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TITLE: The Carolina Autism Transition Study (CATS)

PRINCIPAL INVESTIGATOR: Laura Carpenter, MD

RECIPIENT: Medical University of South Carolina
                              Charleston, SC 29425

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14. ABSTRACT

This report provides the final report for the project entitled "The Carolina Autism Transition Study (CATS)." The goal of this study is to characterize the longitudinal outcomes of individuals identified with ASD at age 8 through population-based surveillance. Services and outcomes for youth ranging in age from 16 and 22 were evaluated. For this project, we obtained agreements with 10 state agencies to receive deidentified data for youth with Autism Spectrum Disorder (with and without Intellectual Disability), Intellectual disability (without ASD) and Population Controls. We received data from the following data sources: Vital Statistics (essential for identification of the population control group); Medicaid; Department of Disabilities and Special Needs; All Payer (includes emergency room, hospitalization, and home health care data); South Carolina Law Enforcement Division; Department of Juvenile Justice; Department of Social Services; Department of Education; Corrections; and the Department of Mental Health. We have published three papers, one community report, and we have two additional papers in preparation.

15. SUBJECT TERMS
Autism; Transition; Epidemiology prevalence

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF	18. NUMBER OF PAGES 19	19a. NAME OF RESPONSIBLE PERSON USAMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U	UU		19b. TELEPHONE NUMBER *(include area code)*

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ABSTRACT

Background: The transition from adolescence to adulthood is a critical period for individuals living with autism spectrum disorders (ASD). Many of the support and intervention services available to youth with ASD end between ages 16 and 21, and there are limited services available specifically for adults with ASD, particularly those without intellectual disability. Adults with ASD are often reported to be unemployed or underemployed, have minimal independence in daily living activities, and rarely report romantic relationships or marriage. However, the methodology used in prior research (e.g. clinic referred samples, survey samples) may be subject to sampling biases and lead to overrepresentation of individuals at risk for the poorest outcomes.

Objective: The goal of the Carolina Autism Transition Study (CATS) is to characterize the longitudinal outcomes of individuals identified with ASD at age 8 through population-based surveillance. Services and outcomes will be analyzed for youth ranging in age from 16 and 22 (as of 2014), and used to identify predictors of specific outcomes in order to provide insight into which factors may influence successful transition for this population.

Specific Aims: The purpose of CATS is threefold: 1) Characterize the service utilization patterns and outcomes of individuals with ASD during the critical period of transition from adolescence to adulthood, 2) Compare longitudinal outcomes of individuals with ASD to a) individuals with ID without ASD; and b) a population control group, and 3) Examine individual characteristics of individuals with ASD at age 8 that may predict long-term outcomes in adolescence and early adulthood.

Study Design: Three groups will serve as participants in CATS: individuals identified with ASD at age 8 through population based surveillance (n=609); individuals identified with intellectual disability without ASD at age 8 (n=1296); and a population control group frequency matched at a 5:1 ratio to ASD participants by birth year and residence (n=3045). Service utilization patterns and outcomes between the ages of 16 and 22 will be determined for these 3 groups through linkages with 14 databases maintained by South Carolina's Revenue and Fiscal Affairs Office (RFA). Outcomes of interest include health care utilization (prescriptions, comorbid medical conditions, hospitalizations), serious life events (death, abuse/neglect, emergency room visits, criminal charges), therapeutic interventions, educational persistence, employment, and social service eligibility (including social security, vocational rehabilitation, disability board assistance, and others). We will also examine individual characteristics at age 8 (e.g. cognitive functioning, school placement, gender, race/ethnicity) that may impact long-term outcomes.

1. **INTRODUCTION:** Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.

   The goal of the Carolina Autism Transition Study (CATS) was to characterize the longitudinal outcomes of individuals identified with Autism Spectrum Disorders (ASD) at age 8 through population-based surveillance. Participants in this study were born in 1992, 1994, 1996, or 1998 and ranged in age from 17-23 at the time of the data linkage conducted for this study. Three groups served as participants in CATS: individuals identified with ASD at age 8 through population based surveillance (n=609); individuals identified with intellectual disability without ASD at age 8 (n=1296); and a population control group frequency matched at a 5:1 ratio to ASD participants by birth year and residence (n=3045). All data linkages were performed by the Health and Demographics section of the South Carolina Office of Research and Statistics, and study investigators were subsequently provided with deidentified data sets resulting from linkages. Several sub-studies have been conducted with the goal of describing and comparing service access and utilization by young adults with ASD (with and without ID), ID, and population controls over a 15-year period, with a particular focus on the transition period.

2. **KEYWORDS:** Provide a brief list of keywords (limit to 20 words).

   Autism; Transition; Epidemiology

3. ACCOMPLISHMENTS:

Project goals from SOW	Timeline (months)	Completion status
Local IRB and DoD HRPO approval	throughout	Completed
Meet with representatives from datasets 1-14; collaboratively identify variables for data request	2-13	Completed
Obtain approval for data linkage for data sets 1-14	3-16	Completed (11 total)
Submit ADDM data; Obtain de-identified linked datasets for 1-7	5-17	Completed
Clean datasets 1-14	6-19	Completed (11 total)
Merge & clean datasets (ADDM + Databases 1-14)	20-22	In Progress
Specific Aim 1: Characterize the service utilization patterns and outcomes of individuals with ASD during the critical period of transition from adolescence to adulthood.		
Aim 1 analyses	22-24	Completed
Dissemination of Aim 1 findings to scientific community (i.e. paper and presentation preparation)	25-26	In Progress
Active dissemination of Aim 1 findings to stakeholders outside the scientific community through presentations and community reports	25-26	In Progress
Specific Aim 2: Compare longitudinal outcomes of individuals with ASD to 1) individuals with ID without ASD; and 2) a comparison group (Population Control; PC).		
Aim 2 analyses	26-29	In Progress
Dissemination of Aim 2 findings to scientific communit7 (i.e. paper and presentation preparation)	29-31	In Progress
Active dissemination of Aim 2 findings to stakeholders outside the scientific community through presentations and community reports	29-31	In Progress
Aim 3: Examine individual characteristics of individuals with ASD at age 8 that may predict long-term outcomes in adolescence and early adulthood.		
Aim 3 analyses	31-33	In Progress
Dissemination of Aim 3 findings to scientific community (i.e. paper and presentation preparation)	33-36	In Progress
Active dissemination of Aim 3 findings to stakeholders outside the scientific community through presentations and community reports	33-36	In Progress

Accomplishments

We secured data agreements and received data for the following 11 data sources: Vital Statistics (essential for identification of the population control group); Medicaid; Department of Disabilities and Special Needs; All Payer (includes emergency room, hospitalization, and home health care data); South Carolina Law Enforcement Division; Department of Juvenile Justice; Department of Social Services; Department of Education; Corrections; and the

We have five CATS papers currently published or preparation.

1) The first is an in depth exploration of lifetime abuse and neglect in our ASD group when compared to ID and controls. We found that people with disabilities were at increased risk for maltreatment in general, and that intellectual disability (with or without ASD) is strongly associated with maltreatment. This paper was published by the Journal of Child Psychology and Psychiatry. We also published a practice brief to improve dissemination of findings in the lay community. The first author (McDonnell), a graduate student at the time, won the *International Society for Autism Research's* Young Investigator Award in 2019 for this study. The study was also highlighted in an online article by the Association for Child and Adolescent Mental Health,

McDonnell CG, Boan AD, Bradley CC, Seay KD, Charles JM, **Carpenter** LA. Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample. J Child Psychol Psychiatry. 2019 May;60(5):576-584. doi: 10.1111/jcpp.12993. Epub 2018 Oct 19. PubMed PMID: 30368827; PubMed Central PMCID: PMC6458088.

McRell, A.S., McDonnell, C.G., Boan, A.,D., Bradley, C.C., Seay, K.D., Charles, J.M., & **Carpenter**, L.A. (2018). A practice brief on Child Maltreatment in Autism Spectrum Disorder and Intellectual Disability: Results from a Population-Based Sample. South Carolina: University of South Carolina College of Social Work and the Medical University of South Carolina Department of Pediatrics.

2) The second is an exploration of emergency department utilization for ambulatory care sensitive conditions. This paper was published by the journal Autism Research, and found that people with ASD had higher rates of hospitalizations that could be prevented with access to high quality primary care. Intellectual disability status (with or without ASD) was associated with increased risk for preventable hospitalizations.

Hand BN, Boan AD, Bradley CC, Charles JM, Carpenter LA. Ambulatory Care Sensitive Admissions in Individuals With Autism Spectrum Disorder, Intellectual Disability, and Population Controls. Autism Res. 2019 Feb;12(2):295-302. doi: 10.1002/aur.2050. Epub 2018 Dec 14. PubMed PMID: 30549435.

3) The third is an examination of emergency department utilization and charges in adolescents with autism spectrum disorder, intellectual disability, and population controls. This paper was published by the journal Autism Research and presented at the International Meeting for Autism Research 2019. This investigation found that youth with ASD had the highest emergency room charges and tended to present for psychiatric concerns. However, youth with intellectual disabilities use the emergency department more frequently.

Hand BN, Boan AD, Bradley CC, Charles JM, Carpenter LA. Emergency department utilization and monetary charges in adolescents with autism spectrum disorder, intellectual disability, and a population comparison group. Autism Res.2019 Jul;12(7):1129-1138. doi: 10.1002/aur.2124. Epub 2019 May 12. PubMed PMID: 31081200.

B. N. Hand, A. Boan, C. Bradley and L. **Carpenter** (2019). *Joint and Independent Contributions of Autism Spectrum Disorder and Intellectual Disability on Emergency Department Utilization during Adolescence*. Poster presented at the annual meeting of the International Society for Autism Research, Montreal, Canada.

4) The fourth study is in preparation and is expected to be submitted to the journal Autism Research within the next two weeks. This study describes and compares service access and utilization by young adults with ASD over a 15 year period and compares access and utilization between those with and without ID, as well as to two control groups (ID and population control; PC). Services examined include education, health care, disability board, health insurance, and mental health. This study also examines negative life experiences for these groups, including maltreatment, criminal charges, hospitalizations, and death.

Bradley CC, Boan AD, Charles, J, & Carpenter LA. Life Experiences of Transition Aged Young Adults with ASD. To be submitted to the journal Autism Research and to the International Meeting for Autism Research 2020.

5) The fifth study is also in preparation and is expected to be submitted to the Journal of Autism and Developmental Disorders in December of 2019 and to the International Meeting for Autism Research 2020. This study investigates the contacts that youth with ASD have with the criminal justice system including charges, charge outcomes, and corrections. We plan to publish a practice brief on this paper to ensure that results are seen not only by the ASD scientific community, but also by the criminal justice community.

Yu, Y, Boan, AD, Carpenter, LA, & Bradley, CC. Transition-age youth with ASD and criminal justice system: Prevalence, outcomes, long-term impact, and comparisons with another developmental disability group and a population comparison group. To be submitted to the Journal of Autism and Developmental Disorders and to the International Meeting for Autism Research 2020.

Opportunities for Training and Professional Development
This project provided training opportunities in ASD epidemiological research to one post-doctoral fellow (Dr. Brittany Hand), and two predoctoral students (Yue Yu, doctoral candidate in clinical psychology; Dr. Christina McDonnell). Both trainees received mentorship from senior study personnel in epidemiological design and analysis and manuscript preparation. Dr. Hand is now an assistant professor at The Ohio State University, where she is initiating a career in the epidemiological study of ASD. As the result of her work on CATS, she has received two grants to continue studying healthcare in ASD (see below). Dr. McDonnell is now an assistant professor at Virginia Tech, where she is continuing her research in ASD. She received the the *International Society for Autism Research's* Young Investigator Award in 2019 for her work on CATS. Yue Yu is a current predoctoral candidate with our team at MUSC.

Dates: 06/01/2019-05/31/2022
Mechanism: NIH/NCATS KL2TR002734, Scholar Career Development Award
Title: Personalized primary care delivery for adults with autism: A community-academic partnership
PI: **Hand, BN**
Primary Mentor: Jennifer H. Garvin, PhD

Dates: 01/01/2020-12/31/2022
Mechanism: Autism Speaks Adult Transition Research Grant, Demonstration Project

Title: Demonstrating the effects of a primary care center designed for transition-aged youth with autism
PI: **Hand, BN**

Dissemination to communities of interest

For our paper on maltreatment, we also published a community practice brief to help ensure that the information was received not only by the scientific community, but by the child welfare community. We also plan to publish a practice brief for our criminal justice paper.

Plans for next reporting period
N/A

4. **IMPACT:** Describe distinctive contributions, major accomplishments, innovations, successes, or any change in practice or behavior that has come about as a result of the project relative to:

What was the impact on the development of the principal discipline(s) of the project?

Thus far we have conducted five substudies under the larger umbrella of CATS. We have found that youth with ASD are at increased risk for maltreatment, hospitalization, mortality, and other negative outcomes. One important finding that crosses all five of our CATS studies is that intellectual disability status (regardless of ASD diagnosis) is often the most important factor in predicting outcomes. Epidemiological studies of ASD which do not analyze by cognitive functioning may be missing very important information.

What was the impact on other disciplines?

We published a practice brief on our maltreatment paper in an effort to increase recognition of the increased risk of maltreatment for youth with disabilities. Our finding that children with intellectual disability, regardless of ASD status, are two to three times more likely to experience maltreatment than population controls is particularly sobering and important. We plan to publish a similar practice brief for our upcoming paper on the justice system.

What was the impact on technology transfer?
Not applicable to this investigation.

What was the impact on society beyond science and technology?

We believe that the studies conducted under CATS provide important information regarding poor outcomes for youth with ASD, particularly those with ID. Thus far, our studies have documented increased risk for very serious outcomes including maltreatment, emergency department utilization for conditions that could be managed in primary care, high health care costs, and mortality. These are sobering findings that place an clear lens on the importance of providing high quality, evidenced based interventions and supports for individuals and families impacted by ASD.

5. **CHANGES/PROBLEMS:**
   Changes in approach and reasons for change

After meeting with RFA data managers during year 1, we determined that four datasets originally planned for inclusion were in such poor condition that they cannot be included in our study. These included: Vocational Rehabilitation; Free Clinic Visits; Public Safety; Alcohol and Drug. Further, information from Employment and Wage can only be released at the aggregate level with cell sizes of 10 or more, which is not acceptable for the goals of our study. Therefore, we did not pursue these five data sources.

Actual or anticipated problems or delays and actions or plans to resolve them

Our project required separate approvals for each database that we planned to link with for the study. Some data requests took an unexpectedly long time to gain approval, and the governing agency, the Office of Revenue and Fiscal Affairs, declined to provide us with any data until all approvals were in place to facilitate returning data with unique identifiers that could be linked across data sets. This delay placed us behind schedule in beginning data cleaning and analysis.

Changes that had a significant impact on expenditures

The post-doctoral fellow budgeted to begin in year 1 did not begin until year 3.

Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents

Not applicable

Significant changes in use or care of human subjects

Not applicable

Significant changes in use or care of vertebrate animals.

Not applicable

Significant changes in use of biohazards and/or select agents

Not applicable

6. **PRODUCTS:** List any products resulting from the project during the reporting period. If there is nothing to report under a particular item, state "Nothing to Report."

- **Publications, conference papers, and presentations**
  Report only the major publication(s) resulting from the work under this award.

  Journal publications. *List peer-reviewed articles or papers appearing in scientific, technical, or professional journals. Identify for each publication: Author(s); title; journal; volume: year; page numbers; status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*
  McDonnell CG, Boan AD, Bradley CC, Seay KD, Charles JM, **Carpenter** LA. Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample. J Child Psychol Psychiatry. 2019 May;60(5):576-584. doi: 10.1111/jcpp.12993. Epub 2018 Oct 19. PubMed PMID: 30368827; PubMed Central PMCID: PMC6458088.

  Hand BN, Boan AD, Bradley CC, Charles JM, Carpenter LA. Ambulatory Care Sensitive Admissions in Individuals With Autism Spectrum Disorder, Intellectual Disability, and Population Controls. Autism Res. 2019 Feb;12(2):295-302. doi: 10.1002/aur.2050. Epub 2018 Dec 14. PubMed PMID: 30549435.

  Hand BN, Boan AD, Bradley CC, Charles JM, Carpenter LA. Emergency department utilization and monetary charges in adolescents with autism spectrum disorder, intellectual disability, and a population comparison group. Autism Res.2019 Jul;12(7):1129-1138. doi: 10.1002/aur.2124. Epub 2019 May 12. PubMed PMID: 31081200.

  Bradley CC, Boan AD, Charles, J, & Carpenter LA. *Life Experiences of Transition Aged Young Adults with ASD*. To be submitted to Autism Research.

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Books or other non-periodical, one-time publications.

None

Other publications, conference papers, and presentations. *Identify any other publications, conference papers and/or presentations not reported above. Specify the status of the publication as noted above. List presentations made during the last year (international, national, local societies, military meetings, etc.). Use an asterisk (*) if presentation produced a manuscript.*

B. N. Hand, A. Boan, C. Bradley and L. **Carpenter** (2019). *Joint and Independent Contributions of Autism Spectrum Disorder and Intellectual Disability on Emergency Department Utilization during Adolescence.* Poster presented at the annual meeting of the International Society for Autism Research, Montreal, Canada.

McRell, A.S., McDonnell, C.G., Boan, A.,D., Bradley, C.C., Seay, K.D., Charles, J.M., & **Carpenter**, L.A. (2018). A practice brief on Child Maltreatment in Autism Spectrum Disorder and Intellectual Disability: Results from a Population-Based Sample. South Carolina: University of South Carolina College of Social Work and the Medical University of South Carolina Department of Pediatrics.

- **Website(s) or other Internet site(s)**

none

- **Technologies or techniques**

none

- **Inventions, patent applications, and/or licenses**

no

Other Products
none

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?

Name:	*Laura Carpenter*
Project Role:	*PI*
Researcher Identifier (e.g. ORCID ID):	https://orcid.org/0000-0002-6448-9242
Nearest person month worked:	3.6 CM
Contribution to Project:	*Dr. Carpenter oversaw the direction of the project, including budget management, scientific design, timeline, and personel management.*
Funding Support:	*N/A*

Name:	*Catherine Bradley*
Project Role:	*Co-Investigator*
Researcher Identifier (e.g. ORCID ID):	https://orcid.org/0000-0003-4475-2805
Nearest person month worked:	3.6 CM
Contribution to Project:	*Dr. Bradley helped to secure the data agreements for this study, and contributed to the interpretation of results and manuscript preparation for the study.*
Funding Support:	*N/A*

Name:	*Andrea Boan*
Project Role:	*Co-Investigator*
Researcher Identifier (e.g. ORCID ID):	https://orcid.org/0000-0002-4935-9079
Nearest person month worked:	2.4 CM
Contribution to Project:	*Dr. Boan helped to refine the questions being asked, cleaned and analyzed the data, and assisted with manuscript preparation for the study.*
Funding Support:	*N/A*

Name:	Jane Charles
Project Role:	*Co-Investigator*
Researcher Identifier (e.g. ORCID ID):	
Nearest person month worked:	0.36 CM
Contribution to Project:	*Dr. Charles helped to refine the questions being asked and provided expertise on the participant cohort being used for the study. She also assisted with manuscript preparation.*
Funding Support:	*N/A*

Name:	*Brittany Hand*
Project Role:	*Post Doctoral Fellow*
Researcher Identifier (e.g. ORCID ID):	https://orcid.org/0000-0003-2026-8461
Nearest person month worked:	6 CM
Contribution to Project:	*Dr. Hand helped to refine the questions being asked, cleaned and analyzed some data, and assisted with manuscript preparation for the study.*

Funding Support:	*N/A*

Name:	*Christina McDonnell*
Project Role:	Predoctoral Intern
Researcher Identifier (e.g. ORCID ID):	https://orcid.org/0000-0001-5152-2288
Nearest person month worked:	
Contribution to Project:	*Dr. McDonnell helped to refine the questions being asked, and assisted with manuscript preparation for the study.*
Funding Support:	*MUSC/DVA Joint Clinical Internship Program*

Name:	*Yue Yu*
Project Role:	Predoctoral Intern
Researcher Identifier (e.g. ORCID ID):	ORCID ID: 0000-0002-7417-0171
Nearest person month worked:	
Contribution to Project:	*Yue Yu helped to refine the questions being asked, and assisted with manuscript preparation for the study.*
Funding Support:	*MUSC/DVA Joint Clinical Internship Program*

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?

Nothing to report

What other organizations were involved as partners?

Organization Name: South Carolina Revenue and Fiscal Affairs Office (RFA)
Location of Organization: Columbia, SC
Partner's Contribution to the Project: RFA oversees the databases that will be linked to our autism database for this study. We have met in person with the various data managers, and they have overseen our data applications (attending meetings or corresponding with relevant agencies).

8. **SPECIAL REPORTING REQUIREMENTS**

COLLABORATIVE AWARDS: For collaborative awards, independent reports are required from BOTH the Initiating PI and the Collaborating/Partnering PI. A duplicative report is acceptable; however, tasks shall be clearly marked with the responsible PI and research site. A

Not Applicable

QUAD CHARTS:

Not Applicable

9. **APPENDICES:**

None