

AWARD NUMBER: W81XWH-20-1-0435

TITLE: Community Participation, Service Needs, and Health Outcomes
Among Adults with Autism

PRINCIPAL INVESTIGATOR: Lindsay Shea, DrPH

CONTRACTING ORGANIZATION: Drexel University

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| 13. SUPPLEMENTARY NOTES | | | | | | |
| 14. ABSTRACT <p>This research focuses on self-reported community participation preferences and experiences among autistic adults. The ability to participate in communities is a key facet of living an independent, meaningful, and fulfilling life. Among those who are able to meaningfully participate in their communities, previous research has documented greater feelings of well-being and self-reported health, with decreasing levels of social isolation, depression, and anxiety. Autistic adults have similar desires to participate in their communities as neurotypical peers, yet data is lacking about their community participation desires and experiences, along with an understanding of how existing service and support systems influence access and ability to meaningfully participate. Autistic adults are also likely to experience specific barriers to community participation given social and communication differences are a core component of autism spectrum disorder (ASD), and accessing transportation is a noted logistical barrier for this population.</p> <p>Research also documents the need to hear from autistic adults directly, as they remain significantly understudied when compared to children, and reliance on caregiver- or proxy-reported information is not always aligned to the wants and needs of autistic individuals. To address this gap, we are conducting a longitudinal survey effort with autistic adults who participated in the Pennsylvania Autism Needs Assessment (one of the largest existing studies with autistic adults) and agreed for future contact. Autistic adult participants will be recruited to complete a similar, yet updated, survey across two annual waves to create up to three distinct timepoints for longitudinal and cross-sectional analyses. Recruited individuals comprise a diverse group among multiple dimensions with strong variation in participant urbanicity, gender, race/ethnicity, and socioeconomic status. Survey domains will establish a baseline for a respondent's community participation via the Temple University Community Participation Measure, and inquire about service use experiences, relationships with family and peers, and experiences with COVID-19 to identify barriers and facilitators of community participation. To strengthen these analyses further, we will link survey results to respondent's Medicaid claims upon consent.</p> <p>The scope and design of this research is poised to document and answer key questions to maximize integration into communities for autistic adults, and identify community supports and services that can contribute to optimal participation outcomes. By determining community participation experiences and preferences among autistic adults, we will provide foundational information and guidance to improve existing services and catalyze development of new intervention strategies that support community integration. This research has significant benefits to autistic adults through direct assessment of their community preferences and perspectives, and service use correlates, to drive responsive policies. The larger autism community, including families and caregivers of autistic adults, will also benefit from an understanding of the supports and opportunities available that enhance independent living and quality of life for autistic adults.</p> | | | | | | |
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1. **INTRODUCTION:** Provide a brief list of keywords (limit to 20 words). Narrative that briefly (one paragraph) describes the subject, purpose and scope of the research.

Community participation is a critical component of a fulfilling and healthy life, yet autistic adults face barriers to community inclusion, and research regarding services and supports to ameliorate these obstacles are lacking. Our focus is to identify self-reported community participation experiences and preferences of autistic adults over distinct time points and analyze associations with service use histories and other contextual factors, including the COVID-19 pandemic. These findings are poised to drive policies aligned with the needs and desires of autistic adults and can pinpoint barriers and facilitators of optimal community participation outcomes. Autistic adults who previously responded to the Pennsylvania Autism Needs Assessment will be invited to participate in an updated instrument over two time points to establish a baseline for community participation along with service use experiences, and other lifestyle factors that may be associated with community participation.

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

Autism, longitudinal survey, community participation, service utilization, health outcomes

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?

List the major goals of the project as stated in the approved SOW. If the application listed milestones/target dates for important activities or phases of the project identify these dates and show actual completion dates or the percentage of completion.

1. Administer the Pennsylvania Autism Needs Assessment and Temple University Community Participation measure.
 - a. Target completion: Month 19
 - b. Actual completion/% complete: 90%
 - c. Description: As a longitudinal study design, our survey will be distributed annually across two waves. Survey implementation synthesized the Pennsylvania Autism Needs Assessment and the Temple University Community Participation Measure into a single survey instrument, along with additional items to capture community participation correlates and the emerging impact of COVID-19. After a successful first survey wave, which yielded a sizable sample of autistic adults across Pennsylvania, the study team revised the instrument for the upcoming second wave, based on participant feedback, consultation with autistic adults, and new public health guidelines related to the COVID-19. Wave two is currently in progress with preliminary demographic information from survey respondents presented in Appendix 1. Consultations with our program officer and approval from our institutional review board and program officer yielded new opportunities to further increase the transferability and generalizability of these findings for individuals across the diverse autism spectrum. For this current wave, we have increased our overall sample by accessing our network of caregivers who responded to the Pennsylvania Autism Needs Assessment for a child who is now at least 18 years old. Caregivers connected us to, or shared the survey with, their autistic adult child, and comprise our caregiver-recruited sample.

2. Data Analysis

- a. Target completion: Month 24
- b. Actual completion/% complete: ~50%
- c. Description: Data analysis across both survey waves is currently underway, with data collection continuing for the second survey wave. These include cross-sectional analyses at each survey time-point, and longitudinal analyses that link collected data across time-points. Given the urgency that the COVID-19 pandemic presents for public health, survey results on COVID-19 questions, particularly questions related to vaccine willingness or hesitancy have been analyzed first. "Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults" has been published in *Vaccine*. Another manuscript with follow-up data on these trends and incorporating information on COVID-19 boosters in progress.

3. Acquire and link small-area contextual data to Pennsylvania Autism Needs Assessment, Temple University Community Participation measure, and health service utilization outcomes.

- a. Target completion: Month 27
- b. Actual completion/% complete: ~50%
- c. Description: Linking contextual data to the collected survey data is in progress and will finalize upon the close of wave 2 data collection in August. Examples of these small-area contextual factors are found in the first published manuscript supported by this award and include county population density and 2020 presidential election results, which were shown to have a significant impact on vaccine acceptance and hesitancy among autistic adults.

4. Medicaid Claims and Encounters Analysis

- a. Target completion: Month 27
- b. Actual completion/% complete: ~5%
- c. Description: Linkages between community participation and overall service use and health outcomes will be performed upon completion of data collection for the in-progress second survey wave. These analyses are a key aim of the overall research project and are a significant priority for the team.

5. Publications and Dissemination

- a. Target completion: Month 30
- b. Actual completion/% complete: ~12.5%
- c. Description: The first manuscript produced from this data has been published in *Vaccine* and focuses on COVID-19 vaccination acceptance and hesitancy among autistic adults. A manuscript exploring COVID-19 impacts on community participation has been drafted and will be submitted for publication in August, while a poster presentation on the topic, "A Snapshot of Self-Reported Experiences Under the COVID-19 Pandemic" was accepted and presented at the International Society for Autism Research (INSAR) 2022 annual meeting. Robust analyses are planned and will drive the development of upcoming manuscripts that will analyze community participation changes over time, barriers and facilitators of community participation, and service use impacts on community participation.

What was accomplished under these goals?

For this reporting period describe: 1) major activities; 2) specific objectives; 3) significant results or key outcomes, including major findings, developments, or conclusions (both positive and negative); and/or 4) other achievements. Include a discussion of stated goals not met. Description shall include pertinent data and graphs in sufficient detail to explain any significant results achieved. A succinct description of the methodology used shall be provided. As the project progresses to completion, the emphasis in reporting in this section should shift from reporting activities to reporting accomplishments.

During the report period, study staff finalized wave 1 survey implementation and began subsequent analyses of 194 complete responses. Given the public health crisis due to the COVID-19 pandemic, data related to vaccine acceptance and hesitancy was prioritized to convey this information in a timely manner. We successfully published the manuscript, “Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults” in *Vaccine*, and presented a poster on community participation experiences during the COVID-19 pandemic at the International Society for Autism Research (INSAR) 2022 Annual Meeting.

Following a successful first survey wave, respondent feedback, further consultation with autistic individuals, and evolving public health guidelines helped inform changes to the survey instrument for a second wave release in 2022. New information on COVID-19 vaccine boosters, mask wearing, and other public health practices were added, while other previous survey items were removed to offset potential respondent fatigue (SPECIFY?).

To reach more autistic adults, caregivers who responded to the caregiver module of the 2018 Pennsylvania Autism Needs Assessment (PANA) were recruited and asked to share our wave two survey with their autistic adult children, should their child be able to self-report. Incorporating these individuals will allow the study team to produce a larger sample that is more representative of the full spectrum of autistic adults, since those with greater communication differences and co-occurring intellectual disability often had their parent/caregiver answer the 2018 PANA. Incoming data from wave two of our longitudinal survey effort, which is currently in progress, is poised to be a larger, more representative sample to address key study aims. Sample characteristics at the time of this report are included as Appendix 1.

Wave two survey data collection is slated to wrap up at the end of August 2022. As of the time of this report, we are experiencing substantial retention of our original sample, with nearly 60% completing surveys at both time points, and more than 100 new autistic adult respondents recruited through their caregivers. Preliminary demographics of our full sample are included as supplementary material.

Upon final data collection, the research team has a series of manuscripts planned that are directly aligned with the study aims. These include a further exploration of COVID-19 vaccination and booster acceptance, the impact of the COVID-19 pandemic on community participation, barriers and facilitators of community participation, and service use impacts on community participation.

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."

Describe opportunities for training and professional development provided to anyone who worked on the project or anyone who was involved in the activities supported by the project. "Training" activities are those in which individuals with advanced professional skills and experience assist others in attaining greater proficiency. Training activities may include, for example, courses or one-on-one work with a mentor. "Professional development" activities result in increased knowledge or skill in one's area of expertise and may include workshops, conferences, seminars, study groups, and individual study. Include participation in conferences, workshops, and seminars not listed under major activities.

In the past year Dylan Cooper attended a ResearchTalk Qualitative Research Summer Intensive (QSRI) course: *Learning from Marginalized Courses via Community-based Participatory Research*. This virtual course provided a robust foundation for embracing the lived experiences of diverse and marginalized communities and incorporating these voices in all facets of research design and implementation.

Wei Song led an abstract submission for the International Society for Autism Research on community participation and COVID-19 with Dylan Cooper, Kaitlin Koffer Miller, and Lindsay Shea as co-authors. The four attended the International Society for Autism Research (INSAR) 2022 Annual Meeting in May 2022.

How were the results disseminated to communities of interest?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how the results were disseminated to communities of interest. Include any outreach activities that were undertaken to reach members of communities who are not usually aware of these project activities, for the purpose of enhancing public understanding and increasing interest in learning and careers in science, technology, and the humanities.

The research team believes it is critical to translate research for impacted communities.

After publication of “Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults” in *Vaccine*, the study team disseminated key findings through the Policy Impact Project’s social media channels to convey information with communities of interest. This article was also disseminated through over 34 news outlets including U.S. News. The Policy Impact Project is based at the A.J. Drexel Autism Institute and focuses on translating research to policymakers and community members to make research more accessible. Multiple Twitter threads and LinkedIn posts were used to share the findings of this study with the hundreds of Policy Impact Project followers. The articles were also re-shared by and engaged with by followers. The collective impact of these shares resulted in hundreds of impressions from other users, with nearly 75 users engaging with the tweeted article.

A newsletter was also emailed to all autistic adults eligible to participate to share findings that emerged from the first survey wave and send appreciations from the research team for their participation. Resources, including information on employment and access to Medicaid services, from the Autism Services, Education, Resources, and Training (ASERT) Collaborative were also shared with our sample in this newsletter.

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."

Describe briefly what you plan to do during the next reporting period to accomplish the goals and objectives.

In the following months before the award is completed in December 2022, the study team will prioritize the analysis of wave two survey data to drive the development of a series of aims-related manuscripts. This includes a focus on COVID-19 vaccination and booster acceptance, COVID-19 impacts on community participation, barriers and facilitators of community participation, and service use impacts on community participation. Additional plans include creating translational materials to share with the participants of this study and the larger autism community to share key findings of this study in an accessible manner.

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?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

This research advances understandings of autistic individuals' community participation desires and needs to inform and improve existing service systems that support community inclusion. The analyses focus on community participation preferences, experiences, and correlates, to determine factors and perspectives associated with optimal community participation. Autistic individuals and families will gain insight on service offerings that support greater outcomes and policymakers will acquire knowledge to develop responsive community participation-related policies. Findings regarding community participation during the COVID-19 pandemic will yield information about how autistic individuals were affected by social distancing, public health messaging and practices, and other changes the pandemic spurred. Other key information gleaned related to the pandemic includes autistic individuals' willingness or reticence to receive a COVID-19 vaccine.

Describe how findings, results, techniques that were developed or extended, or other products from the project made an impact or are likely to make an impact on the base of knowledge, theory, and research in the principal disciplinary field(s) of the project. Summarize using language that an intelligent lay audience can understand (Scientific American style).

What was the impact on other disciplines?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how the findings, results, or techniques that were developed or improved, or other products from the project made an impact or are likely to make an impact on other disciplines.

Featuring survey items on COVID-19 extends the value of this research initiative and generates findings that can inform and tailor public health messaging that effectively targets hard-to-reach populations like autistic adults.

What was the impact on technology transfer?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe ways in which the project made an impact, or is likely to make an impact, on commercial technology or public use, including:

- *transfer of results to entities in government or industry;*
- *instances where the research has led to the initiation of a start-up company; or*
- *adoption of new practices.*

Nothing to report

What was the impact on society beyond science and technology?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe how results from the project made an impact, or are likely to make an impact, beyond the bounds of science, engineering, and the academic world on areas such as:

- *improving public knowledge, attitudes, skills, and abilities;*
- *changing behavior, practices, decision making, policies (including regulatory policies), or social actions; or*
- *improving social, economic, civic, or environmental conditions.*

Data collection and statistical analyses are ongoing, however, a manuscript focusing on self-reported vaccination and hesitancy amongst autistic adults was published in *Vaccine* in April 2022 and provides one of the first accounts of the COVID-19 vaccination acceptance and hesitancy amongst autistic adults, providing important direction for public health outreach and communication. Positive associations with a desire to protect others, concern about contracting COVID-19, and trusting the vaccine safety were found among COVID-19 vaccine accepters. Meanwhile, vaccine-hesitant autistic adults were concerned about the safety of the vaccine and did not endorse a lack of concern about contracting COVID-19. This information has significant utility for informing public health messaging, particularly among vulnerable groups like autistic adults.

5. **CHANGES/PROBLEMS:** The Project Director/Principal Investigator (PD/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. If not previously reported in writing, provide the following additional information or state, "Nothing to Report," if applicable:

Changes in approach and reasons for change

Describe any changes in approach during the reporting period and reasons for these changes. Remember that significant changes in objectives and scope require prior approval of the agency.

To reach more autistic adults, caregivers who responded to the caregiver version of the 2018 Pennsylvania Autism Needs Assessment were recruited to share our wave two survey with their autistic adult children, should their child be able to self-report. Incorporating these individuals will allow the study team to produce a larger sample, potentially more representative of the full spectrum of autistic adults, since those with greater communication differences and co-occurring intellectual disability often had their parent/caregiver answer the 2018 PANA. Data from wave two of our longitudinal survey effort, which is currently in progress, is poised to be a larger, more representative sample to address key study aims.

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.

Nothing to report

Changes that had a significant impact on expenditures

Describe changes during the reporting period that may have had a significant impact on expenditures, for example, delays in hiring staff or favorable developments that enable meeting objectives at less cost than anticipated.

Nothing to report

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

Describe significant deviations, unexpected outcomes, or changes in approved protocols for the use or care of human subjects, vertebrate animals, biohazards, and/or select agents during the reporting period. If required, were these changes approved by the applicable institution committee (or equivalent) and reported to the agency? Also specify the applicable Institutional Review Board/Institutional Animal Care and Use Committee approval dates.

Significant changes in use or care of human subjects

Nothing to report

Significant changes in use or care of vertebrate animals.

Nothing to report

Significant changes in use of biohazards and/or select agents

Nothing to report

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.

Song W., Cooper, D., Koffer Miller, K., & Shea, L. (2022). *A Snapshot of Self-Reported Experiences Under the COVID-19 Pandemic*. International Society for Autism Research (INSAR) 2022 Annual Meeting, Austin, TX, United States.

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).*

Shea, L. L., Becker, A., Lee, B. K., Miller, K. K., Cooper, D., Anderson, K., Salzer, M. S., & Vanness, D. J. (2022). Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults. *Vaccine*, 40(24), 3288–3293. <https://doi.org/10.1016/j.vaccine.2022.04.060>

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).*

Nothing to report

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.*

Nothing to report

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.

Nothing to report

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.

Nothing to report

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.

Nothing to report

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.

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: Dr. Lindsay Shea
Project Role: Principal Investigator
Nearest person month worked: 2
Contribution to Project: Oversaw all project activities and obtained appropriate approvals.

Name: Dylan Cooper
Project Role: Project Manager
Nearest person month worked: 2
Contribution to Project: Under supervision of the P-I, helped guide survey recruitment and implementation.

Name: Dr. Mark Salzer
Project Role: Community Participation Expert
Nearest person month worked: 1
Contribution to Project: Informed survey items, particularly related to community participation measures.

Name: Dr. David Vanness
Project Role: Health Economist
Nearest person month worked: 1
Contribution to Project: Informed survey structures best equipped to capture key outcome data.

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.

There are no significant changes to report in the active other support for the PI or other senior key personnel. Other support documentation for Dr. Lindsay Shea, Dr. Mark Salzer, Dr. David Vanness, and Dr. Brian Lee are include in the appendix for reference.

What other organizations were involved as partners?

If there is nothing significant to report during this reporting period, state "Nothing to Report."

Describe partner organizations - academic institutions, other nonprofits, industrial or commercial firms, state or local governments, schools or school systems, or other organizations (foreign or domestic) - that were involved with the project. Partner organizations may have provided financial or in-kind support, supplied facilities or equipment, collaborated in the research, exchanged personnel, or otherwise contributed. Provide the following information for each partnership:

Organization Name:

Location of Organization: *(if foreign location list country)*

Partner's contribution to the project *(identify one or more)*

- **Financial support;**
- **In-kind support** *(e.g., partner makes software, computers, equipment, etc., available to project staff);*
- **Facilities** *(e.g., project staff use the partner's facilities for project activities);*
- **Collaboration** *(e.g., partner's staff work with project staff on the project);*
- **Personnel exchanges** *(e.g., project staff and/or partner's staff use each other's facilities, work at each other's site); and*
- **Other.**

Nothing to report

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 report shall be submitted to <https://ebrap.org> for each unique award.
QUAD CHARTS: If applicable, the Quad Chart (available on <https://www.usamraa.army.mil>) should be updated and submitted with attachments.

N/A

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. Reminder: Pages shall be consecutively numbered throughout the report.

Please see attached.

APPENDIX 1. Wave 2 Survey Instrument

Introductory text for DoD V1 Respondent (D):

Hello and thank you for taking this survey again! This current survey will be very similar to the survey that you took last year and will ask about activities you do in your community that are important to you and your experiences with the COVID-19 pandemic. Thanks to your first response, we were able to learn so much about activities that are important to adults on the autism spectrum and how to best support you so that you can continue to do these activities.

- This survey should take about 20 minutes to complete.
- You may have a caregiver or support staff help you complete the survey (e.g., read questions, record your responses), but please make sure that your responses to these questions are your own. We want to make sure that **you** are sharing your own thoughts and feelings.
- If you have any questions while taking this survey you can reach out to our research staff at sl3765@drexel.edu for help. We can also set up time to help you take the survey over the phone.
- This survey can be stopped and started at any time by clicking the same link that was sent to your email.
- Please **do not share** this link as this is a survey designed for you.
- Once you finish and submit the survey you will be eligible for a \$40 amazon gift that you will receive by email.

Introductory text for No V1 Response (N):

Hello and thank you for your interest in taking our follow-up survey to the Pennsylvania Autism Needs Assessment. We want to see how things have changed in the past few years so that we can better understand how to help the autism community in Pennsylvania. Questions in this survey ask about activities that are important to you that you do in your community and your experiences related to the COVID-19 pandemic.

- This survey should take about 20 minutes to complete.
- You may have a caregiver or support staff help you complete the survey (e.g., read questions, record your responses), but please make sure that your responses to these questions are your own. We want to make sure that **you** are sharing your own thoughts and feelings.
- If you have any questions while taking this survey you can reach out to our research staff at sl3765@drexel.edu for help. We can also set up time to help you take the survey over the phone.
- This survey can be stopped and started at any time by clicking the same link that was sent to your email.
- Please **do not share** this link as this is a survey designed for you.
- Once you finish and submit the survey you will be eligible for a \$40 amazon gift that you will receive by email.

Introductory text for Caregiver-Recruited Sample (C):

Hello and thank you for your interest in taking our survey on community participation and your experiences during the COVID-19 pandemic. You are invited to take this survey because you are an adult, and your parent or caregiver answered the Pennsylvania Autism Needs Assessment in 2018. Answering these questions helps us to learn and better support the autism community!

- This survey should take about 20 minutes to complete.

- You may have a caregiver or support staff help you complete the survey (e.g., read questions, record your responses), but please make sure that your responses to these questions are your own. We want to make sure that **you** are sharing your own thoughts and feelings.
- If you have any questions while taking this survey you can reach out to our research staff at sl3765@drexel.edu for help. We can also set up time to help you take the survey over the phone.
- This survey can be stopped and started at any time by clicking the same link that was sent to your email.
- Please **do not share** this link as this is a survey designed for you.
- Once you finish and submit the survey you will be eligible for a \$40 amazon gift that you will receive by email.

Do you consent to take part in this research study?

- Yes, I have reviewed the document and consent to take part in this research study.
- No, I have reviewed the document and do not consent to take part in this research study. By selecting no I will not be able to finish the survey.

Do you give permission for the Pennsylvania Department of Human Services to provide Medicaid claims information to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University? This is an optional request and will not impact your ability to participate in this survey.

- Yes, I give permission for the Pennsylvania Department of Human Services to provide Medicaid claims information to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University.
- No, I do not give permission for the Pennsylvania Department of Human Services to provide Medicaid claims information to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University.

Do you give permission for the Office of Vocational Rehabilitation to provide records to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University? This is an optional request and will not impact your ability to participate in this survey.

- Yes, I give permission for the Office of Vocational Rehabilitation to provide records to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University.
- No, I do not give permission for the Office of Vocational Rehabilitation to provide records to the Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University.

DoD V1 Respondent (D): First, we'd like to know if information about where you live or other aspects of your life have changed since you took this survey in 2021. Since you may not remember your answers, the questions in this section will have your previous answers included in the question.

No V1 Response (N): First, we'd like to know if information about where you live or other aspects of your life have changed since you took the Pennsylvania Autism Needs Assessment. Since you may not remember your answers, the questions in this section will have your previous answers included in the question.

Caregiver-Recruited Sample (C): First, we'd like to know if information about where you live or other aspects of your life have changed since your parent or caregiver answered in 2018.

1. You(r caregiver) reported the following information. Please select if any of the following information is **not** currently true:
- Current home address (piped response)
 - Marital status (piped response)
 - Employment status (piped response)
 - Family planning (having or adopting children) (piped response)
 - Gender identity (piped response)
 - Health insurance (piped response)
 - Living arrangement (piped response)
 - School Enrollment (piped response)

*if selected yes to change in current home address

2. What is current your home address? Please enter the street number, street name, city, and zip code.

*if selected yes to change in current home address

3. Approximately (it does not need to be exact) what month and year did you move to this home? If you have always lived at this address, then simply give us the month and year of your birth. (Qualtrics form to select date)

*if selected yes to change in marital status

4. Please select your new marital status:
- Married
 - Widowed
 - Separated or Divorced
 - Prefer not to answer

*if selected yes to change in employment

5. Please select your new employment status:
- I am working full-time but at a different job.
 - I am working full-time but at the same job.
 - I am working part-time at the same job.
 - I am working part-time at a different job.
 - I started a new full-time job.
 - I started a new part-time job.
 - I was released or fired from my job.
 - I retired from the workforce.

If still employed: In your new employment status, which of the following is closest to your current annual income from employment?

*if selected yes to change in family planning

6. Please select your new family planning or child/children status:
- I plan to have children.
 - I do not want to have children.
 - I am undecided about having children.
 - I had a child or children or adopted a child or children.

*if selected yes to change in gender identity

7. Please select your gender or gender identity:
- Woman
 - Man
 - Other: _____.

*if selected yes to change in health insurance

8. Please select which health insurance change you experienced:
- I lost health insurance.
 - I gained health insurance. I currently have (check all that apply):
 - Private health insurance (from your family, your spouse's plan, your job, or you pay for it every month)
 - Public health insurance or insurance through the government (Medicaid, VA benefits or other veteran's health coverage, Medicare).
 - Are you enrolled on a Medicaid Waiver?
 - Yes, I am enrolled in the:
 - Adult Autism Waiver (AAW)
 - Aging Waiver
 - Community Living Waiver
 - Consolidated Waiver
 - OBRA Waiver
 - Person/Family Directed Support Waiver (P/FDS)
 - Unsure
 - I'm not sure.
 - I changed health insurance but still have coverage. I currently have (check all that apply):
 - Private health insurance (from your family, your spouse's plan, your job, or you pay for it every month)
 - Public health insurance or insurance through the government (Medicaid, VA benefits or other veteran's health coverage, Medicare).
 - Are you enrolled on a Medicaid Waiver?
 - Yes, I am enrolled in the:
 - Adult Autism Waiver (AAW)
 - Aging Waiver
 - Community Living Waiver
 - Consolidated Waiver
 - OBRA Waiver
 - Person/Family Directed Support Waiver (P/FDS)
 - I'm not sure.

*if selected yes to change in living arrangement

9. Please select your current living arrangement:

- Alone without support (rent or own)
- Alone with support (rent or own)
- With a roommate/spouse (rent or own)
- With parents or relatives
- In a residential facility (including state hospital or state center)
- In a group home
- College housing
- Homeless
- Life sharing
- Other _____

10. How happy are you with your current living arrangement?

- Very happy
- Happy
- Unhappy
- Very unhappy

*if selected yes to change in school enrollment

11. Please select your current school enrollment:

- High school
- Two-year college
- Four-year college
- Graduate school
- Vocational/technical school
- Other _____

12. What is the status of your school enrollment?

- Full time
- Part time

13. We want to understand how often you participate in activities in your community and if certain types of activities are important to you. In the following tables, please fill out the number of days during the past 30 days you have participated in each activity outside of your home without a staff person going with you. The next column asks if you participate in each activity Enough, Not Enough, or Too Much ?

| A. How many days during the past 30 days did you do the following activities without a program staff person going with you: | B. Number of Days (without a staff person) _____ (# of Days) | C. Do you do this activity? | | | D. Is this activity important to you? | |
|--|--|-----------------------------|------------|----------|---------------------------------------|----|
| | | Enough | Not Enough | Too Much | Yes | No |
| 1. Go shopping at a grocery store, convenience store, shopping center, mall, other retail store, flea market, or garage sale. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 2. Go to a restaurant or coffee shop. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 3. Go to a church, synagogue, or place of worship. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 4. Go to a movie. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 5. Go to a park or recreation center. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 6. Go to a theater or cultural event (including local school or club events, concerts, exhibits and presentations in the community). | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 7. Go to a zoo, botanical garden, or museum. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 8. Go to run errands (for example, go to a post office, bank, Laundromat, dry cleaner). | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 9. Go to a library. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 10. Go to <u>watch</u> a sports event (including bowling, tennis, basketball, etc.). | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |

| | | | | | | |
|---|--------------------------|--------|------------|----------|-----|----|
| 11. Go to a gym, health or exercise club, including pool, or participate in a sports event (including bowling, tennis, miniature golf, etc.). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 12. Go to a barber shop, beauty salon, nail salon, spa. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 13. Use public transportation (for example, buses, Broad Street Line, subway) (This does NOT include mental health agency vans). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 14. Go to a support or self-advocacy group/organization. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 15. Go to a social group in the community (for example, a book club, hobby group, other group of people with similar interests) (Specify name of group: _____). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 16. Work for pay. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 17. Go to school to earn a degree or certificate (for example: GED, adult education, college, vocational or technical school, job training). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 18. Take a class for leisure or life skills (for example, classes for cooking, art crafts, ceramics, and photography). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 19. Participate in volunteer activities (in other words, spend time helping without being paid). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 20. Get together in the community or attend an event or celebration with family or friends (for example, a wedding, bar mitzvah). | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 21. Entertain family or friends in your home or visit family or friends in their homes. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 22. Go to a community fair, block party, community clean-up day, or other community event or activity. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 23. Go to or participate in civic or political activities or organizations. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 24. Engage in an organized sport (baseball, basketball, soccer game) or other organized physical activity (e.g., exercise class) outside the home. | ____ ____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |

| | | | | | | |
|---|----------------------|--------|------------|----------|-----|----|
| 25. Play games (e.g., chess, card, online gaming) outside the home, such as at a friend's house. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 26. Play games, including online gaming, at your own home where you play with others (they may be physically present in your home or online). | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |
| 27. Hangout or socialize with people you know from school, work, the neighborhood, or other acquaintances. | _____ (# of Days) | Enough | Not Enough | Too Much | Yes | No |

The following questions ask about your relationships with an intimate partner and your relationships with your child(ren).

| | | | |
|---|--|------------------------------------|--|
| 28. Are you currently married or in a domestic partnership/relationship (i.e., not married, but in a committed relationship or living with someone you are in an intimate relationship with)? | Yes | No | |
| 29. (Skip if yes to Q28) Do you get together with someone you consider to be a partner or significant other? | A. How many days in the last 30 days did you get together with someone you consider to be a boyfriend/girlfriend? | B. Do you do this activity? | C. Is this activity important to you? |
| | _____ (# of Days) | Enough Not Enough Too Much | Yes No |
| 30. If you have children ("Yes" on Question #4), but do NOT live with them, please answer these questions... | A. How many days in the last 30 days have you gotten together with your child(ren)? | B. Do you do this activity? | C. Is this activity important to you? |
| Get together with your child(ren) | _____ (# of Days) | Enough Not Enough Too Much | Yes No |

14. Across all of the activities you just reviewed, please select which of the following impacts your participation in these activities in your community.

| How often does this impact your participation in these activities? | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| | Never | Some of the time | Most of the time | Always |
| I have to interact with too many people | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I'm not sure how to get to these activities (for example, I don't have a car) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Activities cost too much money. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I'm not sure what activities occur around me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Activities in my community are not interesting to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How often does this impact your participation in these activities? | | | | |
| | Never | Some of the time | Most of the time | Always |
| I do not have friends or other connections to do things together in the community. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I do not feel safe in new places to me. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| People in my community are unfriendly to me or do not treat me well. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bright lights, unusual noises, darkness, or crowds in public spaces bother me or limit how much I do things. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| How often does this impact your participation in these activities? | | | | |
| | Never | Some of the time | Most of the time | Always |
| I am uncomfortable if people around me are not wearing a COVID-19 mask or face-covering. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am uncomfortable if people around me are wearing a COVID-19 mask or face-covering. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am afraid that I may have to interact with the police in my community | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am afraid that I may be a victim of a crime in my community | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I am afraid I would have a behavioral or mental health crisis in my community | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| There are other reasons I do or do not participate in activities in my community: (Please specify) _____ | | | | |

We want to understand how the COVID-19 pandemic has impacted how you participate in activities in your community.

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15. In general, how has COVID-19 impacted how often you participate in the activities listed previously in the last 30 days compared to before the COVID-19 pandemic?
- Stayed the same. I participate in activities about as often as I did before COVID-19.
 - Increased. I participate in activities more often.
 - Decreased. I participate in activities less often.
16. In general, how has COVID-19 impacted how often you interact with others virtually or online (for example, social media, online activities, interactions with other people that occur online, etc.) in the last 30 days compared to before the COVID-19 pandemic?
- Stayed the same. I interact with others virtually or online about as often as I did before COVID-19.
 - Increased. I interact with others virtually or online more often.
 - Decreased. I interact with others virtually or online less often.
17. Have you or anyone that you know well been diagnosed with COVID-19?
- Yes (select all that apply)
 - I have been diagnosed with COVID-19
 - Someone that I live with (e.g. a family member, roommate, partner/spouse) has been diagnosed with COVID-19
 - Someone outside of my home has been diagnosed with COVID-19 (e.g. a friend, coworker, support staff)
 - No, neither I nor people that I know have been diagnosed with COVID-19.

If Yes to I have been diagnosed with COVID-19

Which best describes your health status when you had COVID-19?

- I had no symptoms
- I had symptoms but did not need to go to the hospital
- I had severe symptoms that made me need to go to a hospital

Do you still experience any long-term effects or symptoms due to COVID-19, that have lasted more than 4 weeks since you were diagnosed?

- Yes I still experience symptoms. If so please describe your symptoms _____.
- No, I do not continue to experience symptoms.
- I am unsure if I still am experiencing any symptoms.

If yes:

How often do these long-term symptoms prevent you from participating in activities in your community? (e.g. work, school, hangout with friends, etc.)

- Never
- Rarely
- Often
- Always

If not Never:

Please describe how these long-term symptoms of COVID-19 impact your ability to participate in activities in your community_____:

If yes to someone else:

Do you know anyone who passed away due to COVID-19?

- Yes
- No

Do you know anyone who was hospitalized due to COVID-19?

- Yes
- No

18. Have you ever thought that you had COVID-19, but did not have a diagnosis?

- Yes
- No
- Unsure

19. Have you experienced stress related to the COVID-19 pandemic?

- No, no stress at all.
- Yes, mild stress such as occasional worries or minor stress-related symptoms such as feeling a little anxious, sad, angry, or mild trouble sleeping.
- Yes, moderate stress with frequent worries, often feeling anxious, sad, or angry, or some trouble sleeping.
- Yes, severe stress with constant worries or feeling extremely anxious, sad, or angry, or frequent trouble sleeping.

20. Throughout the pandemic, please all select of the following sources you would use to get information about COVID-19.

- Social Media
- Cable News
- Local News
- National elected officials
- Local elected officials
- I did my own research
- I did not try to access information about COVID-19
- Other, please specify: (text box)

The following questions ask you to compare the last 30 days to before the COVID-19 pandemic began in March 2020.

21. Thinking of the last 30 days, have your daily routines changed in comparison to before the pandemic? Daily routines including going to work or school, making meals, exercising, self-care, or other ways you normally spend your time.

- No, there have been no changes to my daily routines. I do the same activities in the last 30 days that I did before the pandemic.
- Yes, there have been changes to my daily routines in the last 30 days compared to before the pandemic.
 - These changes have been minor. I do some activities differently (on the phone or computer) instead of in person or I have slightly fewer activities.
 - These changes have been moderate. Several activities I would have completed daily have been disrupted or changed significantly.
 - These changes have been major. Most or all activities I would normally participate in have been canceled, delayed, or substantially changed.

22. Thinking of the last 30 days, has your exercise routine changed compared to before the pandemic?
- No, I did not exercise before the pandemic, and I have not exercised in the last 30 days.
 - No, in the last 30 days I have been exercising as often as I did before the pandemic.
 - Yes, I used to exercise before the pandemic, but stopped exercising now.
 - Yes, I have exercised less now in the past 30 days than I did before the pandemic.
 - Yes, I have exercised more in the last 30 days than I did before the pandemic.

23. Has your access to medical health care changed in the last 30 days compared to before the pandemic?
- No, I have not tried to access care in the last 30 days, and I haven't needed care since the pandemic began.
 - No, there have been no changes to my medical health in the last 30 days. I access a doctor or other health care professional when needed.
 - Yes, my access to medical health care has changed in the last 30 days (check all that apply if Yes):
 - My medical appointments were moved to telehealth instead of in-person visits.
 - I have experienced delays in setting up appointments or getting prescriptions.
 - I have been unable to access needed care.
 - It is easier for me to set up an appointment or get prescriptions.
 - I am more able to access needed care.

24. Has COVID-19 impacted transportation available to you or that you use in your community in the last 30 days?
- Yes
 - No
 - Unsure

If Yes, how was your access to transportation impacted by the COVID-19 in the last 30 days compared to before the pandemic.

- My access increased
- My access decreased
- There was no change in access to transportation

25. Which transportation do you typically use to get where you need to go in the last year?

Choose all that apply.

- Drive yourself in a car
- Passenger in a car with family
- Passenger in a car with friends
- Bus/van operated by a county, municipality, or non-profit
- Taxi or other for-hire vehicle
- Walk
- Bicycle
- Passenger in a car with a volunteer (friend or family) driver
- Public transit
- Transportation is provided by a day program
- Transportation is provided by a group home
- Transportation is provided by school/education institution
- Ride sharing (Uber/Lyft)
- Car share (e.g. ZipCar, Enterprise)
- Other _____

26. Has your access to mental or behavioral health services or supports changed in the last 30 days compared to before the pandemic?
- No, I have not tried to access mental or behavioral health services or supports in the last 30 days, and I haven't needed services or supports since the pandemic began.
 - No, there have been no changes to my mental or behavioral health services or supports in the last 30 days.
 - Yes, my access to mental or behavioral health services has changed in the last 30 days (check all that apply **if Yes**):
 - My appointments moved to telehealth instead of in-person visits.
 - I have experienced delays in setting up appointments.
 - I have been unable to access needed mental or behavioral health services or supports.
 - It is easier for me to set up an appointment.
 - I am more able to access needed mental or behavioral health services or supports.
27. Have your interactions with family or friends changed in the last 30 days compared to before the pandemic?
- No, there has been no change in the last 30 days.
 - Yes, my interactions with family or friends have changed in the last 30 days (check all that apply **if Yes**):
 - I have continued interactions with family or friends through social distancing, phone calls, or social media instead of in person visits.
 - I lost contact with some of my family or friends.
 - I lost contact with most of my family or friends.
 - I lost contact with all family and friends.
 - I have gained contact with all family and friends.
 - I have gained contact with some of my family or friends.
 - I have gained contact with most of my family or friends.
 - I have gained contact with all of family and friends.
28. Has the frequency that you have felt lonely changed in the last 30 days compared to before the pandemic?
- Increased
 - Decreased
 - Remained the same

New vaccine questions for DoD V1 respondents who indicated they took the vaccine:

- Last year you said that you received the COVID-19 vaccine. Have you received a booster shot, meaning that you received an additional dose of the vaccine?
 - Yes, I received the booster shot. I received it in _____ (enter MM/YY)
 - No
 - i. I have an appointment for my vaccination in _____ (MM/YY).
 - ii. I do not have an appointment yet, but I am actively looking to receive a booster, or am waiting to hear from a vaccination site, provider, or other care provider.
 - iii. I do not plan on getting a booster

If any answer other than No, I do not plan on getting a booster:

Please tell us why you are planning to get or have already gotten a COVID-19 booster vaccine. Please select all that apply.

- My employer/school recommended/required it
- I get vaccinated so that I can protect other people from getting infected
- I think I would get seriously ill from COVID-19
- I trust that the vaccine is safe
- Someone I trust either got the vaccine or told me to get the vaccine
- I get vaccinated to protect myself from getting infected
- I get vaccinated to protect myself from getting seriously ill even if I get infected
- Other_____

The COVID-19 booster has changed how I gather with other people and participate in activities in my community.

- Yes
- No

If yes:

After receiving the booster I...(please select all that apply):

- Am more likely to gather with other people who are vaccinated.
- Am more likely to gather with other people regardless of if they are vaccinated
- Am able to work or actively look for a job.
- Feel more comfortable outside of my home.
- Am more likely to dine indoors or outdoors at a restaurant, coffee shop, or café.
- Am more likely to enjoy recreation activities outside of my home, such as go to a movie theater, go to a park or recreation center, go to a social group in the community, or take a class for leisure or life skills.
- Am more likely to go shopping at grocery stores or retail stores.
- Am more likely to go to a barber shop, beauty salon, nail salon, or spa.
- Am more likely to go to a gym, health or exercise club, or participate in a sports event.
- Am more likely to seek medical care/services.

If no to booster:

Please tell us why you do not plan on getting the booster. Please select all that apply

- I'm not concerned about getting COVID-19
- I do not get vaccines
- I'm afraid of needles
- I'm concerned about the cost of getting the vaccine
- There are not enough available vaccines
- Getting the vaccine will be inconvenient
- The vaccine isn't safe
- I'm concerned that the vaccine will make me not feel well
- I'm already protected from my previous vaccine
- I'm concerned that the vaccines won't stop me from getting/giving COVID
- I have already had COVID
- Other, please specify: (text box)

- Do you have any other thoughts about how the COVID booster will impact you that you'd like to share? (text box)

For new respondents or V1 respondents who did not indicate they took the vaccine:

- Have you received a COVID-19 vaccine? Some vaccines may require two doses, while others will only require one dose.
 - Yes, I have all required doses of the vaccine.
 - i. When was your final dose (MM/YY)?
 - Yes, but I still need to get the 2nd dose.
 - i. When is your 2nd dose? (MM/YY)
 - No
 - i. I have an appointment for my vaccination in (MM/YY).
 - ii. I do not have an appointment yet, but I am actively looking to be vaccinated, or am waiting to hear from a vaccination site, provider, or other care provider.
 - iii. I do not plan on getting the vaccine.

If any answer other than No, I do not plan on getting a vaccine:

Please tell us why you are planning to get or have already gotten the vaccine. Please select all that apply.

- My employer/school recommended/required it
- I get vaccinated so that I can protect other people from getting infected
- I think I would get seriously ill from COVID-19
- I trust that the vaccine is safe
- Someone I trust either got the vaccine or told me to get the vaccine
- I get vaccinated to protect myself from getting infected
- I get vaccinated to protect myself from getting seriously ill even if I get infected
- Other _____

Have you received a booster shot, meaning that you received an additional dose of the vaccine?

- Yes, I received the booster shot. I received it in _____ (MM/YY)
- No
 - i. I have an appointment for my vaccination in (MM/YY)
 - ii. I do not have an appointment yet, but I am actively looking to receive a booster, or am waiting to hear from a vaccination site, provider, or other care provider.
 - iii. I do not plan on getting a booster

If any answer other than No, I do not plan on getting a vaccine:

Please tell us why you are planning to get or have already gotten a COVID-19 booster vaccine. Please select all that apply.

- My employer/school recommended/required it
- I get vaccinated so that I can protect other people from getting infected
- I think I would get seriously ill from COVID-19
- I trust that the vaccine is safe
- Someone I trust either got the vaccine or told me to get the vaccine
- I get vaccinated to protect myself from getting infected

- I get vaccinated to protect myself from getting seriously ill even if I get infected
- Other_____

If No, I do not plan on getting a vaccine:

Please tell us why you do not plan on getting the vaccine or booster. Please select all that apply

- I'm not concerned about getting COVID-19
- I do not get vaccines
- I'm afraid of needles
- I'm concerned about the cost of getting the vaccine
- There are not enough available vaccines
- Getting the vaccine will be inconvenient
- The vaccine isn't safe
- I'm concerned that the vaccine will make me not feel well
- I'm already protected from my previous vaccine
- I'm concerned that the vaccines won't stop me from getting/giving COVID
- I have already had COVID
- Other, please specify: (text box)

My COVID-19 vaccine status has changed how I gather with other people and participate in activities in my community.

- Yes, it has changed how I gather with other people and participate in activities in my community.
- No, it has not changed how I gather with other people and participate in activities in my community.

If yes:

Because of my COVID-19 vaccine status, I...(please select all that apply):

- Am more likely to gather with other people who are vaccinated.
- Am more likely to gather with other people regardless of if they are vaccinated
- Am able to work or actively look for a job.
- Feel more comfortable outside of my home.
- Am more likely to dine indoors or outdoors at a restaurant, coffee shop, or café.
- Am more likely to enjoy recreation activities outside of my home, such as go to a movie theater, go to a park or recreation center, go to a social group in the community, or take a class for leisure or life skills.
- Am more likely to go shopping at grocery stores or retail stores.
- Am more likely to go to a barber shop, beauty salon, nail salon, or spa.
- Am more likely to go to a gym, health or exercise club, or participate in a sports event.
- Am more likely to seek medical care/services.
- Do you have any other thoughts about how the COVID vaccine will impact you that you'd like to share? (text box)

If still no to vaccine (1st question):

- Please tell us why you do not plan on getting the vaccine. Please select all that apply
 - I'm not concerned about getting COVID-19
 - I do not get vaccines
 - I'm afraid of needles

- I'm concerned about the cost of getting the vaccine
 - There are not enough available vaccines
 - Getting the vaccine will be inconvenient
 - The vaccine isn't safe
 - I'm concerned that the vaccine will make me not feel well
 - I'm already protected from my previous vaccine
 - I'm concerned that the vaccines won't stop me from getting/giving COVID
 - I have already had COVID
 - Other, please specify: (text box)
- Do you have any other thoughts about how the COVID vaccine will impact you that you'd like to share? (text box)

29. Please describe your satisfaction with the following relationships.

| | I do not have, but would like... | I have, but would like more / better... | I am satisfied with my... | N/A | Prefer Not to Answer |
|--|----------------------------------|---|---------------------------|-----------------------|-----------------------|
| Friends to confide in | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Friends to socialize with | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Relationships with parents | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Relationships with siblings | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Relationships with your children | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Relationship with significant other (e.g. spouse, partner) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Acquaintances | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other relationships _____ | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

The next questions ask about your health status

30. Compared to 12 months ago, would you say that your overall health is:

- Better
- Worse
- The same

Please explain your choice:

31. Have you been newly diagnosed with any of the following in the past year? Choose all that apply.

- Anxiety Disorder
- Attention Deficit/Hyperactivity Disorder (ADHD)
- Bipolar Disorder
- Intellectual Disability
- Obsessive Compulsive Disorder (OCD)
- Central Auditory Processing Disorder (CAPD)
- Oppositional Defiant Disorder (ODD)
- Conduct Disorder (CD)
- Schizophrenia or other psychotic disorder

- Depression
- Seizures/Seizure Disorder/Epilepsy
- Sensory Integration Disorder
- Hoarding Disorder
- Substance Use Disorder
- Learning Disability
- None
- Other

32. Please tell us about your service needs. *Please make sure to fill out all columns.*

| | Are you receiving any of these services? | | Do you need more of these services? | | Have you experienced barriers to accessing this service? | |
|--|--|----|-------------------------------------|----|--|----|
| | Yes | No | Yes | No | Yes | No |
| Counseling Services (Mental Health Counseling, Relationship Counseling, and Drug and Alcohol Counseling) | | | | | | |
| Therapy Services (Speech / Language Therapy, Occupational Therapy, and Physical Therapy) | | | | | | |
| Employment (Supported Employment, Vocational Training, Benefits Counseling, Career Counseling) | | | | | | |
| Medical Services (Primary Health Care, Dental Care, Medication Management, Neurology Services) | | | | | | |
| Behavioral and Social Interventions (One-to-One Support, Behavioral Support, Social Skills Training, Sexual Health Education) | | | | | | |
| Coordination Services (Case management, Supports Coordination, Transition Planning) | | | | | | |

33. Which of the following make it harder for you to get those services? *Choose all that apply.*
(This question will be asked if a respondent answers yes to experiencing barriers to any of the following service categories)

- Transportation
- There are no appointments available, or the next available appointment is too far away
- I would need to use a telephone to schedule an appointment
- No services providers in the area
- Not enough services providers in the area
- Cost of services / My insurance does not cover available services
- Providers do not have enough staff
- Providers in the area will not see people with autism
- Providers in the area will not see people with mental health diagnoses
- Providers in my area do not understand people with autism
- Providers in my area will not adapt their practices to accommodate people with autism
- Other _____

34. "Did anyone help you complete any of the items on this survey?"

- Yes
- No

If yes, who helped you?

- Family member
- Support staff
- Friend
- Other_____

If yes, how did this individual help you? Please select all that apply

- Read the questions and answers aloud
- Explained what certain words meant
- Clicked the answers on the computer, phone, or tablet
- Other_____

Thank you for completing this survey. We appreciate your time and look forward to contacting you again in the future. In the coming days you will be emailed a \$40 amazon gift card.

APPENDIX 2. Preliminary Wave 2 Survey Sample Demographics

| Table 1. Sample Characteristics | | | | |
|--|---------------------|-----|--------------------------|-----|
| | Caregiver Recruited | | Autistic Adult Recruited | |
| | (N = 139) | | (N = 117) | |
| | n | % | n | % |
| Gender / Sex | | | | |
| Female | 31 | 22% | 30 | 26% |
| Male | 107 | 77% | 80 | 68% |
| Other | * | * | * | * |
| Missing (Not Reported) | * | * | * | * |
| Marital Status | | | | |
| Married / Living with partner | 17 | 12% | 17 | 15% |
| Not Married / Not Living with partner | 122 | 88% | 100 | 85% |
| Race/Ethnicity | | | | |
| Non-White | 21 | 15% | 20 | 17% |
| White | 91 | 65% | 87 | 74% |
| Missing (Not Reported) | 27 | 19% | 10 | 9% |
| Medical Insurance | | | | |
| Private | 78 | 56% | 39 | 33% |
| Public | 111 | 80% | 78 | 67% |
| None (Not Reported) | * | * | * | * |
| Living Arrangement | | | | |
| Family/Roommate | 122 | 88% | 91 | 78% |
| Independent or Other | 16 | 12% | 23 | 20% |
| Missing (Not Reported) | * | * | * | * |
| ZIP Code Urbanicity | | | | |
| Metropolitan | 93 | 67% | 88 | 75% |
| Non-Metropolitan | 12 | 9% | 13 | 11% |
| Missing (ZIP Code Not Reported) | 34 | 24% | 16 | 14% |
| | median | IQR | median | IQR |
| Age (years) | 25 | 11 | 31 | 24 |
| Notes: Sample excludes respondents who completed less than 50 percent of survey questions through July 27, 2022. ZIP Code Urbanicity from 2010 rural-urban commuting area (RUCA) codes. | | | | |

APPENDIX 3. Other Support Documentation

Other Support Shea, Lindsay

ACTIVE

*Title: Alternative Approaches to Supporting ASD Services for Young Adults

*Major Goals: The major goal of this project is to conduct a detailed comparison of eligibility for healthcare coverage and healthcare service use in the Medicaid system among adolescents with autism spectrum disorder (ASD) as they age into adulthood.

*Status of Support: Active

*Project Number: 5R01MH117653-04

*Name of PD/PI: Shea, L.L.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2018 – 06/2023

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 4. 2022 | 3.00 |
| 5. 2023 | 3.00 |

*Title: Developing a Gold Standard for Tracking Adult Functional Outcomes in Autism Spectrum Disorder

*Major Goals: The major goal of this project is to develop efficient and validated measures of functional outcomes for adults with ASD across areas of employment, independent living, and social functioning.

*Status of Support: Active

*Project Number: 11923

*Name of PD/PI: Mazefsky, C.

*Source of Support: Autism Speaks

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 03/2020 – 02/2022

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 2. 2022 | 1.20 |

*Title: Autism Intervention Research Network on Physical Health (AIR-P)

*Major Goals: The major goal of this project is to establish and maintain an interdisciplinary, multicenter research network for scientific collaboration and infrastructure to increase the life expectancy and quality of life for autistic individuals, particularly for underserved and vulnerable populations.

*Status of Support: Active

*Project Number: 5UT2MC39440

*Name of PD/PI: Kuo, A.

*Source of Support: Health Resources and Services Administration (HRSA)

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2020 – 08/2025

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 2. 2022 | 1.20 |
| 3. 2023 | 1.20 |
| 4. 2024 | 1.20 |
| 5. 2025 | 1.20 |

*Title: Autism Transitions Research Project

*Major Goals: The major goal of this project is to support primary and secondary research studies that advance the evidence base available on the social determinants and risk factors associated with healthy life outcomes among adolescents and young adults with ASD who are transitioning to adulthood.

*Status of Support: Active

*Project Number: UJ2MC31073

*Name of PD/PI: Shea, L.L.

*Source of Support: Health Resources and Services Administration (HRSA)

*Primary Place of Performance: Drexel University, Philadelphia, PA

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2017 – 08/2022

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 5. 2022 | 1.20 |

*Title: Community Participation Experiences of Autistic Adults

*Major Goals: The major goal of this project is to capture a longitudinal trajectory of participation experiences and preferences of adults with ASD and examine the service utilization and contextual factors that are associated with participation over time, by building upon large, existing data sets.

*Status of Support: Active

*Project Number: W81XWH-20-1-0435

*Name of PD/PI: Shea, L.L.

*Source of Support: US Department of Defense

*Primary Place of Performance: Drexel University, Philadelphia, PA

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2020 – 06/2023

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 2. 2022 | 2.00 |
| 3. 2023 | 2.00 |

*Title: Philadelphia Autism Project

*Major Goals: The major goal of this project is to support autistic individuals and families living in Philadelphia through education, connections, and innovation.

*Status of Support: Active

*Project Number: N/A

*Name of PD/PI: Shea, L.L.

*Source of Support: Philadelphia Department of Behavioral Health and Intellectual disAbilities (DBHIDS)

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2021-06/2022 (awarded annually)

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 0.6 |

*Title: Autism Indicators Dashboard

*Major Goals: The major goal of this project is to create a series of dashboards for US states and the District of Columbia focused on autism spectrum disorder (ASD) prevalence and various policy and service indicators.

*Status of Support: Active

*Project Number: N/A

*Name of PD/PI: Shea, L.L.

*Source of Support: Autism Speaks

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 10/2021 – 07/2022

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 1.20 |

*Title: Psychotropic medication use in persons with autism in the national US population

*Major Goals: The major goal of this project is to provide current estimates of the use of psychotropic medications, and predictors thereof, in children and adults with autism spectrum disorder (ASD) across the US.

*Status of Support: Active

*Project Number: N/A

*Name of PD/PI: Lee, B.K.

*Source of Support: Pennsylvania Department of Health

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 06/2020 – 06/2022

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 2. 2022 | 0.60 |
| 3. 2023 | 0.60 |

PENDING

*Title: Public health and autism science advancing equitable strategies across the life course (PHASES)

*Major Goals: Investigate modifiable health determinants, inequities in health and health services, and examine relationship between health service delivery and health outcomes for autistic individuals across the life span.

*Status of Support: Pending

Project Number: P50HD111142

Name of PD/PI: Robins, D.L./Schendel, D.

*Source of Support: NIH

*Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 7/2022-6/2027

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 1.0 calendar |

| | |
|---------|--------------|
| 2. 2024 | 1.0 calendar |
| 3. 2025 | 1.0 calendar |
| 4. 2026 | 1.0 calendar |
| 5. 2027 | 1.0 calendar |

*Title: Improving Mental Health Service Delivery to Autistic Birthing Women

*Major Goals: The proposed project will be the most comprehensive investigation to date of mental health service delivery and related outcomes among women with autism spectrum disorder (ASD), using national Medicaid data to follow them through pregnancy and postpartum periods. We will compare their experiences to Medicaid-covered women without ASD who have intellectual disability (ID), mental health diagnoses (MH), or none of these diagnoses. We will combine Medicaid claims data with surveys and interviews with obstetric service providers and information on state Medicaid policies in order to gain insight into barriers to and facilitators of linkages to mental health care, laying the foundation for interventions to reduce the risk of adverse outcomes among autistic women.

*Project Number: R01MH130379

*Name of PD/PI: Shea, L.L.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 6/2027

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 3.0 |
| 2. 2024 | 3.0 |
| 3. 2025 | 3.0 |
| 4. 2026 | 3.0 |
| 5. 2027 | 3.0 |

*Title: Autism Transitions Research Project (ATRP)

*Major Goals: The goal of the proposed project is to produce high-impact research across a diverse research team that corresponds to key areas of need to grow the evidence base to support healthy and equitable life outcomes among transition-age autistic youth and young adults. Our objectives include: (1) the production of peer-reviewed publications and National Autism Indicators Reports, (2) the development of a new intervention to support Latinx autistic transition-age youth, and (3) capacity building for equity impact within (a) Title V programs and (b) minority-serving institutions and community colleges.

*Project Number: N/A

*Name of PD/PI: Shea, L.L.

*Source of Support: US Health Resources and Services Administration (HRSA)

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 8/2027

*Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 2.4 |
| 2. 2024 | 2.4 |
| 3. 2025 | 2.4 |
| 4. 2026 | 2.4 |
| 5. 2027 | 2.4 |

*Title: The impact of criminal justice system involvement on mental health and health outcomes among people with mental illnesses

*Major Goals: The proposed study will link data from the Medicaid system, which serves 45 million adults and is the single largest payer of services for people with SMI, to a proprietary dataset that houses national data on more than 300 million individuals in the US. These linkages will allow ascertainment of criminal justice system involvement and result in a first-of-its-kind national sample of justice-involved people with SMI and the largest such cohort studied to date. This will allow for the first large-scale examination of the effects of criminal justice system involvement on health and mental health outcomes among people with SMI and the extent to which associations are mediated by key social determinants of health. In addition, we will use advanced causal inference methods to examine any inequities in health outcomes of justice-involved people of color with SMI that are above and beyond those found in the general population of people with SMI, to examine the impact of structural racism. Finally, to further contextualize and enable application of our findings, we will conduct interviews with mental health directors and criminal justice system leaders in states with the largest and smallest disparities observed in our analyses, to gather system-level information, including state Medicaid and criminal justice policy and practice, to identify targets for system improvement.

*Project Number: R01MH130377

*Name of PD/PI: Shea, L.L.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 6/2027

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 2.4 |
| 2. 2024 | 2.4 |
| 3. 2025 | 2.4 |
| 4. 2026 | 2.4 |
| 5. 2027 | 2.4 |

*Title: The effectiveness of an autistic-delivered peer-support intervention for autistic adults: Community Autism Peer Specialist (CAPS) program

*Major Goals: This study will leverage existing infrastructure to finalize development of a novel support service provided by peers with lived experience, incorporating input from autistic peer specialists, autism researchers, peer support researchers, and experts in peer support training. We

will then conduct a pilot randomized controlled trial to examine the effectiveness of the service while also examining feasibility, acceptability, and implementation procedures in preparation for future large-scale testing and dissemination.

*Project Number: R34MH130830

*Name of PD/PI: Shea, L.L.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 6/2025

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 1.8 |
| 2. 2024 | 1.8 |
| 3. 2025 | 1.8 |

*Title: Safety and Evaluation of Psychotropic Treatments in Autism (SEPTA)

*Major Goals: The major goal of this grant is to evaluate the cardiometabolic outcomes of autistic youth who use psychotropic medications.

*Project Number:

*Name of PD/PI: Lee, B.K.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 6/2027

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 2.4 |
| 2. 2024 | 2.4 |
| 3. 2025 | 2.4 |
| 4. 2026 | 2.4 |
| 5. 2027 | 2.4 |

*Title: Mental health hospitalizations and follow-up care in autistic adults

*Major Goals: The purpose of this study is to examine the mental health hospitalizations of autistic adults and the care patterns following crisis compared to other adults hospitalized for mental health conditions. We will do this using three national sources of data: two all-payer emergency and inpatient hospitalization samples and Medicaid claims.

*Project Number:

*Name of PD/PI: Rast, J.

*Source of Support: NIMH

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 12/2022 – 11/2025

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 0.6 |
| 2. 2024 | 0.6 |
| 3. 2025 | 0.6 |

*Title: Exploring community mobility and participation of autistic adults using smartphone-based Global Positioning System and ecological momentary assessment

*Major Goals: The goal of this project is to provide a complete picture of the real-time community mobility and participation and explore enabling environmental factors that associate with mobility and participation.

*Project Number: N/A

*Name of PD/PI: Song, W.

*Source of Support: National Institute on Disability, Independent Living, and Rehabilitation Research

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 10/2022 – 09/2025

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 0.6 |
| 2. 2024 | 0.6 |
| 3. 2025 | 0.6 |

*Title: Community, identity, and vulnerability: A collaborative qualitative community study with queer and transgender autistic individuals

*Major Goals: The proposed research extends the existing literature by partnering with community organizations that serve queer and autistic transgender people in the largest poorest city in the United States. By engaging in interviewing and ethnographic observation of autistic transgender individuals in community settings, the proposed project will utilize a community-based, community-engaged process to generate prioritized barriers of and facilitators to program access to support the health and mental health of autistic transgender individuals, examine the self-identified service and support needs of autistic transgender individuals linked to health outcomes to generate informed recommendations for best practices, and generate a new needs assessment measure to improve the understanding of community support needs of autistic transgender individuals.

*Project Number: N/A

*Name of PD/PI: Steinberg, H.

*Source of Support: National Institute on Disability, Independent Living, and Rehabilitation Research

*Primary Place of Performance: Drexel University, Philadelphia, PA

*Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 08/2025

*Total Award Amount (including Indirect Costs):

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 0.6 |
| 2. 2024 | 0.6 |
| 3. 2025 | 0.6 |

IN-KIND

*Title: The Community Autism Peer Support (CAPS) Program

Major Goals: Support the development and implementation of an autistic-delivered peer support program in partnership with the Philadelphia Department of Behavioral Health and Intellectual disability Services.

*Summary of In-Kind Contribution: I provide contract oversight, advise on evaluation methods, and attend meetings with collaborators.

*Status of Support: ACTIVE

*Primary Place of Performance: Drexel University

*Person Months (Calendar/Academic/Summer) per budget period

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 0.6 |
| 2. 2023 | 0.6 |

*Estimated Dollar Value of In-Kind Information:

*Title: The Philadelphia Family Navigator Project

Major Goals: Support the development and implementation of caregiver peer navigation and support unit via a family legacy organization program in partnership with the Philadelphia Department of Behavioral Health and Intellectual disability Services.

*Summary of In-Kind Contribution: I provide contract oversight, advise on evaluation methods, and attend meetings with collaborators.

*Status of Support: ACTIVE

*Primary Place of Performance: Drexel University

*Person Months (Calendar/Academic/Summer) per budget period

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 0.6 |
| 2. 2023 | 0.6 |

*Estimated Dollar Value of In-Kind Information:

***Overlap** (summarized for each individual):

If this application is funded, I will reduce my effort on grants 5R01MH117653, 5UT2MC39440, W81XWH-20-1-0435, and the Philadelphia Autism Project so that my overall research effort does not exceed 12.0 calendar months. If future funding exceeds 12 calendar months, effort on a combination of current or future sources will be reduced and reassigned to other study team members in consultation and with approval from necessary program officers.

I, PD/PI or other senior/key personnel, certify that the statements herein are true, complete and accurate to the best of my knowledge, and accept the obligation to comply with Public Health Services terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.

**Other Support
Salzer, Mark**

ACTIVE

Other Support – Project/Proposal

***Title:** ConnectionsRx: A distance-based, community participation intervention for young adults with SMI

***Major Goals:** Dr. Salzer is an investigator on an RCT examining the impact of an intervention aimed at connecting young adults with SMI to one another and community resources to assist them with enhanced community participation

***Status of Support:**

Active Project Number: 90IFRE0049

Name of PD/PI: Snethen

***Source of Support:** NIDILRR/Administration for Community Living

***Primary Place of Performance:** Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2021-09/2024

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 0.24 |
| 2. 2023 | 0.24 |
| 3. 2024 | 0.24 |
| 4. [enter year 4] | |
| 5. [enter year 5] | |

***Title:** Being Needed: Building Social Connections that Matter to Reduce Social Isolation and Loneliness

***Major Goals:** Dr. Salzer is an investigator on a five-year Disability Rehabilitation Research Program (DRRP) aimed at enhancing knowledge about social isolation and loneliness of adults with serious mental illnesses. The DRRP includes a literature review, intervention research study, and dissemination efforts.

***Status of Support:**

Active Project Number: 90DPCP0011

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

Name of PD/PI: McCormick

*Source of Support: NIDILRR/Administration for Community Living

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2021 - 08/2026

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 0.6 |
| 2. 2023 | 0.6 |
| 3. 2024 | 0.6 |
| 4. 2025 | 0.6 |
| 5. 2026 | 0.6 |

***Title:** Up To Me: Erasing the Stigma of Mental Illness on College Campuses

*Major Goals: Dr. Salzer is an investigator on an RCT aimed at examining the effectiveness of an intervention targeting the reduction of internalized stigma among college students with mental illnesses to enhance their academic outcomes.

*Status of Support: Active

Project Number: 90IFRE0056

Name of PD/PI: Kosyluk

*Source of Support: NIDILRR/Administration for Community Living

*Primary Place of Performance: University of South Florida

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2021 - 09/2024

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 0.24 |
| 2. 2023 | 0.24 |
| 3. 2024 | 0.24 |
| 4. 2025 | 0.24 |
| 5. [enter year 5] | |

***Title:** Temple University RRTC on Community Living and Participation of Individuals with Psychiatric Disabilities

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

*Major Goals: PI of this Center which has the mission of advancing the development of interventions that maximize community living and participation of individuals with psychiatric disabilities through rigorous research and knowledge translation activities in partnership with consumers and other key stakeholders.

*Status of Support: Active

Project Number: 90RT0521

Name of PD/PI: Salzer

*Source of Support: NIDILRR/Administration for Community Living

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2018 - 09/2023

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 2.8 |
| 2. 2023 | 2.8 |
| 3. [enter year 3] | |
| 4. [enter year 4] | |
| 5. [enter year 5] | |

***Title:** Career Outcomes of Certified Peer Specialist with Psychiatric Disabilities

*Major Goals: Dr. Salzer is an investigator on a longitudinal study of the early careers of Certified Peer Specialists trained in five states around the country. The study is primarily focused on their employment experiences

*Status of Support: Active

Project Number: 90IFRE0029-01-00

Name of PD/PI: Ostrow

*Source of Support: NIDILRR/Administration for Community Living

*Primary Place of Performance: Live and Learn Society, California

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2019 - 09/2022

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 0.48 |
| 2. [enter year 2] | |
| 3. [enter year 3] | |

Name of Individual: Mark Salzer, Ph.D. Commons ID: Salzer

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 4. [enter year 4] | |
| 5. [enter year 5] | |

***Title:** Rehabilitation Research and Training Center (RRTC) on Health and Function of People with Psychiatric Disabilities

***Major Goals:** Dr. Salzer is an investigator on a study aimed at assisting individuals with serious mental illnesses to re-start their lives, with a focus on health, following the Coronavirus Pandemic.

***Status of Support:** Active

Project Number: 90RTHF0004

Name of PD/PI: Cook

***Source of Support:** NIDILRR/Administration for Community Living

***Primary Place of Performance:** University of Illinois

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2020-09/2025

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 0.41 |
| 2. 2023 | 0.25 |
| 3. 2024 | 0.1 |
| 4. 2025 | 0.1 |
| 5. [enter year 5] | |

***Title:** Community Participation, Service Needs, and Health Outcomes among Adults with ASD

***Major Goals:** Dr. Salzer is an investigator on a study to examine factors associated with community participation among autistic adults and examine the impact of participation on their health outcomes.

***Status of Support:** Active Project Number: AR190018 Name of PD/PI: Shea

***Source of Support:** Department of Defense/Drexel University (Prime)

***Primary Place of Performance:** Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2020 – 06/2023

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

- * Total Award Amount (including Indirect Costs):
- * Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 1.0 |
| 2. 2023 | 1.0 |
| 3. [enter year 3] | |
| 4. [enter year 4] | |
| 5. [enter year 5] | |

PENDING

***Title:** The effectiveness of an autistic-delivered peer-support intervention for autistic adults: Community Autism Peer Specialist (CAPS)

*Major Goals: This proposal aims to develop and test a peer-delivered intervention aimed at enhancing community participation among autistic adults.

*Status of Support: **Current proposal being considered for funding.**

Project Number:

Name of PD/PI: Shea and Salzer

*Source of Support: NIH/NIMH

*Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 06/2025

- * Total Award Amount (including Indirect Costs): Temple Award
- * Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 1.2 |
| 2. 2023 | 1.2 |
| 3. 2024 | 1.2 |
| 4. 2025 | 1.2 |
| 5. [enter year 5] | |

***Title:** Getting Out of the House: Using Behavioral Activation to Increase Community Participation

*Major Goals: This is a proposal to examine a peer-delivered intervention aimed at supporting individuals with serious mental illnesses to take initial steps toward increasing their community participation.

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

*Status of Support: Pending

Project Number:

Name of PD/PI: Salzer

*Source of Support: Administration on Community Living

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 09/2025

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 1.2 |
| 2. 2023 | 1.2 |
| 3. 2024 | 1.2 |
| 4. 2025 | 1.2 |
| 5. [enter year 5] | |

***Title:** Exploring mobility and participation of autistic adults using Smartphone-based GPS and ecological momentary assessment: The role of psychological states and social environmental factors

*Major Goals: This study uses GPS and EMA to examine factors associated with community participation among autistic adults.

*Status of Support: Pending

Project Number:

Name of PD/PI: Shea & Salzer

*Source of Support: Administration on Community Living

*Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 09/2025

* Total Award Amount (including Indirect Costs): Temple Award

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 1.2 |
| 2. 2023 | 1.2 |
| 3. 2024 | 1.2 |
| 4. 2025 | 1.2 |

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 5. [enter year 5] | |

***Title:** Peer-Delivered Decision Support for NEET Young Adults with Serious Mental Illnesses

*Major Goals: This is an R61/R33 proposal to develop and test the feasibility, acceptability, mechanisms of action, and preliminary outcomes of a peer-delivered intervention aimed at enhancing employment and educational outcomes of young adults with serious mental illnesses

*Status of Support: Pending

Project Number:

Name of PD/PI: Thomas

*Source of Support: NIH/NIMH

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 04/2023 – 03/2028

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 1.8 |
| 2. 2024 | 1.8 |
| 3. 2025 | 1.8 |
| 4. 2026 | 1.8 |
| 5. 2027 | 1.8 |

***Title:** Enhancing Community Participation Outcomes among Young Adults with Serious Mental Illnesses through Peer-Delivered Decision Support

*Major Goals: This study aims to test a decision coaching intervention among young adults with serious mental illnesses aimed at enhancing community participation.

*Status of Support: Pending

Project Number:

Name of PD/PI: Thomas

*Source of Support: Administration on Community Living

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 09/2025

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 1.2 |
| 2. 2023 | 1.2 |
| 3. 2024 | 1.2 |
| 4. 2025 | 1.2 |
| 5. | |

***Title:** Community Participation Navigators: Testing a Peer Intervention for Adults with Serious Mental Illnesses

*Major Goals: This proposal aims to test the effectiveness of a peer-delivered intervention to assist adults with serious mental illnesses in identifying the resources necessary to enhance their community participation.

*Status of Support: Pending

Project Number:

Name of PD/PI: McCormick

*Source of Support: Administration on Community Living

*Primary Place of Performance:

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 09/2025

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------------|-----------------------|
| 1. 2022 | 0.6 |
| 2. 2023 | 0.6 |
| 3. 2024 | 0.28 |
| 4. 2025 | 0.6 |
| 5. [enter year 5] | |

COMPLETED (Last 3 Years)

***Title:** Enhancing Community Participation for Adults with Autism Spectrum Disorders through Peer-Mediated Transportation Interventions

***Major Goals:** This study examined the effectiveness of a peer-delivered travel training program for autistic adults.

***Status of Support:** Completed

Project Number: 90IFRE0013-01-00

Name of PD/PI: Elizabeth Pfeiffer

Name of Individual: Mark Salzer,
Ph.D. Commons ID: Salzer

***Source of Support:** Administration on Community Living

***Primary Place of Performance:** Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2018 – 09/2021

***Title:** Increasing Community Participation in Young Adults with Autism Living in Rural Communities

***Major Goals:** This study examined non-peer delivered intervention aimed at enhancing community participation among autistic adults in rural communities.

***Status of Support:** Completed

Project Number: 90IFRE0018

Name of PD/PI: Amanda Pearl

***Source of Support:** Administration on Community Living

***Primary Place of Performance:** Penn State University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2018 – 09/2021

IN-KIND

n/a

***Overlap** (summarized for each individual): There is no overlap. If pending projects are funded, PI will reduce effort on active awards to ensure effort does not exceed 12 calendar months

I, PD/PI or other senior/key personnel, certify that the statements herein are true, complete and accurate to the best of my knowledge, and accept the obligation to comply with Public Health

Services terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.

**Other Support
Vannes, David**

ACTIVE

*Title: Nurse AMIE: Addressing Metastatic Individuals Everyday in Rural PA and WV Major Goals: The goal of this project is to assess the survival benefits of a high-quality technology based supportive care platform among 344 underserved, low income patients with metastatic cancer living in rural Pennsylvania or West Virginia.

*Status of Support: Active

Project Number: 5 R01 CA254659-02

Name of PD/PI: Schmitz, Kathryn

Source of Support: National Cancer Institute

Primary Place of Performance: On Campus

Project/Proposal Start and End Date: (MM/YYYY) (if available): 06/2021-04/2023

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 1.2 |
| 2. 2023 | 1.2 |

PENDING

Title: Using Multiphase Optimization Strategy (MOST) to Optimize a Cost-effective, Sustainable and Scalable Smoking Cessation Package for Smokers in HIV Clinical Care

Goals: This study will utilize Multiphase Optimization Strategy (MOST) to optimize smoking cessation treatment for HIV clinical care by directly targeting patient barriers to quitting and clinical care barriers to reaching and effectively treating a broad heterogeneous population of smokers living with HIV. Given that over 75% of the 1.2 million persons living with HIV in the U.S. receive HIV clinical care annually, the results of this study will have a significant public health impact by optimizing a cost-effective, sustainable and immediately scalable smoking cessation package tailored specifically for the HIV clinical care context. Findings will also add to scientific knowledge by providing a clear basis for further improvement of cessation interventions for smokers living with HIV.

Status of Support: Pending

Project Number: R01

Name of PD/PI: Cantrell, Jennifer

*Source of Support: NIH

*Primary Place of Performance: NYU

Project/Proposal Start and End Date: (MM/YYYY) (if available):

* Total Award Amount (including Indirect Costs):

* Role: Consultant

* Fee:

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | |
| 2. 2023 | |
| 3. 2024 | |
| 4. 2025 | |
| 5. 2026 | |

Title: Optimizing evidence-based HIV prevention targeting people who inject drugs on PrEP

Goals: The goal is to assess the performance of four intervention components (Attention, Executive Functioning, Memory, and Information Processing) aimed at enhancing the ability of PWID on MOUD to process and utilize evidence-based HIV prevention content, leading to improvements in Pre-Exposure Prophylaxis (PrEP) adherence and HIV risk reduction. This innovative trial will be the first to use the MOST framework to optimize an evidence-based HIV prevention approach by compensating for cognitive features that are characteristic of PWID on MOUD, and maximizing PrEP adherence outcomes within real world budget constraints.

Status of Support: Pending

Project Number: R01

Name of PD/PI: Copenhaver, Michael

*Source of Support: NIH

*Primary Place of Performance: University of Connecticut

Project/Proposal Start and End Date: (MM/YYYY) (if available):

* Total Award Amount (including Indirect Costs):

*Role: Consultant

*Fee:

*Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | |
| 2. 2023 | |
| 3. 2024 | |
| 4. 2025 | |
| 5. 2026 | |

IN-KIND

*Summary of In-Kind Contribution: To provide in kind guidance of proposed project with methods and econometrics, providing feedback on the analytical design and plan, and on the interpretation of study results from a methodological perspective. Project title: 1 R01 MD017495-01 (PI: Hsuan, Charleen) Structural Racism and Discrimination in Emergency Department Transfers: Unintended Consequences of the Emergency Medical Treatment and Labor Act (EMTALA)

*Status of Support: Active

*Primary Place of Performance: Pennsylvania State University, University Park, PA

Project/Proposal Start and End Date (MM/YYYY) (if available): 05/2022-12/2026

*Person Months (Calendar/Academic/Summer) per budget period

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 0.6 |
| 2. 2023 | 0.6 |
| 3. 2024 | 0.6 |
| 4. 2025 | 0.6 |
| 5. 2026 | 0.6 |

***Overlap** (summarized for each individual): None.

I, PD/PI or other senior/key personnel, certify that the statements herein are true, complete and accurate to the best of my knowledge, and accept the obligation to comply with Public Health Services terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.

**Other Support
Lee, Brian**

ACTIVE

Title: Catalyzing Systemic Change at Drexel University to Support Diverse Faculty in Health Disparities Research

Major Goals: The major goals of this grant are to create a collaborative structure involving multi-level inputs from University leaders, academic units and faculty to catalyze sustainable institutional change that supports scientific and inclusive excellence in the conduct of health disparities research.

Status of Support: Active

Project Number: 1U54CA267735-01

Name of PD/PI: Diez Roux, Ana (Contact) & Gitlin, Laura (MPI)

Source of Support: NCI

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: 09/2021 – 08/2026

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2021 | 0.0 calendar (mentor) |
| 2. 2022 | 0.0 calendar (mentor) |
| 3. 2023 | 0.0 calendar (mentor) |
| 4. 2024 | 0.0 calendar (mentor) |
| 5. 2025 | 0.0 calendar (mentor) |

Title: Community participation, service needs, and health outcomes among adults with autism

Major Goals: The major goal of this project is to capture a longitudinal trajectory of participation experiences and preferences of adults with ASD and examine the overall service utilization and contextual factors that are associated with participation over time, by building upon large, existing data sets.

Status of Support: Active

Project Number: W81XWH2010435

Name of PD/PI: Shea, Lindsay

Source of Support: Department of Defense

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2020 – 06/2023

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2020 | 0.84 calendar |

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 2. 2021 | 0.84 calendar |
| 3. 2022 | 0.84 calendar |

Title: Psychotropic medication use in persons with autism in the national U.S. population

Major goals: The goal of this project is to provide current estimates of use of psychotropic medications, and predictors thereof, in children and adults with autism spectrum disorder (ASD) across the U.S. Psychotropic medications (those that affect brain function) are often prescribed to persons with ASD.

Status of Support: Active

Project Number: 4100085747

Name of PD/PI: Lee, Brian

Source of Support: Pennsylvania Department of Health CURE grant

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 06/2020 - 06/2022

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2020 | 0.0 calendar |
| 2. 2021 | 0.6 calendar |

Title: Maternal epilepsy, antiepileptic drug use during pregnancy, and risk of autism

Major goals: The goals of this bi-national project are to estimate the risk of child ASD associated with maternal epilepsy, maternal anti-epileptic drug use during pregnancy, and to conduct risk/risk reduction analyses of adverse pregnancy and delivery outcomes associated with maternal anti-epileptic drug use.

Status of Support: Active

Project Number: R01 NS107607-01A1

Name of PD/PI: Lee, Brian (Contact), Magnusson, Cecilia (MPI) and Rai, Dheeraj (MPI)

Source of Support: NIH

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 06/2019 - 04/2023

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2019 | 3.6 calendar |
| 2. 2020 | 3.6 calendar |
| 3. 2021 | 3.6 calendar |
| 4. 2022 | 3.6 calendar |

Title: Autism Services, Education, Resources and Training Collaborative (ASERT)

Major goals: The goal of this project is to improve access to autism resources in Pennsylvania.

Status of Support: Active

Project Number:

Name of PD/PI: Shea, Lindsay

Source of Support: Commonwealth of Pennsylvania, DHHS, Bureau of Autism Services

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2019 - 06/2023

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2019 | 0.6 calendar |
| 2. 2020 | 1.2 calendar |
| 3. 2021 | 1.2 calendar |
| 4. 2022 | 1.2 calendar |

PENDING

*Title: Public health and autism science advancing equitable strategies across the life course (PHASES)

*Major Goals: Investigate modifiable health determinants, inequities in health and health services, and examine relationship between health service delivery and health outcomes for autistic individuals across the life span.

*Status of Support: Pending

Project Number: P50HD111142

Name of PD/PI: Robins, D.L./Schendel, D.

*Source of Support: NIH

*Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 7/2022-6/2027

* Total Award Amount (including Indirect Costs):

* Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 1.2 calendar |
| 2. 2024 | 1.2 calendar |
| 3. 2025 | 1.2 calendar |
| 4. 2026 | 1.2 calendar |
| 5. 2027 | 1.2 calendar |

Title: Safety and Evaluation of Psychotropic Treatments in Autism: the SEPTA Study

Major Goals: The major goals of this grant are to evaluate the cardiometabolic outcomes of autistic youth who use psychotropic medications.

Status of Support: Pending

Project Number: 1R01MH129400-01A1

Name of PD/PI: Lee, Brian

Source of Support: NIMH

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: 12/2022 – 11/2026

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2022 | 3.6 calendar |
| 2. 2023 | 3.6 calendar |
| 3. 2024 | 3.6 calendar |
| 4. 2025 | 3.6 calendar |

Title: LEGENNDS: Linking Epidemiology and GENetics of Neurodevelopmental and Neurodegenerative Disorders Study

Major Goals: Evaluate the link between neurodevelopmental disorders of ASD, ADHD, and ID with later life neurodegenerative disorders of Alzheimer's disease or related dementia, Parkinson's disease, and amyotrophic lateral sclerosis.

Status of Support: Pending

Project Number: 1R01 000000-00

Name of PD/PI: Lee, Brian

Source of Support: NIH

Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: 04/2023 – 03/2028

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period.

| Year (YYYY) | Person Months (##.##) |
|-------------|-----------------------|
| 1. 2023 | 2.4 calendar |
| 2. 2024 | 2.4 calendar |
| 3. 2025 | 3.0 calendar |
| 4. 2026 | 3.0 calendar |
| 5. 2027 | 3.0 calendar |

IN-KIND

N/A

Overlap (summarized for each individual):

If the present application is funded, there is no budgetary, scientific, or effort overlap with any of my current or pending projects.

I, PD/PI or other senior/key personnel, certify that the statements herein are true, complete and accurate to the best of my knowledge, and accept the obligation to comply with Public Health Services terms and conditions if a grant is awarded as a result of this application. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.