

AWARD NUMBER: W81XWH-20-1-0435

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

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CONTRACTING ORGANIZATION: Drexel University, Philadelphia, PA

REPORT DATE: July 2023

TYPE OF REPORT: Annual

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

DISTRIBUTION STATEMENT: Approved for Public Release;
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REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
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1. REPORT DATE July 2023		2. REPORT TYPE Annual		3. DATES COVERED 01Jul2022-30Jun2023	
4. TITLE AND SUBTITLE Community Participation, Service Needs, and Health Outcomes Among Adults with Autism				5a. CONTRACT NUMBER W81XWH-20-1-0435	
				5b. GRANT NUMBER AR190018	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Lindsay Shea, DrPH E-Mail: lj142@drexel.edu				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Drexel University 3141 Chestnut Street, Philadelphia PA, 19104				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Development Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT The research conducted through this award focuses on identifying and documenting self-reported community participation preferences and experiences of autistic adults. Participating in communities is critical to maximizing health, independence, and well-being, while minimizing feeling of loneliness, anxiety, and depression. Although autistic adults experience social and communication differences, their desire to be active within their communities is similar to non-autistic peers. Data, however, is needed to understand desired aspects of community participation in order to inform service and support planning that aligns with the self-reported preferences of autistic adults. It is also critical to capture how services utilized and other person-level factors are associated with differing levels of community participation and differing community activities of importance to understand existing barriers and facilitators. To remedy these gaps, this project surveyed autistic adults who participated in the Pennsylvania Autism Needs Assessment (PANA) (one of the largest existing studies with autistic adults) over two additional survey waves to create three distinct time-points for longitudinal and cross-sectional analyses. As respondents in one of the largest states, PANA participants represent a diverse pool of autistic adults with varying gender identities, race and ethnicity, socioeconomic status, and urbanicity. Follow-up survey efforts included the Temple University Community Participation measure along with items relating to self-reported health, service use and barriers, relationships, and COVID-19 experiences to establish various factors that may impact a respondent's ability to participate in their community. This project is poised to provide landmark data on self-reported community participation experiences and preferences among autistic adults. Findings from this research will propel improvements to existing systems and spur new system interventions that support the community participation desires of autistic adults. The population of adults meeting diagnostic criteria for an autism diagnosis is growing, adding to the urgency of this research to support overall population public health. Findings from this project will also support the larger autism community, including families and caregivers of autistic adults, by highlighting community participation interests and supports that maximize independent living and community integration.					
15. SUBJECT TERMS None listed.					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT Unclassified	18. NUMBER OF PAGES 58	19a. NAME OF RESPONSIBLE PERSON USAMRDC
a. REPORT Unclassified	b. ABSTRACT Unclassified	c. THIS PAGE Unclassified			19b. TELEPHONE NUMBER (include area code)

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1. INTRODUCTION

Participating in communities is key to a healthy and fulfilling life, and despite differences in social and communication styles and abilities, autistic adults still yearn to be active within their communities. Services and supports that foster community integration for autistic adults are minimal, however, and existing efforts rarely account for participation barriers or nominated interests of autistic individuals. Our project leverages one of the largest primary data collection efforts of autistic adults, the Pennsylvania Autism Needs Assessment (PANA), to longitudinally survey autistic adults in order to document community participation, self-reported health, service use and barriers, relationships, and COVID-19 experiences to establish various factors that may impact a participant's ability to participate in their community. Two follow-up surveys will be administered to autistic adults who completed the PANA and agreed to future contact to create three time points for longitudinal and cross-sectional analyses. Study findings will help determine barriers and facilitators to community participation and self-reported areas of community interest to inform existing service systems and generate new opportunities and interventions that support community integration and independent living for autistic adults.

2. KEYWORDS

Autism, longitudinal survey, self-reported, community participation, health outcomes

3. ACCOMPLISHMENTS

- **What were the major goals of the project?**
 - Administer the Pennsylvania Autism Needs Assessment and Temple University Community Participation measure (by web-based, paper, or phone survey to accommodate respondent preference).
 - Target completion: Month 24
 - Actual completion: 100%
 - Description: At this time, all data has been collected from two survey waves. Both waves yielded sizeable samples of autistic adults from the Pennsylvania Autism Needs Assessment. For our second follow-up survey effort, consultations with our program officer and approval from our institutional review board yielded new opportunities to further increase the transferability and generalizability of these findings for individuals across the diverse autism spectrum. We asked respondents to the caregiver version of the Pennsylvania Autism Needs Assessment Survey to connect us with their autistic adult child/dependent to create an additional recruitment pool of self-reporting autistic adults.
 - Data Analysis
 - Target completion: Month 24
 - Actual completion: ~75%
 - Description: All data from our first survey wave has been analyzed, and data at our second survey has been formatted for all analyses. Some analyses of our final survey data, including a follow-up analysis to our published manuscript, "Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults" have been completed to generate results for a newly submitted manuscript titled "A spectrum of pandemic perspectives: Self-reported COVID-19 vaccine and booster acceptance and hesitancy among autistic adults". Currently, the study team is working through final

- longitudinal analyses of all survey waves and cross-sectional analyses of the final wave of survey data.
- Acquire and link small-area contextual data to Pennsylvania Autism Needs Assessment, Temple University Community Participation measure, and health service utilization outcomes.
 - Target completion: Month 27
 - Actual completion: 100%
 - Description: Included small-area contextual factors are described in our first published manuscript through this award's funding on COVID-19 vaccination and hesitancy. These include county population density and county-level 2020 presidential election results. This data was also applied to our final survey wave data and again revealed a significant impact on vaccination preferences for autistic adults.
- Medicaid Claims and Encounters Analysis
 - Target completion: Month 27
 - Actual completion: ~5%
 - Description: Pennsylvania Department of Human Services changed their protocols for acquiring consent for sharing of records, including Medicaid claims, after our survey was launched. We are exploring new opportunities to include Medicaid claims in the analysis, but also include information on health insurance and services received in our survey to approximate and account for service use.
- Publications and Dissemination
 - Target completion: Month 30
 - Actual completion: ~25%
 - Description: We have published one manuscript supported by this award in *Vaccine* focusing on COVID-19 vaccination status and views of autistic adults. A follow-up manuscript incorporating COVID-19 booster vaccines has been recently drafted and submitted for publication. Revisions to another manuscript on the impact of COVID-19 on community participation have been resubmitted to a journal for anticipated publication. Further papers are planned to look at specific areas of participation interests, changes in these areas over time, and associations with service use.

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

During the final report period we completed our final data collection effort, collecting a total sample of 229 respondents with completed surveys, including the TUCP measure. Following, study staff have been working to prepare and optimize the data for analyses and have generated initial reports for manuscript development. These include updated information on vaccination acceptance and hesitancy that newly includes autistic individuals' perceptions and willingness to receive a COVID-19 booster dose. A manuscript with these results has been recently drafted and submitted for publication, which will be the first study to date to explore COVID-19 booster vaccination acceptance among autistic adults. Another manuscript on COVID-19 impacts on community participation has been drafted and submitted for publication.

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

Over the prior reporting period Jonas Ventimiglia has taken the following courses and trainings to further bolster his data analysis skills to apply to project activities and objectives.

- *Data Leadership: Transforming the Corporation's Operations, Management, and Mindset to Leverage Data, AI, and Cloud Computing*, Professional Education, Massachusetts Institute of Technology
- *Survival Analysis using R*, Seminar, Statistical Horizons
- *Longitudinal Models using R*, Seminar, Statistical Horizons

- **How were the results disseminated to communities of interest?**

Nothing to report

- **What do you plan to do during the next reporting period to accomplish the goals?**

Over the final reporting period, we aim to draft, submit, and publish several manuscripts that answer the final research questions and aims of this award. We also plan on disseminating translatable materials to both the autism community and policymakers.

4. **IMPACT**

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

As community participation levels are reverting to pre-pandemic levels, potentially new areas of interest and importance along with new barriers and facilitators to community participation among autistic adults is a critical research topic. This information is important to autistic individuals and their families as they seek greater community integration and independent living. It is also relevant to policymakers who are developing community participation policies, including efforts embedded into Medicaid services as the state and federal level. Programs that capture the experiences and perspectives of autistic adults, and take into account their self-reported desires and interests can be implemented with maximum fidelity, which in turn can improve participation and health outcomes for autistic adults.

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

Collecting information on COVID-19 experiences and perspectives, including vaccination and booster acceptance, can inform public health responses that are aligned with the needs and motivations of vulnerable populations, including autistic individuals.

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

Nothing to report

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

Our analyses are illuminating landmark information on community participation patterns and preferences for autistic adults. We have documented evidence that autistic individuals who have experienced greater pandemic impacts are reporting significantly reduced levels of community participation. These findings further emphasize the need for individualized planning to support optimal community participation outcomes for autistic adults. Further upcoming analyses are poised to highlight participation areas of greatest importance and

participation access in these activities. Additional efforts will focus on service use impacts on community participation along with other barriers and facilitators.

5. CHANGES/PROBLEMS

- **Changes in approach and reasons for change**
 - After release of our survey instrument, the Pennsylvania Department of Human Services updated their protocol for acquiring consent to access and receive personal health records, including Medicaid claims. However, our survey instrument has other domains to capture self-reported service use along with health insurance type and use of any Medicaid HCBS waiver. Types of services are also asked, including counseling, therapy, employment, medical, behavioral and social interventions, and coordination services, along with needing additional services and barriers accessing service types. Using this information will allow us to still fulfill the service use aim of this award.

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

- **Changes that had a significant impact on expenditures**

Nothing to report

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

Nothing to report

- **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

- **Publications, conference papers, and presentations**

- **Journal publications**

- Accepted: 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>

- Submitted: A spectrum of pandemic perspectives: Self-reported COVID-19 vaccine and booster acceptance and hesitancy among autistic adults
 - Submitted: Exploring the relationship between COVID-19 and autistic adults' community participation: Findings from a two-timepoint longitudinal study
- **Books or other non-periodical, one-time publications**

Nothing to report
- **Other publications, conference papers, and presentations**
 - Song, W., Salzer, M., Becker, A., Cooper, D., Vanness, D., Lee, B., Shea, L. (2022). *How does the COVID-19 pandemic impact community participation of autistic adults?* [Conference presentation]. APHA 2022 Annual Meeting and Expo, Boston, MA, United States.
https://apha.confex.com/apha/2022/meetingapi.cgi/Paper/513781?filename=2022_Abstract513781.html&template=Word
- **Website(s) or other Internet site(s)**

Nothing to report
- **Technologies or techniques**

Nothing to report
- **Inventions, patent applications, and/or licenses**

Nothing to report
- **Other products**

Nothing to report

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

- **What individuals have worked on the project?**
 - Dr. Lindsay Shea
 - Project Role: Principal Investigator
 - Nearest person month worked: 2
 - Contribution to project: Oversaw all project activities and obtained appropriate approvals.
 - Jonas Ventimiglia
 - Project Role: Data Analyst
 - Nearest person month worked: 2
 - Contribution to project: Under supervision of the P-I, conducted all project data analyses.
 - Dylan Cooper

- Project Role: Project Manager
- Nearest person month worked: 2
- Contribution to project: Under supervision of the P-I, guided survey recruitment and implementation.
- Dr. Mark Salzer
 - Project Role: Community Participation Expert
 - Nearest person month worked: 1
 - Contribution to project: Guided analyses related to community participation and aided interpretation of community participation results.
- Dr. David Vanness
 - Project Role: Health Economist
 - Nearest person month worked: 1
 - Contribution to project: Informed survey structures to ensure proper data collection. Helped structure and interpret results of data analyses.
- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**

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 included as appendix 3 for reference.

- **What other organizations were involved as partners?**

Nothing to report

8. SPECIAL REPORTING REQUIREMENTS

- **COLLABORATIVE AWARDS:**

N/A

- **QUAD CHARTS:**

N/A

9. APPENDICES

Appendix 1 Wave 2 Instrument

Pennsylvania Autism Community Participation Assessment V2.0

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.

INSERT 501 consent form and 505 consent form for linking to Medicaid claims and Office of Vocational Rehabilitation records.

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?

- ☐ \$0-\$10,000
- ☐ \$10,001-\$20,000
- ☐ \$20,001-\$30,000
- ☐ \$30,001-\$40,000
- ☐ \$40,001-\$50,000
- ☐ \$50,001-\$60,000
- ☐ \$60,001-\$70,000

- \$70,001-\$80,000
- \$80,001-\$90,000
- \$90,001-\$100,000
- \$100,000+

*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)	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)					
2. Go to a restaurant or coffee shop.	_____ (# of Days)					
3. Go to a church, synagogue, or place of worship.	_____ (# of Days)					
4. Go to a movie.	_____ (# of Days)					
5. Go to a park or recreation center.	_____ (# of Days)					
6. Go to a theater or cultural event (including local school or club events, concerts, exhibits and presentations in the community).	_____ (# of Days)					
7. Go to a zoo, botanical garden, or museum.	_____ (# of Days)					
8. Go to run errands (for example, go to a post office, bank, Laundromat, dry cleaner).	_____ (# of Days)					
9. Go to a library.	_____ (# of Days)					
10. Go to <u>watch</u> a sports event (including bowling, tennis, basketball, etc.).	_____ (# of Days)					

11. Go to a gym, health or exercise club, including pool, or <u>participate</u> 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.	<u> </u> <u> </u> (# 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).	<u> </u> <u> </u> (# 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.	<u> </u> <u> </u> (# 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? <u> </u> <u> </u> (# of Days)	B. Do you do this activity? Enough Not Enough Too Much	C. Is this activity important to you? 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)? <u> </u> <u> </u> (# of Days)	B. Do you do this activity? Enough Not Enough Too Much	C. Is this activity important to you? Yes No
Get together with your child(ren)			

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.

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?	
Counseling Services (Mental Health Counseling, Relationship Counseling, and Drug and Alcohol Counseling)	Yes	No	Yes	No	Yes	No
Therapy Services (Speech / Language Therapy, Occupational Therapy, and Physical Therapy)	Yes	No	Yes	No	Yes	No
Employment (Supported Employment, Vocational Training, Benefits Counseling, Career Counseling)	Yes	No	Yes	No	Yes	No
Medical Services (Primary Health Care, Dental Care, Medication Management, Neurology Services)	Yes	No	Yes	No	Yes	No
Behavioral and Social Interventions (One-to-One Support, Behavioral Support, Social Skills Training, Sexual Health Education)	Yes	No	Yes	No	Yes	No
Coordination Services (Case management, Supports Coordination, Transition Planning)	Yes	No	Yes	No	Yes	No

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 Wave 2 Final Sample Demographics

	Caregiver Recruited (N = 141)		Autistic Adult Recruited (N = 128)	
	n	%	n	%
Gender / Sex				
Female	31	22%	32	25%
Male	109	77%	88	69%
Other	*	*	*	*
Missing (Not Reported)	*	*	*	*
Marital Status				
Married / Living with partner	17	12%	18	14%
Not Married / Not Living with partner	124	88%	110	86%
Race/Ethnicity				
Non-White	22	16%	21	16%
White	91	65%	97	76%
Missing (Not Reported)	27	19%	10	8%
Medical Insurance				
Private	79	56%	39	30%
Public	113	80%	84	66%
None (Not Reported)	*	*	*	*
Living Arrangement				
Family/Roommate	124	88%	99	77%
Independent or Other	16	11%	25	20%
Missing (Not Reported)	*	*	*	*
ZIP Code Urbanicity				
Metropolitan	94	67%	98	77%
Non-Metropolitan	12	9%	13	10%
Missing (ZIP Code Not Reported)	34	24%	17	13%
	median	IQR	median	IQR
Age (years)	26	11	32	24

Notes: Sample excludes respondents who completed less than 50 percent of survey questions.

ZIP Code Urbanicity from 2010 rural-urban commuting area (RUCA) codes.

Appendix 3 Other Support Documentation

Lindsay Shea

*Name of Individual: Shea, L.L.

Positions/Scientific Appointments (Last 5 years)

2020– Present	Interim Leader, Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA
2020 – Present	Associate Professor, A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA
2020 – Present	Board Member, University Research Computing Facility, Office of Research and Innovation, Drexel University
2019 – Present	Secondary Appointment, Department of Health Management and Policy, Dornsife School of Public Health, Drexel University, Philadelphia, PA
2018 – Present	Member, AcademyHealth
2017 – Present	Member, Association for Public Policy Analysis & Management
2016 – Present	Director, Center for Policy and Analytics, A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA
2014 – 2020	Assistant Professor, A.J. Drexel Autism Institute, Drexel University, Philadelphia, PA
2012 – 2020	Member, National Autism Leadership Collaborative
2010 – Present	Member, American Public Health Association
2006 – Present	Member, International Society for Autism Research

Project/Proposal

PREVIOUS

Title: Philadelphia Autism Network (PAN) – Self-Advocates (PAN-S)

Major Goals: Continuing the Philadelphia Autism Network series, the goal of this funding is to generate content and education geared towards aging autistic individuals. Content was shaped by autistic individuals' input, feedback from the previously funded PAN-S series, and data from various sources.

Specific Aims:

- Facilitate workshops with autistic speakers driven by autistic-led content and creating a space for discussion and connection.
- Provide translation and interpretation services to increase access.
- Implement evaluation surveys that assess participant satisfaction and knowledge gained.

Project Number: N/A

Name of PD/PI: W. Song, PI / Shea, L.L., Co-I

Source of Support: Eagles Autism Foundation

Source of Support Address:

Eagles Autism Foundation
One NovaCare Way,
Philadelphia, PA 19145

Contracting/Grants Officer: Kirsten Saraceni

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2022 – 12/2022

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Philadelphia Autism Network – Self-Advocates (PAN-S) Webinar Series

Major Goals: The goal of this project was to initiate development of a workshop series created by self-advocates, for self-advocates, while bridging the gap in supporting individuals on the Spectrum to

increase knowledge in a variety of areas. Content priorities were generated by individuals on the Spectrum and using data from the PA Autism Needs Assessment.

Specific Aims:

- Facilitate workshops focused on financial planning, relationships/sexuality, transportation, and employment.
- Assess participant satisfaction and knowledge gained via a two-prong approach: a pre and post-test and a workshop evaluation survey.

Project Number:

Name of PD/PI: Shea, L.L. – Co-I

Source of Support: Eagles Autism Foundation

Source of Support Address:

Eagles Autism Foundation
One NovaCare Way,
Philadelphia, PA 19145

Contracting/Grants Officer: Kirsten Saraceni

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2020 – 12/2021

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Educational Disparities Experienced by Individuals with Autism Spectrum Disorder

Major Goals: The purpose of this study was to use a mixed methods design to explore the educational experience of family members of Black autistic children groups as compared to family members of white autistic children about their experiences with the education system.

Specific Aims: To capture the educational experiences and document disparities of family members of Black autistic children as compared to white autistic children, a concurrent nested design will include the following activities:

1) Qualitative Method: Conducting semi-structured interviews with family members of children between ages 7-24 recruited from those who agreed to future research participation from the 2018 Pennsylvania Autism Needs Assessment (PANA).

2) Quantitative Method: Analyze survey data from the 2018 PANA of the interviewees.

Project Number: N/A

Name of PD/PI: Koffer Miller, K.H.-PI, Shea, L.L. – Co-I

Source of Support: Drexel University Rapid Response Research Fund

Source of Support Address:

Drexel University
3141 Chestnut Street,
Philadelphia, PA 19104

Contracting/Grants Officer: Gwynne Grasberger

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2020 – 12/2021

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: International Society for Autism Research 2020 Policy Brief: Autism and the Criminal Justice System

Major Goals:

Specific Aims:

Project Number: N/A

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

Source of Support: International Society for Autism Research

Source of Support Address:

INSAR

International Society for Autism Research
400 Admiral Blvd. | Kansas City, MO 64106

Contracting/Grants Officer: Jennifer Gentry

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2020 – 12/2020

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Community Autism Peer Support Training and Consultation

Major Goals: Develop and execute the Community Autism Peer Specialist (CAPS) Training Program, an initiative voted on by Philadelphia Autism Project stakeholders. This project includes hiring staff to serve as trainers, developing and providing training, and providing autism consultation.

Specific Aims:

- Support development and implementation of the CAPS Training Program, including curriculum refinement and maintenance.
- Support outreach, recruitment and communication with applicants.
- Provide autism-related consultation to service provider, including technical assistance and autism-related training.

Project Number: N/A

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

Source of Support: Community Behavioral Health (CBH)

Source of Support Address:

Community Behavioral Health (CBH)
801 Market Street
Philadelphia, PA 19107

Contracting/Grants Officer: Katy Kaplan

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2019 – 12/2020

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Exploring Feasibility of Merged Data Analysis Projects in Community-Based Autism Research

Major Goals: The objective of this project is to develop structured report to understand the potential for utilizing merged data analysis of administrative data bases and possibilities to enhance the information through primary data collection for understanding the lived experiences of individuals with Autism Spectrum Disorders in community-based settings. This information is crucial to consider advocating for garnering resources to support full analysis and research leveraging administrative and primary data collection.

Specific Aims: To socialize the concept of existing data analysis among researchers, policymakers, advocates, and funders in improving demand for access and utilization for these data sets.

Project Number: N/A

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

Source of Support: Autism Speaks

Source of Support Address:

Autism Speaks
P.O. Box 37148
Boone, IA 50037-0148

Contracting/Grants Officer:

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2020 – 12/2020

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Measuring Implementation of a Certified Peer Support Service for Transition Age Youth with Autism Spectrum Disorder

Major Goals: To evaluate the impact of peer support on the quality of life, utilization of behavioral health services, unmet needs, employment status and social communication skills of individuals with autism spectrum disorder (ASD).

Specific Aims:

- Leverage existing partnership with Community Behavioral Health (CBH) to establish evaluation priorities. The results of the UHC funding generated a specific evaluation process flow.
- Identify assessment battery composition.
- Implement evaluation processes with service provider.
- Establish a training partnership with CBH to fuel evaluation opportunities.
- Map dissemination pathways for evaluation results.

Project Number: N/A

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

Source of Support: Drexel University Urban Health Collaborative

Source of Support Address:

Urban Health Collaborative
Dornsife School of Public Health
Drexel University
3600 Market Street, 7th Floor
Philadelphia, PA 19104

Contracting/Grants Officer:

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2018 – 06/2019

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Philadelphia Autism Project Care Navigator Summit

Major Goals: The goal of this funding was to facilitate and host a Birth to Five System Navigator Summit to convene stakeholders representing family members and systems that serve children with autism and developmental disability diagnoses in the birth to five age range. The need for a system navigator was a top-voted initiative of the Philadelphia Autism Project. The goal of this Summit is for attendees to learn and provide feedback on existing service navigator models and discuss options and opportunities for creating a system navigator role for autism and developmental disability services.

Specific Aims:

- Facilitation of a 1-day Summit with relevant stakeholders to provide an overview of challenges and needs in a system navigation model, as well as an introduction to models in existence.
- Generation of a recommendation document that shared challenges and priorities in moving forward.
- Pre- and Post-Survey that assessed for what they hoped to gain by attending the Summit, knowledge increase, and interest in future involvement.

Project Number: N/A

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

Source of Support: Philadelphia Department of Public Health, Children with Special Health Care Needs

Source of Support Address:

Maternal, Child, and Family Health
1101 Market St., 9th floor
Philadelphia, PA 19107

Contracting/Grants Officer:

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2018 – 12/2018

Total Award Amount (including Indirect Costs):

Person Months (Calendar/Academic/Summer) per budget period. N/A
Overlap: None

Title: Evaluation of the Philadelphia Autism Centers for Excellence

Major Goals: The goal of this project was to examine the effectiveness and impact of the Philadelphia Autism Centers for Excellence across multiple domains. This publicly-funded evaluation helped Community Behavioral Health (CBH) through the Philadelphia Department of Behavioral Health and Intellectual disAbility Services (DBHIDS) to learn more about the experiences of individuals receiving autism services from local agencies that have been designated as Philadelphia Autism Centers of Excellence.

Specific Aims: The goals of the project were executed by using: analysis of Medicaid claims and encounter data, surveys of family members of individuals receiving services through the Philadelphia Autism Centers for Excellence, focus groups with the Philadelphia Autism Centers for Excellence staff and family members, targeted individual interviews, and chart audits. Agencies include Special People in Northeast (SPIN), the NorthEast Treatment Center (NET), and Child Guidance Resource Center (CGRC). The results of the evaluation provided guidance and concrete recommendations to improve the service experiences of individuals with autism and their families in the City of Philadelphia.

Project Number: N/A

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

Source of Support: Community Behavioral Health (CBH)

Source of Support Address:

Community Behavioral Health (CBH)

801 Market Street

Philadelphia, PA 19107

Contracting/Grants Officer: Katy Kaplan

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2016 – 12/2018

Total Award Amount (including Indirect Costs):

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

Overlap: None

Title: Cooking with Confidence for Individuals with Autism

Major Goals: The goal of this project is to support adults with ASD in gaining daily living culinary skills and to provide social engagement opportunities, in partnership with the Free Library of Philadelphia, and through hands-on cooking classes.

Specific Aims:

- Adapt the Free Library of Philadelphia's current Cooking with Confidence program, to consider the needs of autistic individuals.
- Individuals will gain two dimensions of skills and life tools. Hygiene, safety skills, and reading and executing a recipe will be the first dimension of skills taught based on best practice in culinary literacy. The second set of skills include the advancement of literacy, community engagement and dialogue around food, nutrition and culinary literacy. Individuals will experience accessing their community library, and meet peers, while also cooking affordable recipes and learning about the components of a nutritious meal.
- Gather feedback from participants to refine and offer future classes.

Project Number: N/A

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

Source of Support: Drexel University ExCITe Center

Source of Support Address:

ExCITe Center at Drexel University

3401 Market Street, Suite 100

Philadelphia, PA 19104

Contracting/Grants Officer:

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2017 – 06/2018
Total Award Amount (including Indirect Costs):
Person Months (Calendar/Academic/Summer) per budget period. N/A
Overlap: None

CURRENT

Title: Alternative Approaches to Supporting ASD Services for Young Adults

Major Goals: 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.

Specific Aims:

- 1) Compare Medicaid eligibility among adolescents with ASD, including the extent to which they remain eligible for Medicaid-funded services into adulthood compared with adolescents with intellectual disability.
- 2) Compare states with ASD-specific programs, those that serve individuals with ASD through programs established for ID, and states with no programs
- 3) Examine differences across states in changes in type and quantity of ambulatory, inpatient and residential services among Medicaid-eligible adolescents with ASD and adolescents with ID as they age into adulthood.
- 4) Conduct interviews with administrators and advocates in states with the most and least discrepant differences in enrollment and service use for adolescents with ASD and ID

Project Number: R01 MH 117653

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

Source of Support: NIH/NIMH

Source of Support Address:

NIH/NIMH Office of Science Policy, Planning, and Communications
6001 Executive Boulevard, Room 6200, MSC 9663
Bethesda, MD 20892-9663

Contracting/Grants Officer: Denise M. Juliano-Bult

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 (##.##)
1. 2019	0.60 calendar
2. 2020	0.60 calendar
3. 2021	0.60 calendar
4. 2022	0.60 calendar
5. 2023	0.60 calendar

Overlap: None

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

Major Goals: To develop efficient and validated measures of functional outcomes for adults with ASD across areas of employment, independent living, and social functioning

Specific Aims: Examine state-wide service use correlates of functional outcomes to establish the clinical utility and validity of the Adult Functioning Scale, now called the Relationships, Employment, Autonomy, and Life Satisfaction (REALS) Scale.

Project Number: 11923

Name of PD/PI: Mazefsky, C.

Source of Support: Autism Speaks

Source of Support Address:

Autism Speaks
1060 State Road, 2nd Floor
Princeton, NJ 08540

Contracting/Grants Officer: Joan L. New

Project/Proposal Start and End Date: (MM/YYYY) (if available): 03/2020 – 08/2023

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2021	1.2 calendar
2. 2022	1.2 calendar
3. 2023	0.0 calendar

Overlap: None

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.

Specific Aims: We will analyze secondary Medicaid (2008-2019) and Medicare (2014-2016) data to understand how people with autism interact with Medicaid and Medicare across the lifespan and how these interactions relate to later health outcomes. We will use bivariate and multivariate analysis to address the following three research aims: 1) to examine patterns of enrollment, service participation, and expenditures among Medicaid enrollees with autism across the lifespan, 2) to identify changes in the distribution of characteristics and health-related needs among Medicaid enrollees with autism relative to individuals with intellectual disability, other chronic conditions, and other Medicaid enrollees; and 3) to explore underlying factors that influence service use patterns and trends.

Project Number: UT2MC39440

Name of PD/PI: Kuo, A.

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

Source of Support Address:

University of California Los Angeles (UCLA),
Office of Contract and Grant Administration (OCGA),
10889 Wilshire Boulevard, Suite 700,
Los Angeles, CA 90095-1406

Contracting/Grants Officer: UCLA Subaward Officer, Mellani Nolan

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 (##.##)
1. 2021	1.70 calendar
2. 2022	1.70 calendar
3. 2023	0.24 calendar
4. 2024	0.24 calendar
5. 2025	1.20 calendar

Overlap: None

Title: Community Participation Experiences of Autistic Adults

Major Goals: 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.

Specific Aims:

- 1) Examine how participation frequency, volume, type, preferences, and satisfaction change over time.
- 2) Identify key barriers to and facilitators of community participation among adults with ASD.
- 3) Examine how participation is associated with overall service utilization and health outcomes

Project Number: W81XWH-20-1-0435

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

Source of Support: U.S. Department of Defense

Source of Support Address:

USA Med Research ACQ Activity

820 Chandler St

Fort Detrick, MD 21702-50147

Contracting/Grants Officer:

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. 2021	2.04 calendar
2. 2022	2.04 calendar
3. 2023	2.04 calendar

Overlap: None

Title: Philadelphia Autism Project

Major Goals: To support autistic individuals and families living in Philadelphia through education, connections, and innovation.

Specific Aims:

- Support the execution of community events as needed.
- Resource hub management and outreach.
- Utilization of data to drive training, events and resource development.
- Other mechanisms to meet community needs and implement initiatives, including seed award funding, annual conference, workgroup meetings and Advisory Board meeting facilitation.

Project Number: N/A

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

Source of Support: Philadelphia Department of Behavioral Health and Intellectual disability Services

Source of Support Address:

1011 Market St.

Suite 700

Philadelphia, PA 19107

Contracting/Grants Officer: Valarie Oulds

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022 – 06/2023

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	0.60 calendar

Overlap: None

Title: The effectiveness of an autistic-delivered peer-support intervention for autistic adults: Community Autism Peer Specialist 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.

Specific Aims:

- 1) Enhance the structure of a pilot autistic-peer delivered intervention (Community Autism Peer Specialists, or CAPS) that is currently in use as a Medicaid-reimbursed service in Philadelphia.
- 2) Conduct a hybrid type 1 effectiveness-implementation randomized controlled trial with 40 young autistic adults to test the feasibility and acceptability of the intervention and research procedures, while also examining proposed target mechanisms of action (e.g., self-efficacy, working alliance, perceived social support) and clinical outcomes such as community participation, loneliness, and resilience.

Project Number: R34 MH 130830

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

Source of Support: NIH/NIMH

Source of Support Address:

NIH/NIMH Office of Science Policy, Planning, and Communications
6001 Executive Boulevard, Room 6200, MSC 9663
Bethesda, MD 20892-9663

Contracting/Grants Officer: Jennifer Humensky

Project/Proposal Start and End Date: (MM/YYYY) (if available): 08/2022 – 06/2025

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	1.80 calendar
2. 2024	1.80 calendar
3. 2025	1.80 calendar

Overlap: None

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.

Specific Aims:

- 1) Investigate modifiable health determinants of autistic individuals
- 2) Evaluate inequities in health and health services, especially under-represented minorities and economically disadvantaged persons on the autism spectrum
- 3) Examine the relations between health services delivery and health outcomes

Project Number: P50 HD 111142

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

Source of Support: NIH/NICHHD

Source of Support Address:

NIH/NICHHD Information Resource Center
P.O. Box 3006
Rockville, MD 20847

Contracting/Grants Officer: Alice S. Kau

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/30/2022 – 08/31/2027

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	3.72 calendar
2. 2024	3.72 calendar
3. 2025	3.40 calendar

Year (YYYY)	Person Months (##.##)
4. 2026	3.40 calendar
5. 2027	3.40 calendar

Overlap: One of the PHASES projects will examine health trajectories among adolescent and young adult Medicaid enrollees, comparing autistic to 1) non-autistic enrollees without intellectual disability and 2) non-autistic enrollees with intellectual disability. The proposed project overlaps with this PHASES project in data sources, age group of interest, and statistical models used to estimate trajectories across health conditions. The proposed project differs from the PHASES project in its focus on demographic factors and social determinants of health associated with *within* autism heterogeneity in health trajectories across age groups, and in its application of life course epidemiology models to study these relationships.

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.

Specific Aims:

- 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
- 3) Capacity building for equity impact within (a) Title V programs and (b) minority-serving institutions and community colleges

Project Number: UT6MC45902-01-00

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

Source of Support: U.S. Health Resources and Services Administration (HRSA)

Source of Support Address:

HRSA Headquarters
5600 Fishers Lane
Rockville, MD 20857 USA

Contracting/Grants Officer: Stephannie Young

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2022 – 08/2027

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	2.40 calendar
2. 2024	2.40 calendar
3. 2025	2.40 calendar
4. 2026	2.40 calendar
5. 2027	2.40 calendar

Overlap: None

Title: ‘LEGENDS: Linking Epidemiology and Genetics of Neurodevelopmental and Neurodegenerative Disorders Study’

Major Goals: To characterize the natural history, familial aggregation and genetic links between neurodevelopmental and later life neurodegenerative disorders, and identify potential targets for intervention that may mitigate risk for neurodegenerative disorders.

Specific Aims:

- 1) Characterize the natural history of autism (ASD), attention-deficit hyperactive disorder (ADHD), and intellectual disability (ID), dementia (ADRD), Parkinson’s disease (PD), and amyotrophic lateral sclerosis (ALS)

- 2) Characterize the familial aggregation of the above listed disorders
- 3) Explore genetic links between neurodevelopmental and later life neurodegenerative disorders
- 4) Identify potential targets for intervention that may mitigate risk

Project Number: R01 NS 131433

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

Source of Support: NIH/NIA, NINDS

Source of Support Address:

NIH Neurological Institute

P.O. Box 5801

Bethesda, MD 20824

Contracting/Grants Officer: Rebecca Eve Hommer

Project/Proposal Start and End Date: (MM/YYYY) (if available): 05/01/2023 – 04/30/2028

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	1.20 calendar
2. 2025	1.20 calendar
3. 2026	1.20 calendar
4. 2027	1.20 calendar
5. 2028	1.20 calendar

Overlap: We recently received funding for 1R01NS131433-01 (LEGENDS) which I will start pulling 1.2 calendar months on once 5R01MH117653 (Alternative Approaches) ends in June 2023. I will also be reducing my effort on 5UT2MC39440 (AIR-P) to accommodate this additional funding source. 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.

PENDING

Title: Program Evaluation of Pilot Program providing Intensive Mobile Treatment Services for Youth and Young Adults with Intellectual/Developmental Disabilities (IMTS-IDD)

Major Goals: To undertake a program evaluation that will include activities related to gathering, reviewing, and utilizing youth and family feedback for continuous quality improvement throughout the pilot of the Intensive Mobile Treatment Services for Youth and Young Adults with Intellectual/Developmental Disabilities (IMTS-IDD). This pilot is offered by the New Jersey Department of Children and Families' (DCF) Children's System of Care (CSOC) and provides services to eligible youth ages 5-20 years old with intellectual/developmental disabilities (I/DD) who present with complex, challenging behavior and/or co-occurring mental health conditions.

Specific Aims: PAC at Drexel will conduct in-depth interviews with families over the course of the intervention, and potentially after the intervention for those youth who exit the program prior to 24 months. PAC will interview the families at baseline and then at 12 months and 24 months. PAC will work with COI and CSOC colleagues to identify the appropriate number and nature of interviews, with plans to interview one member of each participating family consistently.

Project Number: Not available

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

Source of Support: Rutgers University / New Jersey Department of Children and Families

Source of Support Address:

Department of Children and Families

P.O. Box 729

Trenton, NJ 08625-0729

Contracting/Grants Officer: Margaret Koller

Project/Proposal Start and End Date: (MM/YYYY) (if available): 01/2023 – 12/2024

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	1.80 calendar
2. 2024	1.80 calendar

Overlap: None

Title: Opioid Use, Prenatal Care, and Outcomes among Medicaid-Insured Pregnant Women and Infants

Major Goals: The goal of this project is to examine opioid use disorder among pregnant women using a mixed method approach with merged Medicaid and Census-based Area Deprivation Index Data.

Specific Aims:

1) examine national patterns and multilevel predictors of prenatal health care service use, maternal health, birth outcomes, and infant health 1-year post-birth among pregnant women with and without opioid use disorder who are insured by Medicaid to identify multilevel predictors of substance use treatment and modifiable targets of intervention.

Project Number: Not available

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

Source of Support: University of Pennsylvania / NIH

Source of Support Address:

National Institutes of Health

6555 Rock Spring Dr,

Bethesda, MD 20817

Contracting/Grants Officer: Not Available

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2023 – 08/2027

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	1.80 calendar
2. 2025	1.80 calendar
3. 2026	1.80 calendar
4. 2027	1.80 calendar

Overlap: None

Title: Advancing Health Equity Through Innovative Community Capacity Building, Data Science, and Delivering Community-Centered Structural Interventions & Outcomes: Drexel's ComPASS Coordinating Center (C3)

Major Goals: To create, coordinate, and sustain an NIH Community of Practice focused on community centered outcomes research (CCOR)

Specific Aims:

1) promote and synergize the conduct, coordination, and training of rigorous and policy-relevant transdisciplinary research

2) focus on solutions generated by community-based organizations and NIH-defined health disparity populations, underrepresented in federal research ecosystems by enhancing research capacity

3) developing and delivering flexible team-based, multimodal capacity-building activities

4) executing sophisticated data science-driven evaluation and dissemination strategies

5) establishing a ComPASS and CCOR Community of Practice

Project Number: Not available

Name of PD/PI: Carroll-Scott, A.

Source of Support: NIH/NINR

Source of Support Address:

National Institute of Nursing Research
31 Center Drive, Room 5B03
Bethesda, MD 20892-2178

Contracting/Grants Officer: Not available

Project/Proposal Start and End Date: (MM/YYYY) (if available): 10/2023 – 09/2028

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	1.80 calendar
2. 2025	1.80 calendar
3. 2026	1.80 calendar
4. 2027	1.80 calendar
5. 2028	1.80 calendar

Overlap: None

Title: Improving Mental Health Service Delivery to Autistic Birthing Women

Major Goals: To generate the most substantive work to date to support the improvement, design, and implementation of mental health care for autistic women during the pregnancy and postpartum periods. This will be accomplished by using surveys and interviews of obstetric service providers identified through Medicaid claims, and by using 2018-2026 national Medicaid claims linked to community-level information about social determinants of health, state Medicaid policy data, and other data sources.

Specific Aims: Identify modifiable mechanisms of mental health service delivery to autistic women during pregnancy and postpartum and to examine subsequent mental health and health outcomes among them and their infants, in comparison to peers without ASD.

Project Number: R01 MH 130379

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

Source of Support: National Institute of Mental Health

Source of Support Address:

National Institute of Mental Health
Office of Science Policy, Planning, and Communications
6001 Executive Boulevard, Room 6200, MSC 9663
Bethesda, MD 20892-9663

Contracting/Grants Officer: Not available

Project/Proposal Start and End Date: (MM/YYYY) (if available): 12/2023 – 11/2028

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	3.00 calendar
2. 2025	2.40 calendar
3. 2026	2.40 calendar
4. 2027	2.40 calendar
5. 2028	2.40 calendar

Overlap: None

Title: Leveraging claims data to compare disparities in health outcomes for autistic people and people with Down syndrome

Major Goals: This is an administrative supplement to the active grant P50111142. The supplement aims to use Medicaid and Medicare claims data to examine occurrences of epilepsy and dementia among individuals with Down syndrome compared to those with autism.

Specific Aims:

1. Compare the incidence and prevalence of epilepsy and ADRD among adults with ASD+ID and adults with DS.
2. Contrast the course of functional decline and mortality in adults with ASD+ID and those with DS after a diagnosis of epilepsy and/or ADRD.
3. Examine differences between subgroups defined by race/ethnicity and sex in Aims 1 and 2.

Project Number: 3P50HD111142-01

Name of PD/PI: Robins, D.L. & Schendel D. are PIs of the parent grant; Co-I Shea will be leading this supplement.

Source of Support: National Institute of Child Health and Development

Source of Support Address:

National Institute of Child Health and Development

P.O. Box 3006

Rockville, MD 20847

Contracting/Grants Officer: Jill Rogers

Project/Proposal Start and End Date: 9/2023-8/2024 Total

Award Amount (including Indirect Costs):

Year (YYYY)	Person Months (##.##)
1. 2024	0 calendar

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

IN-KIND

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

*Source Support: Community Autism Peer Support (CAPS)

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

*Estimated Dollar Value of In-Kind Information:

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

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

*Source of Support: The Philadelphia Family Navigator Project

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

*Estimated Dollar Value of In-Kind Information:

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

I, PD/PI or other senior/key personnel, certify that the statements herein are true, complete and accurate to the best of my knowledge, agree to update such disclosure at the request of the agency prior to the award of support and at any subsequent time the agency determines appropriate during the term of the award and accept the obligation to comply with Section 223(a) of the William M. (Mac) Thornberry National Defense Authorization Act for Fiscal Year 2021. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties.

Mark Salzer

*Name of Individual: Mark Salzer Commons
ID: Salzer

Other Support – Project/Proposal

*Title: Delaware TTA Contract

*Major Goals: The Temple University Collaborative on Community Inclusion will conduct training and provide technical assistance that promotes the use of evidence-based practices in five Peer Centers (Two Ace Resource Centers - MHP; Hopes and Dreams Resource Center - Brandywine Counseling & Community Services, Inc.; Creative Vision Factory and the Canby Park drop-in center – Horizon House) and with peer specialists in various agencies and positions that leads to prepared and resilient communities.

*Status of Support: Active Project

Number: 35-06-22-003 Name of

PD/PI: Salzer

*Source of Support: State of Delaware/DHHS

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 7/2022-6/2023

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2022	0.96 Cal
5. 2023	0. 96 Cal

*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): 9/2021-9/2024

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2022	0.24

2. 2023	0.24
3. 2024	0.24

***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

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: 5820-1333-00-A 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): 09/2021-9/2024

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
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2.	2023	0.36
3.	2024	0.36

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

***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

***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 (##.##)
2. 2023	0.3
3. 2024	0.1
4. 2025	0.1

***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

* 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

***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:** Active Project

Number: 900252

Name of PD/PI: Shea and Salzer

***Source of Support:** NIH/NIMH

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

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

* 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

***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: Active

Project Number: HHS-2023-ACL-NIDILRR-IFRE-0000

Name of PD/PI: Elizabeth 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.

Year (YYYY)	Person Months (##.##)
2. 2023	0.84
3. 2024	0.84
4. 2025	0.84

***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: Active

Project Number: 90IFRE0061-01-00 Name of

PD/PI: McCormick

*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 (##.##)
2. 2023	0.36
3. 2024	0.36
4. 2025	0.36

***Title:** Eastpointe Technical Assistance

*Major Goals: Dr. Salzer leads technical assistance and training efforts in NC to assist in the promotion of community inclusion policies, programs, and practices.

*Status of Support: Active

Project Number: 490743

Name of PD/PI: Salzer

*Source of Support: Eastpointe

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 07/2022-06/2023

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
2. 2023	1.2

***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.

*Status of Support: Pending

Project Number: HHS-2023-ACL-NIDILRR-IFRE-0000

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): 9/30/23 – 9/29/26

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
2. 2023	1.2
3. 2024	1.2
4. 2025	1.2
5. 2026	1.2

***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.

*Source of Support: Drexel University (Administration on Community Living)

*Primary Place of Performance: Drexel University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 9/30/23 – 9/29/26

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
2. 2023	1.2
3. 2024	1.2
4. 2025	1.2
5. 2026	1.2

***Title:** Temple University RRTC on Community Living and Participation of Individuals with Serious Mental Illnesses

***Major Goals:** This proposal supports Temple’s Rehabilitation Research and Training Center to expand knowledge on how environmental factors can improve community living and participation among people with SMI as well as advance the development of interventions to maximize community living and participation of individuals with SMI through rigorous research.

***Status of Support:** Pending

Project Number: HHS-2023-ACL-NIDILRR-RTCP-0023

Name of PD/PI: Salzer

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

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

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2023-08/2028

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	4.8
2. 2025	4.8
3. 2026	4.8
4. 2027	4.8
5. 2028	5.4

***Title:** Rehabilitation Research and Training Center (RRTC) on Aging Among Adults with Serious Mental Illnesses

***Major Goals:** This proposal supports research to advance a Lived Experience Research Network to support people with SMI into older adulthood.

***Status of Support:** Pending

Project Number: HHS-2023-ACL-NIDILRR-RTHF-0000

Name of PD/PI: Phil McCallion

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

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

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2023-08/2028

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	0.36
2. 2025	0.6
3. 2026	0.6
4. 2027	0.6
5. 2028	0.6

***Title:** Rehabilitation Research and Training Center (RRTC) on Community Living and Participation Among Transition Age Youth with Serious Mental Health Conditions From Disadvantaged, Vulnerable, or Marginalized Backgrounds

***Major Goals:** This proposal supports research to improve community living and participation outcomes for transition age youth with serious mental health conditions from disadvantaged, vulnerable or marginalized backgrounds.

***Status of Support:** Pending

Project Number: HHS-2023-ACL-NIDILRR-RTCP-0050

Name of PD/PI: Kathryn Sabella

***Source of Support:** Administration for Community Living/University of Massachusetts (Prime)

***Primary Place of Performance:** University of Massachusetts

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2023-08/2028

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2024	0.6
2. 2025	0.6
3. 2026	0.6
4. 2027	0.6
5. 2028	0.6

***Title:** Temple University College of Public Health Prevention Research Center

***Major Goals:** This proposal supports The College of Public Health at Temple University in establishing and maintaining a multi-disciplinary prevention center (Center) with an initial focus on reducing social isolation in an at-risk population, adults with SMI.

***Status of Support:** Pending Project

Number: RFA-DP-24-004 Name of

PD/PI: David Sarwer

***Source of Support:** National Center for Chronic Disease Prevention and Health

Promotion/CDC/DHHS

*Primary Place of Performance: Temple University

Project/Proposal Start and End Date: (MM/YYYY) (if available): 09/2024-09/2029

* Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2025	1.8
2. 2026	1.8
3. 2027	1.8
4. 2028	1.8
5. 2029	1.8

IN-KIND

***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.

David Vanness

*Name of Individual: David J Vanness
Commons ID: DVANNESS

Other Support – Project/Proposal

ACTIVE

*Title: Structural Racism and Discrimination in Emergency Department Transfers: Unintended Consequences of the Emergency Medical Treatment and Labor Act (EMTALA)

Major Goals:

*Status of Support: Active

Project Number: 1 R01 MD017495-01

Name of PD/PI: Hsuan, Charleen

Source of Support: National Center on Minority Health and Health Disparities

Primary Place of Performance: On Campus

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

*Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
1. 2023	0
2. 2024	0
3. 2025	0
4. 2026	0

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	(fee)
2. 2023	(fee)
3. 2024	(fee)
4. 2025	(fee)
5. 2026	(fee)

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	(fee)
2. 2023	(fee)
3. 2024	(fee)
4. 2025	(fee)
5. 2026	(fee)

PENDING

NONE

IN-KIND

NONE

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

NONE

Brian Lee

Name of Individual: Brian Lee Commons
ID: BKLEE1

Other Support

ACTIVE

Title: Public Health and Autism Science advancing Equitable Strategies across the life course (PHASES)

Major Goals: This study Center uses an integrated public health research framework to characterize and mitigate health inequities in vulnerable subgroups on the autism spectrum.

Status of Support: Pending

Project Number: 1P50HD111142-01

Name of PD/PI: Robins, Diana Source of

Support: NIH

Primary Place of Performance: Drexel University Project/Proposal

Start and End Date: 09/06/2022 – 08/31/2027 Total Award Amount

(including Indirect Costs):

Project 002 Title: Leveraging Trajectories of Health and Services Use to Improve the Health of Autistic Young Persons

Project Total Award Amount (including Indirect Costs):

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

Project 003 Title: Advancing the System of Care for Autistic Older Adults

Project Total Award Amount (including Indirect Costs): Months

(Calendar/Academic/Summer) per budget period.

Year (YYYY)	Person Months (##.##)
1. 2023	0.6 calendar
2. 2024	1.8 calendar
3. 2025	1.8 calendar
4. 2026	1.8 calendar
5. 2027	1.8 calendar

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

Name of Individual: Brian Lee
Commons ID: BKLEE1

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 (##.##)
2. 2023	0.0 calendar (mentor)
3. 2024	0.0 calendar (mentor)
4. 2025	0.0 calendar (mentor)
5. 2026	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 (##.##)
3. 2023	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.

Name of Individual: Brian Lee
Commons ID: BKLEE1

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 - 06/2023 Total

Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
3. 2023	0.0 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 (NCE 04/2024)

Total Award Amount (including Indirect Costs):

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

Year (YYYY)	Person Months (##.##)
4. 2023	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

Name of Individual: Brian Lee
Commons ID: BKLEE1

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

Year (YYYY)	Person Months (##.##)
4. 2023	1.2 calendar

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

Major Goals: The major goal of this study is to determine whether certain neurodevelopmental disorders – autism, attention-deficit hyperactive disorder, and intellectual disability – may increase risk of later life neurodegenerative disorders such as dementia, Parkinson’s disease, and amyotrophic lateral sclerosis.

Status of Support: Active

Project Number: 1R01NS131433

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. 2024	2.4 calendar
2. 2025	2.4 calendar
3. 2026	3.0 calendar
4. 2027	3.0 calendar
5. 2028	3.0 calendar

IN-KIND

N/A

Overlap (summarized for each individual):

There is no overlap.

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.
