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TITLE: The Carolina Autism Transition Study (CATS)

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5e. TASK NUMBER

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13. SUPPLEMENTARY NOTES

14. ABSTRACT

This report provides a description of the **Year 1** progress made and plans for **Year 2** 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 will be analyzed for youth ranging in age from 16 and 22, and used to identify predictors of specific outcomes in order to provide insight into which factors may influence successful transition for this population. During year one, our team met with the data managers for all of the proposed data base linkages, identified all variables of interest for inclusion in the study, and secured data agreements with eight sources. During the second year of this study we will submit our data for linkage, receive datasets that can be linked via unique identifiers, and merge and clean these datasets. We will then begin analyses for Aim 1: *Characterize the service utilization patterns and outcomes of individuals with ASD during the critical period of transition from adolescence to adulthood*.

15. SUBJECT TERMS

Autism; Transition; Epidemiology prevalence

16. SECURITY CLASSIFICATION OF:			**17. LIMITATION OF ABSTRACT**	**18. NUMBER OF PAGES**	**19a. NAME OF RESPONSIBLE PERSON**
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Prescribed by ANSI Std. Z39.18

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.

TABLE OF CONTENTS

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) is to characterize the longitudinal outcomes of individuals identified with Autism Spectrum Disorders (ASD) at age 8 through population-based surveillance. Services and outcomes will be analyzed for youth ranging in age from 16 and 22, and used to identify predictors of specific outcomes in order to provide insight into which factors may influence successful transition for this population. Three groups 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 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.

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

Autism; Transition; Epidemiology

3. **ACCOMPLISHMENTS:** The PI is reminded that the recipient organization is required to obtain prior written approval from the awarding agency Grants Officer whenever there are significant changes in the project or its direction.

What were the major goals of the project?

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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	85% complete; 8 data requests approved; 1 under review; 5 determined to be inappropriate for inclusion
Submit ADDM data; Obtain de-identified linked datasets for 1-7	5-17	Not initiated (collaborative decision to wait on all to be approved and to do one large linkage)
Clean datasets 1-14	6-19	Not initiated
Merge & clean datasets (ADDM + Databases 1-14)	20-22	Not initiated
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	Not initiated
Dissemination of Aim 1 findings to scientific community (i.e. paper and presentation preparation)	25-26	Not initiated
Active dissemination of Aim 1 findings to stakeholders outside the scientific community through presentations and community reports	25-26	Not initiated
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	Not initiated
Dissemination of Aim 2 findings to scientific communit7 (i.e. paper and presentation preparation)	29-31	Not initiated
Active dissemination of Aim 2 findings to stakeholders outside the scientific community through presentations and community reports	29-31	Not initiated
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	Not initiated
Dissemination of Aim 3 findings to scientific community (i.e. paper and presentation preparation)	33-36	Not initiated
Active dissemination of Aim 3 findings to stakeholders outside the scientific community through presentations and community reports	33-36	Not initiated

What was accomplished under these goals?

During year one of this three year award, our team met with the data managers for all of the proposed data base linkages, identified all variables of interest for inclusion in the study, and secured data agreements with eight sources (see details below).

Regarding datasets managed by SC's Revenue and Fiscal Affairs Office (RFA), we have secured data agreements for the following eight datasets: 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; and Department of Education. Our data request to the Department of Mental Health is under review. Once our request for the Department of Mental Health is approved, we will submit our complete dataset for linkage to the nine datasets at once. All datasets will be linked via a unique identifier assigned by RFA.

After meeting with RFA data managers, we have determined that four datasets originally planned for inclusion are in such poor condition that they cannot be included in our study. These include: 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 are not pursuing these five data sources at this time for inclusion in our study, but we will continue to check in with data managers regularly over the next two years to monitor potential data quality improvements.

We are continuing negotiations to apply for Department of Motor Vehicles data. We have determined that this is a separate source of information that cannot be linked to our other datasets.

Overall progress on the study's goals is excellent. We had proposed to merge and clean all databases during months 7-10 of year two, and anticipate being ahead of schedule for this task. This will allow us to begin analyses several months ahead of schedule as well.

What opportunities for training and professional development has the project provided?
If the project was not intended to provide training and professional development opportunities or there is nothing significant to report during this reporting period, state "Nothing to Report."

Professional Development: All study personnel participated in the International Meeting for Autism Research held in Baltimore, MD in May of 2015.

How were the results disseminated to communities of interest?

Nothing to Report

What do you plan to do during the next reporting period to accomplish the goals?
If this is the final report, state "Nothing to Report."

Aim 1 analyses will be completed during Year 2 of the study. We will submit results to a major journal (Autism Research), and we will submit results for presentation at a major scientific meeting (International Meeting for Autism Research).

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?

Nothing to Report

What was the impact on other disciplines?

Nothing to Report

What was the impact on technology transfer?

Nothing to Report

What was the impact on society beyond science and technology?

Nothing to Report

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

After meeting with RFA data managers, we have determined that four datasets originally planned for inclusion are in such poor condition that they cannot be included in our study. These include: 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 are not pursuing these five data sources at this time for inclusion in our study, but we will continue to check in with data managers regularly over the next two years to monitor potential data quality improvements.

Actual or anticipated problems or delays and actions or plans to resolve them
Describe problems or delays encountered during the reporting period and actions or plans to resolve them.

Our project requires separate approvals for each database that we plan to link with for the study. We met with each data manager and identified the important variables of interest for the study, and submitted all data requests between months 4 and 6 (originally scheduled to take place between months 3 and 16). These efforts placed us ahead of schedule. However, some data requests took an unexpectedly long time to gain approval, and one is still outstanding. The governing agency, RFA, has asked that we wait on linking data until all approvals are in place to facilitate returning data with unique identifiers that can be linked across data sets. While we are still on track with our plan of work, this delay in securing all approvals has been unexpected. Currently, at month 12, only one approval is still outstanding.

Changes that had a significant impact on expenditures

We are delaying the hire of a post-doctoral fellow until we have all data linked and ready to clean and analyze (first period of Year 2).

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

Significant changes in use or care of human subjects

None

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).*

none

  Books or other non-periodical, one-time publications. *Report any book, monograph, dissertation, abstract, or the like published as or in a separate publication, rather than a periodical or series. Include any significant publication in the proceedings of a one-time conference or in the report of a one-time study, commission, or the like. Identify for each one-time publication: Author(s); title; editor; title of collection, if applicable; bibliographic information; year; type of publication (e.g., book, thesis or dissertation); status of publication (published; accepted, awaiting publication; submitted, under review; other); acknowledgement of federal support (yes/no).*

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.*

none

- **Website(s) or other Internet site(s)**
  List the URL for any Internet site(s) that disseminates the results of the research activities. A short description of each site should be provided. It is not necessary to include the publications already specified above in this section.

none

- **Technologies or techniques**
  Identify technologies or techniques that resulted from the research activities. In addition to a description of the technologies or techniques, describe how they will be shared.

none

- **Inventions, patent applications, and/or licenses**
  Identify inventions, patent applications with date, and/or licenses that have resulted from the research. State whether an application is provisional or non-provisional and indicate the application number. Submission of this information as part of an interim research performance progress report is not a substitute for any other invention reporting required under the terms and conditions of an award.

none

- **Other Products**

  Identify any other reportable outcomes that were developed under this project. Reportable outcomes are defined as a research result that is or relates to a product, scientific advance, or research tool that makes a meaningful contribution toward the understanding, prevention, diagnosis, prognosis, treatment, and/or rehabilitation of a disease, injury or condition, or to improve the quality of life. Examples include:

  - *data or databases;*
  - *biospecimen collections;*
  - *audio or video products;*
  - *software;*
  - *models;*
  - *educational aids or curricula;*
  - *instruments or equipment;*
  - *research material (e.g., Germplasm; cell lines, DNA probes, animal models);*
  - *clinical interventions;*
  - *new business creation; and*
  - *other.*

none

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

What individuals have worked on the project?
Provide the following information for: (1) PDs/PIs; and (2) each person who has worked at least one person month per year on the project during the reporting period, regardless of the source of compensation (a person month equals approximately 160 hours of effort). If information is unchanged from a previous submission, provide the name only and indicate "no change."

NO CHANGE TO ANY PERSONNEL

Name:	*Laura Carpenter*
Name:	*Andrea Boan*
Name:	*Catherine Bradley*
Name:	*Jane Charles*

Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?
If there is nothing significant to report during this reporting period, state "Nothing to Report."

If the active support has changed for the PD/PI(s) or senior/key personnel, then describe what the change has been. Changes may occur, for example, if a previously active grant has closed and/or if a previously pending grant is now active. Annotate this information so it is clear what has changed from the previous submission. Submission of other support information is not necessary for pending changes or for changes in the level of effort for active support reported previously. The awarding agency may require prior written approval if a change in active other support significantly impacts the effort on the project that is the subject of the project report.

Two of Dr. Carpenter's active support grants have closed and been replaced with other research. Dr. Carpenter's Autism Speaks sponsored grants entitled "South Carolina Children's Educational Surveillance Study: Comparison of DSM-IV & DSM Prealence" and "Autism and Developmental Disabilities Monitoring Network Augmentation with Screening and Assessment" closed February 2016 and January 2016, respectively. These grants (and their efforts) were replaced with a clinical trial sponsored by Cognoa, Inc. entitled "Evaluation of Cognoa's Screening Tools for Clinical Triage of ASD." There were no other changes in Dr. Carpenter's support.

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: If applicable, the Quad Chart (available on https://www.usamraa.army.mil) should be updated and submitted with attachments.

Not Applicable

9. APPENDICES:

Attach all appendices that contain information that supplements, clarifies or supports the text. Examples include original copies of journal articles, reprints of manuscripts and abstracts, a curriculum vitae, patent applications, study questionnaires, and surveys, etc.

None