AWARD NUMBER: W81XWH-20-1-0473

TITLE: The Influence of Social, Educational, and Work Experiences on Psychologic

PRINCIPAL INVESTIGATOR: Somer Bishop, PhD

CONTRACTING ORGANIZATION: Regents of the University of California

REPORT DATE: JULY 2021

TYPE OF REPORT: Annual

PREPARED FOR: U.S. Army Medical Research and Development Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. REPORT DATE	2. REPORT TYPE	3. DATES COVERED
JULY 2021	Annual	07/01/2020-06/30/2021

4. TITLE AND SUBTITLE

The Influence of Social, Educational, and Work Experiences on Psychological Health for Transition-Aged Youth with Autism Spectrum Disorders

5a. CONTRACT NUMBER
W81XWH-20-1-0473

5b. GRANT NUMBER
AR190086P3

5c. PROGRAM ELEMENT NUMBER

6. AUTHOR(S)

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5d. PROJECT NUMBER

5e. TASK NUMBER

5f. WORK UNIT NUMBER

7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)

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8. PERFORMING ORGANIZATION REPORT NUMBER

9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES)

U.S. Army Medical Research and Development Command
Fort Detrick, Maryland 21702-5012

10. SPONSOR/MONITOR'S ACRONYM(S)

11. SPONSOR/MONITOR'S REPORT NUMBER(S)

12. DISTRIBUTION / AVAILABILITY STATEMENT

Approved for Public Release; Distribution Unlimited

13. SUPPLEMENTARY NOTES

14. ABSTRACT

The Specific Aim of this project is to test associations between depressive symptoms, quality of life, and various educational (high school inclusion, college attendance, achievement, school engagement; liking/avoidance), vocational (independence, liking/avoidance, engagement), and social (peer victimization, exclusion, social activities, friendships, interpersonal interactions) experiences among individuals with ASD with average or above cognitive functioning.

An additional exploratory aim is to determine whether the strength of relationships between specific experiences and depressive symptoms differ based on functional (e.g., IQ, adaptive behavior) and behavioral (e.g., core ASD symptoms) factors.

15. SUBJECT TERMS

None listed

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRDC
Unclassified	Unclassified	Unclassified	Unclassified	9	19b. TELEPHONE NUMBER *(include area code)*

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Year 1 Progress Report for AR190086P3, "The Influence of Social, Educational, and Work Experiences on Psychological Health for Transition-Aged Youth with Autism Spectrum Disorders"

1. INTRODUCTION

Adolescents and adults with autism spectrum disorder (ASD) experience sharply elevated lifetime rates of depression relative to both typically developing individuals and those with other developmental disabilities. The objective of this research is to identify specific day-to-day experiences that are associated with depressive symptoms and quality of life among adolescents and young adults with ASD. Many aspects of social, vocational, and educational experiences are mutable, making them ideal potential targets for interventions to improve psychological health for people with ASD. The Specific Aim of this study is to test associations between depressive symptoms, quality of life, and various educational, vocational, and social experiences among individuals with ASD with average or above cognitive functioning. An additional exploratory aim is to determine whether the strength of relationships between specific experiences and depressive symptoms differ based on functional (e.g., IQ, adaptive behavior) and behavioral (e.g., core ASD symptoms) factors. To accomplish these objectives, we will recruit 250 families of individuals with ASD between the ages of 15 and 25 from existing research and clinical registries. We will use a multi-trait (i.e. multiple aspects of psychological health and daily experiences), multi-method (e.g., self- and parent-reports; surveys, diagnostic interviews, daily reports) design to examine relationships between depressive symptoms, quality of life, and multiple types of experiences of these youth. All surveys will be completed via the internet, and interviews will be conducted over the telephone. Knowledge gained from this project will lay the groundwork for clinical efforts to improve psychological health in adolescents and young adults with ASD.

2. KEYWORDS:

Autism spectrum disorder, depression, quality of life, employment, education, relationships, social activities, academic

3. ACCOMPLISHMENTS:

- **What were the major goals of the project?**

The major goal of this project is to examine how particular educational, vocational, and social experiences are related to depressive symptoms and quality of life for adolescents and adults with ASD. Specific target dates for study activities and progress on those activities are detailed in the next subsection "What was accomplished under these goals?"

- **What was accomplished under these goals?**

As detailed in the scope of work, major activities for Year 1 of this grant included preparatory activities for data collection. Initial activities including finalizing the study protocol and measures and building study-specific data collection and storage platforms through RedCap. Because we were planning to begin data collection during the COVID-19 pandemic, additional care was taken to develop a protocol that would be feasible for youth and families who might be under additional distress due to the pandemic. We also considered and ultimately included some additional questions related to the COVID-19 pandemic so that we would be able to understand how mental health and day-to-day activities (the primary constructs of interest in this study) might be impacted by COVID-19. After finalizing study protocols and measures, we submitted a Single IRB application, and received approval at the primary site (Vanderbilt University Medical Center) and at the relying sites (University of California San Francisco, Cincinnati Children's Hospital Medical Center). We also received study approval from the Department of Defense Human Research Protections Office. We hired project staff at each site to assist in data collection and other tasks related to the research protocol. We developed online data collection instruments and data entry databases, and trained research staff in administration and scoring procedures for the study measures.

Major activities for Year 1 also included recruitment and data collection from families enrolled in the Simons Simplex Collection (SSC) registry. Though we had anticipated beginning data collection in month 7 of the grant (i.e., January 2021), because of the COVID-19 pandemic we chose to delay commencing data collection until March 2021. This is because, in January 2021, the pandemic was surging in many areas across the United States. Beginning data collection at this time would have hampered our ability to test our specific aim: not only did we anticipate that individuals with ASD could be experiencing pandemic-related mental health challenges, but also these individuals' day-to-day activities were severely restricted at this time. Because youth would be less likely to be attending in-person school, working, and interacting socially with a range of other people (all key constructs of interest in this study), we determined it best to delay our data collection by two months to allow for the surge of COVID-19 cases to pass and the loosening of social distancing restrictions. Data collection on our first participant took place on March 1, 2021, and we have currently enrolled 45 participants across project sites.

Data collection has been delayed somewhat further by unanticipated challenges in recruiting from the SSC registry. There has been a fairly complicated process of reconsenting families into the registry once the adult with ASD turns 18 – this has resulted in fewer potential participants than anticipated. When we proposed the project, we were anticipating that over 700 youth and adults with ASD would be eligible. However, many adults with ASD in the registry did not reconsent to be contacted once they turned 18; thus, fewer than 300 families were available for recontacting. Further, the response rate for those 300 families has been lower than expected. This is due, at least in part, to COVID-19 and the additional stressors that autistic individuals and their families are facing. It is also due to the restrictions in the methods we are able to use to contact and recruit families. Instead of using multiple methods of contact to reach out to eligible families (e.g., mailings, telephone calls), each family received an email about the study and two follow-up reminder emails.

In order to trouble shoot these challenges and meet our recruitment goals, we have now identified other recruitment sources. On April 20, 2021 we received permission from our Program Officer to broaden the registries used for participant recruitment to include other individuals who were ascertained in a similar manner as those in the SSC registry. We plan to recruit from a different registry run by the Simons foundation (which is larger than the one that we had proposed) and from research registries at our participating universities. In all of these cases, adolescents/adults with autism will have received a clinical diagnosis of ASD from an expert clinician based on a comprehensive diagnostic assessment– just as in the SSC registry. In most cases we will also have access to existing phenotype data, just as in the SSC registry. In essence, these recruitment venues will provide comparable samples to the one we had proposed in the grant, and will not affect our ability to test the aims of the project in any way. We are currently waiting for IRB approval to recruit from these registries and will begin this additional recruitment prior to the end of Year 1 of the grant.

Thus, we completed all preparatory activities for data collection on the general timeline proposed in the Scope of Work. Challenges due to COVID and using the SSC registry have led to delays in our data collection timeline affecting our quarterly enrollment, however, with the revised and approved recruitment plan, we are well poised to recruit our entire sample of 250 adolescents/adults with ASD during the timeline proposed in the Scope of Work (months 6-18 of the grant period).

- **What opportunities for training and professional development has the project provided?**

  Nothing to Report.

- **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?**

  During the next project period, we will recruit participants from the additional registries to meet our recruitment goal of 250 adolescents and adults with ASD and their families. We will collect data from these participants, clean the data, and prepare datasets for analysis. We will analyze data to address the specific and exploratory aims, and submit an abstract detailing our findings to the Annual Meeting for the International Society for Autism Research. We will submit two manuscripts detailing study findings prior to the end of the next reporting period.

4. IMPACT

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

  As we are still collecting data, there is nothing yet to report.

- **What was the impact on other disciplines?**

  As we are still collecting data, there is nothing yet to report.

- **What was the impact on technology transfer?**

  Nothing to report.

- **What was the impact on society beyond science and technology?**

  As we are still collecting data, there is nothing yet to report.

5. CHANGES/PROBLEMS:

As stated in #3 above, we experienced delays in data collection due to COVID-19 and challenges recruiting from the SSC registry. To address this challenge, we have received permission from our Program Officer to recruit from additional research and clinical registries. This change is currently being reviewed by our IRB, and once it is approved, we will send it to the DoD Human Research Protections Office. Though we are broadening our recruitment venues, there are no changes to the aims of the project, the research protocol, nor any of the research activities.

Delays in recruitment, data collection, and subject participation have significantly impacted our expenditures. We spent less funds than we had budgeted during Year 1 of this project. By carrying these funds forward to Year 2, we will have sufficient funds for personnel and subject participation to collect data from the remaining 205 families, thus meeting our recruitment goal of 250 families.

6. PRODUCTS:

Nothing to report.

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."*

Name:	*Bishop, Somer, PhD*
Project Role:	*PI/PD*, University of California, San Francisco
Researcher Identifier (e.g. ORCID ID):	*0000-0002-2592-4715*
Nearest person month worked:	2.4 Person Months
Contribution to Project:	Dr. Bishop assisted with protocol development and implementation. She has overseen all aspects of the day-to-day management of the study at UCSF, supervising UCSF study staff on recruitment of participants, data collection, and data entry and implementation of the project design.
Funding Support:	*NA*
Name:	Lampinen, Linnea
Project Role:	Research Assistant, University of California, San Francisco
Researcher Identifier (e.g. ORCID ID):	
Nearest person month worked:	4.8 Person Months
Contribution to Project:	Ms. Lampinen assisted in protocol development and documentation. She also coordinated participant recruitment and data collection, and collaborated with research staff at the other sites to ensure consistency and integrity of data across all sites.
Funding Support:	*NA*

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

Changes:

Somer Bishop, PhD
No changes to report

What other organizations were involved as partners?

- **Organization Name:** Simons Foundation
- **Location of Organization:** New York, New York
- **Partner's contribution to the projec**t - **Other.** The Simons Foundation provides support to all researchers to make use of research registries that are managed and funded by the foundation. For the present study, we worked with Simons staff to recruit study participants from two of their research registries: the Simons Simplex Collection registry and the SPARK registry.

8. SPECIAL REPORTING REQUIREMENTS

- **COLLABORATIVE AWARDS:**
  Award Number: W81XWH2010475
  Log Number: AR190086
  Recipient: Vanderbilt University Medical Center
  Principal Investigator: Dr. Julie Lounds Taylor
  This is a collaborative, multiple-PI award. The other PI, Dr. Julie Lounds Taylor from Vanderbilt University Medical Center, has submitted a separate report.

- **QUAD CHARTS:** see attached

9. APPENDICES: N/A

The Influence of Social, Educational, and Work Experiences on Psychological Health for Transition-Aged Youth with Autism Spectrum Disorders

AR190086P3
W81XWH2010473

PI: Somer Bishop, PhD **Org:** University of California, San Francisco **Award Amount:** $278,078.00

Study/Product Aim(s)

- The Specific Aim of this study is to test associations between depressive symptoms, quality of life, and various educational, vocational, and social experiences among individuals with ASD with average or above cognitive functioning.
- An additional exploratory aim is to determine whether the strength of relationships between specific experiences and depressive symptoms differ based on functional and behavioral factors.

Approach

We will recruit 250 families of individuals with ASD between the ages of 15 and 25 from existing research and clinical registries. We will use a multi-trait, multi-method (e.g., self- and parent-reports; surveys, diagnostic interviews, daily reports) design to examine relationships between depressive symptoms, quality of life, and multiple types of experiences of these youth.

UCSF Center for ASD & NDDs
Service Training Advocacy Research

Accomplishment: We completed all preparatory activities for data collection including hiring and training staff, finalizing protocols, developing data entry databases, and getting IRB approvals. Data collection began in Year 1 and is ongoing in Year 2.

Timeline and Cost

Activities CY	20/21	21/22
Preparatory activities (e.g., finalize protocol/ measures, hire/train staff, IRB approval)		
Recruit and collect data from 250 participants		
Clean and prepare data for analysis		
Analyze data, prepare manuscripts and conference abstracts		
Estimated Budget ($K)	**$163,637**	**$114,441**

Updated: (06/23/2021)

Goals/Milestones

CY20/21 Goal – Study preparatory activities
☑ Finalize protocol, hire and train staff
☑ Receive IRB approval
☑ Gain access to research registry
CY21/22 Goals – Collect data from 250 participants
☐Recruit 250 participants
☐Collect data from all participants and clean data for analysis
CY21/22 Goal – Data analysis and manuscript preparation
☐ Submit abstract to professional meeting
☐ Submit two manuscripts for publication

Comments/Challenges/Issues/Concerns

- COVID-19 has delayed our data collection timeline.
- To meet our recruitment goals, we will be recruiting from additional research registries (approved by program officer).

Budget Expenditure to Date

Projected Expenditure: $163,637
Actual Expenditure thru 04/30: $139,741