	0	1
Malignant Neoplasm of digestive organs & peritoneum	150.0 - 159.9	1	5
Malignant Neoplasm of respiratory & intrathoracic organs	160.0 - 165.9	1	2
Malignant Neoplasm of bone, connective tissue, skin, etc	170.0 - 176.9	0	26
Malignant Neoplasm of testis	186.9	0	2
Malignant Neoplasm of kidney	189.0	1	3
Malignant Neoplasm of other & unspecified sites	190.0 - 199.1	6	68
Malignant Neoplasm of lymphatic & hematopoietic tissue	200.0 - 208.9	0	80
Neoplasms of Uncertain Behavior	238.9	1	0
Neoplasms of Uncertain Behavior	239.0 - 239.9	8	15
Subtotal		18	202
Endocrine, Nutritional, Metabolic, Immune Systems			
Other metabolic and immunity disorders	270.0 - 279.9	3	4
Disorders of lipoid metabolism	272.0 - 272.9	0	4
Disorders of mineral metabolism	275.0 - 275.3	3	1
Lipidoses	272.7	0	3
Other & unspecified disorders of metabolism	277.0 - 277.9	4	25
Deficiency of cell - mediated immunity	279.1	1	1
Combined immunity deficiency	279.2	0	2
Unspecified immunity deficiency	279.3	1	0
Subtotal		12	40
Blood and Blood - Forming Organs			
Other specified aplastic anemias due to enzyme deficiency	282 - .3	1	1
Constitutional aplastic anemia	284.0	0	1
Other specified aplastic anemias	284.8	1	0
Genetic anomalies of leukocytes	288.2	1	0
Subtotal		3	2
Nervous System and Sense Organs			
Cerebral degenerations usually manifest in childhood	330.0 - 330.9	2	15
Other cerebral degenerations	331.0 - 331.9	1	9
Anterior horn cell disease	335.0 - 335.9	9	2
Infantile cerebral palsy, quadriplegia	343.2	0	3
Infantile cerebral palsy, unspecified	343.9	0	30
Other conditions of brain	348.1 - 348.5	8	10
Other & unspecified disorders of the nervous system	349.8 - 349	1	4
Muscular dystrophies & other myopathies	359.0 - 359.2	2	22
Subtotal		23	95

Circulatory System			
Ventricular fibrillation and flutter	427.4	0	2
Other specified cardiac dysrhythmias	427.8 – 427.9	0	6
Cardiomyopathy	425.0 – 425.4	9	12
Ill-defined descriptions & complications of heart	429.0 – 429.9	5	13
Subtotal		14	33
Respiratory System			
Chronic Respiratory Failure	518.83	3	5
Subtotal		3	5
Digestive System			
Diaphragmatic hernia	553.3	1	0
Acute and Subacute Necrosis of Liver	570	0	2
Chronic liver disease and cirrhosis without mention of alcohol	571.4 - 571.9	2	0
Other sequelae of chronic liver disease	572.8	3	3
Subtotal		6	5
Genitourinary System			
Chronic renal failure	585	1	0
Renal Failure, Unspecified	586	8	2
Subtotal		9	2
Congenital Anomalies			
Anencephalus & similar anomalies	740.0 - 740.2	33	0
Spina bifida	741.0 - 741	5	3
Other congenital anomalies of nervous system	742.0 - 742.9	43	45
Bulbus cordis & cardiac septic closure anomalies	745.0 - 745.9	51	9
Other congenital anomalies of heart	746.0 - 746.9	236	51
Other congenital anomalies of circulatory system	747.0 - 747.9	41	9
Other Anomalies of larynx, trachea, and bronchus	748.3 - 748.9	100	3
Other congenital anomalies of digestive system	751.0 - 751	13	3
Congenital anomalies of urinary system	753.0 - 753.9	46	4
Anomalies of skull and face bone	756.0	0	2
Anomalies of spine	756.1-756.9	48	4
Chromosomal anomalies	758.0-758.9	119	11
Multiple Congenital Anomalies	759.7	26	3
Other specified anomalies	759.8	8	8
Congenital anomaly, unspecified	759.9	10	3
Subtotal		779	158
Conditions of the Perinatal Period			
Extreme Immaturity	765.0	126	0
Extreme Immaturity, Less than 500 Grams	765.1	65	0
Chronic respiratory disease arising in the perinatal period	770.7		
Subtotal		211	4

Grand Total	1627	1078	549
Nine Year Average	181	120	61

As a result, we worked with several pediatricians and hospital-based specialists to help us refine the list of diagnosis codes to create an algorithm that would factor other elements into the list of diagnostic codes to better discriminate among those with a diagnosis and those more likely to utilize support services that we planned to offer as part of the CHI PACC program. Utah's Algorithm predicts there may be between 76,000 to 139,000 children (0-18) in the U.S. who might benefit from palliative care and support services annually. The lower figure of 76,000 is based on 18% of the population of children with life-threatening conditions on Medicaid, while the higher number of 139,000 is based on 30% of that group qualifying for Medicaid.⁶

Although the Utah Algorithm may not be the definitive method of identifying children with life-threatening conditions through the medical claims system, projecting from the Utah numbers to the U.S. population, it may provide a reasonable estimate of the potential range of children in the U.S. who may benefit from CHI PACC program and services. Extrapolating from the Utah and national data to states may also provide some indication of the potential candidates for CHI PACC program and services.

Kentucky has added further refinements to the Utah Algorithm and once we compare its results in predicting the target population, we may have a tool that can help estimate the potential number of children who may benefit from CHI PACC programs based on state or regional demographics and health care data.

Estimating the Potential Population in the Military

To begin, the *mCare* project may wish to estimate the potential population by extrapolating from national and the Utah data as a means of coming up with the potential range of children who might benefit from the *mCare* project, before undertaking a more comprehensive survey of medical charts or claims.

If medical charts or claims are used, Table 1 ICD-9 codes or the Comparison List of ICD-9 codes may be useful for the first cut. Once this data base is compiled, the Utah and Kentucky refinements, Utah Algorithm, and Kentucky Severity Index may help to better pin-point the size and characteristics (cost, utilization, profile) of the proxy target population.

⁶ In Utah's analysis a disproportionate number of deaths from life-threatening conditions occurred among children on Medicaid. Whereas 18% of children in Utah were on Medicaid, 30% of the deaths from life-threatening conditions. Virginia also tracked deaths from life-threatening conditions for all children in the State and those on Medicaid and found a similar disparity.

Table 2: Estimating the Size of the Target Population: Demographics

Descriptor	United States	Military <u>% of US child population]</u>	Pilot Site <u>% of child population]</u>
Total population (Source)	281,421,906 (US 2000 Census)		
Population of children 0-18	72,325,430 (US 2000 Census)		
Percent of population under 18-21	(Under 18) 25.7% (US 2000 Census)		
Percent of population in urban areas & rural areas			
Persons per household	2.63 (US 1990 Census)		
Median household income	\$34,076 (1995 model-based estimate)		
Percent of children below poverty (\$14,600 per 3 person household in 2001)	20.8%. (1995 model-based estimate)		
Percent population non- white	24.9% (US 2000 Census)		
Children without health insurance	14.9% (1996 US Census Brief)		

Table 3: Estimating the Size of the Target Population By Extrapolating from National Data: Child Deaths and Children with Chronic Conditions

Descriptor	United States	Military	Pilot Site
Children who die annually	53,000 <i>(Am. Acad. Of Pediatrics)</i>	<i>(State vital statistics)</i>	<i>(Extrapolate from State vital statistics)</i>
Estimated no. of children who die annually with a designated life-threatening diagnosis <i>(State Vital Statistics)</i>	18,204 <i>(Extrapolated from State Data data)</i>	<i>(1990-1999 average, Utah vital statistics)</i>	<i>(MMIS and UT vital statistics data)</i>
Estimated number of children who die annually with complex chronic conditions <i>(Feudtner)</i>	15,000 <i>(Feudtner, et. al-excludes most perinatal diagnoses)</i>	<i>(Extrapolate from Feudtner data)</i>	<i>(Extrapolate from Feudtner data)</i>
Estimated number of children within 6 months of death with complex chronic conditions	<i>(point in time)</i> 5,000 <i>(annual)</i> 20,000 <i>(Feudtner, et. al)</i>	<i>(Extrapolate from Feudtner data)</i>	<i>(Extrapolate from Feudtner data)</i>
Estimated number of children (0-17) with severe chronic illness who would benefit from palliative care. <i>(NACHRI)</i>	1,374,183 <i>(NACHRI estimates 1.9% of population)</i>	<i>(Extrapolate from NACHRI data)</i>	<i>(Extrapolate from NACHRI data)</i>
Estimated number of children with a severe chronic condition <i>(GAO report)</i>	1,000,000 <i>(GAO report 1989 & Children's Hospice International)</i>	<i>(Extrapolate from GAO report)</i>	<i>(Extrapolate from GAO report)</i>
Estimated number of children with a designated ICD-9 diagnostic code indicating a life-threatening condition. <i>(state Medicaid)</i>	1,223,746 <i>(Extrapolate from Medicaid FFS claims data)</i>	<i>(Extrapolate from Medicaid FFS claims data)</i>	<i>(Based on Utah Medicaid FFS claims)</i>
Prevalence of Various Serious Conditions Among Utah Children <i>(C. Norlin Prevalence Rates)</i>	1,114, 300 <i>(Extrapolated from national/Utah prevalence rates)</i>	<i>(Extrapolate from national/Utah prevalence rates)</i>	<i>(Extrapolate from national/Utah prevalence rates)</i>
Estimated number of children with chronic life-limiting conditions. ChiPPs	446,000 <i>(ChiPPs paper, March 2001)</i>	<i>(Extrapolate from ChiPPs paper)</i>	<i>(Extrapolated from ChiPPs paper)</i>

Table 4: Estimating the Size of the Target Population by Extrapolating from Other Sources

Descriptor	United States	Military	Pilot Site
Annual hospital discharge cases for children with a designated life-threatening diagnosis (<i>Utah 1999 Hospital Discharges</i>)	218,200 (<i>Extrapolated from Utah hospital discharge data</i>)	(<i>Based on your State's hospital discharge cases</i>)	(<i>Extrapolated from your State's hospital discharge data</i>)
Estimated number of children who would benefit from palliative care (daily census) (<i>ChiPPs</i>)	6000-8000 (<i>ChiPPs paper, March 2001</i>)	(<i>Extrapolate from ChiPPs paper</i>)	(<i>Extrapolate from ChiPPs paper</i>)
Children who live with chronic life-limiting conditions (UK)	72,235 (<i>UK estimates 10:10,000</i>)	(<i>Extrapolate from UK estimate</i>)	(<i>Extrapolate from UK estimate</i>)
Children not expected to survive childhood because of a life-threatening condition. (Utah Pediatric Specialists)	60,266 (<i>Extrapolated from Utah survey</i>)	(<i>Extrapolate from Utah survey</i>)	(<i>Extrapolate from Utah survey</i>)
Children not expected to survive childhood because of a life-threatening condition as defined in the Utah Algorithm (Includes tech waiver)	139,081-75,869 (<i>Extrapolated from Utah Medicaid claims & Utah Algorithm</i>)	(<i>Extrapolate from Utah Medicaid claims & Utah Algorithm</i>)	(<i>Extrapolate from Utah Medicaid claims; CY2000 based on Utah Algorithm</i>)

APPENDIX 18

Community Resources for Children with Life Threatening Conditions

Children's Hospice Project

12/21/05

Prepared by,

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The Coordinating Center

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Background

Children of families in the military who have life threatening conditions can benefit from access to community resources to support their medical, educational, rehabilitation, social and emotional needs. The Coordinating Center studies community resources with a focus on types of resources available, access to resource information as well as the identification of any other factors that may have an effect on utilization of such services. Findings related to community resources will be used to inform other aspects of the Children's Hospice Project. The goal of the work performed by The Coordinating Center is to identify opportunities to improve access and utilization of community resources for children in the military under a model of care that is consistent with the philosophy of CHI/PACCTM models of palliative care.¹

The Coordinating Center evaluates community resources that may be available to children of military families the National Capital Area (NCA). As part of this evaluation, The Center examines types of existing community-based services, as well as their availability from several perspectives including location and accessibility. The primary purpose of this evaluation is to identify opportunities for utilization of services that exist outside of the scope of the military health care system that may be unknown to or

¹ The CHI/PACCTM philosophy and model is a palliative care model promoted by Children's' Hospice International and is designed to manage medical, spiritual and psychological services needed by families to care for children and adolescents diagnosed with life-threatening and potentially life limiting conditions, from the time of diagnosis, with hope for a cure, through end of life care, and to bereavement follow-up.

underutilized by families. Ideally, the project will lead to the development of an optimal model of care that ultimately supports families in the military and military readiness².

The national agenda promotes the delivery of family - centered services to children with chronic conditions.³ To be consistent with these initiatives, this community resource component of the Children's Hospice Project will incorporate considerations for resources that support family as well as the child with a life limiting condition. In addition, resource types will focus on those that may address needs of the family and child along the continuum, from time of diagnosis, through critical points during their lives, and at the end of life. The same philosophy is embraced by the CHI/PACCTM philosophy, which is to assist children and families within their homes and communities and to support the independence and care giving functions of the families through access to services and resources in the community and home. Additionally, the Department of Defense expresses significant interest in the concept of military readiness. This concept incorporates a comfort level of the soldier or officer that their family will be safe and provided for during episodes of military deployment. Therefore services that support the needs of the military family can be considered to support the military readiness of the soldier. Military parents may experience additional anxiety related to episodes of deployment if there are inadequate supports in place for their family and children while they are absent. This is particularly significant when a parent is deployed and leaving a child who has a life threatening illness.

² The Congressional Budget Office (CBO) uses the Joint Chiefs of Staff's definition of readiness, which is also referred to as *operational* or *current* readiness: the ability of forces to deploy quickly and perform initially in wartime as they were designed. (Joint Chiefs of Staff, *The Dictionary of Military and Associated Terms*, Joint Publication 1-02 (March 23, 1994)

³ The American Academy of Pediatrics supports this concept of family-centered care through their medical home initiatives. <http://www.medicalhomeinfo.org/about/index.html>

The Coordinating Center focuses on community based resources existing in the five-catchment areas representing the National Capitol Area as listed below:

- WRAMC
- Fort Detrick
- Fort Meade
- Fort Belvoir
- Aberdeen Proving Ground

The process used by The Coordinating Center to address the community resource evaluation includes a broad literature review, collection and analysis of resources found to exist in the 5 catchments areas listed and analysis of processes used to access resource information. It is anticipated that the process will yield some answers to the following questions related to resources. The questions are:

- What types of supports are available to children with life threatening condition and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?
- What strategies can be incorporated in a new model design to optimize access to information about community resources?

Resource Review

A literature review is conducted to learn more about the broad subject of community resources, and describe the experience of finding and accessing resource services to ultimately support children with life threatening conditions and their families. For the purposes of this review, the working definitions are as follows:

- Community - A group of people living in the same locality and under the same government; the district or locality in which such a group lives; a group of people having the same interests.⁴
- Resource - Something that can be used for support or help, or an available supply that can be drawn on when needed; means that can be used to cope with a difficult situation.⁵

Of necessity, these definitions are broad and subject to individual connotation.

The broad-based definitions also accommodate the unique family perceptions of what is or is not supportive in the community in a particular situation. Considering the potential for omitting possible helpful supports to families from an inpatient and community standpoint, this report will incorporate the broad definitions as the basis for the study. Obviously, with such broad definitions, any one study may not feasibly capture every possible community resource in the areas identified. Therefore, additional searches for resources may need to occur once the specific population for Children's Hospice Project has been determined and their needs assessed through focus groups. It is anticipated that this exercise of reviewing community resources will demonstrate some trends and commonalities about the topic.

Sources and search parameters

The literature review was implemented at The University of Maryland Health Science Library, local public libraries, Fort Meade library used only by military families as well as other less formal community locations such as non professional journals, local newspapers, pediatrician office brochures, local health department information and at

⁴ Definition from Dictionary.com, 2004

⁵ Definition from Dictionary.com, 2004

local community fairs. The initial search for information on resources was at the University of Maryland Health Science Library used by medical professionals such as nurses, physicians, and social workers. Multiple database searches were performed with various search words used. Assistance was obtained by trained library staff to identify the most appropriate search words as well as the most appropriate databases for which to search. The following table depicts the results of the search.

Database	Search Words	Results	Related to Children's Hospice Community Resource
Social Work Abstracts 1997-2003	Children Programs and Services	87	21
CINAHL 1982 - 2003	Children Programs and Services	119	42
CINAHL 1982 - 2003	Care and Services for Terminal Illness	53	14
Psych Info	Hospice and Palliative Care Services	12	7
Psych Info	Children Program and Services	139	41
Directory on Disc*	Searches are pre-defined through categories of resource information		Results relate to specific category queried

Directory on Disc⁶ is a community information database designed to assist communities in finding information and services to provide an entry point for social assistance. This database provides information related to relationship issues, domestic violence, suicide, mental health concerns, substance abuse, grief, pregnancy, rape, abuse, crisis, housing assistance, disabilities, teen concerns, youth behavior problems and community information and referrals.

⁶ Directory on Disc is a product of 2-1-1 Big Bend, founded in 1970 as an independent non profit organization widely respected and recognized as a leading resource for confidential hotline support services and provides a free searchable resource database at www.211bigbend.org. United Way of the Big Bend has been the primary funding source.

Following the review of literature at the Health Science Library, extensive

Internet searches were performed with the following search results:

Search Word	Search Engine	Results of Query	Possible applicability of Information found on 1st 10 pages of result review
Community Resources	Google	33,300,000	Search results are too variable for usefulness
Community Resources	Yahoo	44,700,000	Search results are too variable for usefulness
Children and Hospice	Google	1,200,000	Specific Hospices and General Information on Hospice and Children/Parents Dying
Children and Disabilities	Google	9,1800,000	General Information on Disabilities
Children Programs and Services	Google	21,000,000	National Programs/State and County Hospitals
Hospice and Palliative Care Services	Google	302,000	Specific Hospices and General Information on Hospice
Children and Terminal Illness	Google	541,000	Specific National/State Resources and Literature Reviews
Community Resource	MSN	9,649,923	Search results are too variable for usefulness
Children and Hospice	MSN	168,362	Specific Hospices and General Information on Hospice and Children/Parents Dying
Children and Disabilities	MSN	841,002	General Information on Disabilities
Children Programs and Services	MSN	2,169,473	Overview of Services Available/National Programs
Hospice and Palliative Care Services	MSN	31,138	Specific Hospices and General Information on Hospice
Children and Terminal Illness	MSN	67,406	Literature Reviews and Generic Information for Parents, Siblings and Classmates
Community Resource and chronic conditions	Yahoo	1,730,000	Condition specific Information, Community Databases

Responses and Challenges in Resource Development

One of the challenges experienced while performing the literature review on community resources is the unmanageable volume of responses to Internet and Database

searches. The literature search, in some ways mimics some of the ways that families go about trying to locate information about resources for their children with life threatening conditions. Therefore, at least some of the challenges that we encountered would be similar to those that are encountered by families. The primary challenge identified through this exercise of searching for community resources and related literature is the overwhelming number of search responses that created an unmanageable volume of information. For example, in Internet research, when we typed the key phrase "community resource" 44,700,000 websites were returned. When we used the keywords "children with life- threatening illnesses" 541,000 websites were cited. Similar phenomena occurred when we searched the HSL databascs on the topic. A strategy to reduce the search to more manageable result is to be more specific about the resource being sought. This ability to search for specific keywords to locate resourcees has implications related to a family's level of skill related to querying the Internet. This strategy could be used if families had the information and confidence to query on a specific resource.

A second challenge with the initial literature review was the ratio of time spent and value attained through data searches. Sorting through a high volume of information to find potentially useful resourcees is extremely time consuming. Often, the significant time spent yielded minimal return in terms of meaningful and targeted information. Keeping in mind that children with life threatening conditions have time intensive needs, including frequent appointments to physicians, and complex medication and treatments regimens, this kind of search seems to be an unreasonable expenditure of time for families caring for their child with complex needs. In fact, when parents are dealing with

a child who is hospitalized, they have indicated that they feel emotionally torn between providing constant support to their hospitalized child and caring for their other children at home⁷. Assuming these parents and those who are primary caregivers in the home have time to sort through volumes of information to find effective supports may be an unreasonable expectation. In addition to time spent locating information regarding resources, some resources require additional time and effort to obtain and complete an application for the desired service. In some instances such as Grant a Wish, Supplemental Security Income (SSI) or application for developmental disability services, there is a requirement for physician documentation and signature. For families, who are in desperate need of support and services, the process may pose barriers that prevent the family from ever accessing the desired support. In relation to military families, who are dealing with stresses associated with single parenting and deployment, additional time and steps add yet an additional layer of action to successfully access the needed service.

While the Internet has become one of the most widely used communication media, assessing the credibility of the publisher as well as the relevance and accuracy of a document retrieved from the Net can be a problem. With the availability of Web server software, anyone can set up a Web site and publish any kind of data, which is then accessible to all. The Health on the Net (HON) Foundation has elaborated the Code of Conduct to help standardize the reliability of medical and health information available on the World Wide Web. The HON code defines a set of rules to hold Web site developers to basic ethical standards in the presentation of information and help make sure readers know the source and purpose of the data they are reading.⁸ In some situations, web sites

⁷ Melnyk and Alpert-Gillis, 1998

⁸ <http://www.hon.ch/HONcode/Conduct.html>

reviewed provide no appropriate documentation regarding the credibility, currency or accuracy of the information they are presenting.

As part of the search exercise, contacts were made at the local public libraries and a military specific library to determine the availability of resources and information as well as the process to conduct searches performed for and by families. While there are multiple databases offering resource information, there are also resource guides, stocks of pamphlets in health centers and physician offices, flyers and fact sheets found in libraries, schools and military treatment centers, much of the information is vague as to details of service and mechanisms for funding the service. Some resources found in pamphlet information were identified to be no longer relevant or programs and services that were no longer funded. This phenomena may be attributed to the services advertised and funded by less stable sources, such as foundations, short term demonstration projects or under funded public programs. As traditional helping organizations reflect the economic situation in the country, the capacity of funders and foundations to continue to achieve their missions in the community may be affected. In some situations, this may lead to longer waiting lists for services and curtailed or lost services for families and children. The military family is not immune from this phenomenon.

A publication cited to be the single largest and most widely referred to directory in the disability field is Exceptional Parent (EP) magazine.⁹ This publication has been in existence for over 35 years. Exceptional Parent magazine is published monthly and includes one special January issue each year that is the EP Annual Resource Guide. This annual guide includes comprehensive directories of organizations, associations, products and services for the special needs communities. The monthly publication is designed to

provide information and support for parents, families, physicians and professionals who are supporting people with special needs. In addition to the publication, the information is also accessible through subscription on-line. Cost of this publication is approximately \$35.00 for the first year subscription.

There is an emotional toll on families of children with life threatening conditions that may affect their capacity to reach out for assistance. The literature sheds light on the fact that families caring for severely disabled children with complex health care needs experience extraordinarily high levels of responsibility in the absence of sustained support.¹⁰ Thus, families, as the primary managers of their children's care, are often the primary seekers of assistance and information as well. Yet, there are critical times in the child's situation when the emotional responses of families work against their capacity to function effectively in this area. For example, when children are hospitalized, especially for unplanned admission, or their situation changes negatively, some parents may experience anxiety and sometimes panic. At such times, their own behaviors may reflect disequilibrium, disorganization, vulnerability and even psychosomatic symptoms. Expressions of denial, anger, protest, guilt and sadness, and mourning typically follow these initial reactions.¹¹

The family experience may be exacerbated when there are other children in the family and particularly in military families should they occur when the spouse is deployed outside the home jurisdiction. If a family is relocated due to military responsibility, this will typically include a change in healthcare providers. Often families have established relationships with providers who are familiar with their child's care and

⁹ www.eparent.com

¹⁰ Robinson, Jackson and Townsley, 2001

are then in a situation that they must establish new relationships with new providers and services.

The Exceptional Family Member Program (EFMP)¹² is one example of a military specific program for all active duty service members providing personnel function and a family support function. The EFMP personnel function is a mandatory program for all active duty service members and is standard across all services. The purpose is to identify military personnel who have a family member with special medical and/or educational needs, document the services they require and consider those needs during the personnel assignment process. This function involves the personnel and medical commands and the Department of Defense educational system overseas. Unlike the personnel function, the EFMP family support function is not mandatory. The Department of Defense (DoD) allows, but does not require, the Military Services to offer family support services to exceptional family members. Consequently, this practice differs from service branch to service branch. In the Army and the Marine Corps, family centers are staffed with individuals whose responsibility is to provide support to families with exceptional family members. They are called EFMP Coordinators. In the Navy, the EFMP staff who support the Personnel Function may also provide family support services, but the Navy does not staff their family centers with EFMP Coordinators. In the Air Force, the Special Needs staff are located in the Military Treatment Facility (MTF) only. The EFMP Re-Assignments Branch is a personnel function. Family Support Center

¹¹ Melnyk and Alpert-Gillis, 1998

¹² EFMP description obtained from Military HOMEFRONT , a web based resource described as the central, trusted, up to date source for service members and their families to find information about all DoD quality of life programs and services.

staff provides Family Life Education, Information and Referral and Personal Finance Management services but do not have a designated Coordinator.

A recurring theme in the literature is that parents express the significance of maintaining the role of decision-maker and be seen as pivotal in the effort to locate and use resources to benefit their children with life threatening conditions. Indeed, parents themselves express that among their primary concerns is the perceived loss of the parental role.¹³ Yet, as health care systems grow more complex and difficult for parents and professionals to navigate, professionals are being asked to be accountable for assisting in more direct ways and they are expected to respond more effectively to the needs of families in ways that respect parental choices and decisions. To make the relationship between the family and the helping professional work on behalf of the child, open and honest communication between families and professionals, including health care providers and ancillary personnel is essential. This is especially the case when families are confronted with disappointing results, unexpected outcomes, uncertainties about their children's conditions and controversies about the direction to take on their behalf¹⁴

Resource Analysis in the National Capital Area

Federal and State Resources

Federal Programs for children are typically categorized under the areas of health, education, income support, mental health and social service. The federal level programs are complex, and therefore the tables contained in this document include only selected

¹³ Melnyk and Alpert-Gillis, 1998

¹⁴ Gilmer, 2002

information that has been deemed relevant to children with life threatening conditions. Eligibility criteria can be very detailed and in many situations is defined broadly by federal statute, but with more detailed criteria determined by each state. Federal programs are subject to availability of funding and may change based on proposed shifts to block grants or issues of national priority.

An important factor regarding federal level programs is that many are administered at a state level. Administration of a federal program at a state level allows the state to customize the program based on each state's perceived needs and populations. As a result, these programs often have varying eligibility criteria as well as varying allowances for participation and benefits. Thus, a family may qualify for a program in one state, however if the family is relocated by request of the military, there is no guarantee that they will qualify in the other state for a similar program. This phenomenon coupled with complex or generic program descriptions and lengthy application processes may create a gap or disruption in services for children who have very complex medical situations.

Refer to the *Resource Description Table* (Appendix A) for further detail regarding federal, state and local community programs relevant to children with life threatening conditions. The table provides descriptions of the program types and resources provided through each specific program.

The Medicaid Program can be a significant source of support for some families who have children with special healthcare needs and meet qualifying criteria for the program. Although the Federal government establishes general guidelines for the Medicaid Program, each state establishes program requirements. The Medicaid Program

provides medical benefits to low income people who have no medical insurance or inadequate medical insurance. Medicaid is the nation's largest health care program, providing health and long-term care services to 53 million low- income pregnant women, children, individuals with disabilities, and seniors. Whether or not a person is eligible for Medicaid will depend on the State where he or she lives. States are required to include certain types of individuals or eligibility groups under their Medicaid plans and they have the option to include others. The states' eligibility groups are considered to fit one of the following categories: categorically needy, medically needy, or special groups.¹⁵

In addition to the Medicaid program, states have a health insurance program for children up to age 19, State Children's Health Insurance Program (SCHIP). These programs are for children whose parents have too much money to be categorically eligible for Medicaid, but not enough to buy private insurance. Most states offer this insurance coverage to children in families' whose income is at or below 200% of poverty level. However, states have different eligibility requirements. Not all the insurance programs provide the same benefits, but they all include immunizations and care for healthy babies and children at no cost. Families may have to pay a premium or a co-payment for other services depending on their income.¹⁶ The SCHIP Program may not be a relevant resource for military families if the child already has access to Tricare.

Medicaid is a vital health care safety net and provides important services to those who cannot obtain care from any other source. Medicaid coverage is also critical for reducing the number of the uninsured currently estimated at 45 million nationwide.

¹⁵ For further information regarding specific state Medicaid eligibility see <http://www.cms.hhs.gov/Medicaid/eligibility>

¹⁶ Dept. of Health and Human Services, Centers for Medicare and Medicaid Services and Center for Medicaid and State Operations, *Medicaid at a Glance 2003*, A Medicaid Information Source.

Medicaid spending, however, has increased dramatically over the last 5 years, driven by a 40 percent increase in caseload and a 4.5 percent per year increase in the health care price index, strengthening the impetus for reform. According to the National Governors Association Preliminary Report dated June 15, 2005, comprehensive Medicaid reform may focus on reforming Medicaid and on strengthening other forms of health insurance and long-term care coverage.

This potential for Medicaid reform may have implications for states designing home and community based waivers such as the CHI/PACCTM models. Home and community based services are reported to be under fiscal crisis as Medicaid long term care expenditures are projected to increase. Some are concerned that the fiscal crisis may impede the growth of Home and Community Based Waiver Programs. In addition, in states where state waiver programs exist, there are long waiting lists for the programs.¹⁷ Of eight states identified in a Kaiser funded study, a wait time for the home and community based waiver programs range from unknown to 31 months.

Children's Hospice International (CHI), with technical assistance from the Centers for Medicare and Medicaid Services (CMS), Congressional Members, and healthcare leaders, developed the CHI/PACCTM programs to overcome existing barriers to appropriate care for children with life-threatening conditions and their families. These state models have applied to CMS to become Medicaid funded programs under the 1915C Medicaid Home and Community based waivers. CHI/PACCTM has received \$3.2 million in federal appropriations for multi-state demonstration programs in Florida, Colorado, Utah, Virginia and additional states. Children's Hospice International has

applied for additional appropriations to further CHI PACC models throughout the country in fiscal year 06.¹⁸

Military Resources

Children with life threatening conditions often use a myriad of medical, educational, and community based services to meet their comprehensive and complex needs. Their families, who nurture them at home, must learn to navigate systems on their children's behalf and find that they too experience needs for support as they meet the day to day responsibilities of caring for children with such challenging health concerns. In addition to the specialized health needs of these children, military families experience additional challenges requiring a spectrum of other supports. There exists a multitude of military supported programs aimed at providing resources to help active duty families. Active reserve military are also afforded resources within the military system to support some of the specific needs that military reserve families face.

Military HOMEFRONT is a web portal and described as "the central, trusted, and up-to-date source for Service members and their families to obtain information about all Department of Defense Quality of Life programs and services".¹⁹ A systematic review of the Military HOMEFRONT website was conducted. The method used for the evaluation was identifying all topics listed on the site map. These topics were reviewed and rated based on their relevance to children with life threatening conditions. .

Generally, these programs identified on this Web site address resources in the areas of transition, educational opportunity, deployment, employment issues for self and spouse,

¹⁷ Information presented at the GSA Annual Meeting in San Diego Nov. 23, 2003 by Martin Kitchener PHD MBA and Charlene Harrington PhD funded by Kaiser Commission on Medicaid and the Uninsured and the The Institute for Disability and Rehabilitation Research (NIDRR)

¹⁸ <http://www.chionline.org/programs/>

financial management, housing, family support, recreation, etc. Please refer to Appendix B, *Review of Military HOMEFRONT Web Site* for a listing of the topics and the relevance to the population.

In addition to reviewing Military HOMEFRONT, a site visit to Military One Source was conducted in 2004. Please refer to the Military One Source Report, Appendix C for further analysis of services and recommendations related to a new model design.

Other Resources

Refer to Appendix D *Community Resource Table* to see a listing of resources located in the general community of the National Capital Area. The resources have been categorized by the following topics:

- Associations and Care Organizations
- Hospitals and Health Facilities
- Hospice
- Medical Information Sources
- Government Resources
- Adaptive Technology
- Child Care
- Financial Assistance
- Medical Providers
- Hotlines
- Interpreters and Translation Services
- Mental Health
- Recreation and Camps
- Support Groups
- Transportation
- Respite Care
- Utility Assistance Programs
- Wish Granting Programs
- Special Education Information and Laws
- Home Health Care
- Durable Medical Equipment and Supplies

¹⁹ <http://www.militaryhomefront.dod.mil/>

- Bereavement Services
- Self Esteem
- Adult Day Care
- Hearing/Visually Impaired
- Vocational/Rehabilitation Services
- Caregiver Resources
- Resource Directories
- Case Management Services
- Community Resources
- Pharmacy Programs
- Planning
- Therapeutic Services
- Literature

In addition, an extensive list of web based databases can be accessed to support children with special needs and life threatening conditions. A listing of resource databases identified in the resource review is included as Appendix E, *Web Databases Resource Directory*.

Findings and Experiences from Resource Research

The following is a list of some experiences The Coordinating Center encountered during the exercise to identify resource information. It is plausible that families may encounter similar situations in their efforts to find resource information and should be considered in developing the new model design. These experiences include but are not limited to the following:

- Difficulty obtaining information; no return phone call or contact.
- Unable to obtain information upon initial contact.
- Often transferred to another person
- Preference is to give information directly to consumer as opposed to a surrogate caller
- Home health care contact information changes frequently
- There appears to be much information regarding resources for Children with Cancer or developmental disabilities available for families on the Internet.
- Using the term "*Terminal illness*" as a keyword search often links to services appropriate for individuals with a diagnosis of Cancer rather than other life threatening conditions.

- Chapters and Associations were identified as local resources when researching specific areas in Maryland.
- Difficulty distinguishing between which category to place resource
- May find numerous programs under one agency.
- Organizations such as the Department of Social Services and Developmental Disability Administration may have different practices based on region of location within the state
- When using the Internet there appears to be very few resources that are military specific.
- Military resources are difficult to locate through civilian research.
- There appears to be inconsistencies in the resources located on military bases and those identified through the national web site.
- Military resources differ from base to base and service branch
- It is often difficult to identify the cost for the services from the information provided
- When calling an organization for resource information, you are often referred to the web site rather than providing the information over the telephone.
- Web site information is often generic and does not include the specific detail regarding the service
- Resources may be for those children and families that are already enrolled within the health care system such as Johns Hopkins - Harriet Lane Compassionate Care Program
- County libraries are available to assist in locating local community resources.
- Health care databases are located at the local libraries for public use.
- Librarians can be used to research specific questions or topics.
- Schools, camps, senior center, etc. provide the library with information related to upcoming events and general information.
- Grass root resources are more readily found through the local library rather than the Internet.
- Networking between county libraries is available
- Disease based associations can offer education and direct families toward other resources related to the diagnosis.
- Community Resource as a keyword search is too broad and yields an unmanageable number of responses
- Utilization of the search word "hospice" or "terminal" yields only end of life services and does not capture resources that may support the chronicity of palliative care patterns.
- Health Science Library results yield little as to specific resources and application for service information that could be helpful to families searching for specific service delivery
- There is an abundance of information available on the Internet attributing to results that are unmanageable due to over abundance of information that is time consuming to sort through
- Internet search results are limited by search words entered and may create barriers to families seeking information

- Web sites that identify specific services and information vary on the elements of information provided
- Some web sites do not indicate how current the information is and do not provide complete information about the resource such as funding for the service or the application process
- Website searches provided voluminous amounts of information and broader variety of possible resources
- Local public library provides assistance with searches by librarian and does not require individual to have Internet search skills or access to technology to gather basic information.
- Some local public libraries have prepared information that can be accessed on county specific services and programs as well as information on some federal programs.
- Military library at Ft. Meade provided limited information on resources in the community and referred to the local public library system
- Reliability of information received is inconsistent
- Directory on Disk is a product available at a reasonable cost to communities as a pre-designed database containing information on social assistance and tailored to the specific community. However, this is not currently available in all communities throughout the country.
- The Internet has become one of the most widely used communication media.
- The Health On the Net Foundation has elaborated the Code of Conduct to help standardize the reliability of medical and health information available on the World

Process Analysis

Locating basic information regarding a resource is typically the first step toward accessing that resource. However, the information may not be useful unless it yields actual access to the needed service. An analysis of the typical process used by an individual to access some type of a resource has been documented in the form of a data flow diagram. See Appendix F for *Data Flow Diagram*. The purpose of this is to identify possible areas of vulnerability that may preclude completion of the process to the point of service delivery. The analysis should be considered while developing the new model of care for children in the military who have life threatening conditions with attention to incorporate quality measures in the process to minimize the potential for unsuccessful service delivery.

For any typical request for resources, a professional, nonprofessional or family member may identify a need for a community resource. Then, there is some research done to identify a source for such resource to yield potential resource options to meet the resource request. This research can be done by the requestor or by another third party, such as a professional or nonprofessional invested in supporting the request. In most situations, there is some referral or application process required to access the resource. The referral or application process can vary from providing basic demographic information to extensive financial and medical reviews prior to the approval for the resource requested. Depending on the type of resource requested, some situations will warrant the identification of a provider to deliver the resource. In some situations, further research to locate funding will be necessary prior to service delivery. Subsequent to approval for the resource, identification of the provider if applicable and identification of a funding mechanism the service delivery would occur. In some situations, reimbursement is requested following service delivery and would follow.

The basic tasks identified in this process are:

- Identification of a resource need by family, professional or other nonprofessional
- Research for possible options for desired resource
- Application to obtain resource
- Identification of a service provider
- Locating a funding source
- Delivery of the service
- Reimbursement for the cost of the service or resource

Each task within the process has been analyzed to note vulnerabilities within the process.

Process Task	Vulnerabilities
<i>Request a resource</i>	<ul style="list-style-type: none"> • Miscommunication regarding type of resource requested • Resource requested does not meet the need of the child/family • Lack of knowledge on requestors part related to type of resource needed or what may be available
<i>Research resource options</i>	<ul style="list-style-type: none"> • Resource information obtained is inaccurate or lacks correct contact information • Resource information obtained does not adequately represent what was requested
<i>Apply for resource</i>	<ul style="list-style-type: none"> • Application requires specific information that is not readily available to applicant • Application requires signature from other entity such as physician, or other professional requiring additional steps prior to completion • Application requires multiple estimates for the service requested • Poor or no direction for application completion • Application is denied based on information presented • Application gets lost during process • Application is too complex for family to complete
<i>Identify provider for resource</i>	<ul style="list-style-type: none"> • Provider will not accept reimbursement amount or method • Unable to find a provider • Provider of low quality
<i>Locate funding source</i>	<ul style="list-style-type: none"> • Unable to identify funding for resource • Not medically necessary resource • End of budget year request that will be postponed for funding in the upcoming fiscal year •
<i>Deliver resource or service</i>	<ul style="list-style-type: none"> • Resource is never delivered • Resource or service is delivered but is of poor quality
<i>Reimburse for resource or service when applicable</i>	<ul style="list-style-type: none"> • Funding is delayed due to internal processes of funder • Reimbursement is required prior to service delivery • Service provider is not part of network for reimbursement

Case Management / Care Coordination

Case management is defined by the Case Management Society of America (CMSA) as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes".²⁰ Although third party

²⁰ Definition obtained from CMSA Standards of Practice, 2002

payers and managed care programs often use the term "case management", others prefer the term "care coordination". Typically case management may include activities such as disease management, benefits management and utilization review, while "care coordination" occurs when an individualized plan of care is implemented by a variety of service providers.²¹ Care coordination is often the preferred term used in context of family centeredness as parents play such an integral role in the management of their child's care. Therefore, for the purposes of this report for the Children's Hospice Project, case management will be presented within a conceptual framework best described as child and family centered and the term care coordination seems to better describe this service for children with life threatening conditions.

Care coordination is a service commonly found in some of the state level programs discussed in this report, particularly those serving children with special health care needs. For example, care coordination is a component service provided with early intervention programs, developmental disability programs as well as the community based waivers for children. Care coordination is also identified by Children's Hospice International as a key component of the CHI/PACCTM model.

According to the Massachusetts Consortium for Children with Special Health Care Needs, "care coordination is a central, ongoing component of an effective system of care for children and youth with special health care needs and their families."²² This same concept is widely accepted by the American Academy of Pediatrics based on their

²¹ Committee on Children with Disabilities, Pediatrics, 1999

²² Care Coordination: Definition and Principles, prepared by the Care Coordination Work Group, Oct 2005

support of the medical home concept.²³ The AAP Committee on Children with Disabilities recently concluded that care coordination is an integral component to the efficient management of the multiple complex issues related to caring for children with special health care needs to result in optimal outcomes for children and their families. In addition, based on the needs of children across multiple health and human service systems, care coordination is a process that links children and families to services and resources. The care coordination of children with complex health care needs is often not provided by the pediatrician based on lack of time and staff.²⁴

Care coordination activities may offer benefits to families and to providers. Some specific activities that care coordination can provide in relationship to accessing resources may include but is not limited to the following:

- Assess the individual needs of the child and family
- Develop an individualized plan of care for the child incorporating the multidisciplinary team
- Understand the range of available community resources and public benefits
- Identify, locate and monitor community resources to assist the child and family
- Facilitate access to health and other services that support the needs of the child and family
- Optimize resources that are available to the child, while avoiding duplicative or unnecessary services and costs
- Facilitate effective communication between families and providers

²³ Defined by the AAP, A medical home is an approach to comprehensive primary care, that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.

²⁴ Gupta, O'Connor and Quezada-Gomez, Pediatrics 2004

- Assist the family to become more effective advocates for their child's needs

Refer to Appendix G for the *Care Coordination Presentation* provided to the Children's Hospice Project Team related to case management and care coordination.

Conclusions

Based on this extensive review of potential resources for children with life threatening conditions, there appears to be an abundance of possible sources of support available to military families living in the National Capital Area. Further analysis of resources compared to the needs assessment could reveal gaps in existing resources for children and families in the military. These gaps will be further evaluated and ultimately incorporated into a new model design as other components of The Children's Hospice Project are completed.

A Resource Profile Chart has been developed to identify types of resources relevant to children with life threatening conditions and the general location of these resources. It is important to note that most organizations and programs that house resources for families have specific factors and guidelines that determine a child and family's eligibility for the specific service. The details of these factors are far too many to include in the chart. The purpose of the chart is to be a general reference to identify some possible options and guidance to families seeking resources. See Appendix H for the *Resource Profile Chart*.

At the beginning of this report, the following questions were identified:

- What types of supports are available to children with life threatening condition and their families?
- Where is information about community resources located?
- What is the process for accessing community resource information?
- What are some of the barriers for families in identifying and finding resource information?

- What strategies can be incorporated in a new model design to optimize access to information about community resources?

Finally, in an effort to answer the questions posed at the beginning, please refer to *Resource Overview Analysis* in Appendix I for an overview of the general conclusions relating to Resources as they relate to the various levels (federal, state, military, local) discussed in this report.

Recommendations for Considerations in New Model Design

Education

- Educate families and providers regarding the types of resources that exist and where they may be located
- Educate families of children with life threatening conditions to utilize existing Military Services such as Military One Source and Military Home front
- Educate Military One Source staff on the variety of specific resources that exist for families who have children with life threatening conditions to enhance dissemination of information to families who are seeking community support

Coordination and Facilitation

- Consider care coordination as a means to assist families in accessing existing resources both in the military and private sectors.
- Develop linkages for families with Military One Source to optimize an Information and Referral role they are currently contracted to deliver to active military personnel
- Encourage the collaboration of existing community programs that provide various types of coordination such as public libraries, Infant and Toddler Programs,

school programs, Military One Source, etc. that already exist within the military or civilian world.

System Design

- Design information systems to support the dissemination and access to resource information focused on supporting children with life threatening conditions
- Encourage family networking through such chat forums as Military and Specialized Training of Military Parents (STOMP). This type of networking provides families with experience and information on strategies to problem solve system barriers. A parent may get information to assist them in navigating systems and accessing services to support their children's needs.
- In a new model design, incorporate quality indicators and metrics to measure usage and access to all possible resources that support families. By optimizing the use of resources within the military system, such as Tricare and Military One Source and supplanting resources that families can access outside of the military system, a full spectrum of services appear to be available to support families. This type of quality review may assist the developing model to better identify potential areas for process improvement especially related to the process for accessing the resource and address some of the areas of vulnerability.

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Attachments

- A. Resource Description Table
- B. Review of Military HOME FRONT Web Site Information
- C. Military One Source Report
- D. Community Resource Table
- E. Web Databases Resource Directory
- F. Data Flow Diagram
- G. Resource Profile Chart
- H. Resource Overview Analysis
- I. Care Coordination Presentation

Attachment A

Resource Description Table

Category	Program Types	Program Description	Types of Resource Provided
Federal Level*	Social Security Income (SSI)	Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues. It is designed to help aged, blind, and disabled people, who have little or no income. http://www.ssa.gov/notices/supplemental-security-income/	Financial support (cash) to meet basic needs for food, clothing, and shelter.
	Early Periodic Screening and Diagnostic Testing (EPSDT)	The EPSDT program consist of two mutually supportive, operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources. http://www.cms.hhs.gov/medicaid/epsdt/default.asp	The (EPSDT) service is Medicaid's comprehensive and preventive child health program for individuals under the age of 21. EPSDT was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA 89) legislation and includes periodic screening, vision, dental, and hearing services. In addition, requires that any medically necessary health care service listed at section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State's Medicaid plan to the rest of the Medicaid population.
Federal/ State administered	Developmental Disabilities (ADD)	The <u>Developmental Disabilities Act</u> requires ADD to ensure that people with developmental disabilities and their families receive the services and supports they need and participate in the planning and designing of those services. The DD Act established eight areas of emphasis for ADD programs; Employment, Education, Child Care, Health, Housing, Transportation, Recreation, and Quality Assurance. ADD meets the requirements of the DD Act through the work of its four programs: http://www.acf.dhhs.gov/programs/add/Factsheet.html	State Councils on Developmental Disability pursue systems change in some aspect of service or support availability, design or delivery that promotes positive and meaningful outcomes for individuals with developmental disabilities and their families. <u>Protection and Advocacy (P & A)</u> systems, one in each state, protect the legal and human rights of individuals with developmental disabilities. P&A strategies include legal, administrative, and other remedies; information and referral; investigation of incidents of abuse and neglect; and education of policy-makers. <u>University Centers for Excellence in Developmental Disabilities (UCEDDs)</u> are components of a university system or are public or not-for-profit entities associated with universities. UCEDDs provide interdisciplinary pre-service preparation of students and fellows, community service activities, and the dissemination of information and research findings. <u>Projects of National Significance (PNS)</u> is a discretionary program providing ADD with the opportunity to focus funds on emerging areas of concern. This program supports local implementation of practical solutions and provides results

<p>Special Education - State Grants Program for Children with Disabilities</p>	<p>This is an entitlement program of the U.S. Department of Education, Office of Special Education Program administered by state and local education agencies to ensure that all children with disabilities receive a free, appropriate public education (FAPE).</p>	<p>and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change.</p> <p>States must provide free, appropriate public education (FAPE) to children ages 6 to 17. States may choose to provide services to students' ages 18 - 21. To qualify for federal assistance for ages 3 - 5, states must make FAPE available to all children ages 3 - 5 with disabilities.</p> <p>Services include:</p> <ul style="list-style-type: none"> • Preplacement evaluation • Re-evaluation at least once every three years • Individualized education program • Appropriate instruction in the least restrictive environment <p>Related and supportive services include:</p> <ul style="list-style-type: none"> • Audiology • Psychological services • Physical therapy • Occupational therapy • Transportation • Speech pathology • Counseling services • Medical services for diagnostic or evaluation purposes • Social work services
<p>Early Intervention Program for Infants and Toddlers with Disabilities</p>	<p>This is an entitlement program administered by education departments, health departments or other local agencies and co-leads, dependent on state where child resides.</p>	<p>The program purpose is to provide a system of comprehensive, multidisciplinary, coordinated services to infants and toddlers age 0 - 3 with disabilities and to their families.</p> <p>Services include:</p> <ul style="list-style-type: none"> • Multidisciplinary evaluation and assessment • Individualized Family Service Plan • Audiology • Family training • Medical services for diagnostic purposes • Nursing services

<p>Medicaid Programs</p>	<p>The Medicaid Program provides medical benefits to low-income people who have no medical insurance or inadequate medical insurance. States are required to include certain types of individuals or eligibility groups under their Medicaid plans and they may include others. States eligibility groups will be considered one of the following: categorically needy, medically needy, or special groups. <i>Medicaid At-a-Glance 2003</i></p>	<ul style="list-style-type: none"> • Nutrition services • Occupational therapy • Physical therapy • Service coordination • Other early intervention services for example, assistive devices, speech therapy) <p>Mandatory State Plan Services include:</p> <ul style="list-style-type: none"> • Inpatient hospital (excludes inpatient institutional mental health) • Outpatient hospital • Laboratory and x-ray • Certified pediatric and family nurse practitioners • Nursing facility services for age 21 and older • EPSDT for under age 21 • Family planning services and supplies • Physician services • Medical and surgical services of a dentist • Home health services for beneficiaries who are entitled to nursing facility services under the state's Medicaid plan (intermittent or part-time nursing services provided by home health agency or by a registered nurse when there is no home health agency in the area, home health aides, medical supplies and appliances for use in the home) • Nurse mid-wife services • Pregnancy related services and service for other conditions that might complicate pregnancy • 60 day postpartum pregnancy related services <p>See <i>Medicaid Services State Plan Chart</i> for specific types of optional Medicaid State Plan services.</p>	<p>The purpose of this program is to provide core public health functions to improve the health of mothers and children. The target population includes children with special health needs, including by not limited to disabilities. Services may include:</p> <ul style="list-style-type: none"> • Comprehensive health and related services for children with special health care needs • Basic health services (preventive screenings, prenatal and postpartum care, delivery, pediatric care, nutrition, immunization, drugs, lab tests, dental • Enabling services such as transportation, case management, home visiting,
<p>Maternal and Child Health Services Title V of Social Security Act</p>	<p>This is a health program of the U.S. Department of Health and Human Services, Maternal and Child Health Bureau that is administered by the state Maternal and Child Health programs in cooperation with local public health, Medicaid and other public and private providers</p>		

Foster Care Adoption Assistance	<p>These programs are administered by state public child welfare agencies or departments of social services to assist states in paying maintenance costs for adopted children with special needs and to prevent inappropriate stays in foster care.</p>	<p>translation, services, other services.</p>	<p>Services include:</p> <ul style="list-style-type: none"> • Direct cost of foster care maintenance • Placement • Case planning and review • Training for staff, parents, and private agency staff • Maintenance subsidies for dependent child from time of placement for adoption until age 18 or (21) • Training for staff and adoptive parents
Employment	<p>These programs are administered by state vocational rehabilitation offices and to prepare persons with disabilities to engage in competitive employment and to create and sustain jobs for disabled individuals who require competitive employment.</p> <p>*Although these services are usually implemented at 21 years of age, they should be considered in transition planning from youth to adult services.</p>		<p>Services include:</p> <ul style="list-style-type: none"> • Job training, referral, placement, follow up • Surgery, prosthetic and orthotic devices • Assistive devices • Treatment for emotional disorders • Interpreter and reader services • Transportation • Occupational licenses • Tools, equipment, supplies • Counseling • Coordination of services for students transitioning from school to work • Development of employment activities • On-site job coaches • Modification of job/ workplace
Legal Rights Protection and Advocacy for Individual Rights	<p>This program is administered through state protection and advocacy agencies to enable persons with disabilities to be a part of everyday community life at school, work and home by protecting their legal and human rights</p>		<p>Services include:</p> <ul style="list-style-type: none"> • Provides information and referral • Seeks to end discrimination against persons with disabilities particularly with respect to fair housing and employment issues
TRICARE	<p>TRICARE covers most health care that is medically necessary. But there are special rules or limits on certain types of care. TRICARE provides various levels of coverage such as TRICARE Standard, TRICARE Extra and TRICARE Prime. TRICARE Standard is the basic TRICARE health care program,</p>		<p>Funding for specified health care costs as dependent upon type of policy</p> <p>Case Management under certain conditions</p> <p>Standard is a fee-for-service plan that gives beneficiaries the option to see any TRICARE-certified/authorized provider (doctor, nurse-practitioner, lab, clinic, etc.). Standard offers the greatest flexibility in choosing a provider, but it will also involve greater out-of-pocket expenses. Beneficiaries may be</p>

Military

	<p>offering comprehensive health care coverage, for people not enrolled in <u>TRICARE Prime</u>. Active duty service members must take action to enroll in Prime, and many other beneficiaries choose to enroll in Prime also. Standard does not require enrollment.</p>	<p>required to file their own claims.</p> <ul style="list-style-type: none"> • Standard requires that you satisfy a yearly deductible before TRICARE cost sharing begins, and you will be required to pay co-payments or cost shares for outpatient care, medications, and inpatient care. • Established provider network for health care providers • TRICARE Standard helps pay most hospital bills for semi-private rooms, meals (including special diets), diagnostic tests, and treatment. It covers medical supplies such as bandages and syringes. And, it helps pay for covered care at some health care centers other than hospitals. • Prime is TRICARE's managed-care option, similar to a civilian HMO (health maintenance organization).
Exceptional Family Member Program	<p>The Military Services use the term Exceptional Family Member Program (EFMP) to refer to two different functions: a personnel function and a family support function.</p>	<p>The EFMP personnel function:</p> <ul style="list-style-type: none"> • Is a mandatory program for all active duty service members. • Is standard across all Services. • Identifies family members with special medical and/or educational needs, • Documents the services they require, and • Considers those needs during the personnel assignment process (especially when approving family members for accompanied travel to overseas locations). • Involves the personnel and medical commands and the Department of Defense educational system overseas. <p>The EFMP family support function:</p> <p>Is not mandatory. <u>DoD policy on family centers</u> allows, but does not require, the Military Services to offer family support services to exceptional family members within the Military Services' family support systems.</p> <p>Differs from Service to Service.</p> <p>Information regarding programs available to military families, leadership and service providers.</p>
Military HOMEFRONT website	<p>"Military HOMEFRONT is the central, trusted, up-to-date source for Service members and families to obtain information about all Quality of Life programs and services."</p> <p>http://www.militaryhomefront.dod.mil/</p>	
Military One Source	<p>Military <i>OneSource</i> is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify.</p> <p>There are hundreds of organizations that exist that</p>	<p>The primary role for Military <i>OneSource</i> is to provide education and options for potential resource supports.</p>
Based on specific		<p>Programs & Services :</p>
Disease		

Specific	condition of individual	<p>provide information and resources for persons who have a specific disease or condition. These are too numerous to list individually. As an example of some of the possible disease or condition specific organizations, the website for the National Organization of Rare Disorders provides a comprehensive list of conditions, some of which are life threatening or may be a co-existing condition for someone with a life threatening condition.</p> <p>http://www.rarediseases.org/programs/links/library</p>	<p>The following list represents a "Library Of Links" as outlined on the National Organization of Rare diseases as an example of the types of programs and services related to condition related resources.</p> <ul style="list-style-type: none"> • <u>NORD's Database of 2,000 Patient Organizations and Government Agencies</u> • <u>NORD Member Organizations (125)</u> • <u>Academic Clinical And Or Research Centers for Rare Diseases (1)</u> • <u>Cancer Resources (1)</u> • <u>Clinical Trials (3)</u> • <u>Conferences & Presentations (1)</u> • <u>General Health Sites (9)</u> • <u>Genetics For Medical Professionals (2)</u> • <u>Genetics Information (3)</u> • <u>Government Sites (14)</u> • <u>Health Policy Information (1)</u> • <u>Health Privacy Information (3)</u> • <u>International Sites (8)</u> • <u>Laboratory Testing</u> • <u>Medicare/Medicaid Information (8)</u> • <u>National Family Caregivers Month</u> • <u>Newborn Screening (2)</u> • <u>Planning For Children With Special Needs (1)</u> • <u>Resources for People with Disabilities (1)</u> • <u>Umbrella Organizations (23)</u> • <u>Universities/Hospitals (8)</u> • <u>Women's Health (1)</u> • <u>Other Sites of Interest (4)</u> <p>http://www.rarediseases.org/programs/links/library</p> <p>The following list represents categories of community resources identified in the National Capital Area.</p> <ul style="list-style-type: none"> • Associations and Care Organizations • Hospitals and Health Facilities • Hospice • Medical Information Sources • Government Resources
Other Local community resources	Disease Based Foundations Local resources		

-
- Adaptive Technology
 - Child Care
 - Financial Assistance
 - Medical Providers
 - Hotlines
 - Interpreters and Translation Services
 - Mental Health
 - Recreation and Camps
 - Support Groups
 - Transportation
 - Respite Care
 - Utility Assistance Programs
 - Wish Granting Programs
 - Special Education Information and Laws
 - Home Health Care
 - Durable Medical Equipment and Supplies
 - Bereavement Services
 - Self Esteem
 - Adult Day Care
 - Hearing/Visually Impaired
 - Vocational/Rehabilitation Services
 - Caregiver Resources
 - Resource Directories
 - Case Management Services
 - Community Resources
 - Pharmacy Programs
 - Planning
 - Therapeutic Services
 - Literature

ATTACHMENT B

	A	B	C	D	E	F
1	Military HOMEFRONT Site Map Review for topics and relevance to Children with Life Threatening Conditions					
2						
9	<p>Rating of Relevance High (1) -cshcn/medical focus Moderate (2)- child and family, but not elderly Low (3) is elderly and generically relevant to DoD personnel and situations</p>					
	Site Map Topic Headings	Relevance to Population 1=high 2=moderate 3=low	Level 3	Level 2	Level 1	Target Audience for information
10	Quick Links (External)	0				
11	Military OneSource	1				
12	DoD Severe Disabilities Impact Aid	1		DoD Impact Aid	DoD Impact Aid	Troops and Families
13	Special Needs	1		Education	Education	Troops and Families
14	Child Abuse Risk Factors	1		Child Abuse	Interpersonal Abuse	Troops and Families
15	Reporting Child Abuse	1		Child Abuse	Interpersonal Abuse	Troops and Families
16	Preventing Child Abuse	1		Child Abuse	Interpersonal Abuse	Troops and Families
17	New Parent Support Program	1	Preventing Child Abuse	Child Abuse	Interpersonal Abuse	Troops and Families
18	Never Shake a Baby	1	Preventing Child Abuse	Child Abuse	Interpersonal Abuse	Troops and Families
19	Child Advocates	1		Child Abuse	Interpersonal Abuse	Troops and Families
20						

	A	B	C	D	E	F
21	Medical and Dental	1	Medical and Dental	Medical and Dental	Medical and Dental	Troops and Families
22	Defense Eligibility Enrollment Reporting System	1		Medical and Dental	Medical and Dental	Troops and Families
23	Military Treatment Facility Locator	1		Medical and Dental	Medical and Dental	Troops and Families
24	Navigating Health Care	1		Medical and Dental	Medical and Dental	Troops and Families
25	Exceptional Family Member Program (EFMP) Confidentiality	1			Special Needs/EFMP	Troops and Families
26		1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
27	Army Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
28	Army EFMP Coordinators	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
29	Navy Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
30	Navy EFMP Coordinators	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
31	USMC Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
32	USMC EFMP Coordinators	1	USMC Exceptional Family Member Program	Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
33	Air Force Exceptional Family Member Program	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
34	Air Force Special Needs Officers	1	Air Force Exceptional Family Member Program	Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families

	A	B	C	D	E	F
	National Guard State Family Programs	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
35						
36	Coast Guard Work Life Programs	1		Exceptional Family Member Program (EFMP)	Special Needs/EFMP	Troops and Families
37	Early Intervention	1		Early Intervention	Education	Troops and Families
38	Eligibility	1		Early Intervention	Education	Troops and Families
39	Military Issues	1		Early Intervention	Education	Troops and Families
40	Contacts	1		Early Intervention	Education	Troops and Families
41	Eligibility	1		Special Education 3-21 years of age	Education	Troops and Families
42	Military Issues	1		Special Education 3-21 years of age	Education	Troops and Families
43	Regulations	1		Special Education 3-21 years of age	Education	Troops and Families
44	Contacts	1		Special Education 3-21 years of age	Education	Troops and Families
45	Program for Persons with Disabilities	1		TRICARE	Medical Care	Troops and Families
46	Contacts	1		TRICARE	Medical Care	Troops and Families
47	Case Management	1		TRICARE	Medical Care	Troops and Families
48	Hospice Care	1		TRICARE	Medical Care	Troops and Families
49	Respite Care	1		TRICARE	Medical Care	Troops and Families
50	Navigating Military Health Care	1		TRICARE	Medical Care	Troops and Families
51	Eligibility	1	Medicaid	Federal Programs	Medical Care	Troops and Families
52	Military Issues	1	Medicaid	Federal Programs	Medical Care	Troops and Families
53	Application Process	1	Medicaid	Federal Programs	Medical Care	Troops and Families

	A	B	C	D	E	F
54	Contacts	1	Medicaid	Federal Programs	Medical Care	Troops and Families
55	Eligibility	1	Title V	Federal Programs	Medical Care	Troops and Families
56	Military Issues	1	Title V	Federal Programs	Medical Care	Troops and Families
57	Application Process	1	Title V	Federal Programs	Medical Care	Troops and Families
58	Contacts	1	Title V	Federal Programs	Medical Care	Troops and Families
59	Family Connections	1		Family Connections	Medical Care	Troops and Families
60	Family Stories	1		Family Stories	Medical Care	Troops and Families
61	EFM Support	1		Family Support	Medical Care	Troops and Families
62	Special Needs Child Care	1		Family Support	Medical Care	Troops and Families
63	Respite Care	1		Family Support	Medical Care	Troops and Families
64	SSD (Social Security Disability)	1	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
65	State Resources	1		Resources	Medical Care	Troops and Families
66	FAQs	1		Resources	Medical Care	Troops and Families
67	ToolBox	1		Resources	Medical Care	Troops and Families
68	For Children	2		Child Development Programs	Children and Teens	Troops and Families
69	For Teens	2		Child Development Programs	Children and Teens	Troops and Families
70	Kids Information on Deployment Stuff	2			Deployment	Troops and Families
71	Preschool	2		Education	Education	Troops and Families
72	K-12	2		Education	Education	Troops and Families

	A	B	C	D	E	F
73	Scholarships	2		Education	Education	Troops and Families
74	Children & Youth	2		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
75	Libraries	2		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
76	The Healthy Parenting Initiative	2		Parenting	Parenting	Troops and Families
77	The New Parent Support Program	2		Parenting	Parenting	Troops and Families
78	Techniques for the Fussy Baby	2		Parenting	Parenting	Troops and Families
79	Head Start/Sure Start	2		Head Start/Sure Start	Education	Troops and Families
80	Recreation	2		Family Support	Medical Care	Troops and Families
81	Food Stamps	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
82	FSSA (Family Subsistence Supplemental Allowance)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
83	WIC/WIC (Women, Infants and Children Program)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
84	SSI (Supplemental Security Income)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
85	EIC (Earned Income Credit)	2	Federal Programs	Financial & Legal Issues	Medical Care	Troops and Families
86	Transition Planning	2			Medical Care	Troops and Families
87	Guardianship	2			Medical Care	Troops and Families
88	What's New	2		Resources	Medical Care	Troops and Families
89	US Army	3				
90	US Marine Corps	3				
91	US Navy	3				
92	US Air Force	3				
93	US Coast Guard	3				
94	National Guard	3				
95	Reserves	3				

	A	B	C	D	E	F
96	Faces of Defense	3				
97	Military.com	3				
98	Militarybenefits.com	3				
99	MilSpouse.org	3				
100	Pre-Paid Phone Cards	3				
101	Calendar	3		Calendar	Special offers Calendar	Troops and Families
102	Special Observances	3		Calendar	Calendar	Troops and Families
103	Army and Air Force Exchange Service	3			Commissaries and Exchanges	Troops and Families
104	Defense Commissary Agency	3			Commissaries and Exchanges	Troops and Families
105	Marine Corps Exchange	3			Commissaries and Exchanges	Troops and Families
106	Navy Exchange	3			Commissaries and Exchanges	Troops and Families
107	Deployment Preparation	3			Deployment	Troops and Families
108	DeploymentLink	3			Deployment	Troops and Families
109	During Deployment	3			Deployment	Troops and Families
110	Return and Reunion	3			Deployment	Troops and Families
111	Post-Deployment	3			Deployment	Troops and Families
112	FAQs	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
113	Terms & Acronyms	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
114	DoD Supplemental Impact Aid	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
115	Laws, Regulations & Policies	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
116	Funding History & Forms	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
117	Additional Resources	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
118	Federal Education Programs	3		DoD Impact Aid	DoD Impact Aid	Troops and Families

	A	B	C	D	E	F
119	DoD Education Programs & Resources	3		DoD Impact Aid	DoD Impact Aid	Troops and Families
120	Impact Aid	3		Education	Education	Troops and Families
121	Veterans Military Education and Training	3		Education	Education	Troops and Families
122	Voluntary Education	3		Education	Education	Troops and Families
123	General Information	3		Eldercare	Eldercare	Troops and Families
124	Medicaid	3		Eldercare	Eldercare	Troops and Families
125	Medicare	3		Eldercare	Eldercare	Troops and Families
126	Resources	3		Eldercare	Eldercare	Troops and Families
127	Social Security Administration	3		Eldercare	Eldercare	Troops and Families
128	TRICARE for Life	3		Eldercare	Eldercare	Troops and Families
129	Casualty Assistance	3		Emergencies and Disasters	Emergencies and Disasters	Troops and Families
130	Emergency Assistance	3		Emergencies and Disasters	Emergencies and Disasters	Troops and Families
131	DoD Resources	3		Jobs	Employment	Troops and Families
132	Government Resources	3		Jobs	Employment	Troops and Families
133	Service Resources	3		Jobs	Employment	Troops and Families
134	Other Resources	3		Jobs	Employment	Troops and Families
135	Family Member Employment	3			Employment	Troops and Families
136	Guard and Reserves	3			Guard and Reserves	Troops and Families
137	Military Housing	3		Military Housing	Housing	Troops and Families
138	Renting and Buying	3		Military Housing	Housing	Troops and Families

	A	B	C	D	E	F
139	What is FAP?	3			Interpersonal Abuse	Troops and Families
140	Domestic Abuse	3			Interpersonal Abuse	Troops and Families
141	Domestic Abuse Risk Factors	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
142	Victim Advocates	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
143	Reporting Domestic Abuse	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
144	Civilian and Military Protective Orders	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
145	Transitional Compensation Program	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
146	Preventing Domestic Abuse	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
147	Defense Task Force on Domestic Violence	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
148	Resources	3		Domestic Abuse	Interpersonal Abuse	Troops and Families
149	Transitional Compensation Program Resources	3			Interpersonal Abuse	Troops and Families
150		3			Interpersonal Abuse	Troops and Families
151	Legal Matters	3	Legal Matters	Legal Matters	Legal Matters	Troops and Families
152	Military Severely Injured	3		Military Severely Injured	Military Severely Injured	Troops and Families
153	Business Programs	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
154	Fitness & Sports	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
155	Funding Standard	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
156	Glossary	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families

	A	B	C	D	E	F
	History			Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
157	Leisure Travel	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
158	Links	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
159	Patronage	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
160	Recreation	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
161	Single Service Member	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
162	What's New?	3		Morale, Welfare and Recreation (MWR)	Morale, Welfare and Recreation (MWR)	Troops and Families
163	Defense Finance and Accounting Service	3		Pay and Benefits	Pay and Benefits	Troops and Families
164	OSD Military Compensation Site	3		Pay and Benefits	Pay and Benefits	Troops and Families
165	Hot Information Sites	3		Personal Finances	Personal Finances	Troops and Families
166	Don't Get Scammed	3		Personal Finances	Personal Finances	Troops and Families
167	Financial Readiness Programs	3		Personal Finances	Personal Finances	Troops and Families
168	Points of Contact	3		Networking / Partnerships	Networking / Partnerships	Troops and Families
169	Planning	3		Relocation	Relocation	Troops and Families
170	Plan My Move	3		Planning	Relocation	Troops and Families
171	Plan My Budget	3		Planning	Relocation	Troops and Families
172	Plan My Housing	3		Planning	Relocation	Troops and Families
173		3				

	A	B	C	D	E	F
174	Plan My Travel	3		Planning	Relocation	Troops and Families
175	Plan My Timeline	3		Planning	Relocation	Troops and Families
176	Hints and Tip Sheets	3		Relocation	Relocation	Troops and Families
177	Career Education	3		Children over 21	Education	Troops and Families
178	Vocational Rehabilitation	3		Children over 21	Education	Troops and Families
179	Housing Needs	3		Children over 21	Education	Troops and Families
180	Community Living	3		Children over 21	Education	Troops and Families
181	Section 811	3		Children over 21	Education	Troops and Families
182	Loans for Accommodations	3		Children over 21	Education	Troops and Families
183	Age Limitations	3		Children over 21	Education	Troops and Families
184	Medicare	3		Federal Programs	Medical Care	Troops and Families
185	Services & Benefits	3	Medicare	Federal Programs	Medical Care	Troops and Families
186	Eligibility	3	Medicare	Federal Programs	Medical Care	Troops and Families
187	Application Process	3	Medicare	Federal Programs	Medical Care	Troops and Families
188	Contacts	3	Medicare	Federal Programs	Medical Care	Troops and Families
189	Estate Plans	3		Financial Planning	Medical Care	Troops and Families
190	Tax Benefits	3		Financial Planning	Medical Care	Troops and Families
191	IRS Assistance	3		Financial Planning	Medical Care	Troops and Families
192	Resources	3		Financial Planning	Medical Care	Troops and Families
193	Monthly Expenses Calculator	3		Financial Planning	Medical Care	Troops and Families

	A	B	C	D	E	F
194	Transition Assistance	3			Transition Assistance	Troops and Families
195	United In Memory/UIM	3			United In Memory/UIM	Troops and Families
196	Pentagon Memorial	3			United In Memory/UIM	Troops and Families
197	Pentagon Renovation and Construction	3			United In Memory/UIM	Troops and Families
198	Operation Solace	3			United In Memory/UIM	Troops and Families
199	Helping Families Cope	3			United In Memory/UIM	Troops and Families
200	Defend America	3			United In Memory/UIM	Troops and Families
201	PFAC After Action Report	3			United In Memory/UIM	Troops and Families
202	Benefactors	3			United In Memory/UIM	Troops and Families
203	Links	3			United In Memory/UIM	Troops and Families



Attachment C

Military *OneSource*

Background Information

On June 17, 2004 an onsite visit was made to the Ceridian office in Plymouth Meeting, Pennsylvania for the purpose of understanding the Military *OneSource* Program available to active military personnel. Military *OneSource* is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify. The primary role for Military *OneSource* is to provide education and options for potential resource supports.

The site visit included spending the day with Ronald White, Director for Military Program Management and Dan Lafferty, Clinical Supervisor for the program. Mr. White has an extensive background in social work as well as international experience related to information and referral supports. Mr. Lafferty is a licensed social worker with certification as an Employee Assistance Professional with military experience in the Air Force. Both have expert experience in the area of employee benefits.

In addition to providing services for the military, Ceridian serves over 10,000 organizations internationally, which translates to over 10 million employees. This Employee Assistance Program (EAP) benefit has been phased in to the various branches of the military over the past four years and is currently available to the Army, Marine Corps, Air Force and Navy. Mr. White estimates that 2.6 million individuals in the military have access to this benefit. Extensive and active marketing campaigns have been implemented to ensure awareness of the service as well as information about its use. Utilization data is tracked and sorted by service branch and reviewed to identify areas for further marketing opportunities for Ceridian.

During the visit, Ceridian personnel emphasize the company's commitment to meeting the needs of the population as it operates an extensive quality assurance program that is evident throughout the facility and through interviews with various personnel.

In an effort to build a collaborative relationship between Military *OneSource* and the project team, Carol Marsiglia led a discussion regarding the *mCare* Project. Juli Lausch prepared an extensive list of questions to be addressed throughout the tour and again at the end of the day. Dcona Howard also attended the day. The discussion included an overall description of the project and phases for development of a model of care for children of military families who have life threatening conditions. In addition, use of community and military resources was emphasized to identify areas of potential interface between Ceridian services and needs of the population. Mr. White indicated a willingness to support the project through the use of Ceridian services. The role of the company as it relates to Military *OneSource* is that of referral and education. Therefore, it is important to note that accessing services identified by Ceridian is the responsibility of the military personnel seeking assistance and beyond the scope of service provided by Ceridian.

There are three Ceridian service centers in the United States that serve the military at home and abroad. These offices are located in Plymouth Meeting, PA, Minneapolis, MN and Miami, FL. The Plymouth Meeting and Minneapolis locations are described as mirror images of each other with Miami specializing in multilingual and multicultural services. All locations have access to a translation service.

Tour of Service Center

Information Technology and Telecommunications

Jo-Anne Mullen, Director and Jerry McDonnell, who are ultimately responsible for the overall security of the data system, presented an overview of the Information Technology and Telecommunications Center. A predictive algorithm is used to process calls to ensure efficiency in answering call volume. The time standard set to respond to a call is 20 seconds with no automated answering system used. The calls are answered by a trained triage specialist who then forwards the calls to the appropriate content specialist. There are over 200 phone numbers used to access the

organization's services. International access is available and the organization accepts collect calls.

Mullen and McDonnell described an extensive disaster plan and reported that it is tested regularly. They stated that in the event of a disaster, all calls can be moved to an alternate center through "5 key strokes" and that this is a transparent process to the caller. As part of the disaster plan, a redundancy plan is in effect. All data is replicated at the Minneapolis center allowing consultants at other centers to access all data information necessary for business continuity, as well as storage of backup at an alternate location in Louisville, Kentucky. Backups occur multiple times throughout the day.

In addition to telephone based communications, the service is web based and operates on multiple servers that are reportedly able to handle extremely high volume loads with no evidence of performance problems. Utilization trends are reported to vary with the Army population, in that 70 % of requests are received via Internet with 30% via telephone. The other military branches are reported to be approximately 80% Internet with 20% telephone requests.

Mr. White indicates that they anticipate greater Army telephone usage over time, similar to other organizational patterns. Generally, utilization reporting is based on service type, location, and demographics such as military grade and family member using the service. Custom reports can be designed and provided upon request.

Fulfillment Center

The Fulfillment Center houses educational materials and publications that are provided to the Ceridian consultants to meet the needs of the individuals making information requests. Information distributed has been developed by or cited from experts in a particular content area. For military specific content, such as items that can be sent overseas, military personnel review the information. For more generic topics, such as coping with stress, only information validated by experts in the field is used. Some publications can be reproduced within the Fulfillment Center and some are purchased for distribution.

Service Delivery/ Research

Masters level consultants handle all calls for Military *OneSource* and the staff is configured into teams. Clinical Supervisors are responsible for Consultant Teams and are to be notified of all situations defined as significant. Examples of these would include such issues as domestic, child or elder abuse, as well as concerns that have legal implications. The Clinical Supervisor is then responsible to ensure that all actions and resources have been provided to the requestor to address the issue. In addition, the Clinical Supervisor is responsible for reviewing two cases per month for each Consultant on their team as a part of the quality assurance process for services.

Call information such as demographics and requests are documented in the Case Management System, which is a custom developed software system used by the Ceridian staff. The software is an integrated system that communicates with scheduling for tracking purposes, reporting for utilization and communication with Fulfillment area as well as with other members of the service delivery team. During normal business hours, calls are triaged and assigned to Consultant Specialists or Consultant Generalists, dependant upon caller needs. During non-business hours, calls are handled by Consultant Generalists and assigned as necessary to specialists. Calls are accepted 24 hours per day, 7 days per week and 365 days per year. Consultant Specialists are available in the area of adoption, childcare, disability, education and international resources. All other topics are handled by Consultant Generalists. Consultants use an internal database of existing resource information or they send a request to a researcher for more specific information. The researcher also has access to an internal database of resources, as well as an Internet capability search. The researcher can utilize multiple strategies to access information requests. All information for contact is validated by the researcher prior to submission back to the consultant for distribution to the requester. For health specific information, researchers are expected to use web sites that are credible based on their URL including "edu", "gov" or "org".

The service center itself is a rather large area of individually divided workspaces separated by low level partitions, each equipped with a desk computer and telephone. The area is remarkably quiet despite the constant communication between requesters of information and Consultants. Each Consultant wears earphones and therefore no telephone tones are overheard in the work areas.

The service delivery system is currently in the process for accreditation by the Commission on Accreditation.

Quality Management

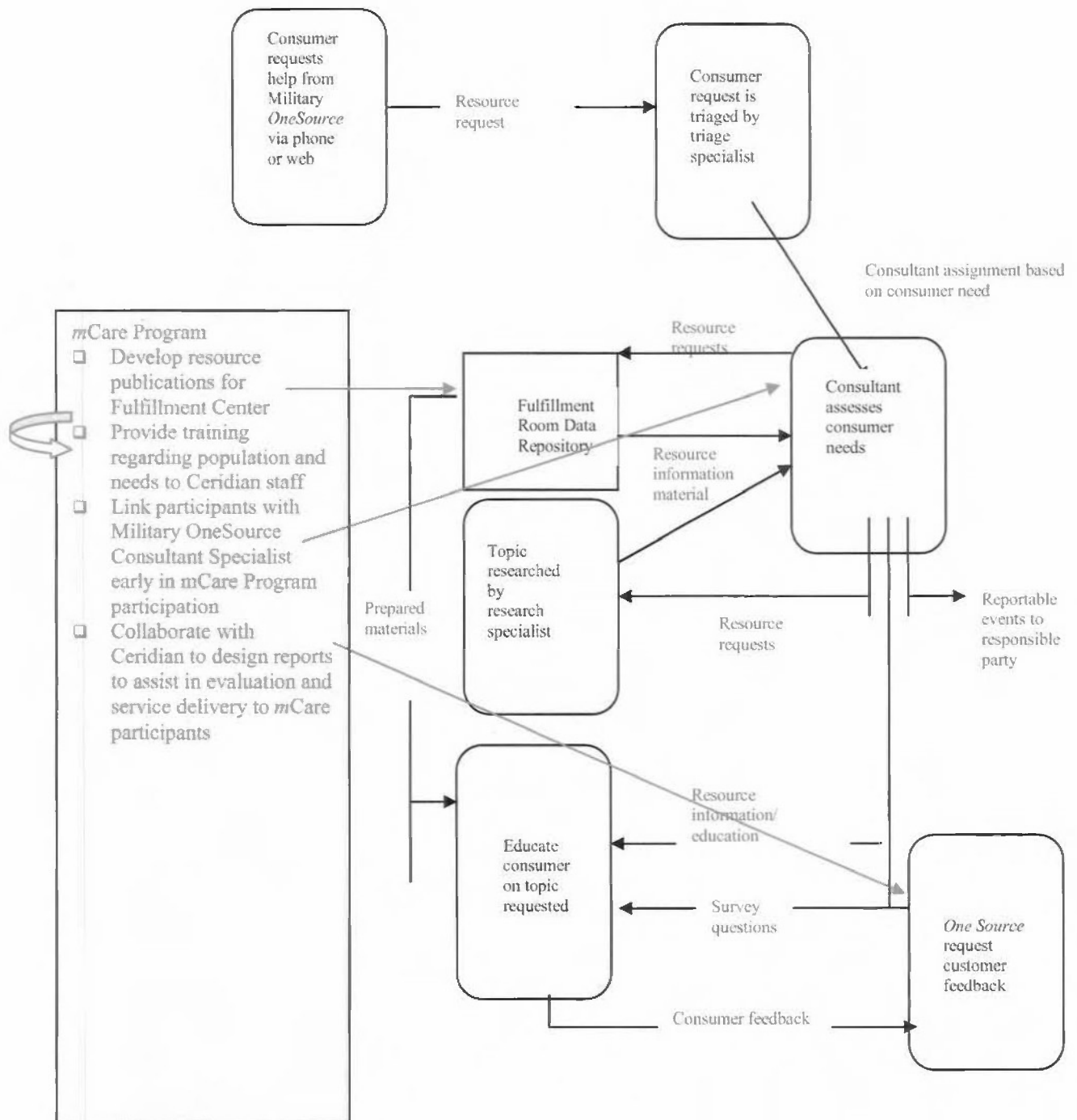
An emphasis on quality is evident throughout the organization as demonstrated by real time data and quality targets posted throughout the service center. These quality targets include answered calls, average hold time and calls abandoned. Goals that are below target are shown in red while on target goals are green. Diane Opere is a manager in Quality Services. She explained that user feedback is extremely important to the organization and is measured through various modes. There is an Interactive Voice Audit Survey and an online survey offered to all customers. The Interactive Voice Audit System allows the customer to answer survey questions in an anonymous way. The online survey is sent 1 week following intervention by Military *OneSource*. Overall return rates are reported at 25% for telephone audit and 28% electronically. Under certain circumstances, referral options are tagged “do not use” based on responses from consumers. Customer feedback reports are submitted to clinical supervisors on a monthly basis. Ceridian reports that they are currently working with the Military Research Center at Purdue relative to outcome measures. The company is currently attempting to demonstrate outcomes such as time saved and decreased stress in seeking resource information. Next generation outcome work will be geared toward measurement of military readiness and retention. Ceridian is reportedly considered a business associate as it relates to the Health Information Accountability and Portability Act (HIPAA).

Recommendations

- Incorporate use of Military *OneSource* Program in future program model to support access to military and community resources as well as general educational information on family related topics.
- Identify information topics that apply to children with life threatening conditions for inclusion in Military *OneSource* databases.
- Collaborate with Ceridian to incorporate publications that target the needs of children with life threatening conditions, specifically including CHI publications relating to palliative care.

- Identify additional resource linkages to Military *OneSource* that are specific to the *mCare* population.
- Offer training for Military *OneSource* Supervisors, Consultants (general and specialist) and researchers regarding *mCare* population.
- Consider reporting needs for *mCare* population and collaborate with Ceridian to submit reports for targeted population.
- Incorporate Health on the Net Code Guidelines related to the distribution of medical and health specific information to ensure credibility and quality.
- Identify any issues related to HIPAA regarding the distribution of resource or health information as it relates to model/program design.
- Educate families participating in *mCare* on the benefits of telephonic mode to promote comprehensive response to the needs request.
- Address the gap regarding accessing services as it relates to the education and resource information role of Military *OneSource* verses more intensive care coordination.
- Develop a means to measure outcomes related to the use of Ceridian services with the *mCare* population.

Data Flow Diagram
Military *OneSource* Process for Resource Information Requests



ATTACHMENT D

ID #	RESOURCE NAME	NEW CATEGORY
25	Life Link	Adaptive Technology
60	Adaptive Mail	Adaptive Technology
62	Ablenet	Adaptive Technology
	Crestwood Communication Aids	Adaptive Technology
	Direct Link, Emergency Monitoring System	Adaptive Technology
75	Medic Alert	Adaptive Technology
115	Enabling Devices	Adaptive Technology
116	Integrations	Adaptive Technology
117	Sport Time	Adaptive Technology
118	Flighthouse	Adaptive Technology
156	Dakota Link	Adaptive Technology
157	Horchel Lifting Systems	Adaptive Technology
162	Abilitations	Adaptive Technology
163	Southpaw Enterprises	Adaptive Technology
169	Health Science	Adaptive Technology
170	Dynavox	Adaptive Technology
	Maryland Accessible Telecommunications Program	Adaptive Technology
228	ATLFA – Virginia	Adaptive Technology
411	Assistech	Adaptive Technology
413	AVRS Inc.	Adaptive Technology
414	Computer Prompting and Captioning	Adaptive Technology
416	Future Home	Adaptive Technology
420	Assisted Access and NFSS Communication	Adaptive Technology
	RESNA – Rehab. Engineering and Assistive Technology	Adaptive Technology
424	Office of Volunteers for Medical Engineering	Adaptive Technology
428	Wheelchair Society	Adaptive Technology
486	Montgomery College Disability Support	Adaptive Technology
	Montgomery College Disability Support – Takoma Park Campus	Adaptive Technology
	Montgomery College Disability Support – Germantown Campus	Adaptive Technology
488	SHARE Network	Adaptive Technology
905	Asbury Methodist Adult Day Care	Adult Day Care
430	Misler Adult Day Center	Adult Day Care
431	Support Center – Rockville	Adult Day Care
434	Bethesda Fellowship House	Adult Day Care
439	The League for People with Disabilities – Fehsenfeld Medical Day Program	Adult Day Care
500	The League for People with Disabilities – Adult Day Services for Seniors	Adult Day Care
501	Randolph Hill's Nursing and Adult Day Care	Adult Day Care / Nursing Home
432	Charlestown	Assisted Living
95	Tranquillity at Fredericktowne	Assisted Living
261	Automatic Senior Assisted Living	Assisted Living
607	Winter Growth	Assisted Living / Adult Day Care
435	Renaissance Gardens-rehabilitation care unit	Assisted Living / Health Facility
96	Bello Machre	Associations and Care Organizations
69	Bello Machre - Community Living	Associations and Care Organizations
70	Bello Machre - Family Living	Associations and Care Organizations
71	Bello Machre - Support Services	Associations and Care Organizations
72	The Magic Foundation	Associations and Care Organizations
82	Epilepsy Foundation	Associations and Care Organizations
98	Abilities Network	Associations and Care Organizations
99	ARC of Anne Arundel County	Associations and Care Organizations
200	CHADD	Associations and Care Organizations
	Spina Bifida Association of America	Associations and Care Organizations
213	Birthright International	Associations and Care Organizations
214	Learning Disabilities Association of America	Associations and Care Organizations
216	The ARC of Frederick County – Support services	Associations and Care Organizations
219	United Way of Frederick County	Associations and Care Organizations

220	American Red Cross – Frederick County	Associations and Care Organizations
226	Salvation Army – Frederick County	Associations and Care Organizations
231	Alzheimer's Association – Frederick	Associations and Care Organizations
	The Arthritis Foundation – Western Maryland	
27	Chapter	Associations and Care Organizations
	Care Net Pregnancy Center	Associations and Care Organizations
42	Cystic Fibrosis Foundation	Associations and Care Organizations
249	Yes I Can International	Associations and Care Organizations
259	The Leukemia & Lymphoma Society	Associations and Care Organizations
	Allergy/Asthma Network – Mothers of Asthmatics	
305	Inc.	Associations and Care Organizations
307	Asthma and Allergy Foundation	Associations and Care Organizations
311	Autism Society of America	Associations and Care Organizations
316	Bear Necessities Pediatric Cancer Foundation	Associations and Care Organizations
317	The Brain Injury Association of MD	Associations and Care Organizations
327	Maryland Lupus Foundation –	Associations and Care Organizations
329	Sickle Cell Association of America	Associations and Care Organizations
37	Chesapeake Potomac Spina Bifida Association	Associations and Care Organizations
54	Hospice Network of Maryland	Associations and Care Organizations
56	National Children's Cancer Society	Associations and Care Organizations
80	United Cerebral Palsy – National Headquarters	Associations and Care Organizations
	UCP of Central Maryland- No Boundaries	
81	Assistive Technology Center	Associations and Care Organizations
	UCP Central Maryland – Central MD	
82	Headquarters	Associations and Care Organizations
	United Cerebral Palsy of Central Maryland – In	
86	Home Support – Central	Associations and Care Organizations
94	Americans for Better Care of the Dying	Associations and Care Organizations
15	American Brain Tumor Association	Associations and Care Organizations
	Community Services for Autistic Adults and	
	Children	Associations and Care Organizations
	ARC of Montgomery County – Children's	
10	Services	Associations and Care Organizations
	ARC of Montgomery County Family and	
1	Community Resources	Associations and Care Organizations
8	ARC of Montgomery County	Associations and Care Organizations
	Easter Seals Society for Disabled Children and	
1	Adults	Associations and Care Organizations
4	Jewish Social Services Agency	Associations and Care Organizations
3	Kennedy Institute	Associations and Care Organizations
3	UCP of Prince George's & Montgomery Co.	Associations and Care Organizations
1	Alexander Graham Bell Association for the Deaf	Associations and Care Organizations
	American Speech, Language & Hearing	
	Association	Associations and Care Organizations
1	Candlelighters – Childhood Cancer Foundation	Associations and Care Organizations
	Believe in Tomorrow – National Children's	
	Foundation	Associations and Care Organizations
	CANCERcare	Associations and Care Organizations
	National Association of Hospitality Houses	Associations and Care Organizations
	National Multiple Sclerosis Society	
	(Headquarters)	Associations and Care Organizations
	Hospice Foundation of America	Associations and Care Organizations
	Super Sibs	Associations and Care Organizations
	National Hospice and Palliative Care	
	Organization	Associations and Care Organizations
	Hospice Education Institute	Associations and Care Organizations
	Association for the Support of Children with	
	Cancer	Associations and Care Organizations
	Muscular Dystrophy Association	Associations and Care Organizations
	Muscular Dystrophy Family Foundation	Associations and Care Organizations
	Parent Project Muscular Dystrophy	Associations and Care Organizations
	Cystic Fibrosis Research, Inc.	Associations and Care Organizations
	Families of Spinal Muscular Atrophy	Associations and Care Organizations
	SMA Support	Associations and Care Organizations

774	Prader-Willi Syndrome Association	Associations and Care Organizations
775	National Spinal Cord Injury Association	Associations and Care Organizations
790	National Fragile X Foundation	Associations and Care Organizations
800	American Spinal Injury Association	Associations and Care Organizations
821	The Wellness Community	Associations and Care Organizations
829	American Association on Mental Retardation SEEC	Associations and Care Organizations
830	Richcroft Inc.	Associations and Care Organizations
831	Multiple Sclerosis Society - Maryland	Associations and Care Organizations
832	Changing People's Lives (CPL)	Associations and Care Organizations
833	Alliance Inc.	Associations and Care Organizations
834	Lt. Joseph P. Kennedy Institute	Associations and Care Organizations
835	Center for Social Change Inc.	Associations and Care Organizations
836	Community Living Inc.	Associations and Care Organizations
843	Center for Community Integration	Associations and Care Organizations
850	ALSA (ALS Association)	Associations and Care Organizations
855	Hospice Patients Alliance	Associations and Care Organizations
858	Brain Tumor Society	Associations and Care Organizations
859	Children's Brain Tumor Foundation	Associations and Care Organizations
860	Childhood Leukemia Foundation	Associations and Care Organizations
863	Pediatric Brain Tumor Foundation	Associations and Care Organizations
865	American Cancer Society	Associations and Care Organizations
866	American Chronic Pain Association	Associations and Care Organizations
884	The Multiple Sclerosis Association of America	Associations and Care Organizations
899	MSF - Multiple Sclerosis Foundation	Associations and Care Organizations
217	The ARC of Frederick County - Service Coordination	Associations and Care Organizations / Case Management Services
894	National Cystic Fibrosis Awareness Committee	Associations and Care Organizations / Community Resource Associations and Care Organizations / Medical Information Sources
765	National Organization for Rare Disorders	Associations and Care Organizations / Medical Information Sources
806	Madison's Foundation	Associations and Care Organizations / Resource Directories
801	Children's Hospice International	Associations and Care Organizations / Resource Directories
907	World Association of Physically Disabled	Associations and Care Organizations / Resource Directories
387	Joni and Friends United Cerebral Palsy of Central Maryland - Respite Care	Associations and Care Organizations / Respite Care
739	Starlight Starbright Children's Foundation	Associations and Care Organizations / Wish Granting Programs
722	National Family Caregivers Association	Associations and Care Organizations/ Caregiver Resources
802	MAAP Services for Autism and Asperger Spectrum	Associations and Care Organizations/ Medical Information Sources
79	Hospice of the Chesapeake - Spiritual and Bereavement Care Center	Bereavement Services
239	Healing Hearts for Bereaved Parents	Bereavement Services
333	KIDSAID	Bereavement Services
455	The Compassionate Friends	Bereavement Services
578	Griefnet.org	Bereavement Services
585	St. Agnes - Bereavement Services	Bereavement Services
649	Stella Maris, Center for Grief and Loss	Bereavement Services
856	Dougy Center for Grieving Children and Families	Bereavement Services
857	Beyond Indigo	Bereavement Services
962	Crisis, Grief and Healing	Bereavement Services
975	Comfort Zone Camp	Bereavement Services
356	TAPS - Tragedy Assistance Program for Survivors, Inc.	Bereavement Services
337	Centering Corporation	Bereavement Services
361	Wendt Center for Loss and Healing	Bereavement Services
189	Initiative for Pediatric Palliative Care	Bereavement Services / Community Resources
123	Compassion Books	Bereavement Services / Literature
27	When Children Die: Improving Palliative and End- of Life Care for Children	Bereavement Services / Literature
	Exceptional Parent	Caregiver Resource / Resource Directories
	The Family Tree	Caregiver Resources

54	Caring Communities	Caregiver Resources
208	Family Resource Center	Caregiver Resources
210	YWCA West County Family Support	Caregiver Resources
246	Families Plus	Caregiver Resources
27	Parent's Place of Maryland	Caregiver Resources
70	Family Services Agency	Caregiver Resources
71	Family Caragiver Alliance	Caregiver Resources
771	Family Voices	Caregiver Resources
809	Strength for Caring	Caregiver Resources
810	Family Partnership of Frederick County	Caregiver Resources
811	Friends of the Family	Caregiver Resources
812	Adelphi/Langley Park Family Support Center	Caregiver Resources
813	Families Foremost Center	Caregiver Resources
199	Department for Family Support Services (Kennedy Krieger)	Caregiver Resources / Case Management Services
804	Matrix Parent Network and Resource Center	Caregiver Resources / Resource Directories
878	Baltimore Health Care Access Inc.	Case Management Services / Resource Directories
309	Health Services for Children with Special Needs	Case Management Services / Respite Care
	Child Care Choices – Assistance in Locating	
237	Childcare	Child Care
	ARC of Montgomery County – Family and Infant	
442	Child Care Center	Child Care
	ARC of Montgomery County – Child Care Center	
444	– Silver Spring	Child Care
445	Locate Child Care	Child Care
757	www.student-sitters.com	Childcare
28	Turnaround Inc.	Community Resources
206	Frederick Community Action Agency	Community Resources
212	Benefits Information Source	Community Resources
222	Gale Houses Inc.	Community Resources
27	YMCA – Frederick County	Community Resources
	Advocates for Homeless Families	Community Resources
42	Frederick Arts Council	Community Resources
235	Seton Center	Community Resources
245	Frederick County Cooperative Extension	Community Resources
247	Goodwill Industries	Community Resources
250	Heartly House	Community Resources
252	Historical Society of Frederick County	Community Resources
258	Legal Aid Bureau	Community Resources
260	Literacy Council of Frederick County	Community Resources
265	Independence Now	Community Resources
	MD Association of Resources for Families and	
300	Youth	Community Resources
318	Learning Services Corporation	Community Resources
320	Autism Outreach Inc.	Community Resources
325	Coalition to End Lead Poisoning	Community Resources
391	Shepherds Table	Community Resources
392	Laurel Advocacy and Referral Services	Community Resources
	Catholic Charities of the Archdiocese of	
395	Baltimore	Community Resources
396	Bethesda Cares Inc.	Community Resources
421	Maryland Disabilities Forum	Community Resources
447	Child Welfare League of America	Community Resources
448	Children's Defense Fund	Community Resources
451	Dept. of Neighborhood & Community Services	Community Resources
452	Adventist Community Services	Community Resources
47	C-4 Clothes Closet	Community Resources
	Interfaith Services	Community Resources
	Florence Crittendon Services of Greater	
472	Washington	Community Resources
485	Jewish Council for Aging	Community Resources
57	Creative Options	Community Resources
108	Partners in Care	Community Resources
109	Big Brother / Big Sister of Central Maryland	Community Resources

113	Maryland Disability Law Center	Community Resources
877	EFM Connections	Community Resources / Caregiver Resources / Case Mgt. Services
243	Frederick County Developmental Center	Community Resources / Government Resources
900	Transplant Resource Center of Maryland	Community Resources / Medical Information Sources
	The Special Needs Network	Community Resources / Planning
	Respite Resources & Information - Virginia	
908	Commonwealth University	Community Resources / Respite/ Resource Directories
597	Making Choices for Independent Living	Community Resources / Vocational/Rehabilitation Services
410	Apria	Durable Medical Equipment
39	CPR Medical	Durable Medical Equipment & Supplies
66	Hard Manufacturing	Durable Medical Equipment & Supplies
67	Vail - Enclosed Beds	Durable Medical Equipment & Supplies
104	Mid Atlantic Healthcare	Durable Medical Equipment & Supplies
112	DS Medical	Durable Medical Equipment & Supplies
114	Transtracheal Systems	Durable Medical Equipment & Supplies
119	Quantum Rehabilitation	Durable Medical Equipment & Supplies
120	Home Mediserve	Durable Medical Equipment & Supplies
154	Advanced Respiratory	Durable Medical Equipment & Supplies
155	Medirents	Durable Medical Equipment & Supplies
159	Roberts Home Medical	Durable Medical Equipment & Supplies
164	LEVO	Durable Medical Equipment & Supplies
165	Chesapeake Rehab	Durable Medical Equipment & Supplies
166	Home Delivery of Incontinent Supplies	Durable Medical Equipment & Supplies
167	ROHO	Durable Medical Equipment & Supplies
425	Spectrum Medical	Durable Medical Equipment & Supplies
83	MAMSI	Financial Assistance
84	Jill Fox Fund	Financial Assistance
85	Digital Federal Credit Union	Financial Assistance
100	Assistive Technology Guaranteed Loan Program	Financial Assistance
	Disabled Children's Relief Fund	Financial Assistance
200	Vision USA	Financial Assistance
201	REACH	Financial Assistance
335	Kidney Disease Program of Maryland	Financial Assistance
336	American Kidney Fund	Financial Assistance
	Foundation of Dentistry for the Handicapped -	
339	Donated Dental Services Program	Financial Assistance
347	Children's Organ Transplant Association	Financial Assistance
456	Clayton Dabney Foundation for Kids	Financial Assistance
511	MCHP	Financial Assistance
525	Bou Ten Sci - Charity Fund	Financial Assistance
	Medical Care for Children Partnership / Catholic	
546	Charities	Financial Assistance
547	Justin Scott Foster Foundation	Financial Assistance
569	Kelly Anne Dolan Memorial Fund	Financial Assistance
594	Jeremy Foundation	Financial Assistance
601	Lungs for Life Foundation	Financial Assistance
662	Challenged America	Financial Assistance
	Alexander G. Bell Association for the Deaf -	
696	Grant for School age children	Financial Assistance
	Alexander G. Bell Association for the Deaf -	
697	Grant for Arts and Sciences	Financial Assistance
	Alexander G. Bell Association for the Deaf -	
698	College Scholarship	Financial Assistance
	AMBUCS - Therapeutic Tricycles for Disabled	
699	Children	Financial Assistance
	Delta Gamma Memorial Scholarship	Financial Assistance
701	Ferdinand Torres Scholarship	Financial Assistance
702	Karen D. Cersel Memorial Scholarship	Financial Assistance
703	R.L. Gilette Scholarship	Financial Assistance
704	Rudolf Dillman Memorial Scholarship	Financial Assistance
	Assistive Technology Fund by the Association of	
705	Blind Citizens	Financial Assistance

706	Reggie Johnson Memorial Scholarship- Association of Blind Citizens	Financial Assistance
707	Christian Record Services Scholarships	Financial Assistance
711	Casey Martin Award and Non-Profit Grant Award	Financial Assistance
710	Billy Barty Foundation Scholarship	Financial Assistance
712	Cystic Fibrosis Scholarship Foundation	Financial Assistance
713	Minnie Pearl Foundation Scholarship	Financial Assistance
713	Brighter Tomorrow Grant	Financial Assistance
823	PAF Patient Assistance Program	Financial Assistance
839	Cancer Fund of America	Financial Assistance
840	National Transplant Assistance Fund	Financial Assistance
871	First Hand Foundation	Financial Assistance
695	Alexander G. Bell Association for the Deaf - Grant for Infant and pre-school age Montgomery County -Child Care Subsidy Program	Financial Assistance
446	The Genentech Endowment for Cystic Fibrosis Tobramycin Solution for Inhalation Therapy	Financial Assistance / Child Care Financial Assistance / Pharmacy Program
750	(TOBI) Foundation	Financial Assistance / Pharmacy Programs
0	Maryland DHR/DSS	Government Resources
1	Anne Arundel County - DSS	Government Resources
2	Allegany County - DSS	Government Resources
3	Cecil County - DSS	Government Resources
4	Baltimore City - DSS	Government Resources
5	Carroll County - DSS	Government Resources
6	Baltimore County - DSS	Government Resources
7	Calvert County - DSS	Government Resources
8	Dorchester County - DSS	Government Resources
9	Frederick County - DSS	Government Resources
10	Garrett County - DSS	Government Resources
11	Harford County - DSS	Government Resources
12	Howard County - DSS	Government Resources
13	Kent County - DSS	Government Resources
14	Montgomery County- DSS	Government Resources
15	Prince George's County - DSS	Government Resources
16	Charles County - DSS	Government Resources
17	Queen Anne's County - DSS	Government Resources
18	St. Mary's County - DSS	Government Resources
19	Somerset County - DSS	Government Resources
20	Talbot County - DSS	Government Resources
21	Washington County - DSS	Government Resources
22	Wicomico County - DSS	Government Resources
23	Worcester County - DSS	Government Resources
24	Caroline County - DSS	Government Resources
221	Adult Protection Services Prince George's County	Government Resources
234	Attorney General's Office of Consumer Protection	Government Resources
236	Chamber of Commerce - Frederick Co.	Government Resources
253	Housing Authority of the City of Frederick	Government Resources
326	Maryland Lead Poisoning Division	Government Resources
359	Maryland Department of Aging Worcester County - Senior Information & Assistance Center	Government Resources
360	MD Area Agency on Aging - Allegany County	Government Resources
361	MD Area Agency on Aging - Anne Arundel Co.	Government Resources
362	MD Area Agency on Aging - Baltimore City	Government Resources
363	MD Area Agency on Aging - Baltimore County	Government Resources
364	MD Area Agency on Aging - Calvert County	Government Resources
365	MD Area Agency on Aging - Kent/Caroline/Talbot Counties - Upper Shore Aging	Government Resources
366	MD Area Agency on Aging - Carroll County	Government Resources
367		

368	MD Area Agency on Aging – Cecil County	Government Resources
369	MD Area Agency on Aging – Charles County	Government Resources
	MD Area Agency on Aging –	
370	Dorchester/Somerset/Wicomico Counties	Government Resources
?	Frederick County Dept. of Aging	Government Resources
	MD Area Agency on Aging – Garrett County	Government Resources
373	MD Area Agency on Aging – Harford County	Government Resources
374	Howard County – Office on Aging	Government Resources
375	MD Area Agency on Aging – Montgomery County	Government Resources
	MD Area Agency on Aging – Prince George's	
376	County	Government Resources
	MD Area Agency on Aging – Queen Anne's	
377	County	Government Resources
	MD Area Agency on Aging – St. Mary's County –	
378	Dept. of Aging	Government Resources
379	MD Area Agency on Aging – Washington County	Government Resources
400	Access Board	Government Resources
401	ADA Information for the Mid-Atlantic Region	Government Resources
403	Maryland Codes Administration	Government Resources
404	Montgomery County Permitting Service Dept.	Government Resources
	Dept. of Health and Human Services –	
405	Accountability and Customer	Government Resources
406	Office of Human Rights	Government Resources
407	MC Public Schools – Diversity and Training	Government Resources
457	Commission on Disabilities – Baltimore County	Government Resources
458	Dept. of Citizen Services – Carroll County	Government Resources
459	Commission on Disabilities – Frederick County	Government Resources
460	Department of Disabilities	Government Resources
	Department of Community Resources – Harford	
	County	Government Resources
	Commission on Disability Services - Howard	
462	County	Government Resources
	Commission on People with Disabilities –	
463	Montgomery County	Government Resources
	Commission on Individuals with Disabilities –	
464	Prince George's County	Government Resources
465	Committee on the Disabled – St. Mary's County	Government Resources
808	HRSA Information Center	Government Resources
828	Maryland DDA	Government Resources
634	Planning Now – Resource Guide	Government Resources / Planning
110	Maryland Rehabilitation Center	Government Resources, Vocational/Rehabilitation Services
121	MD Department of Rehab. (DORS) - Central	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Workforce	
122	Technology Center	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Client	
123	Assistance	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Disability	
124	Determination	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Hagerstown,	
125	Regional	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Hagerstown,	
126	Local	Government Resources, Vocational/Rehabilitation Services
127	MD Department of Rehab. (DORS) - Cumberland	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Frederick	Government Resources, Vocational/Rehabilitation Services
129	MD Department of Rehab. (DORS) - Westminster	Government Resources, Vocational/Rehabilitation Services
130	MD Department of Rehab. (DORS) - Oakland	Government Resources, Vocational/Rehabilitation Services
	MD Department of Rehab. (DORS) - Frederick	
131	Business Center	Government Resources, Vocational/Rehabilitation Services

132	MD Department of Rehab. (DORS) - Annapolis - Regional	Government Resources, Vocational/Rehabilitation Services
133	MD Department of Rehab. (DORS) - Annapolis - Local	Government Resources, Vocational/Rehabilitation Services
134	MD Department of Rehab. (DORS) - Glen Burnie	Government Resources, Vocational/Rehabilitation Services
135	MD Department of Rehab. (DORS) - Waldorf	Government Resources, Vocational/Rehabilitation Services
136	MD Department of Rehab. (DORS) - Leonardtown	Government Resources, Vocational/Rehabilitation Services
137	MD Department of Rehab. (DORS) - Prince Frederick	Government Resources, Vocational/Rehabilitation Services
138	MD Department of Rehab. (DORS) - Baltimore City	Government Resources, Vocational/Rehabilitation Services
139	MD Department of Rehab. (DORS) - Salisbury	Government Resources, Vocational/Rehabilitation Services
140	MD Department of Rehab. (DORS) - Cambridge	Government Resources, Vocational/Rehabilitation Services
141	MD Department of Rehab. (DORS) - Easton	Government Resources, Vocational/Rehabilitation Services
142	MD Department of Rehab. (DORS) - Elkton	Government Resources, Vocational/Rehabilitation Services
143	MD Department of Rehab. (DORS) - Towson - Regional	Government Resources, Vocational/Rehabilitation Services
144	MD Department of Rehab. (DORS) - Towson	Government Resources, Vocational/Rehabilitation Services
145	MD Department of Rehab. (DORS) - Bel Air	Government Resources, Vocational/Rehabilitation Services
146	MD Department of Rehab. (DORS) - Catonsville	Government Resources, Vocational/Rehabilitation Services
147	MD Department of Rehab. (DORS) - Dundalk	Government Resources, Vocational/Rehabilitation Services
148	MD Department of Rehab. (DORS) - Ellicott City	Government Resources, Vocational/Rehabilitation Services
149	MD Department of Rehab. (DORS) - Lanham	Government Resources, Vocational/Rehabilitation Services
150	MD Department of Rehab. (DORS) - Wheaton	Government Resources, Vocational/Rehabilitation Services
151	MD Department of Rehab. (DORS) - Oxon Hill	Government Resources, Vocational/Rehabilitation Services
152	MD Department of Rehab. (DORS) - Germantown	Government Resources, Vocational/Rehabilitation Services
153	MD Department of Rehab. (DORS) - D.C. Suburbs - Regional	Government Resources, Vocational/Rehabilitation Services
154	Columbia Lighthouse for the Blind	Hearing / Visually Impaired
155	National Association of the Deaf	Hearing / Visually Impaired
156	Services for the Visually Impaired	Hearing / Visually Impaired
157	Better Hearing Institute	Hearing / Visually Impaired
158	Montgomery County Association for the Deaf	Hearing / Visually Impaired
159	The Gateway School - Hearing and Speech Agency	Hearing / Visually Impaired
160	Guiding Eyes for the Blind	Hearing / Visually Impaired
161	Guide Dog Foundation for the Blind	Hearing / Visually Impaired
162	New Eyes for the Needy	Hearing / Visually Impaired
163	Pilot Dogs Inc.	Hearing / Visually Impaired
164	National Federation of the Blind	Hearing/Visually Impaired
165	Community Care Nursing	Home Health Care
166	New Care Home Health Services	Home Health Care
167	Infinity Nursing Services	Home Health Care
168	All About Home Care	Home Health Care
169	Crystal Health Care	Home Health Care
170	Home Helpers	Home Health Care
171	Advanced Nursing and Home Support	Home Health Care
172	BT HealthCare Services	Home Health Care
173	Compassionate Care Health Services	Home Health Care
174	Johns Hopkins Respiratory Program	Home Health Care
175	Generations Nursing Agency	Home Health Care
176	Helping Hands Medical Service	Home Health Care
177	Pioneer Healthcare Services	Home Health Care
178	Priority Nursing Care Inc.	Home Health Care
179	Provide a Nurse	Home Health Care
180	BMA Healthcare	Home Health Care
181	Erod's Home and Personal Care	Home Health Care
182	Reliable Care Services	Home Health Care
183	T&N Reliable Nursing Services	Home Health Care
184	Unique Nurses Inc.	Home Health Care
185	Ennisi and Nursing Care	Home Health Care

592	Home Call Inc.	Home Health Care
605	Access Nursing Services	Home Health Care
606	Automatic Nursing Care Service	Home Health Care
608	Nursing Enterprises	Home Health Care
	Upper Chesapeake Health / St. Joseph Home	
	Care and Choice Care	Home Health Care
	Chesapeake Potomac Home Health Agency	Home Health Care
612	P - B Health Home Care Agency Inc.	Home Health Care
613	Adventist Home Health	Home Health Care
614	Adventist Home Assistance	Home Health Care
615	Adventist Choice Nursing	Home Health Care
617	AMK Nursing Registry	Home Health Care
618	Aathome	Home Health Care
620	Assurance Healthcare Services	Home Health Care
621	Chesapeake Home Health	Home Health Care
622	Community Home Health of Maryland	Home Health Care
623	Comprehensive Nursing	Home Health Care
624	FMH Home Health Services	Home Health Care
625	Home Health Connection	Home Health Care
627	Integrated Care Management	Home Health Care
628	Johns Hopkins Home Health Services	Home Health Care
629	Johns Hopkins Pediatrics at Home	Home Health Care
630	Med Star Health Visiting Nurse Association	Home Health Care
632	Omni Nurse Associates Inc.	Home Health Care
635	Potomac Home Health Care	Home Health Care
636	Potomac Home Support	Home Health Care
637	Personal Touch Home Care of Baltimore	Home Health Care
638	Peninsula Regional Home Care	Home Health Care
639	Southern MD Home Health Services	Home Health Care
640	Staff Builders Home Health Care	Home Health Care
641	Tri-State Home Health & Equipment	Home Health Care
	Visiting Nurse Association of MD	Home Health Care
	Western MD Health System and Home Care	Home Health Care
645	Home Health Care Services LLC-MD	Home Health Care
647	Stella Maris, Home Care	Home Health Care
652	Bayada Nurses	Home Health Care
653	Bayada Nurses - Baltimore	Home Health Care
658	Holy Cross - House Calls	Home Health Care
659	Holy Cross - Private Home Care	Home Health Care
660	North Arundel Hospital Home Care	Home Health Care
661	MGH Community Health Home Care	Home Health Care
663	Interim Health Care - Baltimore, MD	Home Health Care
666	Medical Staffing Service	Home Health Care
667	NQRC	Home Health Care
668	Nursing and Healthcare Training Services	Home Health Care
670	PRN Inc.	Home Health Care
671	Professional Nursing Services	Home Health Care
672	Thomas Patient Care Services	Home Health Care
674	Tender Loving Care - Staff Builders - Baltimore	Home Health Care
675	Chester River Home Care and Hospice	Home Health Care
676	Shore Home Care - Home Health & Hospice	Home Health Care
	Home Health Care - Washington County	
677	Hospital	Home Health Care
678	Coastal Hospice - Hospice Care	Home Health Care
679	Coastal Hospice - Home Health	Home Health Care
680	Garrett County - Health Dept. Home Health	Home Health Care
681	Royal Nurses	Home Health Care
	Lutheran Home Care	Home Health Care
683	Prof. Healthcare Resources - Annandale	Home Health Care
684	Prof. Healthcare Resources - Bethesda	Home Health Care
685	Prof. Healthcare Resources - Washington D.C.	Home Health Care
686	Prof. Healthcare Resources - Lanham	Home Health Care
687	Americare In-Home Nursing	Home Health Care
688	Bel Care Inc. Health Care at Home Ltd.	Home Health Care

	Home Health Corp. of America / Professional	
689	Home Health Care	Home Health Care
690	Baltimore, Co. Home Health Services	Home Health Care
716	Care Plus Health Inc.	Home Health Care
	At Home Care Inc.	Home Health Care
	Amos Associates	Home Health Care
732	Visiting Angels - Living Assistance Services	Home Health Care
918	Capital Home Care Inc.	Home Health Care
641	St. Agnes Hospital Home Care and Hospice	Home Health Care / Hospice
76	Hospice of the Chesapeake	Hospice
	Hospice of the Chesapeake - Prince George's County	Hospice
77		Hospice
78	Hospice of the Chesapeake - Hospice House	Hospice
254	Hospice of Frederick County	Hospice
548	Montgomery Hospice	Hospice
582	Edmarc Hospice	Hospice
609	Upper Chesapeake Health / Harford Hospice	Hospice
619	Hospice Caring- A different Kind of Hospice	Hospice
648	Stella Maris, Hospice Care	Hospice
654	Hospice of Washington County	Hospice
657	Holy Cross - Home Hospice Services	Hospice
691	Heartland Home Healthcare - Sincerus Care	Hospice
692	Heartland Hospice	Hospice
	Heartland Hospice Services for Nursing Home Residents	Hospice
693	Residents	Hospice
721	Bon Secours Richmond - Hospice Services	Hospice
724	Hospice of Baltimore	Hospice
725	Capital Hospice	Hospice
726	Halquist House	Hospice
727	Seasons Hospice	Hospice
	Seasons Hospice - Northern Chesapeake Division	Hospice
729	Community Hospice	Hospice
730	Community Hospice of Virginia	Hospice
731	Community Hospice of Maryland	Hospice
732	Community Hospice of Washington - Inpatient	Hospice
733	Joseph Richey Hospice	Hospice
734	Carroll Hospice	Hospice
735	Jewish Social Service Agency Hospice	Hospice
911	Blue Ridge Hospice	Hospice
912	Hospice of the Rapidan	Hospice
913	Hospice Support Care	Hospice
914	Hospice Support Care of Williamsburg	Hospice
36	Home Call Hospice - Columbia	Hospice / Home Health Care
174	Shriners Hospitals	Hospitals and Health Facilities
175	Shriners Hospitals - Boston	Hospitals and Health Facilities
176	Shriners Hospitals - Canada	Hospitals and Health Facilities
177	Shriners Hospitals - Chicago	Hospitals and Health Facilities
178	Shriners Hospitals - Cincinnati	Hospitals and Health Facilities
179	Shriners Hospitals - Erie	Hospitals and Health Facilities
180	Shriners Hospitals - Galveston	Hospitals and Health Facilities
181	Shriners Hospitals - Greenville	Hospitals and Health Facilities
182	Shriners Hospitals - Honolulu	Hospitals and Health Facilities
183	Shriners Hospitals - Houston	Hospitals and Health Facilities
184	Shriners Hospitals - Intermountain	Hospitals and Health Facilities
185	Shriners Hospitals - Lexington	Hospitals and Health Facilities
1	Shriners Hospitals - Los Angeles	Hospitals and Health Facilities
	Shriners Hospitals - Mexico	Hospitals and Health Facilities
186	Shriners Hospitals - Northern California	Hospitals and Health Facilities
189	Shriners Hospitals - Philadelphia	Hospitals and Health Facilities
190	Shriners Hospitals - Portland	Hospitals and Health Facilities
191	Shriners Hospitals - Shreveport	Hospitals and Health Facilities
192	Shriners Hospitals - Spokane	Hospitals and Health Facilities
193	Shriners Hospitals - Springfield	Hospitals and Health Facilities

194	Shriners Hospitals - St. Louis	Hospitals and Health Facilities
195	Shriners Hospitals - Tampa	Hospitals and Health Facilities
196	Shriners Hospitals - Twin Cities	Hospitals and Health Facilities
197	Matilda Koval Health Center	Hospitals and Health Facilities
1	Middlesex Medical Center	Hospitals and Health Facilities
	J Cumberland Hospital for Children	Hospitals and Health Facilities
299	Children's Hospital	Hospitals and Health Facilities
310	HSC Pediatric Center	Hospitals and Health Facilities
342	GBMC Community Family Health Center	Hospitals and Health Facilities
507	Shepherd's Clinic	Hospitals and Health Facilities
508	Highlandtown Community Health Clinic	Hospitals and Health Facilities
512	Highlandtown Specialty Clinic	Hospitals and Health Facilities
513	Bel Air Edison Family Health	Hospitals and Health Facilities
514	Baltimore Medical- Annapolis Road	Hospitals and Health Facilities
515	Baltimore Medical- Falls Road	Hospitals and Health Facilities
301	National AIDS Hotline	Hotlines
402	ADA Information Line - Dept. of Justice	Hotlines
473	HOTLINE- Montgomery County	Hotlines
509	National Hispanic Family Health Help Line	Hotlines
510	National Hispanic Prenatal Help Line	Hotlines
851	First Call for Help (United Way in Central MD)	Hotlines
495	Birnbaum Interpreting Services	Interpreters & Translation Services
496	Carrie, Quigley and Associates Inc.	Interpreters & Translation Services
807	The Health Resource Inc.	Medical Information
328	MS Active Source	Medical Information Sources
	Pediatric / Adolescent Gastroesophageal Reflux Association (PAGER)	Medical Information Sources
334	Taking the Fear out of Cancer	Medical Information Sources / Resource Directories
64	MS Awareness Foundation	Medical Information Sources
65	MS Lifelines	Medical Information Sources
6	MS Pathways	Medical Information Sources
	All About Multiple Sclerosis	Medical Information Sources
	National Information Center for Children & Youth with Disabilities (NICHY)	Medical Information Sources
265	Emergency Medical Services for Children - Resource Center	Medical Information Sources
302	Rare Cancer Alliance	Medical Information Sources
368	Cystic Fibrosis Information	Medical Information Sources
390	Oley Foundation	Medical Information Sources
408	National Rehabilitation Information Center	Medical Information Sources
409	Cancersource Kids	Medical Information Sources
	National Rehabilitation Information Center - NARIC	Medical Information Sources
423	Association of Cancer Online Resources	Medical Information Sources
567	Bandaides & Blackboards	Medical Information Sources
572	CF Roundtable	Medical Information Sources
602	Cystic Fibrosis Web Ring	Medical Information Sources
646	The National Center of Home Medical Initiatives for Children with Special Needs	Medical Information Sources
651	CFHeart2Heart	Medical Information Sources
747	Cystic Fibrosis Medicine	Medical Information Sources
748	Cystic Fibrosis Worldwide	Medical Information Sources
749	www.yourlunghealth.org	Medical Information Sources
751	www.kidshealth.org	Medical Information Sources
753		
757	Society for Muscular Dystrophy Information, Int'l	Medical Information Sources
77	www.dmdoptions.com	Medical Information Sources
	www.twinenterprises.com/cp	Medical Information Sources
	Fight SMA	Medical Information Sources
768	www.improvingchroniccare.org	Medical Information Sources
769	Children's Cause for Cancer Advocacy	Medical Information Sources
777	4girls Health	Medical Information Sources
782	Birth Defect Research for Children	Medical Information Sources
805	Genetic Alliance	Medical Information Sources

814	www.cancer.com	Medical Information Sources
815	www.chemocare.com	Medical Information Sources
816	Mayo Clinic Online	Medical Information Sources
817	People Living with Cancer	Medical Information Sources
818	M.D. Anderson Cancer Center	Medical Information Sources
819	www.cancerfacts.com	Medical Information Sources
820	www.oncolink.com	Medical Information Sources
825	Cancer-Pain	Medical Information Sources
827	Pediatric Oncology Resource Center	Medical Information Sources
844	National Rehabilitation Information Center	Medical Information Sources
845	HealthCareCoach.com	Medical Information Sources
846	Health Pages	Medical Information Sources
847	Healthfinder	Medical Information Sources
848	National Library of Medicine	Medical Information Sources
849	Medline Plus	Medical Information Sources
852	Health Information Resource Database	Medical Information Sources
853	Combined Health Information Database	Medical Information Sources
864	Teens Living with Cancer	Medical Information Sources
874	Maternal and Child Health Library	Medical Information Sources
890	Cystic Fibrosis Information from Pulmozyme MD DHMH Community Resource Choice	Medical Information Sources
898	Healthchoice provider directory	Medical Information Sources
903	Mdchoice.com	Medical Information Sources
397	Beach Center on Disability	Medical Information Sources / Resource Directories
429	Growthhouse	Medical Information Sources / Resource Directories
468	Hope Street Kids	Medical Information Sources / Resource Directories
737	Cure Search	Medical Information Sources / Resource Directories
740	www.healingwell.com	Medical Information Sources / Resource Directories
901	Health Information Center - Wheaton Library	Medical Information Sources / Resource Directories
854	Respite Match.com	Medical Information Sources / Respite Care
741	www.CysticFibrosis.com	Medical Information Sources / Support Groups
742	65 Roses	Medical Information Sources / Support Groups
743	Cystic-L	Medical Information Sources / Support Groups
755	www.BeckerMuscularDystrophy.org FacioscapuloHumeral Muscular Dystrophy	Medical Information Sources / Support Groups
756	Society	Medical Information Sources / Support Groups
759	Hope for Muscular Dystrophy	Medical Information Sources / Support Groups
780	Our-Kids	Medical Information Sources / Support Groups
820	www.cancersource.com	Medical Information Sources / Support Groups
872	BMT Infonet	Medical Information Sources / Support Groups
346	KidsCope	Medical Information Sources/ Self-Esteem
791	ICan.com	Medical Information Sources/ Support Groups
873	National Cancer Institute	Medical Information Sources / Support Groups
161	Dr. T. Garrillo	Medical Providers
172	Developmental Evaluation Clinic	Medical Providers
173	Center for Spina Bifida	Medical Providers
244	Endocrine and Diabetes Associates	Medical Providers
248	Hagerstown Reproductive Health	Medical Providers
340	Union Memorial Spectrum Dental UMB Dental School - Adult emergency Care	Medical Providers
341	Clinic	Medical Providers
343	Children's Hospital Dentistry	Medical Providers
344	Mitcherling & Mitcherling DDS	Medical Providers
348	Robert B. Testani DDS	Medical Providers
349	North Point Dental	Medical Providers
350	Maurice W. Blakely, DDS Allan M. Dworkin, DDS- Cross Keys Dental	Medical Providers
351	Associates	Medical Providers
352	Kernan Hospital	Medical Providers
353	Billy Davis, DDS	Medical Providers
551	Dental Practice of Dr. Katz and Dr. Jimenez	Medical Providers
552	Richard L. Rubin, DDS / Vivencio Reyes DDS	Medical Providers
553	Karl Pick, DDS	Medical Providers
454	Carol Orlando, DDS	Medical Providers

555	UMD Oral Maxillofacial Surgery Associates	Medical Providers
586	A Mission of Mercy	Medical Providers
494	Auditory Services, Inc.	Medical Providers / Hearing/Visually Impaired
	Brooklane Mental Health Center Programs -	
7	Elder Care	Mental Health
7	Brooklane Mental Health Center Programs - Child	
10	and Adolescent	Mental Health
	Brooklane Mental Health Center Programs -	
31	Special Education	Mental Health
	Brooklane Mental Health Center Programs -	
32	Substance Abuse	Mental Health
	Brooklane Mental Health Center Programs -	
33	Pastoral Counseling	Mental Health
	Brooklane Mental Health Center Programs -	
34	Abundant Life Counseling	Mental Health
	Brooklane Mental Health Center Programs -	
35	Transitional Program	Mental Health
168	The Care Clinic	Mental Health
225	Mental Health Association - Frederick	Mental Health
240	Counseling Services	Mental Health
256	American Association of Pastoral Counselors	Mental Health
263	National Association for the Terminally ill	Mental Health
322	family-marriage-counseling.com	Mental Health
	American Association for Marriage & Family	
355	Therapy	Mental Health
470	Center for Families in Transition	Mental Health
475	Jewish Social Services Counseling	Mental Health
	Rock Creek Foundation for Mental Health -	
489	Affiliated Sante Group	Mental Health
490	St. Luke's House	Mental Health
5	Way Station	Mental Health
	Way Station - Howard County	Mental Health
7	NAMI (National Association of Mental Illness)	Mental Health
904	ProBono Counseling Project	Mental Health
433	Shady Grove Adventist Nursing	Nursing Home
593	St. Catherine's Nursing Home	Nursing Home
323	Cystic Fibrosis Services Pharmacy	Pharmacy Programs
694	Special Needs Alliance	Planning
40	Camp Kaleidescope - Alexandria, VA	Recreation and Camps
	Camp Teen Scene -Therapeutic Recreation	
41	Activities - Alexandria, VA	Recreation and Camps
	After School Program - Therapeutic Recreation	
42	Activities - Alexandria, VA	Recreation and Camps
	Little Dippers - Therapeutic Recreation Activities	
43	- Alexandria, VA	Recreation and Camps
	Kingfishers -Therapeutic Recreation Activities -	
44	Alexandria, VA	Recreation and Camps
	Young Adults Club -Therapeutic Recreation	
45	Activities - Alexandria, VA	Recreation and Camps
	Adult Social Club -Therapeutic Recreation	
46	Activities - Alexandria, VA	Recreation and Camps
	Recreation Buddy -Therapeutic Recreation	
47	Activities - Alexandria, VA	Recreation and Camps
	Recreation Companion -Therapeutic Recreation	
48	Activities - Alexandria, VA	Recreation and Camps
	After-school Mainstreaming -Therapeutic	
4	Recreation Activities - Alexandria, VA	Recreation and Camps
	TOP Soccer -Therapeutic Recreation Activities -	
1	Alexandria, VA	Recreation and Camps
	Art Works -Therapeutic Recreation Activities -	
51	Alexandria, VA	Recreation and Camps
	Saturday Social Club -Therapeutic Recreation	
52	Activities - Alexandria, VA	Recreation and Camps

16-94	Children's Hospital – Recreation & Educational Programs	Recreation and Camps
218	The Silver Lining Foundation for Kids with Cancer	Recreation and Camps
227	Therapeutic and Recreational Riding Center Inc.	Recreation and Camps
244	Children's Museum of Rose Hill Manor	Recreation and Camps
244	The Hole in the Wall Gang Camp	Recreation and Camps
419	Boggy Creek Gang	Recreation and Camps
	The League for People with Disabilities – Camp	
502	Greentop	Recreation and Camps
506	Camp Glow	Recreation and Camps
516	Access Adventures	Recreation and Camps
517	Accessible Journeys	Recreation and Camps
	Camp Superkids by the American Lung Association	
518	Association	Recreation and Camps
519	Camp Honeybee	Recreation and Camps
520	Club Venture by the ARC of Baltimore	Recreation and Camps
521	Camp Pecometh	Recreation and Camps
522	Camp Attaway	Recreation and Camps
523	Camp Winfield	Recreation and Camps
524	Camp Glencoe	Recreation and Camps
526	Trips Inc. – Special Adventures	Recreation and Camps
	Rebounders Gymnastics (I Can Do It Too) for Children with Special Needs	
527		Recreation and Camps
528	Camp Chatterbox	Recreation and Camps
529	Camp Huntington	Recreation and Camps
530	Camp Lee Mar	Recreation and Camps
531	Camp Virginia Jaycee	Recreation and Camps
532	Camp Sky Ranch	Recreation and Camps
537	CRAB – Chesapeake Region Accessible Boating	Recreation and Camps
537	The Guided Tour Inc.	Recreation and Camps
	4 Steps Therapeutic Riding – Hoofprints in the Sand	
535		Recreation and Camps
536	Kamp A Komplish	Recreation and Camps
537	Keystone Pocono Camp	Recreation and Camps
538	YAI – Mainstreaming at Camp	Recreation and Camps
539	Maryland Therapeutic Riding Inc.	Recreation and Camps
540	Unc Summer Arts Camp	Recreation and Camps
541	Camp Fairlee Manor – Easter Seals	Recreation and Camps
542	Pennsylvania Lions Beacon Lodge Camp	Recreation and Camps
543	Roundlake Camp	Recreation and Camps
	Camp Glyndon for Children with Diabetes and Deaf Children	
544		Recreation and Camps
	The Fells Point Summer Drama Camp for Special Needs Children	
549		Recreation and Camps
557	Search Beyond Adventures	Recreation and Camps
558	Easter Seals – Cruises for Kids	Recreation and Camps
	Four H Therapeutic Riding Program of Carroll County	
559		Recreation and Camps
560	Towson University Dance for Special Children	Recreation and Camps
561	Summer Adventure Camp by Lynne Israel	Recreation and Camps
562	The Sky is the Limit Creative Arts Program	Recreation and Camps
563	Freedom Hills Therapeutic Riding Program	Recreation and Camps
568	Children's Oncology Camping Association	Recreation and Camps
	4 H – Therapeutic Riding Center – Frederick County	
57		Recreation and Camps
	Life Horse – Therapeutic Riding Program	
575	Camp Merry Heart	Recreation and Camps
598	Camp Easter Seals East	Recreation and Camps
599	Camp Holiday Trails	Recreation and Camps
738	Special Love for Children with Cancer	Recreation and Camps
867	Camp Quality USA	Recreation and Camps
868	Camp Ronald McDonald for Good Times	Recreation and Camps

181	Potomac Community Resources	Recreation and Camps / Support Groups
	The League for People with Disabilities --	
504	Wellness Center	Recreation and Camps / Therapeutic Services
370	Island Dolphin Care	Recreation and Camps / Therapeutic Services
371	The Resource Network at Kennedy Krieger	Resource Directories
772	HSC Foundation -- Resource Directory	Resource Directories
775	Brave Kids	Resource Directories
772	Through the Looking Glass	Resource Directories
776	ARCH National Respite Network	Resource Directories
778	Disability Central	Resource Directories
779	Kids Together	Resource Directories
	Children with Spina Bifida: A Resource Page for	
783	Parents	Resource Directories
784	Developmental Delay Resources	Resource Directories
785	Family Friendly Fun	Resource Directories
787	Parents Helping Parents	Resource Directories
788	Developmental Disability.org	Resource Directories
789	Down Syndrome Empowerment Network	Resource Directories
792	Information Center for Individuals with Disabilities	Resource Directories
793	Cornucopia of Disability Information	Resource Directories
796	Disability Online	Resource Directories
796	Disability Resources Inc.	Resource Directories
797	Family Village	Resource Directories
	International Center for Disability Resources on	
798	the Internet	Resource Directories
799	New Horizons Unlimited	Resource Directories
842	Disabilityguide.org	Resource Directories
881	Our Final Journey	Resource Directories
	NAHC -- Home Care and Hospice Agency	
89	Locator	Resource Directories
90	Disabilityinfo.gov	Resource Directories
93	Grants for Individuals: The Disabled	Resource Directories
	Resource Guides for People with Developmental	
915	Disabilities / Links	Resource Directories
	Disability Network Directory - Montgomery	
916	County	Resource Directories
917	Guide to Retirement Living	Resource Directories
338	Community Connections	Resource Directories / Community Resources
786	IRSC Internet Resources for Special Children	Resource Directories / Support Groups
73	Bello Machre - Respite Care	Respite Care
255	Maple Shade Clinic -- Respite Care Services	Respite Care
	ARC of Prince George's County Respite Care	
308	Horne	Respite Care
545	Caring Hands Inc.	Respite Care
577	Kennedy Krieger -- Respite Care	Respite Care
	Way Station -- Child & Adolescent Programs --	
579	Respite Care -- Camp Journey	Respite Care
626	Respite Services of Montgomery County	Respite Care
330	Make a Child Smile	Self-Esteem
332	Locks of Love	Self-Esteem
357	Caringbridge	Self-Esteem
358	Captain Chemo	Self-Esteem
365	Hugs and Hope for Sick Children	Self-Esteem
304	Heavenly Hats Foundation	Self-Esteem
333	Chemo Angels	Self-Esteem
	Look Good...Feel Better (for people in cancer	
93	treatment)	Self-Esteem
99	Talking Wellness	Self-Esteem
182	Songs of Love	Self-Esteem
185	Visitingours.com	Self-Esteem
187	Angels of Destiny	Self-Esteem
193	Keiki Cards	Self-Esteem
194	Children's Mental Health Care & Wellness	Self-Esteem

295	Jefferson School (part of Sheppard Pratt)	Special Education / Information and Laws
209	Parent Educational Advocacy Training Center (PEATC)	Special Education / Information and Laws
38	United Cerebral Palsy of Central Maryland – Deirey School	Special Education / Information and Laws
404	United Cerebral Palsy of Central Maryland – Arbutus Development Center	Special Education / Information and Laws
385	United Cerebral Palsy of Central Maryland – Harford Development Center	Special Education / Information and Laws
438	Grafton School	Special Education / Information and Laws
	Montgomery Primary Achievement Center (MPAC)	Special Education / Information and Laws
443	Dyslexia Tutoring Program	Special Education / Information and Laws
909	Bridges Public Charter School	Special Education / Information and Laws
215	PACER	Special Education / Information and Laws
203	Al Anon / Alateen of Anne Arundel County	Support Groups
207	MUMS national Parent to Parent organization	Support Groups
230	Alcoholics Anonymous – Frederick County	Support Groups
321	MD Society for Cleft Lip and Palate	Support Groups
389	CForward.net	Support Groups
393	Self-Help Sourcebook Online	Support Groups
398	International Cystic Fibrosis Support Groups	Support Groups
399	Rest Ministries	Support Groups
417	Squirrel Tales	Support Groups
457	Al Anon – Alateen Washington Metro Area	Support Groups
478	Narcotics Anonymous	Support Groups
480	Friends Health Connection	Support Groups
754	www.livingfortoday.org	Support Groups
758	Muscular Dystrophy Forum	Support Groups
773	Parents of Children with Downs Syndrome	Support Groups
78	Ability On Line	Support Groups
86	Disabilities-R-US.com	Support Groups
88	Onco-Chat	Support Groups
588	Moms United	Support Groups
903	MS World	Support Groups / Medical Information Sources
969	Group Loop	Support Groups / Medical Information Sources
983	MS Watch	Support Groups / Medical Information Sources
306	Ideal Lives	Support Groups / Resource Directories
331	PatchWorx Inc.	Support Groups / Self-Esteem
373	Cerebral Palsy Ability Center	Therapeutic Services
100	Wheelchair Getaways	Transportation
102	Accessible Vans / Ironside Mobility	Transportation
118	Corporate Angel Network	Transportation
136	Angel Flight	Transportation
103	Patienttravel.org	Transportation
01	Viewpoint Mobility	Transportation / Adaptive Technology
03	Ride Away	Transportation / Adaptive Technology
05	Associated Rollx Vans	Transportation / Adaptive Technology
12	Auto Assist and Wheelchair Getaways	Transportation / Adaptive Technology
27	Wheelchair Mobile Transport	Transportation / Adaptive Technology
37	Scott Key Center	Vocational / Rehabilitation Services
90	Jeanne Bussard Center	Vocational / Rehabilitation Services
94	Byte Back	Vocational/ Rehabilitation Services
98	Jewish Vocational Services	Vocational/ Rehabilitation Services
	The League for People with Disabilities – League Industries	Vocational/ Rehabilitation Services
03	The League for People with Disabilities – Vocational Rehabilitation	Vocational/ Rehabilitation Services
	Frederick County JTA - Business & Employment Center	Vocational/Rehabilitation Services
57	Give Kids the World	Wish Granting Program
34	Kids Wish Network	Wish Granting Programs
8	Kids Wish Network	Wish Granting Programs
30	Dream Foundation	Wish Granting Programs
17	The Sunshine Foundation	Wish Granting Programs

493	Famous Fone Friends	Wish Granting Programs
564	Fairy Godmother Foundation	Wish Granting Programs
580	Make a Wish Foundation of the Mid Atlantic	Wish Granting Programs
581	Make a Wish Foundation - Baltimore	Wish Granting Programs
581	Make a Wish Foundation - Western MD	Wish Granting Programs
581	Marty Lyons Foundation	Wish Granting Programs
581	Children's Wish Foundation International	Wish Granting Programs
841	Wishland	Wish Granting Programs
	Children's Hopes and Dreams Wish Fulfillment	
896	Foundation	Wish Granting Programs
897	Wishing Well Foundation USA	Wish Granting Programs
886	Caring Institute	Wish Granting Programs
600		

ATTACHMENT E

Resource Name	ID	Website Address	Brief Description
The Community Resource Directory	662	http://www.hscfoundation.org/	The community services directory provides information on resources to help families/children with special health needs in the National Capital Region. Also available in Spanish.
Children's Hospice International	26	www.chionline.org	A database of institutions caring for children with life-threatening illnesses is available on this web-site.
Planning Now	634	www.md-council.org	This is a publication that discusses future financial planning to assist family members with a disability.
Healing Well	740	www.healingwell.com	This site contains health-oriented information for those dealing with a disease/ chronic illness
Cystic Fibrosis	741	www.cysticfibrosis.com	This web-site provides information relating to Cystic Fibrosis.
65 Roses	742	www.sixtyfiveroses.com	This web-site provides information relating to Cystic Fibrosis.
Cure Search	737	www.curesearch.org	Information is primarily geared towards childhood cancer resources. It also contains information on national associations & care organizations.
Hope Street Kids	466	www.hopestreetkids.org	Information is primarily geared to pediatric cancer patients.
Cystic Fibrosis Medicine	748	www.cysticfibrosismedicine.com	This web-site provides information relating to Cystic Fibrosis.
Your Lung Health	751	www.yourlunghealth.com	Information is primarily geared towards respiratory patients.
Cystic Fibrosis Research	752	www.cfrl.org	This web-site provides information relating to Cystic Fibrosis.
FSH Society	756	www.fshsociety.org	Information is primarily geared towards FSH Muscular Dystrophy
NORD	765	www.rarediseases.org	Information is available regarding rare diseases.
Madison's Foundation	766	www.madisonfoundation.org	Information is available regarding rare life-threatening diseases
Brave Kids	665	www.bravekids.org	The resource directory contains a wide range of information, on a national level.
Chemo Angels	633	www.chemoangels.com	This web-site contains a link to cancer information
Exceptional Parent	223	www.eparent.org	The web-site contains a resource directory for parents of children with disabilities. On-line registration is required to view the web-based version.
Griefnet	578	www.griefnet.org	This web-site contains information for bereavement.
Growthhouse	429	www.growthhouse.org	This is a web-site that provides access to information regarding end-of-life care and life-threatening illness
CancerSource Kids	409	www.cancersourcekids.com	This is a secure web-site where kids can learn about cancer
Cerebral Palsy Resource Center	761	www.twinterprises.com/cp	This web-site contains information on Cerebral Palsy
International Cystic Fibrosis Support Group	398	Http://cf.concoll.edu	This web-site provides information relating to Cystic Fibrosis.

Improving Chronic Illness Care	768	www.improvingchroniccare.org	This web-site contains information pertaining to chronic illness.
Association of Cancer Online Resources	567	www.acor.org	This web-site contains information on Cancer
Through the Looking Glass	772	http://lookingglass.org	This web-site contains a resource directory, geared towards those with disabilities or complex-medical needs
Kids Together	779	www.kidstogether.org	This web-site contains information for persons with disabilities.
Our-Kids	780	www.our-kids.org	This is a web-site with information for those caring for or working with children with physical &/ or mental disabilities and delays.
Children with Spina Bifida	783	www.waisman.wisc.edu/~rowley/sb-kids/index.html	This web-site contains information on Spina-Bifida
Developmental Delay Resources	784	www.devdelay.org	This web-site contains information designed to support persons with special needs.
Family Friendly Fun	785	www.family-friendly-fun.com	This web-site offers information of a wide variety of topics for families with disabilities.
Internet Resources for Special Children	786	www.irsc.org	IRSC is a web-site that contains information for children with disabilities and other health disorders.
Parents Helping Parents	787	www.php.com	The web-site contains an online resources section that provides information for children with special needs.
Down Syndrome Empowerment Network	789	www.downsyndrome.com	This web-site contains on-line information regarding Downs Syndrome.
The National Fragile X Foundation	790	www.fragilex.org	This web-site provide information regarding Fragile-X syndrome *available in Spanish
Comucopia of Disability Information	793	http://codi.buffalo.edu	This web-site contains an internet directory of disability information.
Disability Online	795	www.disabilityonline.com	This web-site contains over 2,000 links to different types of disability information.
Disability Resources Inc.	796	www.disabilityresources.org	This web-site contains a database, and an on-line resource directory to disability information.
Family Village	797	www.familyvillage.wisc.edu	This web-site contains information for those with disabilities and their families
International Center for Disability Resources on the Internet	798	www.icdri.org	This organization has designed a web-site to disseminate information for people with disabilities. *this web page can be translated
New Horizons Un-limited Inc.	799	www.new-horizons.org	This non-profit organization serves people affected by lifelong disability. One of the services is an on-line resource directory.
American Spinal Injury Association	800	www.asia-spinalinjury.org	There are links on the web-site that lead to information about spinal cord injuries.
WAPD	801	www.wapd.org	This web-site contains a resource page, with information for

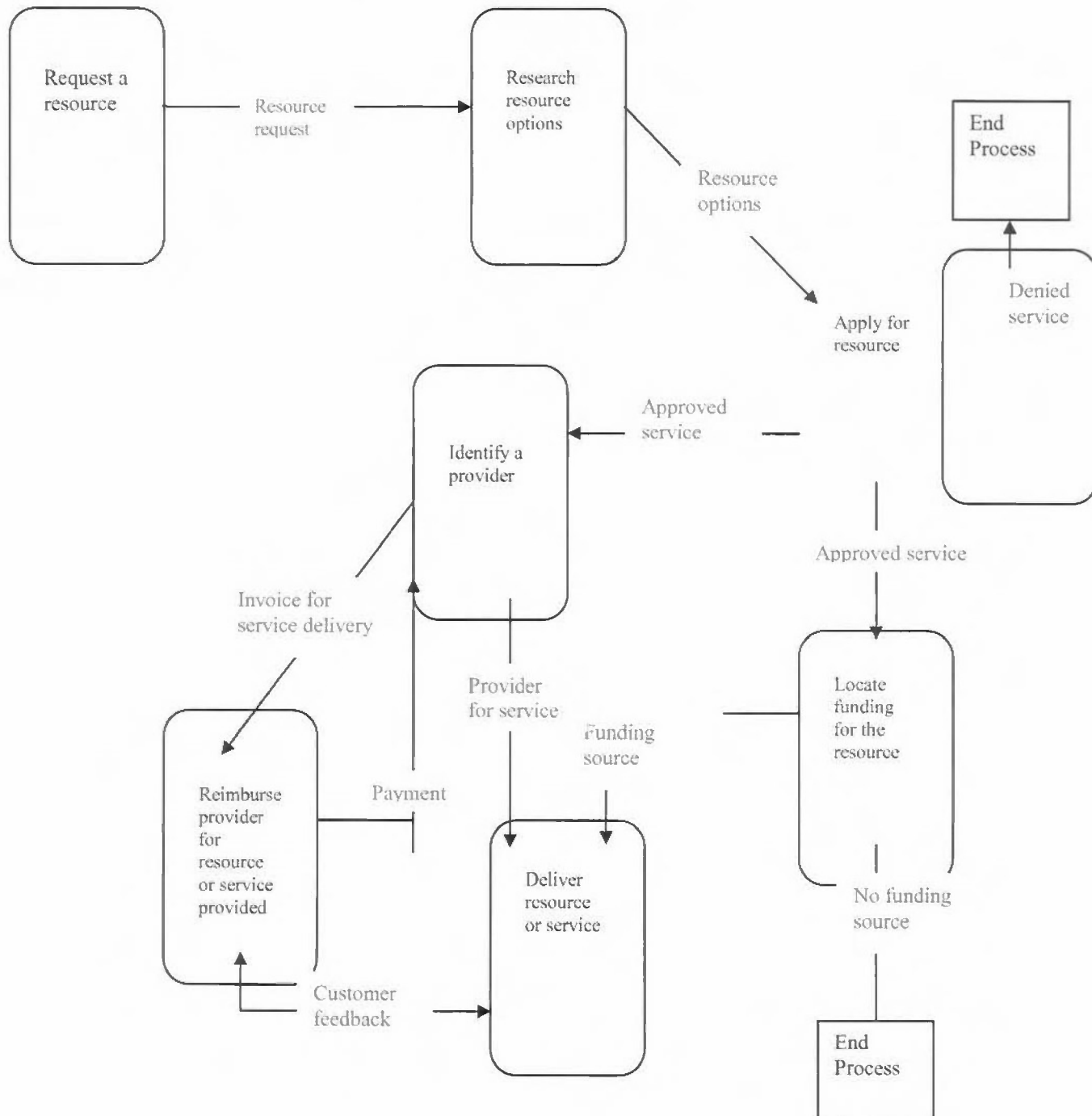
Genetic Alliance	805	www.geneticalliance.org	those with disabilities. This web-site contains information on a variety of genetic conditions
Ideal Lives	806	www.idealives.com	This organization provides information regarding support for those raising children with special needs. *registration is required
Cancer.com	814	www.cancer.com	This web-site contains information on Cancer
People Living with Cancer	817	www.plwc.com	This web-site contains information on Cancer
Cancersource	820	www.cancersource.com	This web-site contains information on Cancer
American Association on Mental Retardation	824	www.aamr.org	This web-site provides access to a variety of information regarding those with intellectual disabilities
Pediatric Oncology Resource Center	827	www.acor.org/ped-onc	This web-site contains information on childhood cancer resources, web links and other references.
Maryland DDA	828	http://ohmh.state.md.us/dda_md	This agency oversees the service delivery system for individuals with developmental disabilities. The web-site contains a resource directory with detailed descriptions of various resources and services, as well as information about eligibility, application and other frequently asked questions.
Cancer Fund of America	839	www.cfoa.org	This web-site contains information on Cancer
National Rehabilitation Information Center	844	www.naric.com	This web-site contains an abundance of disability and rehabilitation-oriented information. Examples of information include: on-line publications, searchable databases and reference and referral data.
Healthfinder	847	www.healthfinder.gov	This is an on-line resource for information regarding government and non-profit health and human services information. Information is available in Spanish.
Medline Plus	849	http://medlineplus.gov	This is a web-site for consumer health information, also available in Spanish. The range of information includes: health topics, medical encyclopedia, health tutorials, drug information, health news, dictionary, directories and other resources (organizations, libraries, databases).
National Health Information Center/Resource Database	852	www.health.gov/nhic/	This is a national health information referral service. Information specialists can refer callers to the appropriate resource. Examples of entries in the database include: disease prevention, federal clearinghouse, foreign language resources, healthcare, health education, public health and school health, among others.

Hospice Foundation of America	616	www.hospicefoundation.org	This web-site contains a variety of information regarding end-of-life issues
National Cancer Institute	873	www.nci.nih.gov	The web-site contains information regarding cancer.
Maternal and Child Health Library	874	www.mchlibrary.info	This web-site contains information regarding Maternal and Child Health
National Dissemination Center for Children with Disabilities	265	www.nichcy.org	The organization provides information on topics regarding children and youth with disabilities, birth through 22.
Beach Center on Disability	397	www.beachcenter.org	The web-site contains resources in English, Spanish, Korean and Chinese, for those with disabilities.
Americans for Better Care of the Dying	394	www.abcd-caring.org	The web-site contains a number of links to useful resources such as: advance care planning, aging, care-giving, chronic illness, end of life hospice, grief, healthcare, pain, relevant organizations
Self-Help Group Sourcebook Online	393	http://mentalhelp.net/selfhelp/	This web-site contains a database of self-help support groups
National Center of Medical Home Initiatives	651	www.medicalcominfo.org	This organization provides support those who care for children with special needs. One can find information about what a medical home is and relevant resources on related topics. Information is also available in Spanish.
Cystic Fibrosis Information	388	http://www3.nbnet.nb.ca/normap/CF.htm	This is a web page by a woman with CF. One can also find it by going to Google and typing "Cystic Fibrosis Information" This site contains over 2,000 links to other resources/sites.
Cystic Fibrosis Web Ring	646	http://i.webring.com/hub?ring=cf_ring	This web-site provides information relating to Cystic Fibrosis.
The Wellness Community	821	www.thewellnesscommunity.org	This site contains information for people affected by cancer
Our Final Journey	881	http://endoflifecare.tripod.com/Caregiving/index.html	This web-site contains a variety of useful information for families with a loved one who has a terminal/chronic illness
NAHC Home Care and Hospice Agency Locator	895	www.nahc.org	Through this web-site, individuals/ consumers/ families can access a database of home care/hospice agencies in areas throughout the country. Click on the 'agency' tab on the right hand side of the screen for more information.
Multiple Sclerosis Foundation	899	www.msfocus.org	This non-profit organization focuses on support and educational programs for persons coping with Multiple Sclerosis (MS). One can also obtain publications on MS at no cost. The web-site and multimedia library can be viewed in Spanish.
Disabilityinfo.gov	900	www.disability.gov	This is an on-line resource that contains disability-related information and information on programs available. Topics include: education, employment, housing, health, income support, technology and transportation.

Grants for Individuals: The Disabled	906	http://www.lib.msu.edu/harris23/grants/3disabled.htm	This web-site contains information on grants, scholarships and financial aid opportunities for individuals with disabilities.
Community Connections	338	www.communityconnections.umd.edu	The resource page lists available resources for children with disabilities / special needs in the local Maryland Metropolitan area
Resource Guides for People with Developmental Disabilities / Links	915	http://www.arcdc.org/resources.html http://www.arcdc.org/links.htm	These are resources compiled by the ARC of Frederick County, catering to people with developmental disabilities. One can download resource directories specific to various counties in the state of Maryland.
Disability Network Directory – Montgomery County	916	http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/DisabilityNetworkDirectory/index.asp	This is a directory of providers, agencies, businesses and advocacy organizations for people with disabilities

ATTACHMENT F

Data Flow Diagram
Process for Accessing Resources for Families



ATTACHMENT G

Service Profile Chart

2 R = Info. 3 and Internal

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
	Federal Programs				State Programs								Military						Private Insurance	Other Resource	
	Projected Service and Resource Needs for at-Care population	BD	EP/OUT	WC	Medical Category/ Specialty	Medical Specialty	Medical Special Populations	DCA Services	L&T Program	Public Education Programs	Social Services	Other (Title V)	Trauma Resc.	Trauma ECHO (Active Duty and equal med. medical critical)	CFMP	Military One Source (Active Duty)	Direct Care System (available during hospitalization only)	Other Military Program		Chenoweth Foundation	Local Resources
1	Physician care (includes primary care and specialty care)				X	X	X					X	X				X		X	IR	
2	Pharmacy				X	X	X					X	X			IR	X		X	X	X
3	Durable Medical Equipment (DME)				X	X	X	X	X	X (for educational goals)		X	X	X		IR			X	X	X
4	Durable Medical Supplies (DMS)				X	X	X			X (for educational goals)		X	X	X		IR			X		
5	Nursing (Private Duty Shift Nursing)				X	X	X	X		X (for educational goals)				X		IR			X		
6	Nursing (Bedside Visit)			X	X	X	X	X		X (for educational goals)		X	X	X		IR			X		X
7	Home Health Aide				X	X	X	X		X (for educational goals)		X				IR			X		X
8	Personal Care Services				X	X	X	X		X (for educational goals)						IR					
9	Social Work Services			X	X	X	X	X	X	X (for educational goals)	X	X	X	X		IR	X				
10	Nutritional				X	X	X	X	X		X	X	X			IR	X		X		
11	Pain and Symptom Management				X	X	X					X	X	X		IR	X		X		
12	Phlebotomy				X	X	X						X			IR	X		X		
13	Occupational Therapy				X	X	X		X	X (for educational goals)	X	X				IR	X		X		X
14	Physical Therapy						X		X	X (for educational goals)	X	X				IR	X		X		X
15	Speech Therapy						X		X	X (for educational goals)	X	X				IR	X		X		X
16	Respiratory Therapy				X (sometimes bundled with CME)	X (sometimes bundled with CME)	X (sometimes bundled with CME)						X			IR	X		X (this service is sometimes included with related CME)		
17	Expressive Therapy (e.g. music, art, play)						X	X	X	X (for educational goals)						IR					X
18	Adaptive Equipment (special seating devices, bathchairs, gait trainers, prosthetics, car seats for children -Hoyer, etc. etc.)				X	X	X	X	X	Some programs will provide bathers			X			IR	X		X		X
19	Care Coordination						X	X	X	X (for educational goals)	Care Worker	X		X	X (report requirement on military history)	IR	X	X	X	IR	IR
20	Phlebotomy						X	X				X		X		IR			X	X	X
21	Family Caregiver Counseling				X	X	X	X	X	X (for educational goals)	X		X			IR		X	X	X	X
22	Individual Counseling				X	X	X	X	X		X		X			IR	X	X	X		
23	Group Counseling				X	X	X	X	X		X					IR	X			X	X
24	Recreational Counseling						X									IR	X		X	X	X
25	Educational services							X	X	X (for educational goals)					X	IR	X (if previously provided by the military)			X	X
26	Central				X	X	X	X			X	X				IR	X (if needed to a medical condition)	X	X		X

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
	Federal Programs				State Programs								Military					Private Insurance	Other Resource		
	Projected Service and Resource Needs for mCare population	MS	SPSDT	WIC	Medicaid Category/Eligibility	Medicaid Medically Necessity	Medicaid Special Populations	DDA Services	I & T Program	Public Education Programs	Support Services	Other (TAN F)	Trauma Basic	Trauma EDIC (Active Duty and most med. medical referrals)	TFWP	Military One Source (Active Duty)	Direct Care System (available during hospitalization only)	Other Military Program		Disease based Foundation	Local Resources
1	Child Care (typical and special needs)							X	PR	X (for educational goals)						PR		X			X
25	Assistive Technology				X	X	X	X	X	X (for educational goals)		X		X		PR			X	X	X
30	Behavior Management				X	X	X		X	X (for educational goals)		X (under special circumstances only)				PR	X	X			X
31	Family Caregiver Training						X	X								PR	X			X	X
32	Financial Support	X		X				X			X					PR		X		X	X
33	Habitatation services (residential, pre-rehabilitation, supported employment)							X		X		X (medical health only)				PR		X		X	X
34	Housing Access Coordination						X	X			X				X	PR		X		X	X
35	Interpreter Translation			X				X	X		X					PR	X		X	X	X
36	Mental Health				X	X	X	X	PR		X	X	X			PR	X			X	X
37	Moving Assistance										X				X	PR		X			X
38	Transportation - ambulatory				X	X	X				X	X	X (for medical monitoring)			PR	X (for medical monitoring)	X	X		X
39	Transportation - ambulatory medical				X	X	X				X					PR				X	X
40	Vehicle Modifications				X	X	X	X				X (under special circumstances)				PR			X	X	X
41	Recreation and culture							X		X	X	X				PR				X	X
42	Medical information Source												X			PR	X		X	X	
43	Wish Granting							X								PR				X	X
44	Carer/Respite Services						X	X	X	X		X				PR				X	X
45	Self-Employment Support							X	X	X						PR			X	X	X
46	Advocacy for Child/Family Needs		X					X	X	X	X	X				PR				X	X
47	Resource Coordination						X	X	X	X	X		X	X		X	X		X	X	X
48	Family Child Education re Healthcare Setting							X	X	X	X	X	X	X			X				
49	Provider Education		X	X	X	X	X	X	X	X		X					X		X	X	X
50	Volunteer Support							X	PR		X						X	X		X	X
51	Spiritual Care							X								PR	X	X			X
52	Oral Lth Services												X (implant only)				X (if available at recipient facility)				

ATTACHMENT H

	Federal	Federal / State	Military	Condition specific	Local Community
Types of supports available	<p><i>Income (SSI)</i></p> <p><i>Standards for Medicaid's comprehensive and preventative child health program for children < 21 yrs.</i></p>	<p><i>DDA advocacy for system change, and service or support programs</i></p> <p><i>Special Education services age 6 - 17 with some states expanding services from age 3- 21.</i></p> <p><i>Early Intervention services for 0 - 3.</i></p> <p><i>Medicaid Programs -state plan services</i></p> <p><i>Medicaid Waiver Programs - for categorically needy, medically needy and special groups</i></p> <p><i>Title V programs</i></p> <p><i>Social Service programs - foster care/ adoption, child protective services, etc.</i></p> <p><i>Employment support services</i></p> <p><i>Legal Protection and Advocacy</i></p>	<p>The following categories of resources are referenced on Military HOMEFRONT website and represents types of supports and information available for families across military branches:</p> <ul style="list-style-type: none"> • Quality of Life Resources • DoD Impact Aid • Education • Child Abuse Prevention • Medical and Dental • Special needs/ EFMP • Education/ Early Intervention • Special Education (3-21 yrs) • Education (> 21) • Medical care/ Tricare • Federal programs/ Title V and Medicaid • Family Connections • Family Support • Financial and Legal • Child Development Programs • Morale, Welfare and Recreation • Parenting • Head Start/ Sure Start • Special discount offers • Commissaries and Exchanges • Deployment • Eldercare • Emergency and Disasters • Employment • Housing and Relocation assistance • Domestic Abuse • Military Severely Injured • Interpersonal Abuse includes domestic • Networking Partnerships 	<p><i>Variety of Resources</i> (about disease, clinical trials, treatment regimes, etc)</p> <p><i>Conferences and presentations</i> related to the condition</p>	<p>Resources that are specific and targeted as opposed to a program of services. Examples of these include but are not limited to:</p> <ul style="list-style-type: none"> • Professional providers • Health information • Adaptive technology • Child care services • Translation services • Recreation and camps • Support groups • Transportation • Respite care • Utility assistance programs • Environmental modifications • Caregiver resources • Case management services • Funding sources • Planning information

			<ul style="list-style-type: none"> Relocation Planning Federal Programs (Medicare) 				
Where to find information	<ul style="list-style-type: none"> Internet (SSA website, Military Homefront website) Local Library Local SSA office 	<ul style="list-style-type: none"> Internet (some links on Military Homefront website) Local Library Local Departments of Social Services Local Departments of Education State offices for Maternal Child Health Can access information via telephone 	<ul style="list-style-type: none"> Military OneSource Military HOMEFRONT website 	<ul style="list-style-type: none"> Internet National or regional offices for the condition' Local Library Provided by physician or healthcare funder 	<ul style="list-style-type: none"> Internet Local Library Word of Mouth Family Networks Local organizations 		
Process for accessing resource	Must apply at a local SSA office for SSI EPSDT is a set of standards for care and not actually a resource that is provided (one must be eligible for Medicaid for legislative standards to apply)	Varies from state to state Some state programs such as Medicaid Waivers have existing waiting lists prior to accessing services. Families may need to meet a financial and or medical eligibility requirement. Some state waivers require a cost neutrality factor.	Process for accessing each program or support varies based upon service desired. However, active military can use Military One Source as an Employee Assistance Program benefit to assist in facilitating programs and resources.	Correspondence Application process varies across organizations May require physician documentation of specific condition	Formal and informal application processes varies across sponsoring organization Sometimes requires documentation from a healthcare provider or other entity		
Barriers for families in identifying and finding resource	Application process May require physician documentation Locations of local offices Lack of knowledge regarding potential resource Income level too high Application process requires persistence and	Application process Varying eligibility requirements (financial, medical, geographic) Some Medicaid programs for special groups have limited slots and lengthy waits for services Lack of knowledge regarding potential resource Information found on websites is global and family may not realize	Service availability and extent of support may depend on the individual's status within the military. Some qualifiers include active vs. retired status, reserves or branch of service.	Application process Acceptable documentation of condition particularly if diagnosis is unclear Lack of knowledge regarding potential resource	Application process Lack of knowledge regarding potential resource Documentation from healthcare provider Applicant may not meet specific target criteria for accessing the service (ex. geographic, age, culture,		

	may require multiple appeals for award	they do not qualify until they have already gone through the process. State programs vary from state to state in regards to eligibility, benefits and service delivery			religious affiliation, etc.)
Strategies that can be incorporated in a new model design to optimize use of resources	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local SSA office Educate families regarding appeal process	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local state offices Educate families regarding appeal process	Encourage the use of Military One Source and develop relationships between family and a coordinator from One Source. See Military One Source Report for more specific recommendations) Encourage families to participate on family networking forums (ie STOMP or discussion forum through Military HOMEFRONT) to encourage dialogue regarding experiences of what works and doesn't work when working with systems to access services. Families who have experience working through various systems may be willing to share their knowledge to assist other families in similar situations.	Access to information related to condition specific resource centers Education for families related to how to identify resource opportunities	Access to information related to local resources. Education for families related to how to identify resource opportunities within their local community

ATTACHMENT I



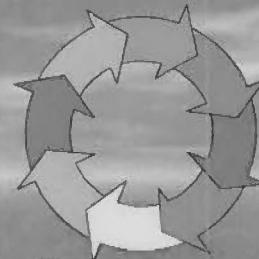
A Matter of Perspective

Prepared by,
The Coordinating Center
August 10, 2005

Otherwise known as.....

- Case management
- Care management
- Benefits management
- Utilization review management (UR)
- Case worker
- Care coordination*

Definition



- Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality, cost-effective outcomes

*CMSA Standards of Practice for
Case Management, 2002*

Setting Industry Standards

- **Commission for Case Management Certification (CCM)**
- **Certification of Disability Management Specialists (CDMS)**
- **Commission on Rehabilitation Counselor Certification (CRCC)**
- **National Association of Social Workers (NASW-C)**
- **CMSA (Case Management Society of America)**
 - **Local and National organization for case managers**
- **URAC**
 - **Set standards for organizational level accreditation in the following areas**
 - HIPAA Certification
 - Case Management
 - Claims Processing
 - Consumer Directed Health
 - Core Accreditation
 - Credentials Verification Organization (CVO)
 - Disease Management
 - Health Call Center
 - Health Network
 - Health Plan
 - Health Provider Credentialing
 - Health Utilization Management
 - Health Web Site
 - HIPAA Privacy
 - HIPAA Security
 - Independent Review
 - Workers' Compensation Utilization Management

About URAC

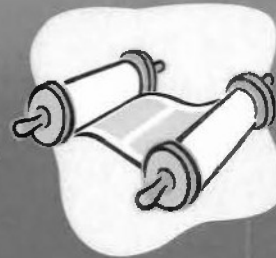
- Nonprofit, independent organization, is well known as a leader in promoting health care quality through certification and accreditation programs.
- Offers a range of quality benchmarking programs and services
- Ensures that all stakeholders are represented in establishing meaningful quality measures for the entire healthcare industry

URAC website

<http://www.urac.org/>

URAC Core Standard's address

- Organizational framework
- Information system
- Delegation
- Qualifications, licensure, scope of practice
- Policies and procedures
- Quality program
- Consents
- And more.....



*Standards at a Glance, Accreditation Program
Guide for Case Management Standards,
Version 2.0, URAC 2002*

Settings for Case Management Services

- Hospitals and Integrated Delivery Systems
- Corporations
- Public Insurance
 - Medicaid and Medicare
- Private Insurance
 - Workman's Comp
 - Disability Liability
 - Auto
 - Accident and health
- Managed Care Organizations
- Independent Case Management Companies
- Government Sponsored Programs
 - Military
 - Correctional Facilities
 - Public Health
- Provider agencies
 - Mental health facilities
 - Home health
 - Ambulatory and Day Care
 - Geriatric services
 - Long term care services
 - Hospice
 - Physician practices
 - Disease management companies



Functions of Case Management

- Assessment
- Planning
- Facilitation
- Advocacy

*CMSA Standards of Practice for
Case Management, 2002*

Assessment

- Case identification (screening)
- The gathering of relevant, comprehensive information from the healthcare team and other appropriate individuals



*CMSA Standards of Practice for
Case Management, 2002*

Planning

- Develop a Plan of Care in conjunction with the individual, family and other healthcare team members
- The goal is to develop an appropriate and fiscally responsible plan to enhance quality, access, and cost-effective outcomes.
- Goal setting
- Contingency plan in the event of health or service complications
- CM should initiate modifications to adapt to changes over time and settings



Facilitation

- CM should actively promote, coordinate, communicate and collaborate on behalf of the individual/ family, PCP, members of the health care team, the payer and others such as legal, educational and spiritual communities
- Reconcile differing points of view to ensure wishes of child/ family are understood
- Facilitate education and prevent risks behaviors to promote optimal wellness



Advocacy

- Respect beliefs, value system, and decisions of the child/family
- Incorporate self determination
- Support and educate the child/family to achieve self advocacy whenever possible



Models for Medical Case Management

*Complex Care Management
Paradigm Health
Annual Report, 2004*

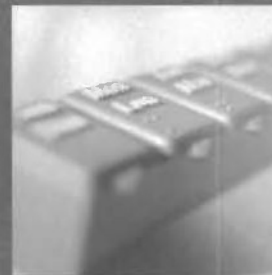
Population Health Model

- Basically healthy individuals who need routine preventative care and short-term treatment for illnesses or injuries
- Third party payers may use this model to minimize risk of more serious illness that attributes to higher health care costs



Disease Management Model

- Individuals with troublesome but manageable chronic illness who need ongoing coordinated care to prevent worsening, but who then function well
- Usually an illness that has a higher level of prevalence in the general population and if managed proactively can yield significant reduction in cost of care and in quality of life
- Often identify potential participants through claims review process.



Individual Model

- Individuals with serious, possibly life threatening chronic conditions who need continuous care, pain and symptom management, advance care planning, assistance with ADL's, suitable housing, and whose family caregivers need additional support.



Social Model

- Often referred to as "case worker"
- May be seen most often in Social Services arena, criminal justice, and educational system
- Often used in the Developmental Disabilities World and sometimes referred to as "service coordination"
- Less emphasis placed on certification and/or professional licensure



The Care Coordination Perspective



- Care Coordination implies a partnership with the person/family and is based in person/family centered philosophy and practice
- It is based on a key concept that health is only one component of the process
- It relies on the idea that planning begins with the person; find the resources to meet the person's needs using all community avenues.

2003 Case Management Salary Survey

- Salaries vary based upon geography, setting, caseload and experience
- Salary range from \$39,000 West suburban areas to \$59,000 in the Pacific rural areas

ADVANCE for Providers of Post-Acute Care

May/ June 2003, p. 51

www.advanceforPAC.com

Caseload and Setting

- Case managers who work in managed care, medical groups or worker's compensation report highest caseloads of greater than 60.
- Lowest caseloads are reported in rehab facilities (22), hospice (23) and business owners (25)

ADVANCE for Providers of Post-Acute Care

May/ June 2003, p. 54

www.advanceforPAC.com

Current Issues in Case Management

- Demonstrating and Improving Outcomes of Case Management
- Consumer Directed Trends
- Chronic Care Management
- Education
- CM/Physician Relationship
- Cultural and Linguistic Competency
- Legal & Ethical Issues
- CM Legislation
- Shifting CM roles and job functions
- Growing need for more CMs



Trends Impacting Case Management

CMSA, 2002

National Conferences Specific to Case Management

- Case Management Society of America (CMSA)
- Medical Case Management Conference (MCMC)

APPENDIX 19

ID#: 33 GO  >

Entered by: TR Date Last Update: 10/5/2004

Type of Resource: Providers

Resource Name: Brook Lane Health Services - Pastoral Counseling

Contact Name:

Address: 13218 Brooklane Drive

P.O. Box 1945

City/State/Zip: Hagerstown MD 21742

Phone/Ext/FAX: 301-733-0330 301-733-4038

TTY/TollFree: 800-342-2992

Web Address: www.brooklane.org

Provider No.:

Email: curtm@brooklane.org

Comments:

organization provides quality behavioral health services. A Pastoral Counselor is a theologically trained & spiritually integrated therapist, skilled & trained to deal with

☐ Nat'l Capital Area

Counties Served

<input type="checkbox"/> Allegany	<input type="checkbox"/> Caroline	<input type="checkbox"/> Frederick	<input type="checkbox"/> Montgomery	<input type="checkbox"/> Talbot
<input type="checkbox"/> Anne Arundel	<input type="checkbox"/> Carroll	<input type="checkbox"/> Garrett	<input type="checkbox"/> Prince George's	<input type="checkbox"/> Washington
<input type="checkbox"/> Baltimore City	<input type="checkbox"/> Cecil	<input type="checkbox"/> Harford	<input type="checkbox"/> Queen Anne	<input type="checkbox"/> Wicomico
<input type="checkbox"/> Baltimore County	<input type="checkbox"/> Charles	<input type="checkbox"/> Howard	<input type="checkbox"/> Somerset	<input type="checkbox"/> Worcester
<input type="checkbox"/> Calvert	<input type="checkbox"/> Dorchester	<input type="checkbox"/> Kent	<input type="checkbox"/> St. Mary's	<input checked="" type="checkbox"/> Entire State
			<input type="checkbox"/> Nationwide	

Office Hours:

	From	To
Monday	8:00	7:00
Tuesday	8:00	7:00
Wednesday	8:00	7:00
Thursday	8:00	7:00
Friday	8:00	7:00
Saturday		
Sunday		

☐ Open 24 Hours
☐ No Regular Hours

Time Zone E

Languages

☐ English ONLY
☒ Spanish
☐ French
☐ Korean
☐ Interpreter Provided
☐ Sign Language
☐ Other

	Yes	No	N/A
Military families ONLY?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Wheelchair accessible?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Daycare?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Cost			
<input type="checkbox"/> Sliding Scale	<input type="checkbox"/> DDA funding		
<input checked="" type="checkbox"/> Cost varies	<input type="checkbox"/> DORS		
<input checked="" type="checkbox"/> Insurance accepted	<input type="checkbox"/> Other funding		

Eligibility Criteria

☐ Varies depending on program
☐ Age Range to
☒ All ages are eligible
☐ Applicant must have a disability
☐ Financial criteria may be considered
☐ Applicant must have specific diagnosis
☐ Applicant must be Resident of State
☐ None

Application Process

☐ No application needed
☒ Basic application to be completed
☐ Varies depending on program
☐ Medical documentation must be provided
☐ Must be completed by person other than family member
☐ Physician Referral Required

Clear

Submit

APPENDIX 20

Process Analysis and Data Flow Diagram

Locating basic information regarding a resource is typically the first step toward accessing that resource. However, the information may not be useful unless it yields actual access to the needed service. An analysis of the typical process used by an individual to access some type of a resource has been documented in the form of a data flow diagram. The purpose of this is to identify possible areas of vulnerability that may preclude completion of the process to the point of service delivery. The analysis should be considered while developing the new model of care for children in the military who have life threatening conditions with attention to incorporate quality measures in the process to minimize the potential for unsuccessful service delivery.

For any typical request for resources, a professional, nonprofessional or family member may identify a need for a community resource. Then, there is some research done to identify a source for such resource to yield potential resource options to meet the resource request. This research can be done by the requestor or by another third party, such as a professional or nonprofessional invested in supporting the request. In most situations, there is some referral or application process required to access the resource. The referral or application process can vary from providing basic demographic information to extensive financial and medical reviews prior to the approval for the resource requested. Depending on the type of resource requested, some situations will warrant the identification of a provider to deliver the resource. In some situations, further research to locate funding will be necessary prior to service delivery. Subsequent to approval for the resource, identification of the provider if applicable and identification of a funding mechanism the service delivery would occur. In some situations, reimbursement is requested following service delivery and would follow.

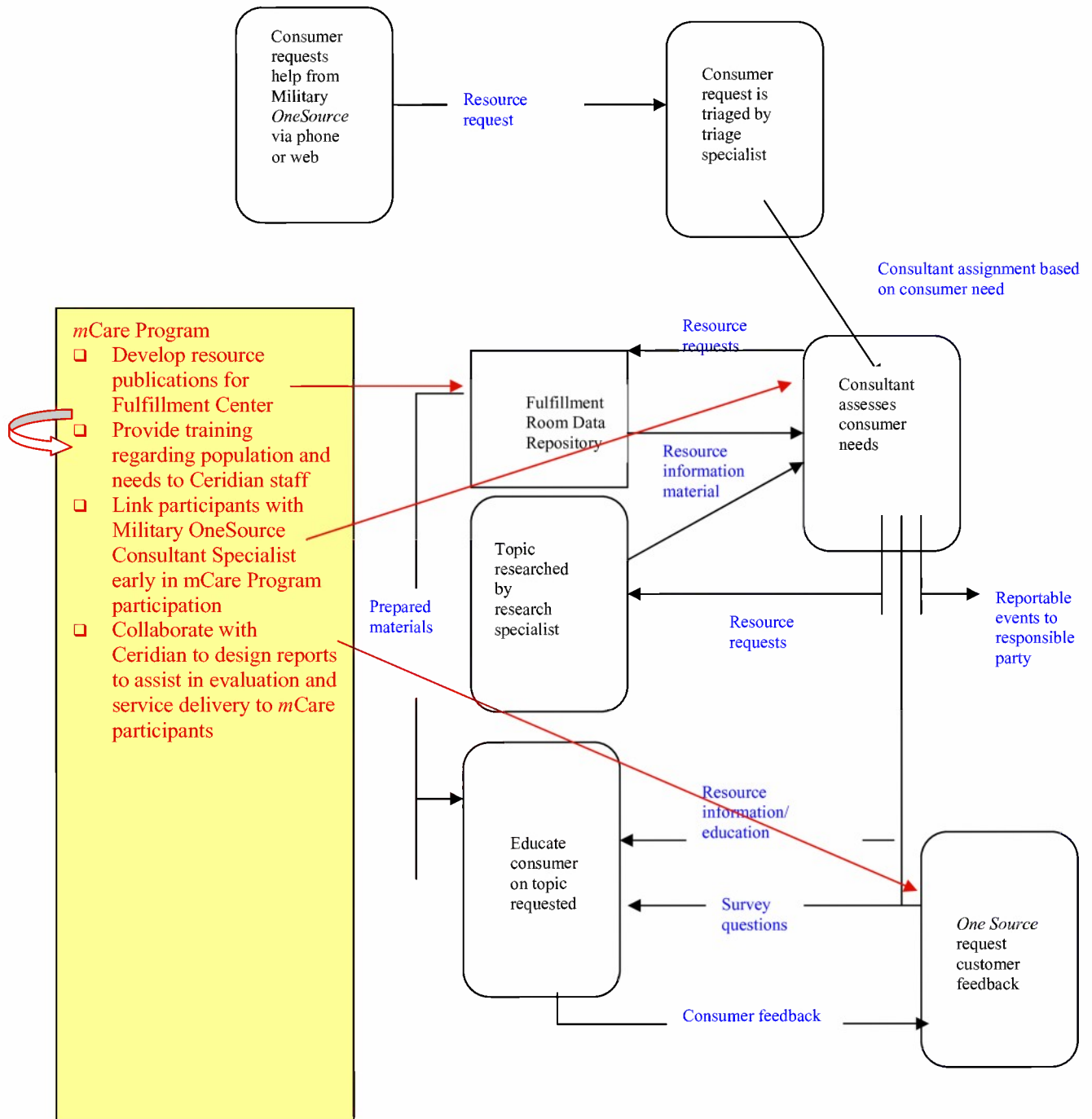
The basic tasks identified in this process are:

- Identification of a resource need by family, professional or other nonprofessional
- Research for possible options for desired resource
- Application to obtain resource
- Identification of a service provider
- Locating a funding source
- Delivery of the service
- Reimbursement for the cost of the service or resource

Each task within the process has been analyzed to note vulnerabilities within the process.

Process Task	Vulnerabilities
<i>Request</i> a resource	<ul style="list-style-type: none"> • Miscommunication regarding type of resource requested • Resource requested does not meet the need of the child/family • Lack of knowledge on requestors part related to type of resource needed or what may be available
<i>Research</i> resource options	<ul style="list-style-type: none"> • Resource information obtained is inaccurate or lacks correct contact information • Resource information obtained does not adequately represent what was requested
<i>Apply</i> for resource	<ul style="list-style-type: none"> • Application requires specific information that is not readily available to applicant • Application requires signature from other entity such as physician, or other professional requiring additional steps prior to completion • Application requires multiple estimates for the service requested • Poor or no direction for application completion • Application is denied based on information presented • Application gets lost during process • Application is too complex for family to complete
<i>Identify</i> provider for resource	<ul style="list-style-type: none"> • Provider will not accept reimbursement amount or method • Unable to find a provider • Provider of low quality
<i>Locate</i> funding source	<ul style="list-style-type: none"> • Unable to identify funding for resource • Not medically necessary resource • End of budget year request that will be postponed for funding in the upcoming fiscal year •
<i>Deliver</i> resource or service	<ul style="list-style-type: none"> • Resource is never delivered • Resource or service is delivered but is of poor quality
<i>Reimburse</i> for resource or service when applicable	<ul style="list-style-type: none"> • Funding is delayed due to internal processes of funder • Reimbursement is required prior to service delivery • Service provider is not part of network for reimbursement

Data Flow Diagram Military *OneSource* Process for Resource Information Requests



APPENDIX 21

Military OneSource System Analysis Report

Background Information

On June 17, 2004 an onsite visit was made to the Ceridian office in Plymouth Meeting, Pennsylvania for the purpose of understanding the Military *OneSource* Program available to active military personnel. Military *OneSource* is a program administered by Ceridian to assist active military members and their families in locating resources and services to meet any needs they may identify. The primary role for Military *OneSource* is to provide education and options for potential resource supports.

The site visit included spending the day with Ronald White, Director for Military Program Management and Dan Lafferty, Clinical Supervisor for the program. Mr. White has an extensive background in social work as well as international experience related to information and referral supports. Mr. Lafferty is a licensed social worker with certification as an Employee Assistance Professional with military experience in the Air Force. Both have expert experience in the area of employee benefits.

In addition to providing services for the military, Ceridian serves over 10,000 organizations internationally, which translates to over 10 million employees. This Employee Assistance Program (EAP) benefit has been phased in to the various branches of the military over the past four years and is currently available to the Army, Marine Corps, Air Force and Navy. Mr. White estimates that 2.6 million individuals in the military have access to this benefit. Extensive and active marketing campaigns have been implemented to ensure awareness of the service as well as information about its use. Utilization data is tracked and sorted by service branch and reviewed to identify areas for further marketing opportunities for Ceridian.

During the visit, Ceridian personnel emphasize the company's commitment to meeting the needs of the population as it operates an extensive quality assurance program that is evident throughout the facility and through interviews with various personnel.

In an effort to build a collaborative relationship between Military *OneSource* and the project team, Carol Marsiglia led a discussion regarding the *mCare* Project. Juli Lausch prepared an extensive list of questions to be addressed throughout the tour and again at the end of the day. Deona Howard also attended the day. The discussion included an overall description of the project and phases for development of a model of care for children of military families who have life threatening conditions. In addition, use of community and military resources was emphasized to identify areas of potential interface between Ceridian services and needs of the population. Mr. White indicated a willingness to support the project through the use of Ceridian services. The role of the company as it relates to Military *OneSource* is that of referral and education. Therefore, it is important to note that accessing services identified by Ceridian is the responsibility of the military personnel seeking assistance and beyond the scope of service provided by Ceridian.

There are three Ceridian service centers in the United States that serve the military at home and abroad. These offices are located in Plymouth Meeting, PA, Minneapolis, MN and Miami, FL. The Plymouth Meeting and Minneapolis locations are described as mirror images of each other with Miami specializing in multilingual and multicultural services. All locations have access to a translation service.

Tour of Service Center

Information Technology and Telecommunications

Jo-Anne Mullen, Director and Jerry McDonnell, who are ultimately responsible for the overall security of the data system, presented an overview of the Information Technology and Telecommunications Center. A predictive algorithm is used to process calls to ensure efficiency in answering call volume. The time standard set to respond to a call is 20 seconds with no automated answering system used. The calls are answered by a trained triage specialist who then forwards the calls to the appropriate content specialist. There are over 200 phone numbers used to access the organization's services. International access is available and the organization accepts collect calls.

Mullen and McDonnell described an extensive disaster plan and reported that it is tested regularly. They stated that in the event of a disaster, all calls can be moved to an alternate center through "5 key strokes" and that this is a transparent process to the caller. As part of the disaster plan, a redundancy plan is in effect. All data is replicated at the Minneapolis center allowing consultants at other centers to access all data information necessary for business continuity, as well as storage of backup at an alternate location in Louisville, Kentucky. Backups occur multiple times throughout the day.

In addition to telephone based communications, the service is web based and operates on multiple servers that are reportedly able to handle extremely high volume loads with no evidence of performance problems. Utilization trends are reported to vary with the Army population, in that 70 % of requests are received via Internet with 30% via telephone. The other military branches are reported to be approximately 80% Internet with 20% telephone requests.

Mr. White indicates that they anticipate greater Army telephone usage over time, similar to other organizational patterns. Generally, utilization reporting is based on service type, location, and demographics such as military grade and family member using the service. Custom reports can be designed and provided upon request.

Fulfillment Center

The Fulfillment Center houses educational materials and publications that are provided to the Ceridian consultants to meet the needs of the individuals making information requests. Information distributed has been developed by or cited from experts in a particular content area. For military specific content, such as items that can be sent overseas, military personnel review the information. For more generic topics, such as coping with stress, only information validated by experts in the field is used. Some publications can be reproduced within the Fulfillment Center and some are purchased for distribution.

Service Delivery/ Research

Masters level consultants handle all calls for Military *OneSource* and the staff is configured into teams. Clinical Supervisors are responsible for Consultant Teams and are to be notified of all situations defined as significant. Examples of these would include such issues as domestic, child or elder abuse, as well as concerns that have legal implications. The Clinical Supervisor is then responsible to ensure that all actions and resources have been provided to the requestor to address the issue. In addition, the Clinical Supervisor is responsible for reviewing two cases per month for each Consultant on their team as a part of the quality assurance process for services.

Call information such as demographics and requests are documented in the Case Management System, which is a custom developed software system used by the Ceridian staff.

The software is an integrated system that communicates with scheduling for tracking purposes, reporting for utilization and communication with Fulfillment area as well as with other members of the service delivery team. During normal business hours, calls are triaged and assigned to Consultant Specialists or Consultant Generalists, dependant upon caller needs. During non-business hours, calls are handled by Consultant Generalists and assigned as necessary to specialists. Calls are accepted 24 hours per day, 7 days per week and 365 days per year. Consultant Specialists are available in the area of adoption, childcare, disability, education and international resources. All other topics are handled by Consultant Generalists. Consultants use an internal database of existing resource information or they send a request to a researcher for more specific information. The researcher also has access to an internal database of resources, as well as an Internet capability search. The researcher can utilize multiple strategies to access information requests. All information for contact is validated by the researcher prior to submission back to the consultant for distribution to the requester. For health specific information, researchers are expected to use web sites that are credible based on their URL including “edu”, “gov” or “org”.

The service center itself is a rather large area of individually divided workspaces separated by low level partitions, each equipped with a desk computer and telephone. The area is remarkably quiet despite the constant communication between requesters of information and Consultants. Each Consultant wears earphones and therefore no telephone tones are overheard in the work areas.

The service delivery system is currently in the process for accreditation by the Commission on Accreditation.

Quality Management

An emphasis on quality is evident throughout the organization as demonstrated by real time data and quality targets posted throughout the service center. These quality targets include answered calls, average hold time and calls abandoned. Goals that are below target are shown in red while on target goals are green. Diane Opere is a manager in Quality Services. She explained that user feedback is extremely important to the organization and is measured through various modes. There is an Interactive Voice Audit Survey and an online survey offered to all customers. The Interactive Voice Audit System allows the customer to answer survey questions in an anonymous way. The online survey is sent 1 week following intervention by Military *OneSource*. Overall return rates are reported at 25% for telephone audit and 28% electronically. Under certain circumstances, referral options are tagged “do not use” based on responses from consumers. Customer feedback reports are submitted to clinical supervisors on a monthly basis. Ceridian reports that they are currently working with the Military Research Center at Purdue relative to outcome measures. The company is currently attempting to demonstrate outcomes such as time saved and decreased stress in seeking resource information. Next generation outcome work will be geared toward measurement of military readiness and retention. Ceridian is reportedly considered a business associate as it relates to the Health Information Accountability and Portability Act (HIPAA).

Recommendations

- Incorporate use of Military *OneSource* Program in future program model to support access to military and community resources as well as general educational information on family related topics.

- Identify information topics that apply to children with life threatening conditions for inclusion in Military *OneSource* databases.
- Collaborate with Ceridian to incorporate publications that target the needs of children with life threatening conditions, specifically including CHI publications relating to palliative care.
- Identify additional resource linkages to Military *OneSource* that are specific to the *mCare* population.
- Offer training for Military *OneSource* Supervisors, Consultants (general and specialist) and researchers regarding *mCare* population.
- Consider reporting needs for *mCare* population and collaborate with Ceridian to submit reports for targeted population.
- Incorporate Health on the Net Code Guidelines related to the distribution of medical and health specific information to ensure credibility and quality.
- Identify any issues related to HIPAA regarding the distribution of resource or health information as it relates to model/program design.
- Educate families participating in *mCare* on the benefits of telephonic mode to promote comprehensive response to the needs request.
- Address the gap regarding accessing services as it relates to the education and resource information role of Military *OneSource* verses more intensive care coordination.
- Develop a means to measure outcomes related to the use of Ceridian services with the *mCare* population.

Resource Profile Chart

1	A	State Programs										Military					S	Other Resource		U
		Federal Programs		E	F	G	H	I	J	K	L	M	N	O	P	Q	R	Private Insurance	Disease based Foundation	Local Resource
		SSI	EPSDT	WC	Medicaid Categorically Needy	Medicaid Medically Needy	Medicaid Special Populations	DDA Services	I & T Program	Public Education Programs	Social Services (Title V)	Other	Tricare Basic	Tricare ECHO (Active Duty and must meet medical criteria)	EFMP	Military One Source (Active Duty)	Direct Care System (available during hospitalization only)	Other Military Program		
2	Projected Service and Resource Needs for mCare population																			
3	Physician care (includes primary care and specialty care)				X	X	X					X	X				X		I/R	
4	Pharmacy				X	X	X					X	X			I/R	X		X	X
5	Durable Medical Equipment (DME)				X	X	X	X	X	X (for educational goals)		X	X	X		I/R	X		X	X
6	Disposable Medical Supplies (DMS)				X	X	X			X (for educational goals)		X	X	X		I/R				
7	Nursing (Private Duty Shift Nursing)				X	X	X	X	X	X (for educational goals)			X	X		I/R				
8	Nursing (Skilled Visits)	X			X	X	X	X		X (for educational goals)		X	X	X		I/R				X
9	Home Health Aide				X	X	X	X		X (for educational goals)		X				I/R				X
10	Personal Care Services				X	X	X	X		X (for educational goals)						I/R				
11	Social Work Services				X	X	X	X		X (for educational goals)		X	X	X		I/R	X			
12	Nutritional	X			X	X	X	X	X	X (for educational goals)	X	X	X	X		I/R	X			
13	Pain and Symptom Management				X	X	X				X	X	X	X		I/R	X			
14	Hospice				X	X	X					X	X	X		I/R	X			
15	Occupational Therapy				X	X	X		X	X (for educational goals)		X	X	X		I/R	X			X
16	Physical Therapy						X		X	X (for educational goals)		X	X	X		I/R	X			X
17	Speech Therapy						X		X	X (for educational goals)		X	X	X		I/R	X			X
18	Respiratory Therapy				X (sometimes bundled with DME)	X (sometimes bundled with DME)	X (sometimes bundled with DME)						X			I/R	X	X (this service is sometimes included with related DME)		
19	Expressive Therapy (ie, music, art, play)						X	X	X	X (for educational goals)						I/R				X
20	Adaptive Equipment (special seating devices, bathchairs, gait trainers, prone standers, car seats for children >40lbs., lifts, etc.)				X	X	X	X	X	Some programs will provide loaners		X	X			I/R	X		X	X
21	Care Coordination						X	X	X	X (for educational goals)	Case Worker	X		X	X (varies dependent on military branch)	I/R	X		I/R	I/R
22	Respite						X	X				X		X		I/R			X	X
23	Family Caregiver Counseling				X	X	X	X	X	X (for educational goals)	X		X			I/R		X	X	X
24	Individual Counseling				X	X	X	X	X		X		X			I/R	X			
25	Group Counseling				X	X	X	X	X		X		X			I/R	X		X	X
26	Bereavement Counseling						X									I/R	X		X	X
27	Education services							X	X	X (for educational goals)					X	I/R	X (if previously provided by the military)		X	X

Resource Profile Chart

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U
	Dental																X (if related to a medical condition)				
28	Child Care (typical and special needs)				X	X	X	X		X (for educational goals)		X				I/R		X			X
29	Assistive Technology							X	I/R	X (for educational goals)						I/R		X			X
30	Behavior Management				X	X	X	X	X	X (for educational goals)			X (under special circumstances)			I/R	X		X		X
31	Family Caregiver Training						X	X								I/R	X				X
32	Financial Support	X		X				X			X					I/R		X			X
33	Habilitation services (day, residential, pre-occupational, supported employment)							X		X			X (mental health only)			I/R		X			X
34	Housing Access Coordination						X	X			X				X	I/R		X			X
35	Interpreter/ Translation			X				X	I/R		X	X				I/R	X		X		X
36	Mental Health				X	X	X	X			X	X				I/R	X				X
37	Moving Assistance										X				X	I/R		X			X
38	Transportation - ambulance				X	X	X				X	X	X (for medical monitoring)			I/R	X (for medical monitoring)	X	X		X
39	Transportation - routine medical				X	X	X				X					I/R					X
40	Vehicle Modifications				X	X	X					X	X (under special circumstances)			I/R			X		X
41	Recreation and camps							X		X	X	X				I/R			X		X
42	Medical Information Source												X			I/R	X		X		
43	Wish Granting							X								I/R			X		X
44	Caregiver Resources						X	X	X	X	X	X				I/R			X		X
45	Self-Esteem support							X	X	X						I/R			X		X
46	Advocacy for Child/ Family Needs		X					X	X	X	X	X				I/R			X		X
47	Resource Coordination						X	X	X	X	X	X	X	X		X	X		X		X
48	Family/ Child Education re: healthcare needs)							X	X	X	X	X	X	X			X				
49	Provider Education		X	X	X	X	X	X	X	X	X	X					X		X		X
50	Volunteer Support							X	I/R		X						X	X			X
51	Spiritual Care							X								I/R	X	X			X
52	Child Life Services												X (inpatient only)				X (if available at inpatient facility)	X			X
53																					

APPENDIX 23

	Federal	Federal / State	Military	Condition specific	Local Community
Types of supports available	<p><i>Income (SSI)</i></p> <p><i>Standards for Medicaid's comprehensive and preventative child health program for children < 21 yrs.</i></p>	<p><i>DDA advocacy for system change, and service or support programs</i></p> <p><i>Special Education services age 6 - 17 with some states expanding services from age 3- 21.</i></p> <p><i>Early Intervention services for 0 - 3.</i></p> <p><i>Medicaid Programs -state plan services</i></p> <p><i>Medicaid Waiver Programs - for categorically needy, medically needy and special groups</i></p> <p><i>Title V programs</i></p> <p><i>Social Service programs - foster care/ adoption, child protective services, etc.</i></p> <p><i>Employment support services</i></p> <p><i>Legal Protection and Advocacy</i></p>	<p>The following categories of resources are referenced on Military HOMEFRONT website and represents types of supports and information available for families across military branches:</p> <ul style="list-style-type: none"> • Quality of Life Resources • DoD Impact Aid • Education • Child Abuse Prevention • Medical and Dental • Special needs/ EFMP • Education/ Early Intervention • Special Education (3-21 yrs) • Education (> 21) • Medical care/ Tricare • Federal programs/ Title V and Medicaid • Family Connections • Family Support • Financial and Legal • Child Development Programs • Morale, Welfare and Recreation • Parenting • Head Start/ Sure Start • Special discount offers • Commissaries and Exchanges • Deployment • Eldercare • Emergency and Disasters • Employment • Housing and Relocation assistance • Domestic Abuse • Military Severely Injured • Interpersonal Abuse includes domestic • Networking Partnerships • Relocation Planning • Federal Programs (Medicare) 	<p><i>Variety of Resources</i></p> <p><i>Information (about disease, clinical trials, treatment regimes, etc)</i></p> <p><i>Conferences and presentations related to the condition</i></p>	<p>Resources that are specific and targeted as opposed to a program of services. Examples of these include but are not limited to:</p> <ul style="list-style-type: none"> • Professional providers • Health information • Adaptive technology • Child care services • Translation services • Recreation and camps • Support groups • Transportation • Respite care • Utility assistance programs • Environmental modifications • Caregiver resources • Case management services • Funding sources • Planning information

Resource Overview Analysis

Where to find information	<ul style="list-style-type: none"> • Internet (SSA website, Military Homefront website) • Local Library • Local SSA office 	<ul style="list-style-type: none"> • Internet (some links on Military Homefront website) • Local Library • Local Departments of Social Services • Local Departments of Education • State offices for Maternal Child Health • Can access information via telephone 	<ul style="list-style-type: none"> • Military OneSource • Military HOMEFRONT website 	<ul style="list-style-type: none"> • Internet • National or regional offices for the condition' • Local Library • Provided by physician or healthcare funder 	<ul style="list-style-type: none"> • Internet • Local Library • Word of Mouth • Family Networks • Local organizations
Process for accessing resource	Must apply at a local SSA office for SSI EPSDT is a set of standards for care and not actually a resource that is provided (one must be eligible for Medicaid for legislative standards to apply)	Varies from state to state Some state programs such as Medicaid Waivers have existing waiting lists prior to accessing services. Families may need to meet a financial and or medical eligibility requirement. Some state waivers require a cost neutrality factor.	Process for accessing each program or support varies based upon service desired. However, active military can use Military One Source as an Employee Assistance Program benefit to assist in facilitating programs and resources.	Correspondence Application process - varies across organizations May require physician documentation of specific condition	Formal and informal application processes varies across sponsoring organization Sometimes requires documentation from a healthcare provider or other entity
Barriers for families in identifying and finding resource	Application process May require physician documentation Locations of local offices Lack of knowledge regarding potential resource Income level too high Application process requires persistence and may require multiple appeals for award	Application process Varying eligibility requirements (financial, medical, geographic) Some Medicaid programs for special groups have limited slots and lengthy waits for services Lack of knowledge regarding potential resource Information found on websites is global and family may not realize they do not qualify until they have already gone through the process. State programs vary from state to state in regards to eligibility, benefits and service delivery	Service availability and extent of support may depend on the individual's status within the military. Some qualifiers include active vs. retired status, reserves or branch of service.	Application process Acceptable documentation of condition particularly if diagnosis is unclear Lack of knowledge regarding potential resource	Application process Lack of knowledge regarding potential resource Documentation from healthcare provider Applicant may not meet specific target criteria for accessing the service (ex. geographic, age, culture, religious affiliation, etc.)

Resource Overview Analysis

Strategies that can be incorporated in a new model design to optimize use of resources	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local SSA office Educate families regarding appeal process	Educate families regarding the potential resource Assist families in facilitation of application process and identification of local state offices Educate families regarding appeal process	Encourage the use of Military One Source and develop relationships between family and a coordinator from One Source. See Military One Source Report for more specific recommendations) Encourage families to participate on family networking forums (ie STOMP or discussion forum through Military HOMEFRONT) to encourage dialogue regarding experiences of what works and doesn't work when working with systems to access services. Families who have experience working through various systems may be willing to share their knowledge to assist other families in similar situations.	Access to information related to condition specific resource centers Education for families related to how to identify resource opportunities	Access to information related to local resources. Education for families related to how to identify resource opportunities within their local community

APPENDIX 24

Web Based Resource Database Note

Initial planning for the Children's Hospice Project included a web based resource data base populated with resource information in the NCA that could be accessed by parents and or professionals to easily get information about supportive resources.

As part of the exercise in reviewing resources, The Coordinating Center proposed the development of a web-based data structure to capture the types of resources available to families. The purpose of this database was to house the resource data identified during this review of resources with the intent that the database structure could be useful at the point a demonstration project is funded. In the early phases of the project, the area of project focus was the NCA, however as the project progressed and the team learned that a one size fits all palliative care model may not be successful across the military system, the development of the database was reconsidered. Based on this shift of focus from the NCA to the full military system, the team felt that there was a need to present the resource information from a broader perspective that could be applied to any community. Therefore, the team determined that the specific data that would be collected and included in a database for the NCA would not be useful in a broad application of model design. In addition, the resource review findings included an extensive list of existing databases that are currently accessible on the Internet for families who have children with special healthcare needs. Based on the evolving nature of the project, the changing needs of the project team, and the existence of other resource databases, the project team requested a more global presentation of resources that currently exist.

APPENDIX 25

Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center (Task Order 3001-088) Kennell and Associates, Inc. February 28, 2006

In November 2005, The Office of the Chief Medical Officer, TRICARE Management Activity, requested Kennell and Associates, Inc. to provide an independent government cost estimate of the implementation of a pilot project in the National Capital Area (NCA) to provide palliative and end-of-life care to children with life-threatening conditions (LTC). (See Appendix G for the complete report.) The Kennell report based its findings on the same case definitions (ICD9 codes) as previously discussed in this paper and as used by Dr. Arday in the FY01/02 analysis when determining the numbers of children and the associated costs. The Kennell report analyzed the additional cost of providing care coordination, home health care, respite care, and bereavement counseling to the families, as these services were identified as the “missing” services in a comprehensive pediatric palliative care and hospice program.

The Kennell report, based on FY04/05 data in the DEERS and M2 database, also had the advantage of the recent establishment of the DEERS Death File in its data analysis. The Kennell report presents a closer approximation to the numbers and costs of children in a pilot or demonstration program in the NCA were one to be implemented in the near future. The Arday report provides more detailed information about expenditures for children with LTC in the NCA and provides data about the entire population of children in the MHS. The two reports complement one another and reinforce the utility of the methods developed in this report of estimating children with LTC in the MHS and within a given catchment area in the MHS.

***Table 24
Number of Unique Pediatric Beneficiaries with LTC
in the NCA During Two Study Periods***

	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
<i>FY 01/02</i>					
Lived	33	48	114	67	262
Died	0	0	4	2	6
Total	33	48	118	69	268
<i>FY 04/05</i>					
Lived	40	58	130	78	306
Died	0	1	8	6	15
Total	40	59	138	84	321

The percentage distribution of cases by diagnosis in FY 04/05 was almost identical to that in FY 01/02, although the total number of cases found was about 20% higher.

Costs to provide and/or purchase care for the population of children with LTC in the NCA were \$15 million higher over the two year study period in FY04/05 than in FY01/02 in which the costs were \$14.6 million for the two year study period (an increase of 100% in health care costs). Some of this increase (20%) is due to the increased number of patients served, but 70% of the increase was estimated to be due to increased health care costs per child. (See Table 25.)

Table 25
FY 04/05 Direct Care and Purchased Care Costs for Children with LTC in NCA

	“Incurable”	“Manageable”	“Curable”	“Co-morbid”	Total
Total Direct and Purchased Care Costs					
Lived	\$2,175,280	\$3,639,386	\$15,377,666	\$6,405,625	\$27,597,957
Died	n/a	\$86,859	\$1,042,216	\$877,821	\$2,006,896
Total	\$2,175,280	\$3,726,244	\$16,419,882	\$7,283,447	\$29,604,853
Costs per Child					
Lived	\$54,382	\$62,748	\$118,290	\$82,123	\$90,189
Died	n/a	\$86,856	\$130,227	\$146,304	\$133,793
Total	\$54,382	\$63,157	\$118,985	\$86,708	\$92,227
Inpatient Days per Child					
Lived	8.5	9.1	16.1	16.1	13.8
Died	n/a	20.0	27.8	46.5	34.7
Total	8.5	9.3	16.8	18.3	14.8

Table 26
Average Cost per Child with LTC in the NCA FY 01/02 Compared to FY 04/05

	FY 01/02	FY 04/05
Total Costs	\$14,646,161	\$29,604,853
Total Number of Children with LTC	268	321
Average Cost per Child	\$56,081	\$92,227

The average cost per child increased from \$56,081 to \$92,227 (increase of 64%) from the two year study period FY 01/02 to FY 04/05. (See Table 26.) The highest average cost per child for each study period was for a child who died during the study period, and the highest among these was children who had “curable” or “comorbid” conditions. From study period FY 01/02 to study period FY 04/05, however, the cost per child who died with a “curable” condition in the NCA actually decreased from \$266,293 to \$130,227.

Major Cost Savings. The Kennell Report estimated the cost per year of providing the “missing services” (i.e., care coordination, home health care including care by personal attendants, respite care and bereavement counseling) to the population of children with LTC living in the NCA and to those with LTC who died. Kennell’s report is based on several assumptions: (1) services were provided to 15 children per year who died and to 225 who survived the year. (2) The combination of family support and education by care coordinators and the increased availability of a robust home health care program is assumed to allow 11 children to move from inpatient care during their terminal illness to home, saving \$30,844 per child per year, or \$346,998 for the NCA MHS per year. (3) Care coordination also generates savings by using telephone triage and parent education to increase the efficiency of use of medical resources, estimated to provide an annual savings of \$275,000 to \$550,000. (4) Care coordination further saves physician time that can then be used to re-capture purchased care patient visits at a potential cost savings of \$430,000.

Major Program Costs. The estimated salary costs/year of six care coordinators and one administrative staff member is \$619,365. Costs of respite care (1 weekend per month/family) is \$313,200. Bereavement counseling costs are estimated at \$15,000.

Kennell estimates a net cost savings per year of \$111,000 - \$388,000 several years after the program reaches a “steady-state” and families/staff are confident in their roles and in the resources available to them (see Table 27).

Table 27
Summary of the mCARE Pilot Project Estimated Savings
at WRAMC for the National Capital Area in FY 06¹

Added Costs for Pediatric Palliative Care Program in the MTF	
Care coordination based at the MTF	\$619,000
Respite care provided for families at home or in the hospital	\$313,000
Bereavement counseling for parents and families after the death of a child	\$15,000
Savings Produced by Providing Suggested Care	
Substituting home care for severely ill children instead of hospital care	\$347,000
Freeing physician time through quality care coordination	\$435,000
Providing some triage and parent education over the phone rather than during visits	\$277,000 – \$554,000
Net Program Savings in FY 06	\$111,000 – \$388,000

¹ Independent Government Cost Estimate for Pediatric mCare Pilot Project at Walter Reed Army Medical Center (Task Order 3001-088). See Appendix G.

APPENDIX 26

Site Visit Report Palliative Care Program Assessment

Program Name: Children's Mercy Hospital/ PACCT Program

Date of Survey: 5/8 -5/9/06

Location of Program: 2401 Gillham Road, Kansas City, MO 64108

Web address (if available): www.childrensmercy.org

Primary Contact: Rosemary Hubble, RN, M.Div, MA **Phone:** (816) 234-3066

Name of Person Providing Information: See attached list.

Title of Person Providing Information: See attached list

Site Visit Completed by: Cheryl Naulty, Carol Marsiglia, Pam Cunningham and Karen Ann Lichtenstein

Program Description:

Children's Mercy health care system includes the state-of-the-art, 241-bed hospital at 2401 Gillham Road in Kansas City, outpatient clinics in midtown and in suburban Johnson County, Kan., and outreach clinics in outlying communities. Children and families from six states are regularly served by the hospital, which sees patients living from coast to coast and overseas.

Approximately five years ago, the hospital system identified the need for a coordinated approach to both inpatient and outpatient care delivery for children diagnosed with life-threatening illness. To respond to that need, the hospital supported the development of the Pediatric Advanced Comfort Care Team referred to as PACCT. The PACCT program is an interdisciplinary team of care providers dedicated to providing palliative care to patients and families from the time of diagnosis of a life-limiting or life-threatening illness. PACCT provides comprehensive palliative care that includes clinical services, education and research.

CMH considered application for a CHI PACC program, but chose to forego that funding opportunity due to the broad geographic area they serve crossing multiple states. In addition, CMH expressed that such a program may be too restrictive as to who could be served in the program.

The program approach is basically a consultative service based within the hospital network (inpatient and outpatient clinics at the hospital site only) to support the primary or subspecialty healthcare team to ensure that both medical and non-medical needs of the patients and families are addressed. The most intensive monitoring of the palliative care service occurs while the child is an inpatient. When children return to outpatient clinics for follow up, the palliative care team will see the child at the time of the visit. The focus of this service is to provide the best quality of life for the child that is consistent with the family's values. The following team members are involved in the delivery of this care and the disciplines are:

- Patient and family
- Physician
- PACCT Nurse Clinician (Coordinators)

- Chaplain
- Social Worker
- Advanced Practice Nurse Case Managers
- Pain Management Specialist
- Psychologist
- Child Life Specialist
- PACCT Medical Director
- Community Hospices

The program currently serves approximately 120 children and families. However, it is reported that the referrals to the PACCT program have consistently increased over the past several years. The PACCT Program attributes that increase to efforts to promote the program through education of physicians and the addition of designated PACCT coordinators.

The designated program staff is comprised of:

- A Program/ Operations Manager
- 1.8 FTE Nurse Clinician (referred to as a Care Coordinator or Care Facilitator)
- Medical Director

Other multidisciplinary team members are accessed through the existing hospital staff from other departments.

The PACCT Program falls under the hospital's Department of Patient Care Services and is not a physician directed service. The program has an Advisory Board that includes representation from parents, social work, child life, chaplaincy, behavioral medicine, integrative pain medicine, physicians, intensive care nursing, education and administration. The Advisory Board meets on a quarterly basis and is divided into sub-committees on education/communication, research, parent support, clinical services and technology. The program emphasizes parent to parent support and recruits other parents who have been served by the program to provide that support.

PACCT collaborates with the local University to support efforts in the area of research (see Research Section) and works collaboratively with a community hospice provider called Carousel.

Population Description

The PACCT population is exclusively comprised of children served at CMH through the inpatient and outpatient department at the main campus site. Total consults for the PACCT program from 2002 through April 2006 reportedly total 216 children. The following categories are used to define the population served in PACCT: (definitions have been requested for categories below)

- Acute life threatening
- Life threatening
- Life limiting
- Life-style limiting

The age of children served in the PACCT program are typically 0 – 18. However, if CMH has been serving a young adult who is beyond 20 years old, the program may choose to continue to provide services within the system. Based on observation, the population understandably reflects the general population of the geographic region of the country and does not seem to represent a broad diversity of ethnic culture.

Service Delivery

- Referrals for PACCT services are initiated by medically licensed personnel and the parents must be in agreement to proceed with the process.
- The PACCT coordinator gathers patient history from records to determine if PACCT care is appropriate and to prepare for contact with the primary care physician.
- If the Primary Care Physician (PCP) is not in agreement with participation, but the PACCT staff assesses a serious need for palliative care, the PACCT Medical Director will have a discussion with the PCP. Ultimately, if the PCP does not agree to the service, the referral is ended.
- If the PCP is in agreement the referral proceeds and the Nurse Clinician meets with the family within 48 hours
- Prior to the initial meeting with the patient, the PACCT coordinator reviews the medical record to identify any psycho-social issues, etc in preparation to meet with the family.
- In addition to the record review, the PACCT coordinator determines the composition of the team and notifies the following departments - SW, Chaplain, Psych, Child Life, Pain Management, etc. For disciplines that are necessary to meet the patient's needs, the PACCT coordinator will ask for an assigned team member.
- An email is then sent to the team to inform them of the PACCT referral.
- At the initial meeting with the patient/family, the PACCT coordinator will explain the service, provide a brochure, answer questions, and discuss the child's illness and what the parent understands about it.
- If the parent agrees to participate, the coordinator provides a binder with PACCT information and assessment documents, brochure, blank Comprehensive Comfort Care Tool (CCCT), DNAR parent document, grief assessment form if appropriate and provide psychiatric evaluation form for completion when appropriate.
- The CCCT may not be appropriate to discuss in the initial meeting and this discussion may occur at a much later date. In the meantime, the PACCT staff may continue follow up visits based on family response to services.
- A meeting is convened with the family and team members to discuss the CCCT and develop an action plan
- The CCCT is fully developed and reviewed by the parents, then signed by the physician.
- The PACCT coordinator monitors the plan by visiting the family (frequency is determined by family and PACCT coordinator) while the child is an inpatient or the coordinator may identify opportunities to connect with the family when they return for outpatient clinic visits at the hospital site.
- When a death occurs, chaplaincy services are responsible for the administrative assistance in addition to any spiritual care. Administrative assistance includes coordinating the medical examiner work when appropriate, being the primary contact for organ/ tissue donation, coordinating in-house autopsy when applicable and primary communication regarding funeral or service arrangements.

- “After Care” is the service that addresses bereavement needs and care and completes the process. This is a separate hospital team that is outside of the PACCT program.

The PACCT nurses serve to initiate palliative care and to facilitate the discussions among the family and the interdisciplinary team. The PACCT is not involved in the daily disease management, approach to pain management, or the process of identifying and/or obtaining resources for the family. Rather the team will monitor the progress of such issues with the family through regular contact and informal discussions. The social workers are primarily responsible for obtaining resources, equipment and other services as identified in the CCCT.

The PACCT nurses along with the primary care physician provide continuity for the family. This physician may be either a general staff pediatrician or a specialist. Residents do not fill this role, but they may be involved through their various clinical rotations or the PACCT elective. There is no consistent continuity among the other disciplines, as the teams are drawn from the staff assigned to specific departments or specialties of outpatient clinics. However, there seems to be sufficient trust and communication between and among the various members of the support staff that information relevant to the continuing care of the family is passed along at the time of readmission.

Funding for Services

The CMH system is currently funding the PACCT Program through philanthropic money that supports 1.8 FTE for the Nurse Clinician positions and the Program Manager role. The Medical Director also serves as an Intensivist in the PICU and is loaned to the PACCT team for this role; therefore, no costs are attributed to the program for medical direction. Other disciplines are funded through their specific departments and basically add the PACCT responsibilities to usual daily responsibilities.

The Social Work department explores insurance benefits to access funding for medical needs. However, CMH reportedly has access to private funding that often covers items and services not funded through traditional health insurance plans.

Research Component

The PACCT program collaborates with a Research Assistant Professor from the University of Missouri-Kansas City to promote evidence based practice through qualitative research. A current initiative is underway to access R-15 funding to develop and study parental values and understand how variables have an impact on communication between healthcare teams. In addition, it is the vision of the researcher that by having a better knowledge of parental values, care can be promoted in a manner that is “ethnically appropriate, culturally sensitive and consistent with the family’s stated values”. The research has proposed using a Parental Values Inventory (PVI) tool, which is an instrument that identifies, assesses and allows families to express their values. Some variables that impact values are reported as: spirituality, coping styles, communication preferences, caregiver control desires and quality of life. Initial funding efforts for researching these issues have been denied but will be pursued further upon collection of additional data.

Education Component

Education is addressed at various levels within the system of care at CMH and specific initiatives are listed below. The PACCT program emphasizes a strong connection between the educational efforts they are making and the buy in factor of staff to the palliative care philosophy at their facility. IPPC training is a tool used for educating providers at CMH. In order to generate energy around palliative care, the facility used a master facilitator such as David Browning from IPPC to introduce the palliative care concept within the institution, and then the PACCT staff conducts IPPC training in a train the trainer model.

The levels of education seem to address the general education of staff related to what palliative care means as well as education specific to the PACCT program and individual opportunities for modeling the palliative care approach as it applies to specific children and families.

PACCT Education initiatives targeted to families are:

- DNAR Care Card
- *Shelter from the Storm* written by Joanne Hilden and Daniel Tobin
- PACCT Brochure describing program services

PACCT Education Initiatives for hospital staff include:

- Department updates for nurses, social work and child life
- Grand Rounds/ Special Events (e.g. David Browning)
- One-on- One with PACCT Clinicians
- Small group lectures
- IPPC curriculum
- Resident/Fellow Program elective (objectives and outline for training are available upon request for mCare project team)
- Child Life Internships
- Nursing Student rotations
- Nursing Orientation
- Journal Club

PACCT Educational Initiatives presentation topics include:

- Basics of palliative care
- Introduction to PACCT
- Loss Exercise
- Ethic of Pediatric Palliative Care
- Caring for Dying Children and Supporting Families
- History of Palliative Care – Palliative care vs. hospice
- Death and dying
- Nutrition and Hydration
- Children and Grief
- Language and the Power of Grief
- Ethics of Self Care

If CMH staff request individual training for their hospital specific unit, the nurse clinicians from the program provide the specified training. The nurse clinicians emphasized that a majority of

the education is provided at an individual level and that “modeling” palliative care practice is a primary strategy for educating coworkers.

Strategies Used for Implementation

- Gain support from key senior administrators to include the CEO and the senior Vice President of the clinical service product line.
- Initiate services in departments of the hospital that had a greater need for education rather than those that already support the philosophy (for example, CMH does not include heme/oncology in their efforts because that department already has a strong base in the philosophy of palliative care)
- Meet with other disciplines (i.e. SW, child life, etc.) to gain support prior to implementing the palliative care program
- Use a master facilitator such as David Browning from IPPC to introduce the palliative care concept within the institution, and then conduct IPPC training in a train the trainer model. This strategy generates energy around the effort
- Base the palliative care model in an arena where children are frequently seen (i.e. Many children are seen in the outpatient clinics and this presents an opportunity to make regular contact with the families to review and modify the CCCT)
- The Nurse clinician is key to the overall success of the program. Suggest hiring for that role based on “the right person” for the job as opposed to focusing a specific certification or educational requirement.
- Identify specific diagnoses that would generate an automatic PACCT referral
- Use champions to promote the program across departments, but target staff who have a sincere commitment to supporting the philosophy of palliative care.
- Use physician champions who are critical to buy in
- Don’t push the issue of palliative care on a department or staff that demonstrates resistance to the concept.
- A palliative care program may reduce referrals to the hospital Ethics Committee and in the event a situation gets to the ethics committee, a PACCT consult is typically made
- Implement program in “baby steps” and “small bites”
- Be persistent in efforts to infuse the principles of palliative care, but balance the effort so not to force the issue
- In the initial phase of program development, CMH used a task force, but once the program was underway, they moved the task force into an advisory committee model.

Strengths of PACCT Program

A primary factor at CMH that supports success of the PACCT Program is the supportive, family centered culture that exists within the facility. Since the hospital system exclusively serves the pediatric population, many of the philosophical practices already in place to support children and families naturally exist and therefore the promotion of palliative care is not foreign to the existing culture.

The staff at CMH attributes much of the success of the program to a key nurse clinician who brings “the right stuff” to the position. There was not an emphasis placed on credentials or certifications for that role (except that it be an RN) but rather to find the right person who could promote the program in a subtle, consistent manner throughout the hospital system. The role of

the primary nurse clinician is to be a neutral “care facilitator” who monitors the CCCT document and is a consistent resource for child and family communication among the entire health care team. The PACCT staff felt that an RN would better serve as an advocate for the patient and family in relating to the physician staff.

Parents indicate that the “web of support” is one of the single most valuable resources provided by the program.

Current Challenges for the Program

- Quantifying outcomes that add credibility to the PACCT initiative to maintain support of hospital administrators
- Expanding the “buy in” factor to all physicians and staff at CMH
- Locating alternatives to philanthropic money for funding nurse clinicians which has a time limit of approximately 1 -2 years
- Dealing with territorial issues within the facility (i.e. the overlap between SW and palliative care clinician)
- Avoiding the presumption that when palliative care staff are involved it means death. This factor is down played by a focus on the role of the clinicians and the supportive nature of the program rather than the final clinical outcome
- Dealing with the fact that Information technology plan for PACCT program is not part of the main clinical documentation system; however some elements link the programs.

Possible Application to the Military Environment

- Program implementation occurred in a hospital based system and gradually expanded, therefore some of the implementation strategies listed above may apply in the military environment.
- Some of the components that exist in the CMH program would also exist in a MTF.
- The only new positions are the 2 PACCT RNs.
- Strong reliance on existing staff within the hospital to provide the direct care allows for tailoring care and services specifically to meet the needs of each child and family and provides for relative autonomy for each interdisciplinary team. PACCT RNs are primarily facilitators.
- Emphasis on developing partnerships among existing resources, both in the hospital as well as in the community.
- Care coordination focused on issues and assigned responsibilities identified in the CCCT.

Documents available for review by mCare team from PACCT visit:

- PACCT brochure
- Pediatric Palliative Care Residency/ Fellowship Elective (program objectives, outline and evaluation form)
- PACCT Powerpoint Presentation of program
- Child Life brochure
- 2004 PACCT Annual Report
- Discharge Planning Tips (used by as an educational and reference tool)
- PACCT Clinical Services Process diagrams

- Comfort Care Communication Tool (sample)
- Contact list and business cards for PACCT and CMH staff

Site Visit Report Palliative Care Program Assessment

Program Name: Seattle Children's Palliative Care Consulting Service

Date of Survey: 5/25/06

Location of Program: Seattle Children's Hospital

Web address:

http://www.seattlechildrens.org/our_services/clinical_services/palliative_care.asp

Primary Contact: Scott McKinstry **Phone:** 206-987-4751

Name of person providing information: Ross Hays MD, Scott McKinstry, Leslie Adams, Michelle Frost RN, Mark Power BCC

Title of person providing information: Medical Director, Program Coordinator, Social Worker, RN, Chaplain (all act as Palliative Care Consultants)

Program Description	
<p>Type of Program: (Mark all that apply.)</p> <p><input type="checkbox"/> Hospice</p> <p><input checked="" type="checkbox"/> Palliative Care</p> <p><input type="checkbox"/> Associated with a Medicaid Waiver</p> <p><input type="checkbox"/> Not a formal program, but Palliative Care Services are provided as part of a specialty clinic (identify type of clinic)</p> <p><input checked="" type="checkbox"/> Other (describe) <u>Consulting Service</u></p> <p>Program has been in existence:</p> <p><input type="checkbox"/> Less than 5 years</p> <p><input checked="" type="checkbox"/> 6 – 10 years</p> <p><input type="checkbox"/> 11 years or more</p>	<p>Program Affiliation:</p> <p><input checked="" type="checkbox"/> Hospital</p> <p><input type="checkbox"/> Community Based Entity</p> <p><input type="checkbox"/> Provider Group (describe)</p> <p><input type="checkbox"/> Hospice component</p> <p><input type="checkbox"/> Other</p> <p>Additional Comments:</p>

Services Provided by Program	
<p>Identify key services provided by your program to support palliative care: (Mark all that apply)</p> <p><input checked="" type="checkbox"/> Care Coordination (some)</p> <p><input type="checkbox"/> Respite</p> <p><input checked="" type="checkbox"/> Medical Care (indirectly)</p> <p><input type="checkbox"/> Clinical Treatments</p> <p><input type="checkbox"/> Counseling services</p> <p><input type="checkbox"/> Bereavement services</p> <p><input type="checkbox"/> Pain Management</p> <p><input type="checkbox"/> Support at time of diagnosis</p> <p><input checked="" type="checkbox"/> Other services (specify)</p> <ul style="list-style-type: none"> Facilitate communication using Decision Making Tool 	<p>How are services funded within your program? (Mark all that apply)</p> <p><input type="checkbox"/> Medicare (if eligible)</p> <p><input type="checkbox"/> Medicaid Waiver</p> <p><input type="checkbox"/> Medicaid (fee for service or managed care program)</p> <p><input type="checkbox"/> Other government (e.g. Tricare, VA, etc.)</p> <p><input type="checkbox"/> Private Insurance</p> <p><input type="checkbox"/> Self Pay</p> <p><input type="checkbox"/> Services are provided in kind</p> <p><input type="checkbox"/> Costs are absorbed by an umbrella program</p> <p><input checked="" type="checkbox"/> Other (specify)</p> <ul style="list-style-type: none"> Paid for by hospital administration fund

Care Coordination

Is care coordination included in your program?

If no:

Is it provided informally or by another external entity?

If yes:

What are the qualifications for your care coordinators?

What activities do the care coordinators perform?

What is the average caseload for a care coordinator?

Do you use an acuity system to determine intensity of care coordination services? (If yes, how does that work?)

What are the criteria to qualify for care coordination services?

How do you measure effectiveness of care coordination?

They facilitate care conferences in the hospital to help develop a care plan and they follow up with individuals to implement the care plan.

How are *access to care* issues addressed within your program?

They accept nearly all referrals.

How are issues related to *communication with providers and relationships* addressed within your program?

The Decision Making Tool (DMT) is the cornerstone of what they do. See attached tool and description.

How are issues related to *emotional toll on parents and family* addressed within your program?

The group addresses the emotional toll on parents and family by facilitating communication and helping to build an understanding between families and health care providers and by developing a plan that incorporates the family's values and preferences.

How does your program incorporate families in the *decision making* processes?

When there is a communication challenge:

- The physician makes a referral to the palliative care team.
- A consultant is assigned to the case by availability.
- The consultant meets with the family to see if the family wants the consultant involved.
- The consultant then meets with the providers.
- The program coordinator schedules a care conference with the family and health care providers.
- The consultant facilitates communication and shared decision making by holding a care conference for about an hour with groups up to 27 people. The key role of the consultant during the conference is to ask clarifying questions.
- After the care conference, the consultant completes the tool with what was discussed at the meeting. Writing about the meeting discussion and action plan on the Decision Making Tool takes about two hours.
- The consultant then follows up with everyone who is listed on the action plan.
- The completed DMT goes into the front of the patients chart and the parents are provided a copy to take with them. They have found a way to include the DMT in the electronic medical record, although it is not as prominent there as when they place it in the front of a paper chart.
- The DMT becomes a tool for continuity of care.
- The DMT is used most effectively when the conference facilitator comes from outside the team of healthcare professionals that provides care for the child.

Community Resources

How does your program assist families to access other community programs and services?

They assist indirectly by helping to implement the action plan, primarily by following up with health care providers to make sure that each team member completes the steps designated in the plan.

Education and Training

Describe any education and training related activities that support your programs.

- Consultants educate providers through care conferences
- They educate residents through presentations on palliative care and communication
- 4th year medical students can do an elective with the palliative care consultants

[illegible]

- They had a needs assessment done in the mid-1990's, followed by a grant-funded demonstration project in which they developed the Decision Making Tool. After the grant, the administration provided \$200,000 to fund the Palliative Care Consulting Service, considering it important value added to care at the hospital and a way to humanize technological processes. They now have 2.9 FTE plus .5 time of the medical director. They are collecting donations to establish an endowment for ongoing work.

Recommended Resources:

- They consider the palliative care guidelines from Canada to be the best. They recommend the work of Jerri Fregger at the children's Hospital in Nova Scotia (IWK).
- They think palliative care will become a JCAHO requirement sometime in the next 10 years.

Considerations for Getting Started:

- Find a physician champion.
- Start in the ICU.
- Use the term "palliative care consultant."
- Identify "trip wires" for calling the palliative care team, such as 8 days or longer in the PICU, a certain number of days on a ventilator, a cancer relapse, a tracheostomy and ventilator.

They think that TRICARE needs a palliative care benefit, with nursing or social work visits, different from the hospice benefit. They gave us the Washington State palliative care benefit as a sample.

Name of surveyor: Jan Hanson and Jason Cervenka

Site Visit Report Palliative Care Program Assessment

Program Name: Children's Hospital Denver/ Butterfly Program

Date of Survey: 6/6 - 6/7/06

Location of Program: 1056 East 19th Avenue, Denver, CO 80218

Web address: <http://www.thechildrenshospital.org/public/info/index.cfm>

Primary Contact: Brian Greffe MD **Phone:**

Name of person providing information: See attached list.

Title of person providing information: See attached list

Program Description:

The Children's Hospital is a private, not-for-profit pediatric health-care network located in Denver, Colorado that is wholly dedicated to caring for children. It has been ranked one of the best children's hospitals in America by U.S. News & World Report for more than a decade. With 1,130 pediatric specialists and more than 2,300 full-time employees, Children's is home to a number of nationally and internationally recognized medical programs.

In 1999, the Butterfly Program was developed with some grant support for children who have life limiting illness. The program was designed as a consultative service to provide palliative care to children throughout the hospital system to include inpatient and outpatient departments. The Butterfly Program worked in conjunction with a Home Health Program owned and operated by the hospital system and a community based Hospice Program through Centura Health. It is best described as "a collaborative effort between the Children's Hospital and Porter Hospice of Centura Health." The initiative started under the leadership of Dr. Brian Greffe and utilized a nurse practitioner as well as other services available in the hospital system such as chaplain and social worker. The Home Health Program was subsequently closed and those services were then provided through an external agency.

This program is currently pursuing a CMS home and community based waiver consistent with other CHI/ PACC programs. Approval for this program is pending. It is anticipated that 200 children across the state of Colorado may be served in that waiver; however, only a subset of those 200 will be in the Butterfly Program.

The Butterfly Program is basically a consultative service that provides support and comfort to families with children ranging from infants to young adults who have a potentially life-limiting illness. Under the supervision of the patient's physician, intermittent services are provided by an interdisciplinary team that includes:

- Physicians
- Butterfly Program Medical Director
- Pediatric Registered Nurses
- Social Workers
- Spiritual Care Providers
- Trained Volunteers
- Bereavement Counselors

- Pharmacists
- Physical and Occupational Therapists
- Dietitians
- Home Health Aides

The program currently serves approximately 45 children and young adults and receives approximately 3 – 4 referrals per month. The average length of time in the program is reported to be approximately 93 days. The range for program participation is approximately 3 months to 3 years. Some Butterfly participants may be identified as inactive during the course of their illness based on the individual needs of the child and family.

The staff designated from Childrens Hospital to the Butterfly Program are:

Medical Director 0.5 FTE

Nurse Practitioner or Inpatient Coordinator .25 FTE (other portion of time is spent on Bone Marrow Transplant Unit)

Spiritual Care Providers 2- 0.5 FTE

Centura Health, a community based provider designates the following staff to the Butterfly Program:

Outpatient Coordinator / Social Worker 0.5

Administrative support 0.45 FTE

Outpatient Chaplain 0.2 FTE

Fund raising efforts

The Program has a Steering Committee that meets quarterly. Some topics addressed the steering committee include current and future fundraising efforts, Medicaid Waiver Updates, CHI Grant and updates, Provider issues, Volunteer Training, policies and procedures development, clinical staff recruitment for the program and other items of concern to the Program.

Population Description

Although the inpatient population is described as including children in the Colorado area, it may serve children across seven states including Wyoming, Nebraska and Montana. However, the community based portion of the Butterfly Program, provided primarily through Centura Health System Services are only provided within the state of Colorado. Centura Health indicates that 98% of the families they see would be Medicaid eligible. A child can participate in the Butterfly Program if they have a 12 month prognosis and they may access curative therapies. It is not required that child have a DNR status to participate in the program.

Dr. Greffe reports that approximately 40% of the program population are followed by oncology with the remaining 60% having other life limiting conditions.

Service Delivery

The following steps address the basic process for the delivery of services in the Butterfly Program:

- A referral is made by a nurse, family or other staff to the Program
- An agreement from the attending physician is obtained to proceed with the referral

- An initial consult is made by Dr. Greffe or the Inpatient or Outpatient Clinical Coordinator
- The Inpatient Coordinator is a nurse practitioner. This person's role is to explain the program and begin to identify the family's concerns, identify specific needs of the child and family, coordinate with the outpatient team if appropriate, discuss DNR, pain management and symptom control. The inpatient coordinator will also enlist the support of the hospital social work team and the nursing staff to address the child's needs. If and when the child transitions out of the hospital facility, the outpatient coordinator who is a licensed clinical social worker from Centura Health will provide similar activities to address the child and family needs. In addition, the outpatient coordinator may address resource needs, counseling issues, and continue discussion related to advance directives.
- Consent to participate in the program is obtained from the parents
- A Palliative Care Plan and progress notes are initiated
- A Family Conference may be convened and the Palliative Care Plan is completed
- The Plan is distributed to the Primary Physician, the Parent and the a copy is placed on the patient's chart
- A chaplain will automatically see families who are participating in the program
- If the child is inpatient, the inpatient coordinator from Children's Hospital will follow during the child's hospital stay
- General hospital interdisciplinary resources are available as needed and would be incorporated into the child's plan as appropriate (includes chaplain or other spiritual care providers, subspecialty physicians, pain management team, pediatric nurses, social workers, child life specialists, trained volunteers, pharmacists, physical and occupational therapists, dieticians and home health aides)
- Ethics consults are arranged when indicated
- If the child is outpatient, the Centura Health outpatient coordinator will be the primary monitor to follow the child
- Home health services are delivered by an independent nursing agency provider or Centura Health
- The outpatient coordinator addresses the ongoing needs of the child and family, such as resource issues, education, emotional support needs, sibling issues, etc.
- Medical care is provided through the primary care physician (also sign for homecare orders) or can be accessed through the special needs clinic
- The Butterfly Program coordinators and medical director are available to the family as an on call basis
- If and when a child enters a formal hospice program, the palliative care team typically transitions out of the process.

In addition to the process steps listed above, the Butterfly Program has access to pain management services and child life staff who are currently available in the hospital facility. Although pain and symptom management are often handled by the primary care physician or the medical director or inpatient coordinator, this team is available to provide consultation regarding pain management solutions. In addition, they may offer some complementary therapies such as aroma therapy, massage therapy or Reichi therapy to the pain management treatment plan.

Child Life services are also available to children who are inpatient as well as to their parents and siblings. Child life specialists play an integral role in promoting communication with the child and family especially during the delivery of difficult information and decision making. Music therapy is another adjunct to the program that can be supplemented as indicated by the child and family needs.

At the time of a child's death, there are options the family can choose if the death is anticipated. In the event the child remains hospitalized during the dying process, the family is offered the use of the "Cocoon". The "Cocoon" is reportedly used approximately 1 – 2 times per month and is an effort to transform the typical hospital room into a more home like atmosphere. Ideally, the room is set up when the child arrives. Children may be moved from a NICU or PICU type setting to the Cocoon environment. The environment includes soft lamp lighting, a butterfly blanket and pillow and beanie baby on the bed. The sheets are soft and colored. They may place a ceramic heart box that has a battery operated votive set inside that "burns" continuously.

There is a CD player with some soft music. The family has access to a basket filled with decaf/reg coffee bags, herbal tea, hot chocolate, etc. In addition are crackers, granola bars, etc. The family also has access to some basic toiletries to use during this time. A disposable camera is available to the family in addition to TV/ VCR and movies. The families are encouraged to use the items. During this time families are offered the option to create a hand or footprint of the child as well as the use of a professional photographer at no additional cost to the family. Spiritual care providers from the hospital play an integral role during this time. Families may choose to have their personal spiritual contact or are offered services from the hospital.

When it is anticipated that a child will die at home, The Butterfly Program develops a specific procedure in conjunction with the family to provide guidance and specific steps that can be carried out at the time of death. These steps address such things as verification of absence of vital signs, notification of nurse managers, funeral home, attending physician, Butterfly social worker, Chaplain and coroner. If additional support is needed, the Butterfly Program Medical Directors and the Inpatient Coordinator (nurse practitioner) can be paged for advice regarding end of life care. See *Death at Home Procedure* attached.

In addition to those options listed above, Children's Hospital has a Bereavement Program. This program works strictly with aftercare issues. There is an average 20 deaths per month reported system wide, however only a small subset are Butterfly Program patients. This program started from recommendations from the Chaplain and was initially structured as a Bereavement Council made up of interested staff, parents and community interest groups such as local funeral director. At that time, there was grant funding available for several months for a "bereavement counselor." The program has since evolved as a service for the hospital. Participation in any of the activities are optional and is presented as possible resource for the family should they choose to participate. The bereavement service currently provides the following activities to support families following the death of a child:

- Initial condolence card with a personal note
- Annual memorial service
- 2 – 9 week Grief Groups (generally attended by 10 -12 parents)

This group is facilitated by an experienced person who is skilled in facilitation of family groups. Generally this is the bereavement counselor, the chaplain or a social worker.

- Lending Library which is a cart of books and literature that families may borrow and the literature is designed for all ages
- Holiday Card signed by bereavement council members and that also informs the families of events.
- Creative Memories Workshop is a Saturday workshop where families receive a starter pack for developing scrapbook type photo albums.
- Offering the bereavement coordinator as a resource person for families. The nature of this resource is not to act as a direct counselor for the family, but rather as a resource to link families with other services that may be indicated following the death of a child.
- Evening in the Fall Event attended by families who have lost a child. Here, the staff typically coordinates a national speaker and offer sibling and baby sitting support for families.

Funding for Services

According to the Director of Medical and Legal Affairs for Children's Hospital, the Butterfly Program operates at a fiscal loss to the organization. At the end of the fiscal year the loss is split with Centura Health System. The hospital system has been willing to accept this loss and continue to support the program because they feel that it is a valuable service to families and express their commitment to providing optimal care. In the event that Colorado is successful in getting the home and community based waiver, Children's is hopeful that some of the services they are currently providing at no cost to the patient, will become reimbursable for a subset of the population.

There is a designated "fund raising" staff member at Centura Health. This person participates in community activities and other fund raising events and reports to the Butterfly Steering Committee. Donations are used to offset the overall fiscal shortfall. For the year 2005, total funds raised are reported to be \$92,755. 2005 Butterfly Program Expenses are reported to be \$180,747. Total reported deficit is \$87,992.

Research Component

There was no specific research discussed related to the Butterfly Program.

Education Component

Although there was no formal education plan in place to support the Butterfly Program, the medical director indicates that the program was initially promoted through education regarding palliative care provided at ongoing physician faculty meetings. The inpatient coordinator (nurse practitioner) focuses her educational efforts on the hospital nursing staff by offering End of Life Nursing Education Curriculum (ELNEC) in the fall each year. It is reported that last year there were at least 100 participants involved in the training.

Other opportunities for education are:

- Physician Rounds, especially with new residents
- Good Grief at Noon is a one hour monthly educational session sponsored by the Bereavement Council and open to all Children's Hospital staff at no

charge. These sessions include various topics related to managing and understanding grief. Nurses who attend can receive 1 CEU per session.

- Palliative care conferences with community physicians
- Education targeted to specific units of the hospital based on their interest or need
- Individual or unit based debriefing and education provided by the Chaplain

Although the Butterfly Program staff has heard of the IPPC trainings, they were not the primary trainings used at this organization.

Strategies Used for Implementation

- Gain support from hospital administrators. In this situation, when the hospital owned home health service was ended, the hospital looked to a partnership with a community entity such as Centura Health to share the cost and operation of the program. The Hospital chose to continue to support the program based on it being a valued service to offer to children and families served by the hospital system.
- Incorporate the palliative care philosophy into areas such as the Bone Marrow Transplant unit that were currently providing similar support to families.
- Address “turf issues” as they experienced them with entities of the hospital such as social workers, physicians and others who had a sense that their departments were already addressing such needs of the families.
- Utilize current staff within the facility and partner with a community entity to address the more global community based needs of a child and family.
- Use a designated fund raiser to support some of the cost of operations.
- Implement the program on incremental levels; start small.
- Utilize a nurse practitioner who can assume some of the workload from the medical director.
- Target staff who have a sincere commitment to supporting the philosophy of palliative care.
- Use a physician champion viewed as key to the buy in factor
- Never replace an interdisciplinary team that is already in place, but utilize these teams to facilitate or participate in meetings that support a palliative care effort and to offer additional supports

Strengths of Butterfly Program

- The Medical Director is passionate about promoting palliative care and is well respected within the hospital system.
- A nurse practitioner as a coordinator who can address some of the medical issues that arise during the course of palliative care
- Having both in and out patient services - provides better continuity and follow through
- The out patient coordinator assumes a dual role of counseling and care coordination
- The long distance component, outside of usual patient catchment area provides training and the identification of and coordination with services when discharging patients to that area
- There is a strong spiritual component

- Wrap around bereavement services are combined with The Butterfly Program and whatever else the hospital already provides
- Excellent training materials have been developed by families

Current Challenges for the Program

- Quantifying outcomes that add credibility to the program; expanding the “buy in” factor to all physicians and staff at Children’s Hospital
- Raising enough funds to cover program cost, although at this point, there seems to be full financial and philosophical support from the hospital administration despite a program deficit
- Dealing with territorial issues within the facility (i.e. the overlap between SW and palliative care clinician)
- Management of data specific to the Butterfly Program
- Ensuring adequate input into state Medicaid office in the development of specific policies for the waiver, once it is approved. Without this, the program might not be able to offer all current services for reimbursement.

Possible Application to the Military Environment

- Build on existing resources
- Focus on a consultative service, not one that assumes direct care
- Although partnership with a specific home health/hospice agency is unlikely, consider what services might be provided on an out patient basis
- Use of outreach to agencies, training and coordination of services at a minimum for the outpatient arena
- Understand that there are multiple bereavement strategies that do not necessarily mandate a formal behavioral health referral

Documents available for review by mCare team from the Butterfly Program in Denver

- Butterfly Program *Palliative Care Plan*
- Butterfly Program Steering Committee Agenda with attachments *Initiating Contact Form*
- *The Butterfly Report* – a progress report on the Butterfly Program for 2006
- *The Butterfly Program* trifold brochure
- Cocoon Cabinet Inventory list
- List of contents for *Child Grief Packet*
- *The Colors of Healing; A Family Centered Bereavement Program*
- Condolence Card sent by Bereavement Program
- *Let the Healing Begin* brochure developed for the Centura Bereavement Center at High Street
- *Helping Your Child When Death is Near* booklet
- *A Dad’s Journey Through Grief* CD
- *Grieving and Hope* CD
- *The Butterfly Program* CD
- *Good Grief at Noon 2006* schedule and topic list

Site Visit Report Palliative Care Program Assessment

Program Name: St. Mary's Healthcare System for Children

Date of Survey: November 1st and 2nd, 2006

Location of Program: Bayside, New York

Web Address: www.stmaryskids.org

Primary Contact: Eileen Chisari, RN, Administrator, Director of Palliative Care Program

Names of Individuals Providing Information: Eileen Chisari, Doreen Sikoscow, Alice Olwell, RN, Edwin Simpser, MD, Yolanda Chiarello, LCSW, Deacon Mike Maroutsis

Surveyors: Cheryl Naulty, MD, Ann Armstrong-Dailey

Program Description:

St. Mary's Hospital for Children was the first children's hospital in New York City and was founded in 1870 by the Sisters of the Community of St. Mary's. The hospital system specializes in post acute care for children with special needs. St. Mary's Health Care System is comprised of two inpatient facilities, St. Mary's Hospital for Children which is a 97 bed facility, and St. Mary's Rehabilitation Center for Children, a 44 bed facility. In addition, there are numerous community based programs such as the Long Term Home Health Care Program, The Institute for Child Development, Early Intervention, and the Care at Home Program. Over 4000 children per week living in the 5 boroughs and surround counties are seen in the outpatient programs. The program is affiliated with the Children's Hospital of New York (Columbia University). Children eligible for care at St. Mary's are those 0-18 years with special needs who are afflicted with conditions such as cerebral palsy, mental retardation, congenital anomalies, complications of prematurity, and metabolic disorders. Approximately 33% of patients admitted to St. Mary's have tracheostomies; there are not ventilator beds in the facility. The average length of stay for a child at the facility is approximately 3 months.

St. Mary's developed the first pediatric palliative care (PPC) program in the United States over 25 years ago as a result of the efforts of its founder, Dr. Bert Grebin. Dr. Grebin explored the concept of PPC with the New York State Department of Health in 1979 and in 1983 the home care program was launched providing end of life (EOL) care to terminally ill children. Subsequently a 10 bed palliative care unit was opened in 1984 at St. Mary's and over the next 10 years critical palliative care elements were added such as pastoral care, volunteers, social work, bereavement, and support groups. Based on feedback from staff and families, the inpatient PPC program shifted from a designated inpatient unit to a scatter bed system in 1996. Additional elements such as music, art, and pet therapies were added between 1994 and 2001 and the Complementary Care Program was initiated in 2000. In 1986 the PPC Program also began providing intermittent treatment services to terminally ill children in St. Mary's Medical Day Care serving up to 35 children in the after school program and 25 children in the Saturday program at any given time.

In 2002, the program developed a Palliative Care Pathway which is a "care map" for providing PPC. The program has continued to grow and in 2003 additional staff dedicated to PPC was recruited with the help of philanthropic dollars. Quality improvement initiatives and advanced care directives were developed in 2004. In 2005 the program launched an initiative regarding the

appropriate use of morphine and also adopted the family centered care model. Treatment vs. non-treatment options and terminology for a natural death also was explored in 2005.

It is estimated that approximately 20% of St. Mary's daily population (3200 patients) might benefit from PPC due to progression of their life-limiting illness.

Population Description

As outlined above, St. Mary's Healthcare System for Children focuses on post-acute medical care and/or rehabilitative therapy for children with a wide range medical needs. The Healthcare System focuses on healthcare needs of children with chronic illnesses (see below) which differs from the population of a typical children's hospital providing tertiary care. The PPC Program is but one of many programs and services offered by the Healthcare System. The following are the more common diagnoses treated – asthma, complications of prematurity, congenital heart disorders, feeding disorders, genetic disorders, HIV/AIDS, post-acute burn treatment, post-surgical rehabilitation, pre and post transplant care, shaken baby syndrome, sickle cell disease, spina bifida, and traumatic brain injury and coma recovery. Any child who is part of the Healthcare System is eligible to receive palliative care services.

Approximately 110 children per year are actively enrolled in the PPC Program. This includes children receiving palliative care services through both the inpatient and community programs.

Service Delivery

Referrals to the program can be made by anyone from the interdisciplinary or Morning Report Team (medicine, nursing, nutrition, social work, rehabilitation, therapeutic activities, pastoral and complementary care). Additionally, inpatient admission referrals may identify the need for palliative care services triggering further team discussion, which may ultimately result in the provision of palliative care services. Access to the palliative care team can be achieved through, and not limited to, phone, e-mail, Morning Report, the interdisciplinary care plan process, palliative care rounds, and consult order.

The PPC Program works with the inpatient primary care team as well as the family of the child. The team functions by combining a consultative approach as well as assuming primary care; they are available to do either. In the event the team does not assume primary care, they still remain very actively involved and remains connected adjunctively in order to continue to be part of the decision making process. There is an outpatient/home care component as well to the program. The model of care delivered is based on a family centered care approach and is integrated into the existing programs in the Healthcare System.

The core team consists of an administrator, 2 physicians, a program manager, a nurse director for complementary care, a deacon (pastoral care), and 2 social workers. In addition, the palliative care program may seek consultation from Psychology/Behavioral Health as needed. There is also interdisciplinary collaboration with pediatric medicine services, social work, nutrition, therapeutic activities, rehabilitation, pharmacy, and unit-based nursing.

The goal of the palliative care program is deliver care “upstream” based on 3 levels illness severity as follows:

- Level I – chronic illness with progression of symptoms and loss of function and /or physical decline
- Level II – life-limiting or terminal illness; anticipated death within 6 months
- Level III – end of life care with death anticipated within 2 weeks

Referral to the program usually occurs with progression of the illness and not at the time of diagnosis. The program provides inpatient palliative care based on a set of interventions known as the Palliative Care Pathway. The Pathway outlines care components, outcomes and outcome measure for the following disciplines - medical, nursing, social work/mental health, nutrition, therapeutic, rehabilitative, complementary care, and pastoral/spiritual care. A separate Palliative Care Pathway also exists for the home care component of the program.

There are both formal and informal palliative care rounds which are patient oriented. The entire palliative care team attends these rounds but they are also open to all the unit staff. There is an AM Report each morning by the palliative care team. Children who are in Level III are discussed daily. The team keeps the families of children in Level III involved in daily decision making.

Some of the unique program components include:

- Focus on Communication with Families
 - Advance care planning
 - Education of families about issues related to death and dying
- Attention to Creating Rituals
 - Crafting a peaceful dying plan
 - Displaying a candle on the unit when a child dies
 - Laying a hand-crafted quilt on the bed of a child who has died
 - Annual tree-planting ceremony and memorial service

The Peaceful Dying Plan constitutes a cornerstone in the delivery of end of life care. It seeks to ensure that the patient's final days are comfortable and peaceful and reflects both the patient's and family's wishes. The Peaceful Dying Plan becomes part of the medical record and includes demographics, information regarding funeral arrangements, pre and post death rituals (special washing, dressing, handling), and special instructions before and/or after death (special dress, music to be played, special toy, staff person to be notified) .

Another unique aspect of the palliative care program is the Doula Program which is made up of volunteers who assist patients and their families during the dying process. The volunteer is assigned only a single patient and family at a time. The patient is receiving either Level I or Level II care. The staff nurses make referrals to the Doula Program. The palliative care program asks for a one and half year commitment from those individuals wishing to become doulas.

The palliative care program has developed a booklet, "Gentle Transitions" for families. This booklet discusses the physical signs and symptoms of approaching death as well as the emotional and spiritual signs of approaching death.

Two weeks following the death of a patient, the social worker makes a home visit and the family is given a box with different memories, a “My Gift to You” keepsake. The patient, family, and staff all contribute to what goes into the box. A blanket is also given the family at this time and the siblings are given a “Sibling Bag” which contains stuffed animals, books, and chimes. The social worker may make home visits for up to 2-3 months post-death and then may consider a referral for additional bereavement counseling if needed.

The home care entity of the program is also very active and consists of medicine, nursing, rehabilitation, and social work. Nutrition and complementary care services are also available on an outpatient basis. Referrals to the home care program can be made by acute care facilities and/or the inpatient palliative care team. The outpatient team is instrumental in helping the patients and families navigate the health care system.

An internal Ethics Committee was formed in 2001 and acts as a recommending body. The committee assists in helping with decisions when dilemmas over care arise such as withdrawal of feeds for example. The committee was also involved in making the final policy with regards to advanced directives.

Funding for Services

The majority of basic services is funded by Medicaid and managed care entities. The inpatient program receives a fixed daily rate, which is not a hospice rate, for the inpatient component of the program. New York State has a history of a very strong Medicaid program for home care as well. Exceptional services (complementary therapy, manager position) are funded through philanthropy. With respect to the Long Term Home Health Program, patients may be eligible for the Katie Beckett Waiver program. Palliative care services are the added on.

Research Component

There is no formal research component to the program as of yet. The palliative care team however is planning to evaluate their Family Centered Care Program via a satisfaction survey. The team began using the survey in February 2006. It is administered in the home following the death of the child. There are 13 items that use the Likert scale as well as the opportunity for open-ended comments. The team is planning to publish their findings from this survey.

The Palliative Care Program has also sponsored focus groups of caregivers in order to obtain qualitative data regarding need. The groups were comprised of parents and caregivers and discussed a variety of palliative care topics. The outcome of these focus groups was that families wanted both support groups as well as informal networks.

In 2004, the program surveyed the nursing staff to get feedback on their views on palliative care. The survey requested what staff felt they needed clarification on regarding the program, what difficulties the staff has had in caring for dying children and their families, what staff would help them better take care of children receiving palliative care and their families. The information obtained from this survey allowed the team to develop their educational initiatives for 2005.

The team will also continue to collect good demographic data including when patients become part of the palliative care team.

Education Component

There have been several educational initiatives that the team has put forth over the past several years and they are as follows:

- Development of the Palliative Care Pathway in 2002 and subsequent in house education of staff on the Pathway.
- Survey given to nursing staff in 2004 regarding their thoughts on the palliative care program and how they felt about taking care of dying children and their families. Results of this survey allowed the team to plan their 2005 educational initiatives.
- In 2006, the Caring Connection curriculum on end of life care was developed and was based on the staff's own experiences which allowed better staff buy-in of the program.
- The Compassionate Partnership training session was also developed in 2006. This is a 3 hour session on palliative/EOL care which is interactive and involves role playing as well as sharing of personal experiences.
- The Peaceful Dying Plan was developed in 2006.
- Self care component is available to staff.
- The program recently sponsored a Pain Awareness Month in September 2006.
- Pain scales for children are located on the nurses' badges and there is a pain flow sheet to help in assessing and treating a child's pain.
- The program wants to focus education of physicians on delivery of bad news.

Strategies Used for Implementation

- The program has greatly benefited from the vision and leadership of Dr. Bert Grebin who developed the Home Care Program for end of life care for children. He has been a champion for children who are dying.
- New York Community Trust remains a benefactor of the program.
- The Board and CEO/President remain very supportive of the program.
- The Palliative Care Program is dedicated to staff education which has allowed staff to feel more comfortable taking care of dying children and their families.
- St. Mary's Healthcare System for Children treats a population that has chronic medical issues many of whom have been diagnosed with a life-limiting condition. This has made the palliative care program a natural fit with the rest of the programs the Healthcare System has to offer.
- The program has a dedicated staff that is always ready to learn from each patient and use previous experiences to improve care for future patients.
- The program has a long history with the Healthcare System (22 years) and is an integral part of the services provided.

Strengths of the St. Mary's Palliative Care Program

- Support of the President and CEO of the organization
- Physician champion who founded the program
- Dedicated staff who understand that there is always room for improvement
- Development of tools such as Palliative Care Pathway and Peaceful Dying plan that allow for better care of patients and their families.

- Full time pain management coordinator who also oversees Complementary Therapy Program to assist in pain management.
- Long history with respect to the delivery of pediatric palliative care.
- Chaplain successful in interacting with 98% of families providing a pathway for rituals.
- Behavioral Health Program actively involved with the palliative care team
- Strong staff educational component
- Palliative care social worker assists and educates other social workers in the facility regarding palliative care issues
- Well established home care programs allowing transition back to home
- Doula Program

Outcomes

The palliative care team has well defined outcome measurements for all three levels of care in the following disciplines – medical, nursing, social work, nutrition, spiritual/pastoral, rehab, and complementary care. There is an interdisciplinary chart review to see if these outcomes have been met for each patient. The team also looks information from caregiver focus groups and family satisfaction survey to measure outcomes. The team also reviews its program each year in detail to determine how to improve the program in the future.

Current Challenges for the Program

The current challenges for the program include the following:

- The program has been able provide its extensive range of services mainly within the confines of an inpatient setting
- No physician formally trained in pediatric palliative care on team
- Physicians in community or in other acute care facilities may or may not be champions of pediatric palliative care and may disregard or change palliative care plan formulated by the team
- Physicians in the acute care facilities may treat in a “salvage mode” approach as they do not want to “give up” on the patient; this may be confusing and stressful for families whose children are then admitted to the chronic care facility and palliative care is offered; this is seen as a systemic problem
- Staff needs to maintain their own perspective in the face of a care provider who may not agree with the need for palliative care; this individual may have been caring for the patient for a long time and may see palliative care as “giving up”
- Address anticipatory grief in parents when child gets admitted; emotionally charged issue for both family and staff

Possible Application to the Military Environment

- Incorporate standards (both interventions and outcomes) from St. Mary’s home based service model
- Incorporate level of care concept at those facilities with resources to do inpatient pediatric palliative care

- Incorporate inpatient program interventions, outcome, and outcome measures for the various disciplines (medical, nursing, social work, nutrition, spiritual/pastoral, rehab, and complementary therapy) as they relate to each military facility
- Decide on set of core standards that would constitute a program and determine what resources are available and how they should be allocated
- Consider revisiting contracts with managed care partners in order for additional services to be made available in the home based on home based service model

Documents Reviewed from the St. Mary's Palliative Care Program

- Home Care Interventions
- Inpatient Programs Interventions
- Palliative Care Staff Survey and results
- Peaceful Dying Plan
- Levels of Care
- Family Satisfaction Survey
- PowerPoint Presentation on Palliative Care Program

Dedicated Core Team

Eileen Chisari, R.N. – Administrator/Director of Palliative Care Program

Edwin Simpser, M.D. and Audrey Berman, M.D. – Medicine

Doreen Sikoscow – Manager

Alice Orwell, R.N. – Directory of Complementary Care

Deacon Mike Maroutsis – Pastoral Care

Yolanda Ciarello, LCSW and Danielle Toto, LCSW – Social Work

Site Visit Report Palliative Care Program Assessment

Program Name: Harriett Lane Compassionate Care (Johns Hopkins Children's Center)

Date of Survey: September 20th, 2006

Location of Program: Johns Hopkins Children's Center, 600 N. Wolfe St., Baltimore, MD 21287

Web Address: http://www.hopkinschildrens.org/pages/clinical/hlcc_who.cfm

Primary Contact: Cynda Rushton, R.N., D.N. Sc., F.A.A.N.

Names of Individuals Providing Information: Cynda Rushton, R.N., D.N.Sc., Nancy Hutton, M.D., Elizabeth Reder, M.A.

Surveyors: Brian Greffe, M.D., Cheryl Naulty, M.D., Ann Armstrong-Dailey

Program Description:

The Harriet Lane Compassionate Care (HLCC) Program is affiliated with the Johns Hopkins Children's Center. The Children's Center is located on the campus of the Johns Hopkins Medical Institutions located in Baltimore, Maryland.

HLCC has been in existence for approximately 6 years. The program provides palliative care to children with life-limiting conditions and their families. The goal of the program is to achieve the best possible quality of life for the child and family, and when death is inevitable, to support the child and family through the dying process and beyond. The program provides the following services: pain and symptom management, psychosocial and spiritual support, advance care planning, and bereavement counseling. The program supports concurrent curative care along with palliative care.

The main focus of the program is to provide education and support for the inpatient and outpatient staff. HLCC is not a clinical service at the present time. At its inception, the decision was made to work firstly with staff by helping them acquire skills which would enable them to do pediatric palliative care effectively. The Program also focused on providing emotional support to the primary care team and allowed for a reconnection for "meaning" with respect to what they were doing. The Team began with small, incremental changes, targeting those areas that expressed the most "angst" regarding patient issues.

Members of the HLCC Program help facilitate Patient Care Conferences when consulted. The family of the patient is not present for this conference. The goal of these conferences is to help clarify patient care issues. All dimensions of patient care are discussed – medical, psychosocial, and spiritual. Once the goals of care have been determined, they are presented to the family in a conference format at a later date. The HLCC team may be asked to participate in this conference as an invited guest. A positive outcome of this approach has been the decrease need for formal ethics consultations.

There are four members of the HLCC team and include a program director, medical director, family care coordinator, and bereavement coordinator. (See Appendix I)

Population Description

The HLCC Program accepts requests for patient care conferences from within the Johns Hopkins Children's Center facility. There are clearly "high density" areas that request patient care conferences from the HLCC team and include PICU, NICU, Oncology, and Emergency Department.

Service Delivery

Involvement of the HLCC Team occurs via the following steps:

- Request for a Patient Care Conference is made by a member of the primary inpatient care team.
- A member of the HLCC Team acts as facilitator for this meeting which does not involve the family.
- The main objective of this care conference is to clarify the goals of the patients care from medical, psychosocial, and spiritual standpoints and primarily serves the health care professionals involved with the patient's care.
- The HLCC Team cultivates a model of patient care which stresses that everyone on the primary care team has the responsibility to do the best that they can in caring for the patient and family.
- The primary care physician for the patient is invited to this meeting as are the assigned social worker and case manager. These latter individuals can work with the individual insurance companies to identify appropriate and available outpatient services if so needed.
- A documentation tool is completed for each Patient Care Conference. This is not a specific care plan but does outline the goals of care for that patient.
- A second conference is subsequently arranged with the patient's family to review the goals of care established in the Patient Care Conference. The HLCC Team is not automatically present at this conference but may be invited on a case by case basis.
- Ethics consults are arranged as indicated.
- There is currently no outpatient pediatric palliative care team in place. Johns Hopkins Medical Institutions does have a formal pediatric home care, Pediatrix at Home. This organization has recently hired Sue Huff, R.N., an individual with a great deal of pediatric palliative care experience, to manage the this program. Her goal for the future is to build a pediatric palliative care component into the program.
- Patients who needs outpatient hospice care and who are living in the appropriate catchment area are referred to Community Hospice of Maryland. This hospice program has both pediatric and adult teams. Two physicians based at the Children's Center, Nancy Hutton, M.D. (a pediatrician and member of the HLCC Team) and Ken Cohen, M.D. (a pediatric oncologist), serve as co-medical directors for the pediatric team. Pediatric patients are able to remain in the program longer than 6 months if necessary.
- The HLCC Program makes itself available for staff debriefings following the death of a patient particularly if the death was sudden or the patient was followed over a long period of time at the institution. The institution has approximately 125 deaths per year; 40 debriefings were held in the last calendar year.

In addition to the above services, the HLCC bereavement coordinator is responsible for the Annual Tribute Service dedicated to those patients who have died. Families along with pediatric staff are invited every year even if has been several years since a particular patient has died. A “photo board” PowerPoint presentation is done in memory of the deceased patients. Families are also encouraged to sign quilt. There are also bereavement groups available to both siblings and parents. The sibling group takes place at the Dougy Center and is open-ended. The parent group is held from September to May and is topic based; 8-12 parents typically attend. There is also a support group for grandparents as well as an opportunity for the family to participate in an Outward Bound program. Families are formally followed for 2 years and are offered telephone supportive sessions as well as referrals to counselors within their community. Quarterly Staff Memorial Services are also held for the staff of the Children’s Center.

Funding for Services

At the present time, the HLCC Program does not submit a bill for its consultative services. All four members of the program are salaried employees of Johns Hopkins. Both the Chairman of Pediatrics and the Director of Nursing have been very supportive of the program. The bereavement coordinator’s salary is covered under Nursing Administration. The HLCC Program meets yearly with the Chairman of Pediatrics to discuss program objectives and future projects. As the program expands, there will be the need to look for philanthropic funding to cover expenses.

Research Component

As the Johns Hopkins Children’s Center is a member of the Initiative for Pediatric Palliative Care (IPPC), the members of the HLCC Team have participated in a number of projects in conjunction with IPPC including:

- Evaluation of the effectiveness of patient care conferences, palliative care rounds and debriefing sessions on health care professional confidence and competence in providing palliative and end of life care.
- Mechanisms of institutional change related to integration of a Pediatric Palliative Care Program
- Measuring the Impact of Initiating a Pediatric Palliative Care Program (presented at AAHPM/HPNA Meeting in January, 2005)
- Survey research regarding health care professional knowledge and attitudes about caring for children with life-threatening conditions

Additional areas of research include:

- Relationship of trust to the experience of caregiver suffering in the pediatric intensive care unit (PICU)
- Exploring the concept of hope in providing pediatric palliative care
- Translating “values history” advance directives for use in pediatrics
- Development of a “pathway” for integrating basic and advanced components of palliative care throughout the Children’s Center
- Integration of palliative care with antiretroviral therapy for children and families in the U.S. and internationally

The HLCC Team also has multiple academic publications which can be found on its website.

Education Component

The HLCC Team participates in a number of formal and informal educational sessions which include:

- Noon conferences for residents and medical students during which 6 topics in pediatric palliative care are covered during the year
- Palliative Care Rounds held monthly on the high density units (NICU, PICU, Oncology)
- Palliative Care Network which is open to anyone in the institution with an interest in pediatric palliative care. There are currently 96 members and the group meets quarterly. There is an education component as well as discussions regarding patient care on the inpatient units.
- The Network also meets yearly off site to participate in an intensive training day which consists of community/team building activities. Education topics for the quarterly meeting are discussed. The November 2006 meeting will have for its topic conflict resolution.
- A regional retreat for IPPC training was held in March, 2006. From the Children's Center, the PICU, NICU, Oncology, and Emergency Department programs each sent a team (M.D., R.N., M.S.W. and bereaved parent).
- The HLCC Team sponsored the Maryland Pediatric Palliative Care Summit on October 13, 2004. Forty professionals (health care professionals, educators, policy makers, administrators) and parents attended to discuss current resources, identify gaps in services and resources, and explore strategies for improving pediatric palliative care.

Strategies Used for Implementation

- The HLCC Team has strong support from both the Chairman of Pediatrics as well as the Director of Nursing.
- Historically, the Chairman of Pediatrics was approached by a hospice nurse who was dissatisfied by the lack of pediatric palliative care services available to patients of the Children's Center. The chairman has continued with his support since the HLCC's inception. The Team meets with the chairman on a yearly basis to review objectives.
- There are few "turf" issues with respect to social work. Some of the social workers are not comfortable with the philosophy of pediatric palliative care. There is a new director for the Department of Social Work who has a strong mental health background who appears to be very supportive of the program.
- Most likely due to continued efforts of the HLCC Team and the Network, more units have been interested in exploring implementation of palliative care into their units.

Strengths of the HLCC Program

- The Team is made up of 4 very committed individuals who bring different strengths to the program.
- The HLCC Program has strong backing from the Chairman of Pediatrics and Director of Nursing.
- The Program participates in a variety of conferences and educational activities to further promote pediatric palliative care within the institution.

- The HLCC Team has brought together almost 100 individuals from within the institution as part of the HLCC Network.
- The Team feels that their work has improved communication and decision making on the inpatient unit.

Outcomes

- The Program is looking at a quality improvement evaluation related to its participation in IPPC.
- Feedback has been obtained from provider's pre and post intervention; no feedback obtained yet from families.

Current Challenges for the Program

- The program remains consultative only at the present time with clinical services to be added in the future if funding permits.
- There is no formal care coordination. The RN case managers function more in the capacity as discharge planners. There are also no formal outpatient coordinators; this is left to the primary or specialty physician.
- There is limited contact with the primary care physicians in the community although they are invited to the Patient Care Conferences.
- There is a gap in mental health services for patients and families in terms of providing continuity of care from inpatient to outpatient.
- There is a limited chaplain service with only 1 full time chaplain and 2 half time chaplains.
- There is no outpatient component to the program at the present time which would allow for seamless continuity of care.
- Lack of funding may become an obstacle in the future should the Team want to expand its services.
- There is currently a disconnect between the HLCC Program and the adult palliative care program. The adult program does have a full time nurse who does the palliative care consults.

Possible Application to the Military Environment

- Build on existing resources
- Redefine position descriptions of existing personnel to include appropriate palliative care responsibilities
- Consider holding a regional IPPC retreat for individuals interested in peds palliative care from all three branches of the military
- Consider introducing pediatric palliative care to “high density” units in military health care institutions which would then pave the way for further expansion within the institutions.

Documents Reviewed from the HLCC Team

- All documents found on the Team’s website

HLCC Team

Program Director

Cynda Rushton, R.N., D.N.Sc., F.A.A.N.

Medical Director

Nancy Hutton , M.D.

Family Care Coordinator

Barbara Hall, R.N.

Bereavement Coordinator

Elizabeth Reder, M.A.

Site Visit Report Palliative Care Program Assessment

Program Name: The Omega Life Program

Date of Survey: 12/07/06

Location of Program: Baltimore Maryland

Web address (if available):

Primary Contact: Leslie Piet RN, MA, CCM **Phone:** (410) 762-5278

Name of person providing information: Leslie Piet

Title of person providing information: Program Developer and Case Manager

Program Description:

The Omega Life Program is palliative care program available to individuals who are receiving services through the Johns Hopkins Health Plan. The Johns Hopkins Health Plan includes but is not limited to Priority Partners, US Family and the Employee Health Programs.

The Omega Program is designed to provide palliative care services through a case management model. Individuals who are eligible for the program receive a case manager to assist in the coordination of services through individualized assessment and development of a plan of care. Case managers address access to relevant providers, pain and symptom management and access to services that promote spiritual and emotional well being. The case management services are designed to address end of life issues when appropriate.

The Program was initiated in 2002 by a case manager who had extensive experience in the hospice setting. The case manager attended the Harvard Palliative Care Education and Practice Program and then promoted interest within the Johns Hopkins Healthcare Plan to develop such a palliative care program. The program was developed and accepted as a service to be offered to individuals within their health system who have a diagnosis of cancer.

The program is currently serving approximately 85 individuals over the age of 18. The palliative case management team is comprised of 2 registered nurses and one case management assistant. The case management team facilitates communication and services through home visits, telephone communication and attendance at patient care meetings. The program promotes a multidisciplinary approach with the ultimate goal of addressing concerns and goals that are important to the patient.

Population Description

The population served in The Omega Life Program exclusively adults 18 years and older who have a diagnosis of cancer. This includes individuals who:

- Have recently been diagnosed
- Are preparing to begin treatment
- Are currently in treatment
- Have completed treatment but continue with signs or symptoms
- Are at high risk for recurrence

Service Delivery

- Referrals for The Omega Life Program are identified through the general referral processes within the health system. These processes include but are not limited to high cost users, request from family, physician or other entity.
- The case manager contacts the individual via phone, then schedules a face to face visit
- An assessment is completed and followed up by the development of a plan of care.
- Services identified on the plan are coordinated by the case manager and appropriate referrals and linkages are made.
- Communication is facilitated by the case manager with the individual, the family and any other entities involved in the care.
- The case manager assists the family in accessing services appropriate at the time of death and beyond

Funding for Services

The case management services are provided by the Health Care Plan and there is no additional cost to the individual. Although case management services typically promote an overall cost savings, it was unclear as to the specific dollars saved with this population.

Research Component

Although the principles of this palliative care program are reportedly based on existing literature and research, there is no specific research identified that is part of this program.

Education Component

The educational program cited by this program developer as the motivation for development of a palliative care program is the Harvard Palliative Care Education and Practice Program. This program in Palliative Care Education and Practice “offers intensive learning experiences for physician and nurse educator who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, as well as to gain expertise in leading and managing improvement in palliate care education and practice at their own institutions.” It is an intensive two session (Spring and Fall) Course for Medical and Nursing Educators.¹

Additionally, education is informally provided via presentations or one to one communication to staff and other providers within the health system. In addition, see the Johns Hopkins Palliative Care Program Site Visit Report for related education to other members of the Hopkins system.

Strategies Used for Implementation

- Identify champions within the organization who have previous expertise and interest in the area of palliative and or hospice care.
- Gain momentum for cultural change by utilizing personal stories or connecting with key organizational players who have experienced end of life issues with family members or close friends. These individuals often recognize the importance and need for palliative care.

¹ Center for Palliative Care at Harvard Medical School, <http://www.hms.harvard.edu/cki/pallcare/pcep.htm>

- Have at least one champion participate in the Harvard Education Program as a catalyst for change
- Incorporate program under the auspices of disease management (i.e. Cancer diagnosis)
- Provide ongoing education to staff and providers to continue forward momentum and growth
- Utilize booklet Five Wishes to promote communication and decision making for advanced directives (there is a pediatric version entitled My Wishes)

Current Challenges for the Program

- Quantifying outcomes

There was limited discussion regarding this topic during the interview.

Possible Application to the Military Environment

- Program implementation occurred as part of the current case management system which is currently system wide in the military (i.e. TMA)
- Incorporate the publication My Wishes as a resource for children with LTC through Military OneSource
- Utilize Harvard Education model as a catalyst for changing culture and achieving enduring change
- Cost containment through case management services could be used as a tool to market this type of model
- Military families participating in US Family program through Johns Hopkins Health System and who meet the criteria for case management and palliative care could utilize the Omega Life Program services

Documents available for review by mCare team from Omega Life Program:

- Palliative Care Case Management trifold brochure
- Five Wishes pamphlet
- My Wishes pamphlet

APPENDIX 27

SITE VISIT REPORT/PALLIATIVE CARE PROGRAM ASSESSMENT SUMMARY

This report is a summary of the five site visits made to various pediatric palliative care programs around the country which were made from May – December 2006. The strengths of each program in terms of what constitutes a good pediatric palliative care program will be outlined under the following headings, Program Description, Population Description, Service Delivery, Funding for Services, Research Component, Education Component, Strategies Used for Implementation, Current Challenges for the Program, and Possible Application to the Military Environment. A final narrative summary and conclusions will follow.

The six sites visited were as follows:

- Children's Mercy Hospital PACCT Program
- Children's Hospital Denver/ Butterfly Program
- Harriett Lane Compassionate Care/Johns Hopkins Children's Center
- St. Mary's Healthcare System for Children/ Bayside, NY
- The Omega Life Program
- Seattle Children's Palliative Care Consulting Service

Program Description

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Pediatric Advanced Comfort Care Team developed 5 years ago to address needs of children with life-limiting illnesses • Provides comprehensive palliative care that includes clinical care, education and research • Consultative service based within the hospital network only (no homecare) (inpt/outpt) • Team members include MD, PACCT Nurse Clinician, Chaplain, Social Worker, Advanced Practice Nurse 	<ul style="list-style-type: none"> • Partnership between the hospital and Centura Health at Home (hospice and home care) • Initially designed to accept outpts with life-limiting conditions and a prognosis of less than 12 months; accepted first patient 6/99 • Program supports concurrent curative and palliative care • Centura Health at Home provides the emotional support on an outpt basis • Developed an inpatient 	<ul style="list-style-type: none"> • Main focus is to provide education and support for the inpt and outpt staff • Program started 6 years ago • Decision to work primarily with the staff to provide emotional support for the team and allow for a reconnection for "meaning" with respect to what they are doing • Program provides consultation on pain and symptom management, psych and spiritual 	<ul style="list-style-type: none"> • Hospital was founded in 1870 and specializes in post acute care for children with special needs • Palliative care program developed by "champion" Dr. Bert Grebin over 25 years ago • Palliative care unit opened in 1984; program has expanded since • Scatter bed system in 1986 • Various programs added over the years such as pastoral care, social work, bereavement, parent support groups, 	<ul style="list-style-type: none"> • Palliative care program available to individuals receiving services through Johns Hopkins Health Plan • Provides palliative care through case management model • Case managers address access to relevant providers, pain and symptom management, and access to services that provide spiritual and emotional well being • Developed in 2002 and offered to individuals with the 	<ul style="list-style-type: none"> • Palliative care program • No Medicaid Waiver • Program has been in existence for over 6 years • Program is affiliated with the hospital

<p>Case Managers, Pain Management Specialist, Psychologist, Child Life Specialist, PACCT Medical Director, Community Hospices</p> <ul style="list-style-type: none"> • Currently servicing 120 pts and families • Part of Patient Care Services and not physician directed • Advisory Board comprised from various departments in the hospital and meets quarterly • Currently not pursuing a CHI-PACC waiver due to geographic catchment area and possible restrictions on who could be served 	<p>consultative service in January 2002 following receipt of CHI-PACC grant</p> <ul style="list-style-type: none"> • Team members include a Medical Director, Inpt Coordinator (PNP), 2 inpt chaplains, Outpt Coordinator (LCSW), Outpt Chaplain, Outpt Social Worker, Bereavement Counselor, Centura Home Care Coordinator • Access to Pain Management Services, Child Life Specialists, Volunteers • Outpt program works with multiple home care agencies including Centura • Steering 	<p>support, advance care planning, and bereavement counseling</p> <ul style="list-style-type: none"> • Program supports concurrent curative and palliative care • Members of program facilitate Patient Care Conferences (no parents present) and discuss all aspects of care (medical, spiritual, psychosocial) • Team is comprised of 4 members: program director (RN), medical director, family care coordinator (LCSW), and bereavement coordinator (MDiv) 	<p>creative therapies such as art music and pet therapies, and complementary therapy</p> <ul style="list-style-type: none"> • Developed Palliative Care Pathway in 2002 which is a care map for providing palliative care • Estimated that 20% of St. Mary's daily population of 3200 pts might benefit from palliative care approach • Core team includes administrator, physicians, manager, director of complementary therapy, deacon/pastoral care, social workers • Program does not enroll pts from time of diagnosis 	<p>diagnosis of cancer</p> <ul style="list-style-type: none"> • Currently serves 85 individuals • Team comprised of 2 registered RNS and one case management assistant • Team facilitates communication and services through home visits, telephone communication, and attendance at pt care meetings 	
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	<p>Committee meets quarterly</p> <ul style="list-style-type: none"> • Enrolled over 250 pts into program since inception • State Medicaid office has submitted 1915c waiver embracing the CHI-PACC model of care (resubmitted October 2006) 		<ul style="list-style-type: none"> • Program has not submitted Medicaid waiver embracing CHI-PACC standards of care although New York State working on such a waiver 		
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Population Description

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> Population exclusively comprised of children through inpt and outpt department at main campus site Categories used to define population include acute life threatening, life limiting, and life style limiting Population reflects general population of the geographic region and does not seem to represent broad diversity of culture No home care population 	<ul style="list-style-type: none"> Inpatient population includes not only pts from Denver metro area but also catchment area for hospital which includes Colorado outside Denver metro area, Wyoming, Montana, and parts of Kansas, Nebraska, South Dakota, and New Mexico Outpt/home care population comprised of pts living in the Denver metro area; 98% are Medicaid eligible 60% of pt population has non-oncologic diagnosis 	<ul style="list-style-type: none"> Program accepts requests for patient care conferences from within the facility "High density" areas that make referrals include PICU, NICU, Oncology, and ED No home care program 	<ul style="list-style-type: none"> Population of program comes from pts requiring post acute care due to a variety of chronic conditions such as complications of prematurity, HIV/AIDS, genetic / metabolic disorders, and traumatic brain injury Any child who is part of the Healthcare System eligible to receive services Established outpatient program 	<ul style="list-style-type: none"> Exclusively serves adults 18 years and older with diagnosis of cancer Eligible pts are those recently diagnosed, preparing to begin treatment, currently in treatment, those who have completed treatment but continue with signs and symptoms, and those at high risk for recurrence 	<ul style="list-style-type: none"> Population served is only pediatrics Population comes from inpatient service following referral from a physician Program does 150 consults per year Program services pts from all over WA and from other states in Pacific Northwest Program does provide services to military families

Service Delivery

Children's Mercy	Children's Denver	Hariett Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> Referrals to program come from medically licensed personnel and parents must be in agreement Nurse clinician meets with family within 48 hours of referral after reviewing record to prepare for meeting PACCT coordinator determines composition of team and notifies various departments such as social work, chaplain, psych, pain management and child life to ask for assigned team 	<ul style="list-style-type: none"> Referrals initially made by RN, MD, or family themselves Attending MD must agree to proceed with referral Initial consult done by inpt or outpt coordinator or medical director Signed consent obtained from parents to participate in the program Inpt coordinator responsible for identifying families concerns, discuss pain/symptom management, discuss DNR, and work with 	<ul style="list-style-type: none"> Request for Patient Care Conference made by member of primary inpt care team Member of HLCC Team acts as facilitator at meeting; parents not invited Goals of pt care (medical, psychosocial, spiritual) discussed at conference Primary MD, assigned social worker, and case manager invited to conference and can help facilitate outpt services Documentation tool completed for each conference; this is not a specific care plan but an 	<ul style="list-style-type: none"> Referrals come from the inpatient medical service Core team consists of an administrator, 2 physicians, program manager, nurse director for complementary care, deacon, and 2 social workers Additional interdisciplinary collaboration with nutrition, therapeutic rec, rehab, pharmacy, and inpatient nursing units Program has 	<ul style="list-style-type: none"> Referrals made through the general referral processes within the health system and include high cost users, request from family, physician or other entity Case manager contacts the pt by phone and then arranges for a visit Following the assessment, a care plan is developed Services as outlined by the plan coordinated 	<ul style="list-style-type: none"> Program provides care coordination, indirect medical care Referring MD makes referral to team and a consultant assigned to the case based on availability Consultant meets with providers and program coordinator schedules care conference with family and health care providers Care conference lasts about an hour during which time consultant facilitates communication and

<p>members; the teams are drawn from staff assigned to specific departments or specialties of outpt clinics therefore there is no consistent continuity</p> <ul style="list-style-type: none"> • If parent agrees to participate, PACCT information, brochure, blank Comprehensive Comfort Care Tool (CCCT), DNAR parent document given to family; additional forms if appropriate include grief form and psychiatric evaluation form • Meeting later convened with family and team members to discuss CCCT and develop an 	<p>inpt primary care team on any relevant issues</p> <ul style="list-style-type: none"> • Written Palliative Care Plan is developed either by inpt or outpt coordinator • If pt transitions to outpt program, the outpt coordinator meets with family to discuss resource needs, counseling issues, and continue discussion regarding advance directives • Chaplain from either inpt or outpt team meets with child depending on location • Inpt coordinator or medical 	<p>outline of goals</p> <ul style="list-style-type: none"> • Second conference arranged with family to discuss these goals; members of HLCC not automatically present at this conference but are invited on a case by case basis • No formal outpt pediatric palliative care team • Well established home care program which may eventually build in a peds palliative care component • Patients needing outpt hospice referred to Community Hospice of Maryland; two MDS from Hopkins act as directors of pediatric team • HLCC Team available for 	<p>defined 3 levels of care with reflect the severity of the illness and life expectancy</p> <ul style="list-style-type: none"> • Referrals take place with progression of life limiting illness and not a time of diagnosis • Palliative care is provided based on set of interventions known as the Palliative Care Pathway which outlines care components, outcomes, and outcome measures • Formal and informal palliative care rounds occur in the 	<p>by case manager who makes appropriate referrals</p> <ul style="list-style-type: none"> • Case manager facilitates communication with pt, family, and others involved with the care • Case manager assists family in accessing appropriate services at time of death and afterwards 	<p>shared decision making</p> <ul style="list-style-type: none"> • Following the conference the consultant completes the Decision Making Tool (DMT) which usually takes up to two hours to complete; tool contains information on meeting discussion and action plan • Consultant follows up with all who are listed on the action plan • Completed DMT goes into the front of the patient's chart and parents also given a copy; there is an option of placing the document in the EMR • DMT becomes tool for
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<p>action plan</p> <ul style="list-style-type: none"> • CCCT reviewed by parents and signed by MD • PACCT coordinator monitors family as needed either in the inpt setting or in the outpt clinics • Chaplaincy services responsible for administrative assistance and spiritual care when death occurs • Bereavement provided by “After Care” program which is a separate hospital team and is outside the PACCT program 	<p>director round on inpts as needed</p> <ul style="list-style-type: none"> • General hospital interdisciplinary services available as needed including Child Life • If child is outpt, outpt coordinator or other social worker and chaplain regularly meets with pt and family • Primary care MD remains involved when pt is outpt and can access medical director or inpt coordinator regarding pain/symptom management questions • Home care for outpts provided by independent agencies or Centura Health 	<p>debriefings following death of pt</p> <ul style="list-style-type: none"> • Additional programs include Annual Tribute Service, bereavement groups for parents and sibs, support group for grandparents, and quarterly staff memorial services • Will consider expanding into more of a clinical service in the future if funding allows 	<p>facility</p> <ul style="list-style-type: none"> • AM Rounds occur each am among core team members • Peaceful Dying Plan completed when patient is terminally ill and reflects both parents’ and patient’s wishes • Doula Program made up of volunteers who assists patients and families during the dying process (“dying coach”) • Booklet, “Gentle Transitions” is for families and discusses the physical, emotional, and spiritual aspects of approaching 	<p>continuity of care</p> <ul style="list-style-type: none"> • DMT used most effectively when the conference facilitator comes from outside the team of healthcare professionals that provide care for the child • Program accepts nearly all referrals
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	<ul style="list-style-type: none"> • Death at Home Procedure developed if child is to die at home • Families may access the “Cocoon” if child is to die in the hospital; Cocoon transforms hospital room into more home like environment and contains sheets, blankets, pillows, soft lighting, video camera, coffee pot, CD player • Families offered booklet that explains system by system, the dying process • Bereavement is provided by either Centura bereavement coordinator as well as Bereavement Program/Grief 		<p>death</p> <ul style="list-style-type: none"> • Social worker visits family 2 weeks after death to give family memory box and siblings a sibling bag • Ethics committee available as recommending body that helps with care dilemmas • Home care component to the program which involves nursing, social work, and chaplain 		
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	<p>Groups offered by the hospital</p> <ul style="list-style-type: none"> • Additional programs include annual memorial service and Creative Memories Workshop which helps families start scrapbook album 				
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Funding For Services

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> Philanthropic funds are used for a 1.8 FTE which includes the nurse clinician position and the program manager position Physician is "on loan" from PICU so no costs incurred Other disciplines are funded by their own departments Social work explores insurance benefits to access funding for medical needs Hospital also has access to private funding to cover items and services not covered by 	<ul style="list-style-type: none"> Costs for the outpatient emotional support are split between the hospital and Centura; program therefore operates at a fiscal loss to the organizations Approval of Medicaid waiver (1915c) may help cover some of those costs in the future Hospital recently has agreed to fund inpatient coordinator time, chaplain time, and secretarial support that had been 	<ul style="list-style-type: none"> No charges submitted for consultative services All four members of team are salaried employees of Johns Hopkins Bereavement coordinator salary covered by Nursing Administration Program will look into obtaining philanthropic dollars as the program expands 	<ul style="list-style-type: none"> Majority of basic services funded by Medicaid and managed care entities Exceptional services (complementary services and manager position) in the program funded by philanthropic funds Patients participating in the Long Term Home Health Program may be eligible for Katie Beckett Waiver 	<ul style="list-style-type: none"> Case management services provided by the Health Care Plan No additional costs to individual Unclear if there are cost savings with this program 	<ul style="list-style-type: none"> Services are funded by hospital administration fund

insurance	<p>covered by grant funding</p> <ul style="list-style-type: none"> • Hospital has also agreed to fund a small percentage of medical director's salary for time spent on the program • Centura staff member dedicated to fund raising the organization, including The Butterfly Program and works with grant writer to secure funding via local granting agencies 				
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Research Component

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Collaboration with researcher from University of Missouri-Kansas City to promote evidence based practice through qualitative research • Consideration of submission of an R-15 grant to develop a project to study parental values and understand how variables have an impact on communication between healthcare teams; will use Parental Values Inventory tool • Initial funding efforts have been unsuccessful but will be pursued again in the future 	<ul style="list-style-type: none"> • No current research efforts in place • Program does send out a parent satisfaction survey and this could be a possible tool for research in the future • Medical Director has contacted palliative care director of adult program regarding collaboration in the future once Children's moves to its new campus • Demographic data being collected 	<ul style="list-style-type: none"> • HLCC member of IPPC (Initiative for Pediatric Palliative Care) and has collaborated on a number of projects with this organization such as evaluation of the effectiveness of patient care conferences, palliative care rounds and debriefing sessions on health care professional confidence and competence in providing palliative and end of life care, mechanisms of institutional change related to integration of 	<ul style="list-style-type: none"> • No formal research component • Plan in the future to evaluate Family Centered Care Program via satisfaction survey; began administering the survey in February 2006 • Focus groups sponsored for caregivers to obtain qualitative data regarding caregiver need • Program surveyed inpatient unit nurses in 2004 to get feedback on views on palliative care within the institution • Demographic data being collected 	<ul style="list-style-type: none"> • No specific research identified with the program 	<ul style="list-style-type: none"> • None cited

		<p>a pediatric palliative care program, measurement of the impact of initiating a pediatric palliative care program, and survey research regarding health care professional knowledge and attitudes about caring for children with life-threatening conditions</p> <ul style="list-style-type: none"> • Additional areas of research include evaluation of relationship of trust to the experience of caregiver suffering in the PICU, exploration of the concept of hope in providing pediatric palliative care, translating “values history” 			
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		<p>advance directives for use in pediatrics, development of a “pathway” for integrating basic and advanced components of palliative care throughout the Children’s Center, and integration of palliative care with antiretroviral therapy for children and families in the US and internationally</p>			
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Education Component

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • IPPC training is tool used for educating providers at the hospital; use of train the trainer model • David Browning acted as facilitator to introduce palliative care concept within the institution • PACCT education initiatives targeted to families include DNAR Care Card, "Shelter from the Storm" book, PACCT brochure describing program services 	<ul style="list-style-type: none"> • Medical director and inpt coordinator offer conferences to both MDs and RNs • Inpatient coordinator has helped arrange for ELNEC (End of Life Nursing Education Curriculum) to be offered over the past 2 years • Additional opportunities for education include beside teaching at both the physician and nursing level, Good Grief at Noon (ed-ucational session) 	<ul style="list-style-type: none"> • Team participates in noon conferences for residents and medical students which are offered 6 times per year during which a variety of palliative care topics are discusses • Palliative care rounds held monthly on high density units (PICU, NICU Oncology) • Palliative Care Network open to anyone with an interest in pediatric palliative care; 	<ul style="list-style-type: none"> • Development of the Palliative Care Pathway with subsequent staff education about the Pathway • Results of staff survey regarding pediatric palliative care issues in 2004 allowed for development of educational objectives in 2005 • Caring Connection curriculum on end of life care developed in 2006 • Compassionate Partnership, 3 hour training session on palliative/end of life care, developed in 2006 • Peaceful Dying Plan developed 	<ul style="list-style-type: none"> • Participation in the Harvard Palliative Care Education and Practice Program • Informal education of staff as needed 	<ul style="list-style-type: none"> • Consultants educate providers through care conferences • Presentations on palliative care and communication given to residents • 4th year medical students can do an elective with the palliative care consultants

<ul style="list-style-type: none"> • PACCT education initiatives for staff include department updates for nurses, social work, and child life, Grand Rounds/Special Events, One-on-One with PACCT clinicians, small group lectures, IPPC curriculum, resident/fellow program elective, child life internships, nursing student rotations, nursing orientation, Journal Club • Variety of presentation topics presented as part of PACCT Educational 	<p>sponsored by The Bereavement Council offered on a monthly basis), education targeted to specific units based on their interest and need, and debriefing sessions offered by the chaplain on an as needed basis</p> <ul style="list-style-type: none"> • Program has developed an Outreach Program to educate hospice programs in CO outside the Denver metro area and in WY and MT focusing on topics in pediatric palliative care 	<p>educational sessions held quarterly</p> <ul style="list-style-type: none"> • Regional IPPC training done in March 2006 • Maryland Pediatric Palliative Care Summit held in 2004 to discuss current resources, gaps in services, and strategies for improving pediatric palliative care 	<p>in 2006</p> <ul style="list-style-type: none"> • Program sponsored Pain Awareness Month in September 2006 		
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<p>Initiatives</p> <ul style="list-style-type: none"> • Individual training on hospital unit provided by nurse clinicians associated with program • Modeling palliative care practice is primary strategy for educating coworkers 					
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Strategies Used for Implementation

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Gain support from key senior administrators such as CEO and senior VP of clinical service product line • Initiate services in areas of the hospital with greatest need rather than in those that already support palliative care philosophy • Identify physician champions and champions with other departments • Meet with other disciplines prior to starting program to gain support • Use master 	<ul style="list-style-type: none"> • Gain support from hospital administrators • Address "turf" issues and stress that services offered by program not meant to replace but supplement ongoing care • Partnership with established hospice program in the community allows for better access to services particularly in the outpt arena • Dedicated fundraiser for program • Buy in of hospital foundation in order to help with fundraising • Implement 	<ul style="list-style-type: none"> • Strong support of program from Chairman of Pediatrics and Director of Nursing • Team meets yearly with Chairman of Pediatrics to discuss objectives • Strong support of Director of Social Work which helps with turf issues • Continued efforts of team has sparked interest in more units to look at implementation of palliative care 	<ul style="list-style-type: none"> • Continued strong support of founder of program • Board of facility and CEO/President supportive of program • Ongoing support of benefactor over many years • Staff education has allowed staff to feel more comfortable taking care of dying children and their families • Patient population of Healthcare System lends itself to incorporating palliative care concepts more readily • Program staff builds on its 	<ul style="list-style-type: none"> • Identification of champions within the organization with previous expertise and interest in palliative care • Build on personal experiences with palliative/end of life care of key organizational players • Participation of champion in Harvard Education Program may act as catalyst for change • Incorporate program under auspices of disease management • Provide ongoing education to staff • Utilize "Five Wishes" booklet to promote communication 	<ul style="list-style-type: none"> • Provision of a service that people in hospital find valuable • MDs request palliative care consult when they need help communicating, understanding families' priorities and developing a plan • Needs assessment done in mid 1990s, followed by grant funded demonstration project in which they created DMT • Following grant, the administration provided \$200,000 to fund the

<p>facilitator to introduce palliative care concepts within the institution</p> <ul style="list-style-type: none"> • Identify a well qualified and passionate coordinator for the program • Identify specific diagnoses that generate an automatic PACCT consult • Do not push palliative care on departments resistant to the concepts • “Small steps” in moving program along • Formation of an advisory committee as program begins to grow 	<p>program on incremental levels</p> <ul style="list-style-type: none"> • Employ nurse practitioner to assist with consultations • Target staff with commitment to palliative care who can be champions within the institution • Market program to subspecialties within the hospital via participation/ presentations at departmental meetings 		<p>experiences in order to improve care for future patients/families</p>	<p>and decision making for advanced directives (My Wishes booklet available for children)</p>	<p>Palliative Care Consult Service as it felt as an important value added to care and a way to humanize technological processes</p> <ul style="list-style-type: none"> • Currently 2.9 FTE and 0.5FTE for medical director • Currently collecting donations to establish and endowment for ongoing work
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Strengths of Program

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Supportive, family centered culture within the institution allows program to thrive • Nurse clinician promotes program in a subtle consistent manner and is seen as a neutral care facilitator; seen as right person for the role as coordinator • Parents indicate "web of support" most valuable resource provided by program 	<ul style="list-style-type: none"> • Medical director and inpatient coordinator demonstrate passion for palliative care and are well respected within the hospital • Having both inpatient and outpatient teams allows for better continuity of care • Outreach Program seminars has allowed for creation of a network which facilitates pts returning to their community • Strong spiritual component • Bereavement services offered by both the program and the hospital 	<ul style="list-style-type: none"> • Committed team members who bring different strengths to the program • Strong backing of program from Chairman of Pediatrics and Director of Nursing • Participation of team in variety of conferences and educational activities which promote pediatric palliative care within the institution • Creation of a network consisting of 100 interested individuals from within the institution • Improvement in communication and decision making on the inpatient unit due 	<ul style="list-style-type: none"> • Support of President and CEO of organization • Long, well established history of delivering pediatric palliative care • Physician champion who founded program • Dedicated staff consistently seeking to better their care • Development of tools such as Palliative Care Pathway and Peaceful Dying Plan • Full time pain management coordinator who also oversees complementary care • Strong spiritual component • Strong commitment to 		

		to program's involvement	education <ul style="list-style-type: none"> • Doula Program (individuals assisting families and patients during dying process) 		
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Current Challenges

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> Quantifying outcomes that add credibility to the PACCT initiative in order to maintain support of hospital administrators Expanding "buy in" to all MDs and staff at hospital Seeking alternatives to philanthropic dollars to fund nurse clinicians Dealing with territorial issues among staff Education of staff that providing palliative care is not synonymous with end of life care Information technology 	<ul style="list-style-type: none"> Quantifying outcomes that add credibility to the program Expanding "buy in" factor to all physicians and staff at the hospital Continue fund raising efforts and grant applications to offset deficit that organizational partners must absorb Dealing with territorial issues among staff Data management specific to The Butterfly Program Ensuring adequate input on 1915c waiver initiatives, if waiver 	<ul style="list-style-type: none"> Program currently consultative only; clinical services in the future depending on funding No formal care coordination and no formal outpatient coordinators Limited contact with primary care MDs in community Gap in mental health services from inpatient to outpatient setting Limited chaplain services No outpatient component to program which would allow seamless continuity of 	<ul style="list-style-type: none"> No physician formally trained in palliative care on team Physicians in community may or may not be champions of palliative care resulting in care plans being changed once pt is discharged Primary care providers may see initiation of palliative care services as giving up Addressing anticipatory grief in parents when child is admitted which is emotionally charged issue for parents and staff 	<ul style="list-style-type: none"> Quantifying outcomes 	<ul style="list-style-type: none"> Challenges as they relate to military include getting services paid for by TRICARE, working with families who are moving, communication with receiving MTF

plan for PACCT program not part of main clinical documentation system	approved, in order that current services offered are reimbursed	care <ul style="list-style-type: none"> • Disconnect between HLCC and adult palliative care program 			
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Program Elements with Potential Applications to the Military Environment

Children's Mercy	Children's Denver	Harriet Lane	St. Mary's	Omega Life	Seattle Children's
<ul style="list-style-type: none"> • Implementation in hospital setting with gradual expansion • Some components of program also exist in military health care system • Strong reliance on existing staff to provide direct patient care which allows tailoring of services and care to meet specific needs of pt and family; PACCT RNs function as facilitators • Development of partnerships among existing resources both in hospital and community • Comprehensive Comfort Care Tool focuses care coordination 	<ul style="list-style-type: none"> • Build on existing resources • Focus on consultative service not one that provides direct pt care • Identify resources (such as home care) that would be available on an outpt basis • Consider outreach team to educate and train outpatient agencies with respect to care coordination • Understand that there are multiple bereavement strategies that may be used with families which may preclude a formal referral 	<ul style="list-style-type: none"> • Build on existing resources • Redefine job descriptions of existing personnel to include appropriate palliative care responsibilities • Consider holding regional IPPC retreat for interested individuals from all three branches of the military • Consider first introducing pediatric palliative care to "high density" units with the military health facilities (NICU, PICU, 	<ul style="list-style-type: none"> • Incorporate standards (interventions and outcomes) from St. Mary's inpatient and home based service models • Incorporate level of care concept as an approach to pediatric palliative care • Decide on set of core standards that would constitute a program and determine what resources are available and how they should be allocated 	<ul style="list-style-type: none"> • Incorporate My Wishes as a resource for children with life limiting conditions through Military OneSource • Utilize Harvard Education model as catalyst for changing culture and achieving enduring change • Cost containment through case management services could serve as marketing tool for this type of model • Military families participating in US Family Program through Johns 	<ul style="list-style-type: none"> • DMT could be used for care coordination and can be tried at one MTF • Identify an MD champion who from any sub-specialty but who has a passion for PC

		Oncology, ED) which could pave the way for further expansion		Hopkins Health System and who meet criteria for case management and palliative care could use Omega Life Program services	
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SUMMMARY/RECOMMENDATIONS

The site visits made as part of the Department of Defense's mCARE initiative indicate the many ways an organization can approach launching a pediatric palliative care program. All of the programs visited have had extensive experience (4-25 years) in providing palliative care. All of the programs embrace the basic concepts of palliative care that address the physical, emotional, psychosocial, and spiritual well being of the patient and family. The success and obstacles that each of these programs has experience during the growth of their palliative care program should help guide the Department of Defense in strategizing how to incorporate pediatric palliative care into the military healthcare system. There are several important components that the military health care system must address with respect to programmatic development. Several of these components are listed below along with possible strategies the Department of Defense could use for successful implementation of pediatric palliative care into its military healthcare facilities. The strategies listed are based on information obtained at each site visit.

Program Champion

- Identification of a program champion willing to get the program off the ground; this individual clearly does not have to be a physician but could also be an advance practice nurse
- Buy in from the administration of the facility is key to the initial and future success of any program and in the case of the military it would be important to have the support of the facility commander and other key individuals in positions of authority; this is well illustrated in Dr. Carlos Parrado's presentation during the Expert Panel meeting
- Encourage program champion to attend an educational program such as IPPC, EPEC, ELNEC, or the Harvard Education Program on Palliative Care to gain state of the art palliative care knowledge; this could ideally be done prior to the program implementation

Implementation Strategies

- Survey each potential facility to identify the perceived need for pediatric palliative care and the individuals interested in delivering this type of care
- Attempt to identify "turf" issues early to avoid confrontation when the program is implemented and consider the approach of offering support as a consultative team to the existing primary care team
- Consider starting small and building the program gradually; consider targeting high density areas (PICU, NICU, ED, Oncology) where individuals are probably more receptive to the concept of pediatric palliative care

- Depending on the size of the military healthcare facility, consider one on one marketing with each appropriate department within the facility
- In determining what services would be offered, consider developing a set of care components for the different disciplines involved (medicine, nursing, social work, spiritual care, child life, etc) along with expected outcomes and outcome measures (see St. Mary's model)
- Adopting level of care model (St. Mary's) may be useful to help identify and allocate resources needed

Personnel

- Identification of services already in place at a facility will dictate what personnel will make up the team
- Program champion may need to wear many hats and may need to be skilled in care coordination/case management in the case of smaller facilities
- Use resources that are already in place particularly if new staff can not be added due to budget constraints; this is well illustrated with the Children's Mercy program as the nurse clinician recruits a team from existing personnel in each department
- Another option to address the personnel issue is to redefine existing job descriptions to include responsibilities for palliative care

Service Delivery

- Decide on a core set of standards that would constitute a program that could be used across the board at each facility
- Program at each facility should expect to be able to offer support in all 4 areas of palliative care – physical, psychosocial, spiritual, and emotional on a consultative basis even if different models are used in delivery of service
- Bereavement services (either inpatient or outpatient) should be identified
- Determine who is able to make referrals (MD/RN/MSW)
- Consider whether a signed consent for services is appropriate
- Program should consider a documentation tool to develop a written palliative care plan that can be updated as patient's condition changes; this tool could follow patient back into community/ home care setting
- Identify home care services and other outpatient resources available in the area
- At the very least it would be important to develop a database at each facility offering pediatric palliative care which would contain demographic data, time allocation for each team member, costs

Education

- Program champions from all three branches of the military could be brought together for an IPPC retreat
- Develop educational initiatives for staff (MDs, RNs, MSWs) when feasible
- Participation in Pediatric and Nursing Grand Rounds
- Make available some basic information to parents such as general information on the program and pediatric palliative/end of life care, booklet that explains dying process, grief packets containing resources available within the facility or community; these items can be adapted from materials that have already been developed by pediatric palliative care programs in the civilian sector

Research

- Typically not a priority when beginning a new program however family satisfaction surveys and outcome measures for various components of the program could nonetheless be collected and analyzed at some future date

APPENDIX 28

Education Curricula on Pediatric Palliative Care

IPPC (www.ippcweb.org)

IPPC is both an educational and quality improvement effort, aimed at enhancing family-centered care for children living with life-threatening conditions. The IPPC curriculum addresses the knowledge, attitudes, and skills that health care providers need in order to better care for these children and their families. IPPC is a project of the Center for Applied Ethics, a division of Education Development Center, Inc. (EDC). EDC has worked closely on this project with the National Association of Children's Hospitals and Related Institutions (NACHRI), the Society of Pediatric Nurses (SPN), the Association of Medical Schools Pediatric Department Chairs (AMSPDC), and the New York Academy of Medicine. The IPPC team itself is comprised of nationally renowned educators and clinicians with expertise in PPC. The IPPC curriculum has been pilot-tested in several leading children's hospitals. These organizations have also implemented IPPC quality improvement projects.

The IPPC curriculum consists of five separate modules. Each module has a number of related activities associated with it. The modules can be downloaded free of charge. The modules are as follows:

Module 1. Engaging with Children and Families

- Activity 1: Speaking the Same Language: Values and Principles of Pediatric Palliative Care
- Activity 2: Knowing Who We Are: Learning from Families about their Needs
- Activity 3: Big Choices, Little Choices: Family-Centered Option for Children and Parents

Module 2. Relieving Pain and Other Symptoms

- Activity 1: Developmental Factors in Pain Assessment and Treatment
- Activity 2: Pain Assessment in the Absence of Self Report
- Activity 3: Chronic Pain, Adolescents, and Pain Assessment
- Activity 4: Pain Management in Children with Life-Threatening Conditions
- Activity 5: The Safe and Effective use of Opioids to Manage Pain
- Activity 6: Addressing Parents' Fears about Opioid Analgesia
- Activity 7: Pain and Other Symptoms at the End of Life

Module 3. Analyzing Ethical Challenges in Pediatric End-of-Life Care Decision Making

- Activity 1: An Ethical and Legal Framework for Caring for Children with Life-Threatening Conditions
- Activity 2: Assessing Benefits and Burdens of Life-Sustaining Treatments
- Activity 3: Honoring Parental Values When Benefits are Marginal or Uncertain
- Activity 4: Using and Forgoing Medically Provided Nutrition and Hydration

- Activity 5: Special Considerations of Adolescents: Truth Telling
- Activity 6: Special Considerations of Adolescents: Decision Making
- Activity 7; Ethical Issues in the Treatment of Pain and Suffering at the End of Life

Module 4. Responding to Suffering and Bereavement

- Activities 1 and 6: The Experience of Professional Caregivers in Pediatric Palliative Care
- Activity 2; Cornerstones of Clinical Practice in Pediatric Palliative Care
- Activity 3: The Experience of the Child Approaching the End of Life
- Activity 4: The Experience of the Family During a Child's Illness
- Activity 5: The Experience of the Family After a Child's Death

Module 5. Improving Communication and Strengthening Relationships

- Activity 1: Difficult Conversations in Pediatric Palliative Care: Communication in the Context of Relationship
- Activity 2: Difficult Conversations in Pediatric Palliative Care: Sharing the Moral Burden of Decision Making with Parents
- Activity 3: Difficult Conversations in Pediatric Palliative Care: Supporting an Adolescent Facing Death

In addition to the above modules, there are also several videos available for purchase. These videos discuss a variety of topics such as family issues/experiences, pain management, caregiver suffering and communication of the end of life.

IPPC has also made quality improvement tools available to institutions. The first is Recommended Domains, Goals and Sample Quality Indicators (for family centered pediatric palliative care) and the second is the Pediatric Palliative Care Institutional Self-Assessment Tool. This tool allows organizations to assess their status on issues related to family-centered palliative care for children with life-threatening illnesses and serve as a means for further discussion and planning. There are two components to the self – assessment tool, a hospital administrative form and a unit level form. In order to access these quality assessment tools, the organization must register with IPPC free of charge. The website does indicate that information regarding faculty development and regional seminars will be made available in the future.

NHPCO – Children's Project on Palliative/Hospice Services (ChiPPS) (www.nhpco.org)

This project seeks to make the best-known practices in the field of pediatric palliative care more widely available to care providers. ChiPPS resources include the NHPCO Pediatric Palliative Care Newsletter, information about conferences related to pediatric palliative care (included IPPC Regional Retreats), information for parents, and materials for pediatric palliative care providers available for purchase. The End of Life Resources section does have information on Children and Family Support.

ELNEC (www.aacn.nche.edu/ELNEC)

The ELNEC project is a national education initiative to improve end of life care in the U.S. The project provides undergraduate and graduate nursing faculty, CE providers, staff development educators, specialty nurses in pediatrics, oncology, critical care, and geriatrics and other nurses with training in end of life care. These individuals can go on to teach the essential information to nursing students and practicing nurses. The project was begun in 2000 with a grant from the Robert Wood Johnson Foundation and has trained over 3400 nurses to date.

The ELNEC-Pediatric Palliative Care course, adapted from the ELNEC-Core curriculum, was piloted in 2003. The national course has been offered annually. Two ELNEC-Pediatric Palliative Care courses will be offered in 2007. Information about pediatric trainers in each state is available on the website.

EPEC (www.epec.net)

The EPEC project is based at Northwestern University's Feingold School of Medicine. The project offers individuals the opportunity to participate in two types of conferences on palliative care. The first is a "Become A EPEC Trainer" conference which is a two day conference discussing the principles of palliative care and effective teaching approaches for dissemination. Once completed, a "trainer" may then use EPEC materials available for purchase to lead future EPEC training sessions locally. The second conference is a Professional Development Workshop designed to enhance teaching and leadership skills. It should be emphasized that the EPEC project is adult oriented with respect to patient population.

HARVARD MEDICAL SCHOOL CENTER FOR PALLIATIVE CARE (www.hms.harvard.edu or pallcare@partners.org)

The Center's Program in Palliative Care Education and Practice offers intensive learning experiences for physician- and nurse-educators who wish to become expert in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, as well as to gain expertise in leading and managing improvements in palliative care education and practices at their own institutions.

The course is delivered in two sections. The first part is a 7 day program on teaching and learning in palliative care. A 6 month interim follows during which time participants work on an individual project and contribute to weekly discussions of problematic cases presented by other participants through e-mail exchanges. The second part is another 7 day block that includes experiential learning and leadership.

The curriculum features teaching the fundamentals of palliative care, teaching about communication at the end of life, managing challenges in palliative care education, and developing and promoting clinical and educational programs in palliative care.

Pediatric Palliative Care Conferences

The Internet is an excellent source for seeking out conferences held throughout the year on topics in PPC. For example, an online course on pediatric pain management is available from ULCA office of CME. There is also a Pediatric Palliative Care Conference scheduled for October 2007 in Akron through the Ohio Pediatric Palliative End-of-Life Network and a similar conference in the fall 2007 and Children's Hospital of Central California.

mCARE Site Visits

As part of the mCARE project, several site visits were made last year by staff members of the mCARE project. Those programs visited included PPC programs at Children's Mercy Hospital, Kansas City, The Children's Hospital, Denver, Seattle Children's Hospital, St. Mary's Hospital for Children, Bayside, and The Johns Hopkins Children Center. Each of these sites has a unique approach to pediatric palliative care with respect to resources available and program development. The PPC team at a MTF could use the site visit results as a means to identify what are important components of a PPC team/program.

Pediatric Palliative Care Quality Plan

PURPOSE

The purpose of this plan is to promote the delivery of quality palliative care to children with life limiting conditions and to their families in the military system. Ultimately it is the intent to support military parents of children with life limiting conditions and promote effective patient partnerships. Ultimately, quality care contributes to supporting military readiness under extreme personal and family situations.

GOALS¹

- 1) Address pain and symptom control, psychosocial distress, spiritual issues and practical needs with the child and family throughout the continuum of care
- 2) Promote advance care planning and the application of principles of palliative care by healthcare professional in all settings
- 3) Provide children and families with the information they need in an ongoing and understandable manner so that they can grasp their condition and treatment options. This includes eliciting their values and goals over time; regularly reassessing the benefits and burdens of treatment; and ensuring that the decision-making process about the care plan is sensitive to changes in the child's condition
- 4) Ensure genuine coordination and continuity of care across settings through regular, high-quality communication among healthcare professionals at times of transition or changing needs and through the provision of effective continuity of care that utilizes the techniques of case management
- 5) Prepare both the child and family for the dying process and for death, when it is anticipated; explore hospice option and ensure that opportunities for personal growth are enhanced and that bereavement support is available for the family; and continue bereavement support for the family beyond the patient's death.
- 6) Deliver palliative care through an organized structure that promotes a child/family centered model of interdisciplinary team care.

It is not necessary to include all 6 goals in your quality plan; an organization can pick those specific goals that reflect the intent of your program or add other goals that relate to your program type.

¹ National Quality Forum, A national Framework and Preferred Practices for Palliative and Hospice Care Quality, A Consensus Report, 2006, p. 4-5.

FRAMEWORK FOR QUALITY IN PEDIATRIC PALLIATIVE CARE

Principles which serve as a foundation for a pediatric model of palliative care are:²

- Children/ adolescents with a life limiting condition and members of their families have easy access to a comprehensive, coordinated, competent continuum of care in their community
- Care is family centered in its philosophy, values, practices and operation and seeks to support the child/ family culture, values, beliefs, priorities, circumstances, choices and structure
- Care and services are delivered in to child and family according to generally accepted ethical standards
- Management and operations are conducted as a comprehensive integrated continuum of services operating according to nationally recognized standards of care, evidence based treatments, and best practices and is accountable to all appropriate licensure, regulatory and accreditation bodies
- Care is delivered through an interdisciplinary approach
- Admission to palliative care services are barrier free and provide timely response to initial and presenting problems with access to on-call staff from the time of admission
- Comprehensive assessment processes and documentation are used to support the goals and plan of care and are identified as important to the child/ adolescent and family. The assessment process is ongoing to support changing and progressing needs
- A comprehensive written plan of care is used to delineate the needs, hopes and goals of each child/adolescent and family. The plan addresses the medical, nursing, psychological, spiritual and practical concerns and problems and identifies achievable outcomes and results. The plan integrates activity of the team implementing medical treatment services and the team implementing palliative services
- Care is delivered in an integrated and coordinated manner that promotes continuity across inpatient, outpatient, and community settings. This care delivery system includes a system for care management and a mechanism to include continuity across relationships important to the child/adolescent and family, such as school, religious affiliation, and community activities
- The range and intensity of symptoms which cause distress to a child/ adolescent and family are managed to achieve the most attainable quality of life
- Care includes access to a competent continuum of counseling and supportive services to assist with the physical, emotional and spiritual issues, interpersonal dynamics and psychosocial dimensions of their experience
- Family members or children/adolescents who die may continue to need supportive and/or professional services following the child's/adolescent's death for a period of time that varies among families and family members.

These principles have been developed by Children's Hospice International for the purpose of CHI PACC program development and were designed specifically for a pediatric population. Other principles of care can be included to meet the needs of the program type.

² Children's Hospice International, CHI PACC Implementation Manual, 2nd edition, 2003, P. 52-70, Principle of Care with Practice Guidelines

OVERSIGHT OF THE QUALITY PROGRAM

Level 1 (*This is the highest level of oversight and may be an Installation Commander of a MTF or other executive role in the organization. Replace this heading with the actual title of the role*)

This role provides the global oversight to the Quality Program and Plan with the assistance of the Level 2 (*insert title of level 2 role*). This role would be responsible for reviewing quarterly Quality reports and provides recommendations to the Quality Committee with input from Level 2 role described below.

Level 2 (*This level is typically leaders of various specialty divisions. They may represent clinical and administrative areas of a facility. Replace this heading with the actual title of the role*)

The Level 2 role is responsible for oversight of quality improvement activities and development of quality indicators within their respective Divisions and scope of responsibilities. This level will act as a resource and provide support to task forces or subcommittees chartered by a Quality Committee.

Quality Improvement Facilitator

The role of the Quality Improvement Facilitator is to monitor quality improvement activities and serve as a resource to the Level 2 role described above. The Quality Improvement Facilitator serves as the chairperson for the Quality Improvement Committee and is responsible for the following:

- Oversight relative to compliance with regulations, standards of care and installation policies.
- Identifies areas needing monitoring; with recommendations and input from other leaders within the organization.
- Assists with the gathering and analyzing of data.
- Assists with identifying patterns and trends.
- Assists with formulating and developing reports,
- Monitors follow up plans from Division and Program Leaders
- Acts as a consultant to issues of quality for subcommittees or other entities within the organization.

Identified patterns and trends may require a quality improvement initiative from the Quality Improvement Committee to the affected divisions. *An initiative, for example, may stem from the Satisfaction Survey. Families may indicate dissatisfaction with the referral/appointment process (i.e. a prolonged delay before seeing a pediatric specialist.). The Task Force assigned, may review the referral/appointment process and identify areas needing improvement.*

TEMPLATE

Quality Improvement Committee

The Quality Improvement Committee supports the Quality Program and Plan through participation, research and recommendations. The Committee will:

- Identify good practices or processes (i.e. - a patient's pain threshold will be kept at a minimum level of 3; on a scale of 1 to 10)
- Identify areas to be monitored (i.e. - pain thresholds of patients)
- Define benchmarks or standards that signal monitoring (i.e. - Focused monitoring will occur when 20% of the patients population experienced a pain level of 6 consistently)
- Identify desired outcomes. (i.e. - 95% of the patients with pain will be kept at a pain threshold of 3)
- Identify specific, measurable goals for a chartered Quality Work Group. (i.e. - Identify alternate treatment regimes for patients who do not response to traditional pain medication.)
- Prioritize quality improvement activities/initiatives.
- Reviews monitoring reports and provide recommendations,
- Encourage collaboration among divisions and programs by chartering task force groups. (i.e. - The medical and nursing division work together to monitor, treat and decrease patients pain levels over 5
- Act as a catalyst to implement change in an effort to improve the quality of services

Please note that the examples used in this section relate to pain management, however any process can be applied within this structure.

The Quality Improvement Committee reviews reports following monitoring activities. The Committee may concur with the recommendations made by program leaders regarding any trends or patterns identified; or make further recommendations. If further information is needed a task force or subcommittee may be initiated. The Quality Improvement Committee will monitor follow up from any action plans generated from the subcommittee or task force.

The membership of the QI Committee includes: *(this is an example of how the committee could be structured)*

- Quality Improvement Facilitator
- Parent representative
- Deputy
- Medical Team member
- Surgical Team member
- Palliative Care Team member
- Social Services Team member
- Chaplain Services
- Information Technology representative (as needed)
- Administrative Support

TEMPLATE

The Quality Improvement Committee meets monthly. *Meeting frequency is determined by the committee but should be a regularly scheduled event.* Reports and minutes will be made available to the Level 2 and Level 1 roles by e-mail, report or presentation.

The Committee annually evaluates the Quality Improvement Plan and determines the priorities for the upcoming year. These priorities are developed with the assistance of the Division and Program Leaders.

A common component to delivering quality is the use of various committees to support decisions related to opportunities for improvement. For the purpose of palliative care, the committee could be an already existing one that addresses issues related to service delivery or quality or could an advisory type committee composed of a subset of stakeholders. Often advisory committees include parents to ensure a balanced perspective for direction.

Palliative Care Committee

(This committee can also be composed of the champions of your palliative care effort. In some situations it may be just a few members who represent the individuals with expertise in your palliative care effort.)

The Palliative Care Committee addresses processes that affect the care of children and their family with life threatening and terminal illnesses.

The Committee will:

- Design, manage and monitor the palliative care delivery system.
- Develop and review policies and procedures.
- Define standards for palliative care.
- Develop tools and methods for measuring standards of palliative practice to improve family satisfaction.
- Addresses ethical issues related to palliative care.
- Collaborate with other involved entities

Subcommittees or Task Force Groups

Subcommittees or Task Force Groups are teams that are initiated by the Quality Improvement Committee. They are cross-functional, multidisciplinary, and formed when an issue is identified and a smaller group is needed to collect additional information or work on strategies to improve care practices, delivery systems, documentation, competencies of personnel etc.

Once the assignment has been completed, the Subcommittee or Task Force will report their findings and recommendations to the Quality Improvement Committee for review.

TEMPLATE

QUALITY IMPROVEMENT MONITORING PROCESS

The framework used for monitoring in this template is the Logic Model; however other models can be substituted as an alternate process for monitoring.

Framework for the Process Improvement and Outcome Analysis -

The **Program Logic Model**³ for Planning, Evaluation and Action, was created by the W.K Kellogg Foundation in 1998, with an update in 2003. The model provides the path to plan, design, implement, and analyze processes that can/will improve the quality of services. As defined by the W.K. Kellogg Foundation – “The program logic model is a picture of how your organization does its work – the theory and assumptions underlying the program. A program logic model links outcome (both short and long term) with program activities/processes and the theoretical assumptions/principles of the program.” By reviewing and answering the questions in each phase the QI Committee or any Division, Program or Task Force can get a clearer picture of the issue and how to address it.

Logic Model Process –

The **first phase** of the logic model is the planning/identification phase.

- What is the problem or issue to solve?
- What are the needs of the patient/family, personnel or facility?
- What resources are available to help solve the problem or issue. (human resources, financial, technology etc).
- What things or people in the organization will influence change?
- What existing processes, tools, events, technology, or actions will help to solve the problem/issue?
- What activities does the organization believe/assume will solve the problem and why.

The **second phase** is to review what the organization intends to produce or change.

- What are the “now” deliverables or products produced by the activities
- What are the benefits/changes in individual behavior, knowledge, skills or functioning levels?
- What are the timeframes to achieve goals - 1-3 years (short term) or 4-6 years (long term)
- What will be the global changes in the organization, community or systems once the problem has been resolved. (This may be seen after several months or several years)

³ Logic Model Development Guide, Battle Creek, MI, W. K. Kellogg Foundation, 1998.

TEMPLATE

The **third phase** is to develop indicators or monitors that will measure the activities performed. Indicators are related to structures, processes or outcomes.

Structures are defined as resources (staff qualifications, office equipment, educational handout) that assist an organization achieve its mission and goals. (i.e. - All pediatric physicians who work with palliative care patients have background in terminal & life threatening illnesses.)

Processes are defined as procedures. (ie - The patient has an appointment with the pediatric medical specialist within 2 weeks of the referral.)

Outcomes are defined as what is expected from a change in a structure or process that has positive effect on personnel, patients/family members or healthcare providers. (ie - 95% of the pediatric patients with terminal or life threatening illnesses was seen by a qualified pediatrician and was initiated into the palliative care program within 2 weeks of the initial referral.)

When to Monitor -

Monitoring timeframes depends on the level of priority identified by the Division or Program or when there is an issue identified in:

- Division, Program or Personnel expectations
- Patient and family satisfaction
- Initiation of a new process or procedure
- High risk procedures
- Problem prone areas
- High cost processes
- Document completeness, accuracy or timely submission

Data can be Collected various areas which include, but not limited to:

- Division or Program reports
- Surveys or Questionnaires
- Complaints
- Patient medical files
- Billing reports

The **sampling size** will be determined by the significance of the study. Routine sampling will be 15 – 20% of the sample population. Critical sampling will be 100% for areas needing full compliance or consisting of a small population.

Sampling percentages can be determined by the entity implementing the Quality Plan.

TEMPLATE

The **fourth phase** is to evaluate the data and to determine if the goal was reached and the problem solved. If the problem/issues are not solved, than the logic model is repeated, with revised assumptions and strategies.

Quality Improvement Reports should follow a consistent format when presented to a committee. An example is provided

Format Elements

- Name of the Study
- Why the Study was Chosen
- Date of the Study
- Timeframe of the sample
- Standards and Thresholds (Benchmark)
- Where data was collected
- Sample Size
- Results
- Analysis/Patterns/Trends
- Recommendations
- Date and to whom report was given
- Action Plans
- Responsible Person to Facilitate Plan
- Due date

Example of Report Format

Pain Management of Children with malignancies.

There were numerous complaints from family members regarding their child suffering with consistent pain.
4/16/07

January to March 2007

90% of the population studied will have a maximum pain threshold of 4 consistently.

Patient medical record

40 children with malignancy (ICD 9 code) 100% of the population. 5 children (12%) had their pain level consistently at level 4 during their treatment.

35 of the 40 children did not receive adequate medication to relieve pain. There were no trends related to one medical specialist.

Review treatment regimes.

Educate medical personnel on treatment regimes.

Review patient population 2 months after plan is in affect.

5/2/07 Report to QI Committee

Review treatment regimes.

Educate medical personnel on treatment regimes.

Medical Division Leader

August 2007

Reporting Pathway -

Reports are presented by the Palliative Care Program to the QI Committee for review and recommendations. Abbreviated reports are given to the Installation Commander from the Deputies. All recommendations provided to the Divisions and Programs will be reviewed for feasibility. Action plans will be executed per a designated timeframe. Results from these actions plans will reported by the Division Leaders to the Palliative Care Program and QI Committee. Outcomes are reported to the Deputies and the Installation Commander.



Plan of Action After Reporting -

Each Level 2 role, following the review of a report may recommend the following actions:

- Alert the affected Program to the concern.
- Revise policies/processes in that Program.
- In-service the affected Program personnel.
- Retrain affected medical or administrative personnel.
- Monitor the area of concern in more detail to gather additional data.

Annual Evaluation of the Palliative Program -

Yearly, each division, program and committee will report on goals achieved in the previous year, accomplishments, and areas still needing improvement with action plans and goals for the following year.

Confidentiality -

All activities set forth by the Quality Improvement Committee, including any information collected by any other associated committee, task force, divisions or program, in order to evaluate the quality of patient service, is to be held in the strictest confidence, and is to be carefully safeguarded against unauthorized disclosure. Reports and data are safeguarded in the Information System by password entry. Hardcopy files are located in the office of the Division and Program leaders

QUALITY IMPROVEMENT EDUCATION

Personnel should receive education regarding quality improvement activities and monitoring annually through:

- Initial orientation
- Biannual Inservices
- Committees
- Quality Improvement Task Force Groups

REVIEW OF THE PROGRAM AND UPDATE OF THE PLAN

The Quality Program & Plan is reviewed and updated by the Quality Improvement Facilitator with the support of the Level 1 and Level 2 roles and the Quality Improvement Committee annually. Final approval of the plan is by the Level 1 or Level 2 roles.

TEMPLATE

A. N'DIX 30

Palliative Care Outcomes

Goals of Care

- 1- For the child/adolescent/family to receive and feel support during the illness and end of life process.
- 2 - For the child/adolescent/family to be comfortable during the illness and end of life process.
- 3- For the child/adolescent/family to be knowledgeable regarding the illness and end of life
- 4- To provide a smooth continuum of care for the child/adolescent/family through communication, referrals and advocacy
- 5 - For the child/adolescent to receive timely and appropriate medical care
- 6- To promote active participation of the child/ adolescent and family in decision making throughout the continuum of care
- 7- To promote the spiritual well being of the child/ adolescent and family

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Systems, Access to Care and Coordinated Care			
Access to Care and Services	Palliative care services are available from the time of diagnosis	Child/ adolescent will be referred to Palliative care services within 48 hrs of diagnosis	Health care record - referral date to palliative care service and date of diagnosis
	Palliative care services are available across the continuum of inpatient, outpatient and community settings.	Palliative care services can be accessed from inpatient, outpatient or the community setting.	Health care records, policies and procedures, satisfaction surveys
	Admission criteria are met to enter the Palliative Program.	The child/adolescent/family is admitted within 24 hours to the Palliative program following initial referral.	Admission criteria, Admission Paperwork, Referral to Team, Health care Record
Systems	Adequate # of providers and facilities in geographical area per population base	Providers/facilities located within 60 miles of child.	Healthcare Provider and Facility List, Complaints, Satisfaction Survey
	Adequate # of multicultural providers per population base	Satisfaction with availability of multicultural providers > 90%.	Background Info on Providers (multicultural), Satisfaction, Complaints

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Systems (cont')	Medication available at pharmacy site where prescriptions are filled	Child/adolescent is able to get medication within 24 hours of physician order .	Pharmacy dispersion logs, Complaints
	Waiting time for appointment less than 2 weeks.	Satisfaction with access to providers and services > 90%.	Appointment logs, Appointments that could not be filled, Satisfaction Survey, Complaints
	The organization has an adequate # of providers 24 hours a day to communicate with the family. Rate of reaching team members > 90%	Child/adolescent/family are able to reach the Palliative Team 24 hours a day for immediate and/or crisis needs. Rates of on-call responses being returned in 15 minutes.	Staffing Census, On Call List, phone calls per shift, complaints, satisfaction survey
Coordinated Care	Child/adolescent has access to coordinated care	Care coordinator is assigned to child/ adolescent/family from the time of admission to palliative care.	Program description, program service list, Intake list with coordinator assignment review
	Coordinated care facilitates access to resources and services, education of family and providers and promotes communication between professionals and family.	Child/ adolescent/ family access services and resources as defined by their individual plan.	Satisfaction survey, plan of care, goals, claims data
	Care Coordinator identifies educational opportunities for providers and child/ adolescent/ family to support the goals of care	Child/ adolescent/ family attends educational opportunities as defined by their individual plan.	Satisfaction survey, plan of care, goals, claims data

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Coordinated Care (cont')	Care Coordinator facilitates communication between child/ adolescent/ family and member of the health care team or other community players.	Family and healthcare team collaborate in plan of care and child/adolescent treatment goals.	Satisfaction survey, plan of care, goals, claims data
	Care Coordinator will promote continuity of care for military related issues such as deployment, relocation, orders, leave, housing , etc. as it relates to the child/adolescent's healthcare.	Family will be able access appropriate entities and individuals to support their specific military needs (example, EFMP, Military One Source, parent to parent discussion forums, etc.)	Satisfaction survey, complaints
Relationships			
Advocacy	The Palliative Care Program defines a process for advocating a child/ adolescent or parent issue.	The family is able to effectively self advocate or have access to someone who can advocate on their behalf for their child/adolescent/ family needs'.	Communication Forms, Policies/Procedures, Client file, Satisfaction, Complaints
Communicating with Healthcare Providers	95% of professional staff who provide direct care to children who have life limiting conditions, will complete a recognized Palliative Care curriculum within 24 months of initial assignment	Healthcare providers are trained to communicate with children/ adolescents/ families regarding palliative care.	Training records, licensure, certification records

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Communicating with Healthcare Providers (cont')	An individualized plan is developed to direct the interventions and care of the child/ adolescent.	100% of children/ adolescents participating in a palliative care program will have an individualized plan developed collaboratively with the child/family and addresses medical and quality of life goals.	Health Care Record, List of patient/family goals
	The Care Team collaborates formally on the care, treatment and goals of the child/adolescent/ family.	The child/ adolescent receives a smooth coordination of referrals, care and treatment for their illness and/or symptoms.	Team Meeting Minutes, Communication Forms, Policies/Procedures, Client file, Satisfaction, Complaints
	Communication is provided in a understandable manner.	There are bi-lingual providers, educational materials and interpreters available to non-English speaking patients/families.	Provider List, Educational Material, Interpreter Service availability
Decision Making	Promote active involvement by child/adolescent/ family in decision making affecting their care, treatment and services provided.	The child/adolescent/family rights and preferences are protected and preserved.	Health Care Record, Meeting minutes, consents for care
	Informed consent is obtained and documented in accordance with organizational policy	The child/ adolescent/family are involved in a complete informed consent process including proposed care, treatment, services, meds, interventions or procedures, benefits, risks, or side effects including potential problems, likelihood of achieving goals, and reasonable alternatives	Health Care record, team records, consent records

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Family Needs			
Social and Emotional Needs	A psycho social assessment is part of a comprehensive assessment for palliative care needs.	The child/ adolescent/ family has access to counseling and supportive services throughout the continuum of diagnosis to end of life and beyond to address issues of bereavement.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
	Social work support is available to child/ adolescent/ family.	Child/ adolescent/ families have access to social work support to address issues related to individual support networks, transportation, childcare and other logistics.	Health care records, policies and procedures, satisfaction surveys
	The family is assessed for financial burdens related to their child's health care needs.	Families desiring assistance with active or potential financial burdens incurred as a result of their child's health care needs will be referred to resources for assistance.	Health Care Record (Assessments, Plan of Care, Client/Family Goals) Policy/Procedures, Usage of Respite/Volunteer services, Satisfaction, Complaints
Search for Meaning/Spiritual Care	A spiritual assessment is performed within 48 hours of child/ adolescent/family admission to palliative care	The child/adolescent//family has access to the chaplain or other spiritually supportive individual identified by the family within 24 hours of referral for service.	Health Care Record (Assessments, Plan of Care, Client/Family Goals) Policy/Procedures, Satisfaction, Complaints
	There is a spiritual resource referral system in place.	The patient/family is referred to community resources that may assist in spiritual needs not met by the chaplain.	Patient Record (Anecdotal Notes, Referrals)

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Palliative and End-of-Life Care			
Palliative Care	The plan of care is developed within 72 hours of the assessment.	The plan of care will reflect child/ youth/family's goals for care and define a family centered approach to palliative care.	Assessment, Plan of Care, Philosophy statements, organizational values, mission
	The plan of care is re-evaluated every 30 days or sooner when indicated by a change in the child/ adolescent or family.	Newly identified issues and concerns are addressed and updated in the Plan for Care.	Health Care Assessment, Revised Plan of Cares for all disciplines
	Goals are identified for each area of need or concern.	The child/family has input to the goals developed for the Plan of Care.	Health Care Record, List of child/family goals
	Each plan of care is implemented within 24 hours.	The patient and family receive treatment and services as indicated in the plan of care.	Health Care Record
	The Palliative/Hospice Team addresses and manages symptoms within 24 hours of notification.	Pain Scale is below 4.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
		Labored breathing is decreased within 15 minutes of intervention.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey
		Nausea is decreased within 15 minutes of intervention.	Health Care Record (Physician Orders, Anecdotal Notes), Complaints from Family, Satisfaction Survey

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Palliative Care (cont')	A rehabilitation assessment is performed by a physical therapist, occupational therapist or speech pathologist within 1 week after needs are identified through the initial physical assessment.	The patient's plan of care addresses the identified needs noted in the assessment.	Health Care Record (Assessment, Plan of Care)
	A dietary assessment is performed within 1 week by a dietitian 1 week after needs are identified through the initial physical assessment.	Intake is adequate for the physical and development needs of the child/ adolescent. (calories/per day)	Health Care Record (Assessment, Plan of Care)
End of Life Care	The wishes of the child/ adolescent/ family are addressed relating to end of life decisions	Care providers assist the child/adolescent/ family to formulate their "wishes" or advanced medical directives and offers options to review or revise as situations change.	Health care record, Plan of care
		The child/ adolescent/ family understand the mechanism for health care professionals and others to honor advance directives within the limits of the law dependent upon the environment of their care.	Health care record, Advanced directives
	There is a process to communicate with the child/adolescent /family regarding expectations at end of life phase.	Families are educated regarding signs and symptoms of imminent death.	Health Care Record (Anecdotal Notes)

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
End of Life Care (cont')	There is a process to address pain and symptoms related to imminent end of life.	Adequate dosages of analgesics or other medications are provided to the child/adolescent throughout the active phases of dying. The pain scale is 2 or less	Health Care Record (Physician Orders, Anecdotal Notes)
	There is an Ethical Committee or Team available to address ethical issues.	The child/ adolescent/ family is satisfied with assistance provided on ethical issues.	Committee Minutes, Satisfaction, Complaints
Education			
Patient/Family Education	Program information is provided during the patient's 1st assessment visit with the provider.	Child/ adolescent / family receives Admission Packets, Handouts, Educational Materials, Policy/Procedures	Admission checklist completed
	There are program materials and in-services regarding palliative care and the end stage of life for families.	Families are educated regarding palliative care and the signs and symptoms of end of life	Health Care Record (Anecdotal Notes), Educational Material
Healthcare providers' education needs	Palliative care professionals are trained, credentialed and or certified in their area of expertise.	Satisfaction with trained providers knowledge regarding palliative care and treatment > 90%.	Credentials, Resumes, Satisfaction, Complaints
	Healthcare professionals attend in-services related to palliative care biannually.	Satisfaction with trained providers knowledge regarding palliative care and treatment > 90%.	Provider In-service records, Satisfaction, Complaints
Residents and fellow's education needs	There are providers trained in the specific diagnosis of the patient.	Care and treatment delivered is appropriate to patient diagnosis and symptoms.	Patient /practitioner assignments, Patient Record/Care Plans

TEMPLATE

Needs	Organizational Monitors	Child/ Family/ Provider Monitors	Location of Data
Resources for education	There are educational materials, in-services or a resource information available to families or the healthcare team.	Families obtain the requested information they need to support the care of their child/ adolescent.	Resource library, in-service, handouts, internet websites, resource materials satisfaction

APPENDIX 31

SAMPLE

Palliative Care Satisfaction Survey

Instructions: We care about your opinions and want to know how satisfied you are with Palliative Care services. We are seeking your opinions, as parents or caregivers. Please tell us whether each statement reflects your actual experience, by **marking** the box that best reflects your opinion.

<i>How satisfied are you with ...</i>	Very Satisfied	Generally Satisfied	Not Satisfied	N/A
The way your child's medical care is coordinated?				
The way your child's other care is coordinated?				
Knowing who to contact for various services?				
Your ability to schedule urgent medical appointments?				
The time to get an urgent medical appointment?				
The time to get a routine medical appointment?				
Communication with your doctors?				
Explanations of medical procedures and treatment options?				
Getting medication for your child?				
Symptom management for your child? (pain control, nausea, bowel/bladder, physical issues)				
The physician's knowledge of your child's illness?				
The nurse's knowledge of your child's care?				
The therapist's (OT, PT, Speech, other) knowledge of your child's care?				
How administrative staff personnel treated you?				
Ability to obtain answers to questions regarding your child's care and services?				
Ability to participate in decisions regarding your child's medical treatment plan?				
Ability to participate in decisions regarding your child's non-medical services?				
Goals set for your child's care?				
Quality of your child's life during their illness?				
Support to meet your family's spiritual needs?				
Your ability to access resources to support your child's and family needs during you child's illness?				
Information provided to you to prepare for end of life ?				
Support provided to address your military needs?				
Ability to balance your responsibility to the military while caring for your child?				

Please flip the survey over for page 2 ➡

SAMPLE

Instructions: We are interested in your experience with accessing resources to support your child's care. We want to know if you received adequate information about resources available. Please circle 'yes' or 'no' if you received adequate information; and whether the resource was helpful. Mark the "not applicable" box if you did not ask for assistance in a specific area.

<i>If needed information about the resources below and did you find the resource helpful?</i>	Got Information?	Not Applicable	Resource Helpful?
Care coordination/ Case Management	Yes/No		Yes/No
Primary care physician	Yes/No		Yes/No
Specialty care physician	Yes/No		Yes/No
Medical equipment and supplies	Yes/No		Yes/No
Adaptive Equipment	Yes/No		Yes/No
Nursing services	Yes/No		Yes/No
Therapy services such as occupational, physical or speech	Yes/No		Yes/No
Chaplain services / Spiritual Counseling	Yes/No		Yes/No
Nutritional services	Yes/No		Yes/No
Age 0 – 3 year services for early intervention	Yes/No		Yes/No
School Program issues due to your child's illness	Yes/No		Yes/No
Recreation and camps for your child	Yes/No		Yes/No
Transportation issues to medical appointments	Yes/No		Yes/No
Expressive therapies (music, art, play, etc)	Yes/No		Yes/No
Educational information for you	Yes/No		Yes/No
Financial concerns or funding needs	Yes/No		Yes/No
Respite care	Yes/No		Yes/No
Emotional Support for your child/ adolescent	Yes/No		Yes/No
Emotional Support for parents	Yes/No		Yes/No
Emotional Support for siblings	Yes/No		Yes/No
Bereavement/Grief Counseling	Yes/No		Yes/No
Future planning needs	Yes/No		Yes/No
Funeral related concerns	Yes/No		Yes/No
Hospice services	Yes/No		Yes/No

Please indicate where your child's healthcare is provided. ____ MTF ____ Civilian ____ Both

Comments regarding the above questions, or any other concerns? Would you like us to call? If so, please provide your name and phone number.

Name: _____ Phone: _____

Please use the enclosed envelope to return your survey.

Thank you for taking the time to fill out this survey.

Children's Hospice Status of Work by Project Objectives

Project Objects	CHI	TCC	USUHS	TMA	Analysis Ready for Implementation into Final Report/Model Design	Narrative Explanation
1. Delineate the needs of children and families eligible for care in the MHS by gathering data from families at five military medical centers/clinics. (Months 1-18)	Tasks completed	No assigned tasks	<p>PENDING</p> <p>The needs assessment was expanded as documented in FY04 proposal. Keesler AFB site changed to Wright Patterson AFB.</p>	No assigned tasks	<p>NCA research close to completion; preliminary analysis done</p> <p>See objective 11.</p>	<ul style="list-style-type: none"> • The timeline for conducting the research associated with the needs assessments (family and provider) was delayed at least 1 year due to the complexity of the IRB processes and the coordination of protocol approvals among USUHS, Detrick, WRAMC, NNMC and Malcolm Grow Medical Center. • Additional delay was related to the need to change sites from Keesler AFB (which was closed following Hurricane Katrina) to Wright Patterson AFB. • Data collection in the NCA is now almost completed. Interviews and focus groups are scheduled for sites outside the NCA. Two IRB approvals are still pending. Refer to attached schedule from USUHS for completion of work. • The attachment from USUHS also provides contingency plans should approvals be delayed or not obtainable at Navy San Diego and Ft. Leavenworth.
2. Delineate the educational needs of healthcare providers in the MHS by holding resident pediatrician and other healthcare provider focus groups at each location. (Months 1-18)	Tasks completed	No assigned tasks	<p>PENDING</p> <p>The needs assessment was expanded as documented in FY 04 proposal. Keesler AFB site changed to Wright Patterson AFB.</p>	No assigned tasks	<p>NCA research close to completion; preliminary analysis done</p> <p>See objective 11.</p>	See objective 1.

Children's Hospice Status of Work by Project Objectives

3. Analyze existing MHS, TRICARE and community resources available to military families including current and potential providers of services and using parent, resident, pediatrician and subspecialty groups to identify unmet needs. (Months 1-12)	No assigned tasks	No assigned tasks for analysis of MHS benefit; see objective 5	Analysis of MHS benefit and TRICARE resources completed.	No assigned tasks	Complete: MHS, Tricare analysis See objective 5 for community resources.	<ul style="list-style-type: none"> • Analysis of the Military Health System and the benefit through TRICARE has been completed. • The analysis of existing community resources has been included with work done for Objective 5.
4. Define eligibility criteria for the target patient population using information on target populations from other CHI PACC® projects, and applied appropriate for the DOD. (Months 9-12)	Tasks completed	No assigned tasks	Defined eligibility criteria Outlined methodology for estimating DOD pop.	Provided data on DOD population	Close to completion.	<ul style="list-style-type: none"> • This objective is close to completion.
5. Design a resource assessment tool for identification of resource segments within a geographic community. Test and evaluate the tool and develop a plan to evaluate resources within all geographic areas in the catchment region. (Months 1-12)	Tasks completed but were determined to no longer be in line with the project direction.	PENDING Resource assessment tool done. Analysis ongoing	No assigned tasks	No assigned tasks	Close to completion. Based on the initial findings of the feasibility, this objective evolved from the requirement for a specific resource tool to a more generic analysis of the types of resources available in government, military and civilian/local communities. Final analysis to include categories of resources, issues related to access/availability and barriers. Provides information not limited to geographic area.	<ul style="list-style-type: none"> • During the course of the feasibility study, an extensive review of potential resources for children with life threatening conditions, revealed numerous possible sources of support available to military families living in the National Capital Area (NCA). Many of the resources are national in scope or government related and, therefore, available in other areas of the country, or otherwise commonly available in most communities. Hence, the information gleaned from this study can be generalized to communities other than the NCA. For this reason a resource database specific to this population in the NCA was deemed unnecessary. In addition, much of the problem seems to lie in the <i>barriers</i> to accessing services rather than in their lack of availability. Further analysis of resources compared to the needs assessment of families could reveal additional gaps in existing resources for children and families in the military. These gaps will be further evaluated and ultimately incorporated into a new model

Children's Hospice Status of Work by Project Objectives

						<p>design as other components of this project are completed.</p> <ul style="list-style-type: none"> • A web-based database was a part of the concept in the initial proposal. The purpose of this database was to house the resource data identified during this review of resources. Since the ultimate goal of the project was to design a model that could be used across the MHS, it was determined that there was a need to present the resource information from a broader perspective, one that could be applied to any community. Therefore, it was determined that specific data would be collected and included in a database for the NCA would not be useful in a broad application of model design. In addition, the resource review findings included an extensive list of existing databases that are currently accessible on the Internet for families who have children with special healthcare needs. • Discussions with key representatives of family programs and children and youth services from the Office of the Secretary of Defense, Military Community and Family Policy, as well as Military One Source, have been conducted to explore supports for families within the military community. The purpose of these discussions is to identify areas of common interest in support of military families and to avoid duplicative efforts.
6. Develop core and discipline-specific competency standards of care and training materials for providers for the target population according to CHI PACC® standards and in collaboration with WRAMC and USUHS to tailor those core competencies to meet the	Tasks incomplete	Work regarding competency standards reassigned to TCC pending contract modification.	No assigned tasks	No assigned tasks	<p>Work on competency standards anticipated for completion Dec 06.</p> <p>See objective 10.</p> <p>Education and training curricula on palliative care available through the Internet. Training initiatives already begun at WRAMC Pediatrics. Team will develop appropriate recommendations for education</p>	<ul style="list-style-type: none"> • It was learned through research on this issue that education and training curricula specific to this population are currently available, at no cost, through the Internet. Training initiatives have already begun in the Department of Pediatrics at WRAMC independent of this project. • The focus of education and training will shift from providers only to identifying <i>all</i> appropriate stakeholders and recommending the type and scope of education required as part of the

Children's Hospice Status of Work by Project Objectives

needs of the DOD target population. (Months 6-18)					and training issues related to the model developed. Anticipated completion Dec 06.	<p>implementation strategies in the proposed model; e.g. case managers on care coordination for this population, families on understanding TRICARE benefits, etc.</p> <ul style="list-style-type: none"> • The focus of education will include strategies for improving such concepts assessing family needs, communication skills, marketing, and resourcing. • Actual core and discipline-specific standards for care will be covered under objective 10.
7. Construct a database to include resources available to military families and plan a design for a user-friendly method for military families and providers. We plan to conduct a survey of a sample of potential consumers to address the way in which they will most likely access and use such a database.	Partially Complete, See Analysis	Partially Complete, See Analysis	No assigned tasks	No assigned tasks	<p>Initial analysis established that the construction of a resource database was not feasible based on research related to types of resources, access/barriers, existing web-based data, military specific resources services, e.g. Military One Source.</p> <p>See objective 5.</p>	See objective 5.
8. Evaluate existing models of care coordination, incorporating the CHI PACC® standards, to determine how to merge the best components of each model into the new CHI PACC® military model for care coordination. (Months 13-24)	Task not complete within contract period.	Work reassigned to TCC pending contract modification; participation in site visits to pediatric palliative care programs.	Participation in site visits, evaluation of programs	Participation in site visits, evaluation of programs	<p>Pending: Survey tool for evaluating existing palliative care programs developed. Site visits scheduled for spring/summer 06. The evaluation of existing care coordination models will be completed by Oct 06.</p>	<ul style="list-style-type: none"> • The existing document, the CHI PACC® Standards and Guidelines of Care, served as the basis for preliminary work on the development of standards and measurable outcomes. These standards and guidelines serve more as the philosophic basis for an approach to palliative care for this population. • During the conduct of the project, care coordination has emerged as the core for any model for pediatric palliative care. The Coordinating Center (a current subcontractor on this project) has significant knowledge and expertise in this area. • Since there are no programs currently functioning under a “CHI PACC® model” that can be replicated, site visits will be conducted to other existing pediatric palliative care programs to survey their models for care coordination and

Children's Hospice Status of Work by Project Objectives

						delivery of services.
9. Analyze data obtained from the family and provider needs assessments to map the networks of services and informal social support used by families in each geographic area and to determine the best design in applying the CHI PACC® model to a program for military children and families. (Months 19-24)	No assigned tasks	Pending	Pending	Pending	Preliminary gap analysis done. Analysis will mature as more data becomes available. Data collection will cease Dec 28, 2006.	<ul style="list-style-type: none"> • Work will progress on this objective as preliminary analyses emerge from the needs assessment research.
10. Design a DOD quality assurance program that is consistent with all state CHI PACC® programs by developing basic components for quality monitors, minimum data sets, a computerized tracking system and an overall program monitoring system. (Months 19-24)	<p>Tasks incomplete.</p> <p>Currently only 1 CHI PACC program is functional; no requirement by the Center for Medicare & Medicaid Services (CMS) for consistent quality assurance and outcome monitoring program.</p>	Work reassigned to TCC pending contract modifications.	Pending	Pending	<p>Model will include quality standards with associated outcome measures and appropriate metrics to assess administrative processes, services delivery processes, patient satisfaction issues and cost, based on published national guidelines</p> <p>Work anticipated for completion Dec 06.</p>	<ul style="list-style-type: none"> • There are no universal quality standards and outcome measures currently being used by any CHI PACC state program. However there is soon to be soon a standard endorsed by The National Quality Forum (NQF). • The Coordinating Center will use “A National Framework for Palliative and Hospice Care Quality Measurement and Reporting” document as a basis for the Quality Plan for the project. This national framework is currently being finalized under the National Consensus Project (NCP) for Quality Palliative Care and is expected to be endorsed by The National Quality Forum (NQF) in April 2006 and will be available for use under the public domain. The NCP is a consortium of five leading national organizations- American Academy of Hospice and Palliative Care, Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership, and National Hospice and Palliative Care Organization- whose mission was to reach consensus on clinical practice guidelines for palliative care. The process to determine these preferred practices has a comprehensive and multi-tiered process which included intensive development and review by palliative care national

Children's Hospice Status of Work by Project Objectives

						experts across the nation. It is anticipated that this framework will be endorsed by NQF by April 2006. This framework will serve at the basis for the Quality and Evaluation Plan of the new model design.
11. Expand the needs assessments of family members and providers to include additional off-site locations. Modify needs assessment template developed from NCA and Keesler Air Force Base findings based on experiences at the additional sites.			IRB approvals in NCA: USUHS, HSRRB (Detrick), WRAMC, NNMCMGMC IRB approvals off-site: Madigan AMC, Wright Patterson AFB Pending approval: San Diego Remote site: Ft. Leavenworth approval pending.		Off-site research site visit scheduled for late spring. San Diego approval may not occur; contingency plans for ensuring appropriate sampling diversity Remote site research may not occur due to complexities of IRB process; contingency plans for ensuring appropriate sampling diversity **Initiation of research delayed by 1 year due to IRB approval process. **	See objective 1.
12. Define the eligibility criteria for the population of children to be served.					See objective 4.	See objective 4.
13. Develop a framework for datasets to support the new model design.	Partially Complete, See Analysis	Partially Complete, See Analysis			Research determined the development of a framework for datasets to support the new model design was not feasible. See objective 7.	<ul style="list-style-type: none"> Determined to be not feasible. See explanation under objectives 5, 7.
14. Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.	Partially Complete, See Analysis	Partially Complete, See Analysis			Research determined the development of a plan for a flexible website for multiple user groups that house various datasets discussed in goal 3 was not feasible. See objective 7.	See objective 13.
15. Develop a plan for the education of families.	Tasks not completed		Pending		See objective 6.	See objective 6.

Children's Hospice Status of Work by Project Objectives

					<p>Team will develop appropriate recommendations for education and training issues related to the model developed.</p> <p>Anticipated completion Dec 06.</p>	
16. Design new model of care with cost projections in preparation for implementation and cost analysis.	No assigned tasks	Pending	Pending	<p>Pending</p> <p>Cost projections based on preliminary model concept being developed by consultants from TMA.</p> <p>Work with TMA to determine scope of recommended model</p>	<p>Preliminary concept of model outlined. Target = new organization representing the integration of WRAMC and NNMC resources, personnel and facilities as per BRAC recommendations.</p> <p>Anticipated completion Dec 06.</p>	<ul style="list-style-type: none"> • The final report will include recommendations for a model together with implementation strategies. • TRICARE Management Activity (TMA) has already indicated that they will not support implementation of a DOD –wide program or a pilot program under their demonstration authority without a directive from Congress and/or funding for such a program. • In order to ensure the best opportunity for implementing a pilot, the model recommended will focus on WRAMC and NNMC and the current coordination and consolidation of the resources of the Department of Pediatrics as per the BRAC recommendations.
17. Develop implementation strategies for the new model design.		Pending	Pending	Pending	<p>See objective 16.</p> <p>Work with TMA, hospital command structure to determine feasibility of actual implementation of pilot or demonstration project</p>	See objective 16.
18. Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.	Partially Complete, See Analysis	Partially Complete, See Analysis	Partially Complete, See Analysis		<p>Pilot study involving patient care is prohibited under current funding by regulation.</p> <p>A model of strategies for implementation and evaluation of various components of the model will be provided as per objectives 16 & 17</p>	<ul style="list-style-type: none"> • Any provision of patient care is beyond the scope of this project due to the current funding prohibition of the funding regulation which has been in place since the inception of the program.

Referenced Documents Satisfying
Children's Hospice Project Objectives for Years 1, 2 and 3
May 28, 2007

Project Objectives	Referenced Page Number	Appendices Page Number
1. Delineate the needs of children and families eligible for care in the MHS by gathering data from families at five military medical centers/clinics.	Findings: Needs Assessment - Methods and Results Pgs 17-44	Appendix 4 Appendix 5 Appendix 6 Appendix 7
2. Delineate the educational needs of healthcare providers in the MHS by holding resident pediatrician and other healthcare provider focus groups at each location.	Findings: Needs Assessment - Methods and Results Pgs 17-44	Appendix 4 Appendix 5 Appendix 6 Appendix 7
3. Analyze existing MHS, TRICARE and community resources available to military families including current and potential providers of services and using parent, resident, pediatrician and subspecialty groups to identify unmet needs.	Findings: Analysis of CHAMPUS/TRICARE Cover of Medically Necessary Services for Children with Life-Threatening Illnesses Pgs 45-47	Appendix 8 Appendix 9 Appendix 10 Appendix 11 Appendix 12 Appendix 13 Appendix 14
4. Define eligibility criteria for the target patient population using information on target populations from other CHI PACC® projects, and applied appropriate for the DOD.	Finding: Eligibility Criteria an Estimate of the Population Pgs 48-54	Appendix 15 Appendix 16 Appendix 17

5. Design a resource assessment tool for identification of resource segments within a geographic community. Test and evaluate the tool and develop a plan to evaluate resources within all geographic areas in the catchment region.	Finding: Resources for Children Pgs 55 – 58	Appendix 18 Appendix 19 Appendix 20 Appendix 21 Appendix 22 Appendix 23 Appendix 24
6. Develop core and discipline-specific competency standards of care and training materials for providers for the target population according to CHI PACC® standards and in collaboration with WRAMC and USUHS to tailor those core competencies to meet the needs of the DOD target population.	Findings: Education Pgs 62-66	Appendix 26 Appendix 27 Appendix 28
7. Construct a database to include resources available to military families and plan a design for a user-friendly method for military families and providers. We plan to conduct a survey of a sample of potential consumers to address the way in which they will most likely access and use such a database.	Findings: Resources for Children Page 58	Appendix 24
8. Evaluate existing models of care coordination, incorporating the CHI PACC® standards, to determine how to merge the best components of each model into the new CHI PACC® military model for care coordination.	Finding: Care Coordination Pgs 59-61	Appendix 26 Appendix 27
9. Analyze data obtained from the family and provider needs assessments to map the networks of services and informal social support used by families in each geographic area and to determine the best design in applying the CHI PACC® model to a program for military children and families.	Results: Gap Analysis Pgs 71-102	Not Applicable
10. Design a DOD quality assurance program that is consistent with all state CHI PACC® programs by developing basic components for quality	Finding: Designing a Quality Program for	Appendix 29 Appendix 30

monitors, minimum data sets, a computerized tracking system and an overall program monitoring system.	Pediatric Palliative Care in a Military Setting Pgs 69-70	Appendix 31
11. Expand the needs assessments of family members and providers to include additional off sight locations. Modify needs assessment template developed from NCA and Keesler Air Force Base findings based on experiences at the additional sites.	Findings: Needs Assessment - Methods and Results Pgs 17-44	Appendix 4 Appendix 5 Appendix 6 Appendix 7
12. Define the eligibility criteria for the population of children to be served.	Finding: Eligibility Criteria an Estimate of the Population Pgs 48-54	Appendix 15 Appendix 16 Appendix 17
13. Develop a framework for datasets to support the new model design.	Findings: Resources for Children Page 58	Appendix 24
14. Develop a plan for a flexible website for multiple user groups that houses the various datasets discussed in goal 3.	Findings: Resources for Children Page 58	Appendix 24
15. Develop a plan for the education of families.	Findings: Education Pgs 62-66	Appendix 26 Appendix 27 Appendix 28
16. Design new model of care with cost projections in preparation for implementation and cost analysis.	Results: Summary of Expert Panel Pg 103-104 Conclusions	Appendix 25 Pgs 33-35

	<p>Pg 105</p> <p>Recommendation Pg 106</p> <p>Options and Implementation Strategies Pgs 107-110</p>	
17. Develop implementation strategies for the new model design.	<p>Results: Summary of Expert Panel Pg 103-104</p> <p>Conclusions Pg 105</p> <p>Recommendation Pg 106</p> <p>Options and Implementation Strategies Pgs 107-110</p>	Appendix 25 Pgs 58-61
18. Design a methodology and conduct a pilot study to evaluate certain identified components of the new model design, e.g. respite care, care coordination. The evaluation should address strategies for implementation of these components.	Pilot study involving patient care is prohibited under current funding by regulation.	Not Applicable.

