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 2021

TYPE OF REPORT: Annual Report

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

REPORT DOCUMENTATION PAGE

Form Approved
OMB No. 0704-0188

1. REPORT DATE	2. REPORT TYPE	3. DATES COVERED
July 2021	Annual Report	01Jul2020-30Jun2021

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)
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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
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 proposed research will focus on a large group of adults with autism spectrum disorder (ASD) and generate comprehensive data on their community participation preferences and experiences, with the goal of improving how services that support community engagement are designed and delivered. Meaningful participation in the community is a core component of living a healthy life. Studies show it is connected to increased feelings of well-being, improved quality of life, and better self-reported health, as well as decreased feelings of social isolation and reduced feelings of depression and anxiety. People with ASD may experience unique barriers to community participation due to social and communication differences as well as logistical barriers such as transportation. To date, very little research has gathered information directly from adults with ASD about their experiences or service use and as a result, we lack information to ensure that policies, systems, and programs are best set up to meet their needs.

First, we will survey adults who previously participated in the Pennsylvania Autism Needs Assessment (one of the largest studies of adults with ASD to date) and agreed to be contacted for future research. This efficient strategy for recruiting a diverse group who live in rural, urban, and suburban areas will allow us to observe differences across race/ethnicity, geographic location, gender, and socioeconomic status. Second, we will gather information to fill major gaps in our understanding of how to maximize the benefits of community-related services. By reporting on community participation experiences and preferences, we will provide the first evidence regarding the types of community activities adults with ASD are participating in, the community activities they value, and what additional services and supports they may need to increase access and participation. Third, we will use unique methods to conduct data analyses, linking Medicaid claims and survey data. This will allow us to evaluate service use among adults with ASD and will point to service development opportunities that can maximize community integration, including identifying service needs to ensure supports in the community are available and delivered.

By identifying community participation service use, experiences, and preferences among adults with ASD for the first time, we will lay the foundation for improving services and enhancing successful community integration. We will also contribute to a longer-term research agenda of developing interventions to address barriers and improve participation. This research will benefit individuals with ASD via increased access to community participation support and through the incorporation of these results into policies that impact the type and quantity of services available to them. Families and caregivers will benefit immediately and longer-term from a better understanding of the services, supports, and community activity opportunities that may help pave the way toward independent living and increase the quality of life of their family members.

15. SUBJECT TERMS

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
Unclassified	Unclassified	Unclassified	Unclassified	42	19b. TELEPHONE NUMBER *(include area code)*

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1. **INTRODUCTION:**

Programs and services supporting community participation among adults with autism spectrum disorder (ASD) are a critical part of comprehensive health services, but research about best practices to construct and deliver them is lacking. Our objective 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. This information can be used to inform policy formation and standards, specifically related to Medicaid services, since they are the primary payer for these types of services in the US. The information will be collected using surveys of autistic adults who had previously participated in the Pennsylvania Autism Needs Assessment. The surveys ask participants questions about their living arrangements, medical information, community participation, and other lifestyle questions.

2. **KEYWORDS:**

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

3. **ACCOMPLISHMENTS:**

What were the major goals of the project?

1. Administer the Pennsylvania Autism Needs Assessment and Temple University Community Participation measure (by web-based, paper, or phone survey to accommodate respondent preference).
    a. Target completion: Month 19
    b. Actual completion/% complete: 50%
    c. Description: As a longitudinal study design, the Pennsylvania Autism Needs Assessment and Temple University Community Participation measure are slated to be released to participants at two waves. Survey implementation required synthesizing both measures into a single survey instrument, which yielded an opportunity for additional items to capture community participation covariates and COVID-19 impact. Wave one has been distributed and accumulated a robust sample of autistic adults across Pennsylvania with preliminary demographic information from survey respondents to date presented in Appendix 1.
2. Data Analysis
    a. Target completion: Month 24
    b. Actual completion/% complete: ~25%

c. Description: Data analysis for the first survey wave is currently underway. Given the urgency that COVID-19 presents, survey results on COVID-19 questions, and particularly questions related to vaccine willingness or hesitancy have been analyzed first. A manuscript with this information has been drafted and submitted for publication.

3. Acquire and link small-area contextual data to Pennsylvania Autism Needs Assessment, Temple University Community Participation measure, and health service utilization outcomes.
    a. Target completion: Month 27
    b. Actual completion/% complete: ~5%
    c. Description: With COVID-19 restrictions causing a slight delay for survey recruitment and the prioritization of analyzing COVID-19 answers due to its public health salience, this task is a priority in the upcoming months. Frequent team meetings will occur to structure the data set to properly link small-area contextual data to the survey results. This step will be completed across both survey waves.
4. Medicaid Claims and Encounters Analysis
    a. Target completion: Month 27
    b. Actual completion/% complete: ~5%
    c. Description: As is the case for task 3, the team decided that it is crucial that COVID-19 information is generated and disseminated to the public as the pandemic carries on. Linkages between community participation and overall service use and health outcomes will be a team focus in the upcoming months and will be discussed in frequent team meetings. This step will be completed across both survey waves.
5. Publications and Dissemination
    a. Target completion: Month 30
    b. Actual completion/% complete: ~5%
    c. Description: The first manuscript produced from this data has been drafted and focuses on COVID-19 vaccination status and preferences among autistic adults. A series of other manuscripts are planned to correspond to the three aims of this study. Publications will be disseminated at both survey waves, and will also showcase changes over time given the longitudinal study design.

What was accomplished under these goals?

During the report period, study staff worked on development of the updated community participation survey, and in response to the current state of the COVID-19 pandemic, formulated additional questions regarding different aspects of willingness/hesitancy to receive the COVID-19 vaccine. The updated community participation survey was released in the spring of 2021.

Of the 582 adults who participated in the PANA in 2018 and offered consent for follow-up research, 434 were deemed eligible for this study and offered a working contact source. Since initial survey release, study staff have followed up regularly with individuals who had not completed the survey to increase survey return. As of this date, 192 individuals have completed greater than 50% of the survey for study inclusion.

Additionally, study staff have developed a draft manuscript regarding initial response to the survey questions surrounding the COVID-19 vaccine to produce the first publicly available data on autistic adults and the COVID-19 vaccine.

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

This project has afforded significant opportunities for training and professional development for key research staff.

Alec Becker completed the "Applied Policy and Program Evaluation for Urban Health" and the "Google Data Analytics Professional Certificate" to bolster his skills in analyzing large data sets and applying this knowledge to policy and program development and evaluation.

Amber Wool attended the 2021 Eastern Evaluation Research Society Annual Conference, which included sessions on how to develop high-impact reports and methods to improve accessibility when developing resources/reports for a variety of audiences.

Dylan Cooper attended a ResearchTalk Qualitative Inquiry Seminar in October 2020: Coding and Analyzing Qualitative Data. This virtual seminar provided a robust foundation and outlined key methods and strategies to effectively and efficiently code and analyze qualitative data.

Kaitlin Koffer Miller attended two ResearchTalk QSRI courses in July and August 2020: Advancing Data Collection and Analysis in Qualitative and Mixed Methods Research with Visual Data Displays and Rapid Turn-Around Qualitative Research. These virtual seminars provided insight and training for analyzing and presenting qualitative information.

Kate Verstreate attends monthly meetings with the Philadelphia Tableau User Group to see lectures from experts in the field of data visualization, share experiences, and learn from professionals across all industries who use Tableau software. Through this professional development opportunity, she now leads and participates in the Drexel University Tableau User Group to share experiences and learn new techniques from Drexel faculty, staff, and students. Kate also taught the course *Data Storytelling in Tableau: How to Convert Analytics into Insights* at the Urban Health Institute at Drexel University.

Wei Song completed Multilevel Modeling by StatHorizons which introduces multilevel structural equation modeling to handle hierarchically clustered data. She also completed a Social Network Analysis Workshop at Drexel University that utilizes R to demonstrate social network concepts, measurements, graphing, and analysis. She also took a course on systematic review and meta analyses that showcased methods to perform these reviews, including formulating research questions, defining inclusion and exclusion criteria, conducting searches, extracting data and running a meta-analysis.

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?

In the second year of the grant, we will be analyzing results from the first wave of survey distribution. A primary area of focus for analysis from the first wave of survey distribution will be on impact of the COVID-19 pandemic on community participation among the survey sample including more in-depth analysis of vaccination and pre- and post- pandemic changes in participation in activities. This will include reviewing the finding and preparing and submitting manuscripts for publication in peer-reviewed journals.

Additionally, preparation, recruitment, and dissemination of the second wave survey distribution will begin during the next reporting period.

4. **IMPACT:**

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

The proposed project offers a unique and timely opportunity to generate new evidence that will help improve participation-related services. The analyses will be able to determine measures of community participation, which will be relevant for individuals and families who are choosing participation services, policymakers developing participation-related policies, and the design and delivery of Medicaid services at the federal and state levels. In addition, the section related to community participation during the COVID-19 pandemic will contribute information about how autistic individuals were affected by various restrictions during this time. This section also inquires about autistic individuals' perceptions and uptake of the COVID-19 vaccines.

What was the impact on other disciplines?

By including measures on COVID-19 into the survey our findings can drive important changes to public health messaging that maximize effectiveness for vulnerable populations, including autistic adults.

What was the impact on technology transfer?

Nothing to report.

What was the impact on society beyond science and technology?

We have not yet finalized statistical analyses beyond an initial manuscript submitted for publication focused on autistic adults and COVID-19 vaccine acceptance and hesitancy. We have structured subsequent study activities to triage manuscript and material development to present results which describe the experiences of adults with ASD who are directly affected by participation-related service design and policy. By linking this survey data to existing data sets, we are poised to gain a comprehensive picture of the role of community participation in health outcomes and to generate concrete information to help improve participation-related services and related health outcomes. In addition, we will present unique and timely insight into the experiences of autistic adults related to the COVID-19 pandemic and related vaccination efforts.

5. **CHANGES/PROBLEMS:**

Changes in approach and reasons for change

Initial survey release was delayed because of COVID restrictions. In response to the ongoing COVID-19 pandemic, additional survey questions were developed regarding the lockdown experiences of survey respondents and vaccine willingness. We have calibrated the study timelines to ensure completion of the study goals within the proposed funding period.

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

The survey instrument release was delayed due to recruitment challenges during the peak of the COVID-19 pandemic. However, this afforded the research team an opportunity to layer in a series of COVID items into the survey that have direct impacts on community participation. Further, given the longitudinal survey design, the research team is well poised to now analyze community participation before and after COVID-19 restrictions were implemented. We anticipate being on time for all future project deliverables and do not foresee any other project delays.

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

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

Nothing to report

Nothing to report

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

Nothing to report

Other publications, conference papers, and presentations.

Nothing to report

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?

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

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

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

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

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

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

What other organizations were involved as partners?

Nothing to report

8. **SPECIAL REPORTING REQUIREMENTS**
   COLLABORATIVE AWARDS:
   QUAD CHARTS:

N/A

9. **APPENDICES:**

Please see attached.

Appendix 1: Survey Instrument

Pennsylvania Autism Community Participation Assessment

Thank you for completing this survey to learn more about your preferences and experiences as you participate in activities your community. You are being asked to complete this survey because you participated in the Pennsylvania Autism Needs Assessment and allowed us to contact you for future research opportunities. Your responses will help us learn more about supporting and improving opportunities for participating in activities in your community. This survey should take about 20 minutes to complete.

We'll insert consent language from the IRB here, including permission to link to Medicaid claims and other administrative data sources.

First, we'd like to know if information about where you live or other aspects of your life have changed in the past two years.

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

2. 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)

3. You previously indicated that your marital status was _____ . Has your marital status changed (for example, did you get married)?
    - Yes, my marital status has changed.
    - No, my marital status has not changed.

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

If No, proceed to question 4.

4. When asked if you were employed, your reported _____. Has your employment status changed (for example, did you get a new job or lose a job)?
    - Yes, my employment status has changed, due to COVID-19.
    - Yes, my employment status has changed, due to reasons unrelated to COVID-19.
    - No, my employment status has not changed.

If Yes: 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 new 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 Yes: 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 No, proceed to question 5.

5. When asked if you had any children, you reported_____. Have you changed your family planning, or had or adopted a child or children?
   - Yes, I have changed my family planning or had or adopted a child or children.
   - No, family planning and number of children has not changed.

If Yes: 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 No, proceed to question 6.

6. You reported your gender or gender identity as _____. Has your gender or gender identity changed?
   - Yes, I have changed my gender or gender identity.
   - No, I have not changed my gender or gender identity.

If Yes: Please select your gender or gender identity:

- Woman
- Man
- Other: _____.

If No, proceed to question 7.

7. When asked about the health insurance coverage you had, your reported _____. Is your health insurance coverage now the same as it was then?
   - Yes, it is the same. I have not changed my health insurance.
   - No, my health insurance status has changed. I lost, gained, or changed health insurance.

If yes, proceed to question 8

If No: Please select which health insurance change you experienced:

- I lost health insurance. Proceed to question 8.
- 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.

8. When asked about your living arrangement, you reported ____. Has your living arrangement changed in the last two years?
   - Yes, my living arrangement has changed in the last two years.
   - No, my living arrangement has not changed in the last two years.

   If Yes: 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 _____

If No, proceed to question 9.

9. How happy are you with your current living arrangement?
   - Very happy (emoji)
   - Happy
   - Unhappy
   - Very unhappy

10. Are you newly enrolled in or have you graduated from high school or any post-secondary education (e.g., a college or university) *in the past two years*?
    - Yes, I am newly enrolled, or graduated in the past two years.
    - No, I am not newly enrolled, nor have I graduated in the past two years.

    If Yes: Please select your current school enrollment:
    - Yes, high school
    - Yes, two-year college
    - Yes, four-year college
    - Yes, graduate school
    - Yes, vocational/technical school
    - No, but I would like to be
    - No
    - Other _____

    If Yes: What is the status of your school enrollment?
    - Full-time
    - Part-time

    If No, proceed to question 11.

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

11. 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)
      - Someone else I know has been diagnosed with COVID-19. Please specify how you know the person who was diagnosed with COVID-19
    - No, I do not know anyone who has been diagnosed with COVID-19.

12. Have your daily routines changed since the COVID-19 pandemic began in March 2020? Daily routines including going to work or school, social activities with friends or family, religious activities, or other ways you normally spend your time.
    - No, there have been no changes to my daily routines. I do the same activities.

- Yes,
    - There have been minor changes. I do some activities differently (on the phone or computer) instead of in person or I have slightly fewer activities.
    - There have been moderate changes. Several activities I would have completed daily have been disrupted or changed significantly.
    - Yes, there have been major changes. Most or all activities I would normally participate in have been canceled, delayed, or substantially changed.

13. Has your exercise routine changed since the COVID-19 pandemic began in March 2020?
    - No, I did not exercise before the pandemic and I do not exercise now.
    - No, I have been exercising as often as I usually do.
    - Yes, I used to exercise but stopped exercising now.
    - Yes, I exercise less now.
    - Yes, I exercise more now.

14. Has your access to medical health care changed since the COVID-19 pandemic began in March 2020?
    - No, I have not tried to access care, or I haven't needed care since March 2020.
    - No, there have been no changes to my medical health care. I access a doctor or other health care professional when needed.
    - Yes, my access to medical health care has changed (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.

15. Has COVID-19 impacted transportation available to you or that you use in your community since the COVID-19 pandemic began in March, 2020?
    - Yes
    - No
    - Unsure

16. Which transportation do you typically use to get where you need to go? *Choose all that apply.*
    - Drive yourself in a private car
    - Passenger in a private car with family
    - Passenger in a private car with friends
    - Bus/van operated by a county, municipality, or non-profit
    - Taxi or other for-hire vehicle
    - Walk
    - Bicycle
    - Passenger in a private car with a volunteer 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 _____

17. Has your access to mental or behavioral health services or supports changed since the COVID-19 pandemic began in March 2020?
    - No, I have not tried to access **mental or behavioral health services or supports**, or I haven't needed services or supports since March 1, 2020.
    - No, there have been no changes to my **mental or behavioral health services or supports**.
    - Yes, my access to mental or behavioral health services has changed (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**.

18. Have your interactions with family or friends changed since the COVID-19 pandemic began in March 2020?
    - No, there has been no change.
    - Yes, my access to family or friends has changed (check all that apply if Yes):
        - I have continued visits 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.

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. When was the last time you left your house for any reason (for walk/exercise, grocery store, pharmacy)?
    _____ days ago

21. Has the frequency that you have felt lonely changed during the COVID-19 Pandemic?
    - Increased
    - Decreased
    - Remained the same

22. Have you received the 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.
  - What was the date of your final dose (DATE text box)?
- Yes, but I still need to get the 2nd dose.
  - When is the date of your 2nd dose? (DATE text box)
- No
  - I have an appointment for my vaccination on [DATE].
  - 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.
  - I do not plan on getting the vaccine.

If any answer except "No – I do not plan on getting the vaccine"

23. Please tell us why you are planning to get or have already gotten the vaccine. Please select all that apply.
    - My employer recommended it/it was needed for a job
    - 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

24. The COVID-19 vaccine has/will change how I gather with other people and participate in activities in my community.
    - Yes, it will change how I gather with other people and participate in activities in my community.
    - No, it will not change how I gather with other people and participate in activities in my community.

If yes

25. When I am vaccinated I will (please select all that apply):
    - Be more likely to gather with other people who are vaccinated.
    - Be more likely to gather with other people regardless of if they are vaccinated
    - Be able to work or actively look for a job.
    - Feel more comfortable outside of my home.
    - Be more likely to dine indoors or outdoors at a restaurant, coffee shop, or café.
    - Be 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.
    - Be more likely to go shopping at grocery stores or retail stores.
    - Be more likely to go to a barber shop, beauty salon, nail salon, or spa.
    - Be more likely to go to a gym, health or exercise club, or participate in a sports event.
    - Be more likely to seek medical care/services.

If the answer to 22 is “No – I do not plan on getting the vaccine”

26. 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
    - I’m concerned there are not enough available vaccines
    - I’m concerned that getting the vaccine will be inconvenient
    - I’m concerned that the vaccine isn’t safe
    - Other, please specify: (text box)

27. Do you have any other thoughts about how the COVID vaccine will impact you that you’d like to share? (text box)

28. 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* **?** (circle the correct response). Finally, circle the correct response to indicate if each activity is important to you.

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?**	
1. Go shopping at a grocery store, convenience store, shopping center, mall, other retail store, flea market, or garage sale.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
2. Go to a restaurant or coffee shop.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
3. Go to a church, synagogue, or place of worship.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
4. Go to a movie.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
5. Go to a park or recreation center.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
6. Go to a theater or cultural event (including local school or club events, concerts, exhibits and presentations in the community).	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
7. Go to a zoo, botanical garden, or museum.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
8. Go to run errands (for example, go to a post office, bank, Laundromat, dry cleaner).	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
9. Go to a library.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
10. Go to watch a sports event (including bowling, tennis, basketball, etc.).	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**

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

23. Go to or participate in civic or political activities or organizations.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
24. Engage in an organized sport (baseball, basketball, soccer game) or other organized physical activity (e.g., exercise class) outside the home.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
25. Play games (e.g., chess, card, online gaming) outside the home, such as at a friend's house.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
26. Play games, including online gaming, at your own home where you play with others (they may be physically present in your home or online).	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**
27. Hangout or socialize with people you know from school, work, the neighborhood, or other acquaintances.	____ ____ (# of Days)	**Enough**	**Not Enough**	**Too Much**	**Yes**	**No**

The following questions ask about your relationships with an intimate partner and your relationships with your child(ren).		
28. Are you currently married or in a domestic partnership/relationship (i.e., not married, but in a committed relationship or living with someone you are in an intimate relationship with)?	Yes	No

29. (Skip if yes to Q28) Do you get together with someone you consider to be a boyfriend or girlfriend?	**A. How many days in the last 30 days did you get together with someone you consider to be a boyfriend/girlfriend?**	**B. Do you do this activity?**			**C. Is this activity important to you?**	
	____ ____ (# of Days)	Enough	Not Enough	Too Much	Yes	No

30. If you have children ("Yes" on Question #4), but do NOT live with them, please answer these questions…	**A. How many days in the last 30 days have you gotten together with your child(ren)?**	**B. Do you do this activity?**			**C. Is this activity important to you?**	
Get together with your child(ren)	____ ____ (# of Days)	Enough	Not Enough	Too Much	Yes	No

29. 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	☐	☐	☐	☐
I'm not sure how to get to these activities (for example, I don't have a car)	☐	☐	☐	☐
Activities cost too much money.	☐	☐	☐	☐
I'm not sure what activities occur around me.	☐	☐	☐	☐
Activities in my community are not interesting to me.	☐	☐	☐	☐
I don't have support or encouragement from family or friends to engage in these activities.	☐	☐	☐	☐
I don't have support or encouragement from service providers to engage in these activities.	☐	☐	☐	☐
I do not have friends or other connections to do things together in the community.	☐	☐	☐	☐
I do not feel safe in new places to me.	☐	☐	☐	☐
I feel unsafe participating in activities in the community because of coronavirus or COVID-19.	☐	☐	☐	☐
People in my community are unfriendly to me or do not treat me well.	☐	☐	☐	☐
Bright lights, unusual noises, darkness, or crowds in public spaces bother me or limit how much I do things.	☐	☐	☐	☐
There are other reasons I do or do not participate in activities in my community: (Please specify) _____				

30. In general, how has COVID-19 impacted how often you participate in the activities listed previously?
    - o Stayed the same. I participate in activities about as often as I did before COVID-19.
    - o Increased. I participate in activities more often.
    - o Decreased. I participate in activities less often.

31. 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 occurs online, etc.)?
    - o Increased. I interact with others virtually or online more often.
    - o Stayed the same. I interact with others virtually or online about as often as I did before COVID-19.

- Decreased. I interact with others virtually or online less often.

32. Do you have any of the following social media account(s)? Please answer yes or no.

	Yes	**No**
Facebook	☐	☐
Instagram	☐	☐
LinkedIn	☐	☐
Meetup	☐	☐
MySpace	☐	☐
NextDoor	☐	☐
Pinterest	☐	☐
Reddit	☐	☐
SnapChat	☐	☐
TikTok	☐	☐
Twitter	☐	☐
WhatsApp	☐	☐
Youtube	☐	☐
Other (please specify) _____	☐	☐

33. How often do you visit any of your social media accounts?
    - Several times a day
    - About once a day
    - A few days a week
    - Once per week
    - A few times per month
    - Don't know
    - Prefer not to say

34. Are you a member of a self-advocacy or support group or other organization?
    - Yes
    - No

35. Has the self-advocacy or support group shifted meetings that were held in-person to online because of COVID-19?
    - Yes
    - No

36.

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	○	○	○	○	○
Friends to socialize with	○	○	○	○	○
Relationships with parents	○	○	○	○	○
Relationships with siblings	○	○	○	○	○
Relationships with your children	○	○	○	○	○
Relationship with significant other (e.g. spouse, partner)	○	○	○	○	○
Acquaintances	○	○	○	○	○
Other relationships _____	○	○	○	○	○

The next questions are about your interactions with police or other criminal justice system professionals.

37. Do you have concerns about interacting with police that prevent you from participating in activities in your community?

○ Yes ○ No

38. Do you have concerns about being a victim of a crime that prevent you from participating in your community?
    - ○ Yes
    - ○ No

The next questions ask about your health status

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

○ Better ○ Worse ○ The same

Please explain your choice:

40. Have you been newly diagnosed with any of the following *<u>in the past two years</u>*? Choose all that apply.
    - ○ Anxiety Disorder
    - ○ Attention Deficit/Hyperactivity Disorder (ADHD)
    - ○ Bipolar Disorder
    - ○ Intellectual Disability (formerly known as Mental Retardation)
    - ○ 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
- Developmental Delay
- Sensory Integration Disorder
- Hoarding Disorder
- Substance Use Disorder
- Learning Disability
- None
- Other

41. Has a doctor prescribed marijuana to you?
- Yes
- No

[If Yes, ask questions 37 and 38, if no, skip to Q39]

42. For what condition were you prescribed marijuana? Check all that apply:
    - Not being able to fall or stay asleep
    - Feeling worried or anxious
    - Pain
    - Headaches
    - Other

43. Have you ever used the marijuana prescribed to you?
    - Yes, I use it currently
    - Yes I have, but do not use it currently
    - No

44. Have you ever used marijuana recreationally?
    - Yes, I use it currently
    - Yes I have, but do not use it currently
    - No

Please answer the following questions as either never, rarely, sometimes, often, or prefer not to answer

45. In the past 30 days, how often did you have an alcoholic drink? We define an alcoholic drink as one beer, one glass of wine, one mixed drink, or one shot of liquor.
46. In the past 30 days, how often did you engage in heavy drinking (defined as 5 or more drinks for men and 4 or more drinks for women)?
47. In 2020 before the COVID-19 pandemic, how many days per month (on average) did you have an alcoholic drink? [[Restrict to integer values 0-30]] | And “I prefer not to answer”

48. In 2020 before the COVID-19 pandemic, how many days per month (on average) did you engage in heavy drinking? [[Restrict to integer values 0-30]] | And “I prefer not to answer”

Please answer the following questions with the approximate amount (it does not need to be exact)

49. In the past 30 days, how many alcoholic drinks did you consume? [[Restrict to integer values 0-999]] | And “I prefer not to answer”
50. In 2020 before the COVID-19 pandemic, how many alcoholic drinks per month (on average) did you consume? [[Restrict to integer values 0-999]] | And “I prefer not to answer”

51. 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

52. 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
- Scheduling Issues
- 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
- Other _____

53. “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____*

Thank you for completing this survey. We appreciate your time and look forward to contacting you again in the future.

Appendix 2: Sample Characteristics

Sample Characteristics (Total n = 192)

	n	%
Gender		
Woman	47	24%
Man	126	66%
Other	13	7%
Missing (Not Reported)	6	3%
Marital Status		
Married	13	7%
Never Married	168	88%
Missing (Not Reported)	11	6%
Race/Ethnicity		
Non-White	22	11%
White	160	83%
Missing (Not Reported)	10	5%
Medical Insurance		
Private	36	19%
Public	143	74%
Missing (Not Reported)	13	7%
Living Arrangement		
Family/Roommate	144	75%
Independent or Other	38	20%
Missing (Not Reported)	10	5%
ZIP Code Urbanicity		
Metropolitan	171	89%
Non-Metropolitan	19	10%
Missing (ZIP Code Not Reported)	2	1%
	median	**IQR**
Age (years)	29	25 - 35

Appendix 3: Other Support Documents

Other Support
Shea, Lindsay

19-20275-03 (Shea) The Philadelphia Autism Project The Philadelphia Autism Project is a citywide initiative aimed at using data and input across an array of stakeholders to identify and address the needs of individuals living with autism and their families. The Philadelphia Autism Project is executed in close partnership with Philadelphia City Council and the Philadelphia Department of Behavioral Health and Intellectual 33isability Services (DBHIDS).	07/01/20 – 06/30/21	0.6 calendar
1R01MH117653 – 03 (Shea) NIMH Alternative Approaches to Supporting ASD Services for Young Adults This project will use national Medicaid data to examine the healthcare experience of adolescents with autism spectrum disorder (ASD) as they age into adulthood as compared to adolescents with intellectual disability (ID). Specifically, we will compare eligibility for services and service usage during the transition into adulthood across states with differing Medicaid policies and programs. Additional data collection will include state interviews and contacting states to catalog Medicaid program differences within and across states.	09/01/18 – 06/30/22	3.0 calendar
3R01MH117653-03S1 (Shea) NIMH Identifying Co-Occurrence and Service Use Profiles of Alzheimer's Disease and Autism Spectrum Disorder The proposed administrative supplement will enable the first national study of the prevalence, incidence, and healthcare service use of individuals with autism spectrum disorder (ASD) and Alzheimer's disease and related dementias (ADRD).	07/01/20 – 06/30/21	2.0 calendar
(Shea) International Society for Autism Research International Society for Autism Research 2020 Policy Brief: Autism and the Criminal Justice System The International Society for Autism Research (INSAR) awarded the third INSAR Policy Brief (2020) focused on autism and the criminal justice system. This award provides for a summit to be held in summer of 2020 convening international research experts focused on the criminal justice system, autism spectrum disorder, or focused on both topics. The summit will provide the groundwork for a policy brief that will be produced and released by INSAR by the end of calendar year 2020.	10/15/19 – 12/31/20	(In-Kind)

W81XWH2010435 (Shea) US Department of Defense (DOD), CDMRP Community Participation, Service Needs, and Health Outcomes among Adults with ASD This study will use self-reported community participation information from adults with ASD to collect additional, longitudinal information about service experiences and community use and access. Community participation will be measured based on the preferences and importance ranking of community activities by adults with ASD and examined across demographic groups in one large, northeastern state. Findings will generate the first data to inform new community participation requirements issued by the Centers for Medicare and Medicaid Services that must be implemented by states in the coming years.	7/01/20 – 6/30/23	2.0 calendar
UJ2MC31073 (Shea) Health Resources & Services Administration Autism Transitions Research Project (ATRP) This series programmatic series of studies will address aims specific to a particular subpopulation, developmental stage and/or service system. Each study includes a focused statement of the related research gap, specific aims, a brief overview of deliverables and a concise statement of how the study responds to the research gap and links to improving health and wellbeing and/or service delivery.	09/01/17-8/31/22	1.2 calendar
UT2MC39440 (Kuo) Health Resources & Services Administration Autism Intervention Research Network On Physical Health (AIR-P) The AIR-P is a large-scale research collaboration dedicated to improving the physical health of children and youth with Autism Spectrum Disorders (ASDs). Composed of an interdisciplinary network of clinicians, scientists and family members, it conducts critical intervention research across 12 autism specialty centers in the U.S. and Canada. The AIR-P aims to increase the evidence base for effective interventions and treatments, develop clinical guidelines and reduce inequalities in ASD care. It also seeks to accelerate the speed at which effective interventions and guidelines are adopted into clinical practice settings.	09/01/20 – 08/31/25	1.0 calendar
11923 (Mazefsky) Autism Speaks Developing a Gold Standard for Tracking Adult Functional Outcomes in Autism Spectrum Disorder The objective of this project is to develop efficient and validated proxy and self-report measures of functional outcome for adults with ASD – the Adult Functioning Scale (AFS) – and establish the validity of the AFS utilizing state-level service utilization data.	03/1/20 – 02/28/23	1.6 calendar

(Shea) City of Philadelphia Philadelphia Service Navigator The Philadelphia Department of Behavioral Health and Intellectual 35isability Services (DBHIDS) created a Family Legacy Organization to include care navigatorsthat will support service navigation among individuals with disabilities, including autism spectrum disorder. The goals of this funded initiative are to evaluate the implementation of the service, including measures of family and caregiver stress, longitudinally and to provide findings and policy recommendations to DBHIDS.	07/1/20 – 06/30/21	(In-Kind)
(Shea) City of Philadelphia Community Autism Peer Support Service Launch The goals of this project are to provide evaluation expertise and autism expertise to Community Behavioral Health (CBH), the behavioral health Medicaid payer in the City of Philadelphia, during the launch of a new Medicaid-funded service line for Community Autism Peer Support staff. The evaluation will include direct data collection from both the peers delivering the service and the peers receiving the service.	04/30/20 – 12/31/2020	(In-Kind)

Other Support
Vanness, David

Current

Title: "Optimizing substance misuse prevention and treatment interventions for enhanced public health impact: Incorporating Bayesian decision analytics into the multiphase optimization strategy (MOST)"
Time Commitments: Academic: 0 Summer: 0
Supporting Agency: National Institute on Drug Abuse
Address:
6701 Rockledge Drive
Bethesda, MD 20892-7710
Contracting/Grants Officer: Sarah Q. Duffy
Performance Period: 7/1/2020-6/30/2022
Level of Funding:
Project Goal: To refine and improve the decision-making methods used to identify optimized interventions in the multiphase optimization strategy (MOST), yielding an approach that intervention scientists will be able to use to more successfully optimize their interventions for effectiveness on one or more outcomes. And to provide training to the student applicant under the F31 mechanism.
Specific Aims: To develop a strategy for decision analytics under the MOST framework and apply that strategy to data from the Heart to Heart 2 optimization trial. (Vanness role: mentor for doctoral student Jillian C. Strayhorn)
Overlap: None

Title: "Nurse AMIE: Addressing Metastatic Individuals Everyday in Rural PA and WV"
Time Commitments: Academic: 0.45 Summer: 0.15
Supporting Agency: National Cancer Institute
Address:
6701 Rockledge Drive
Bethesda, MD 20892
Contracting/Grants Officer: Sallie Jayne Weaver
Performance Period: 6/24/2021-4/30/2022
Level of Funding:
Project Goal: To adapt a tablet-based symptom assessment and supportive care intervention called Nurse AMIE for metastatic cancer and investigate its performance in a randomized trial in a population of primarily low-income, underserved rural patients.
Specific Aims: We will adapt a high-quality tablet-based supportive care platform to metastatic cancer patients of all tumor sites. We will examine whether a tablet-based supportive care platform improves overall survival over 2 years among 344 low-income/underserved metastatic cancer patients living in rural PA and WV. We will examine whether the tablet-based supportive care platform results in improved symptom severity (fatigue, sleep, distress, pain), function, and quality of life as compared to the usual care control group. We will conduct a cost effectiveness analysis of our intervention from the payer's perspective, using estimated costs and quality-adjusted life-years (QALYs). (Vanness role: co-investigator; cost-effectiveness analysis)
Overlap: None

Pending

Title: "Achieving equitable health and economic outcomes internationally: integrating game theory
within the diagonal approach"
Time Commitments: Academic: 0.9 Summer: 0.3
Supporting Agency: University of Maryland Baltimore (via NSF Trans-Atlantic Platform Recovery, Renewal and Resilience in a Post-Pandemic World T-AP RRR Program)
Address:
620 W Lexington St
Baltimore, MD 21201
Contracting/Grants Officer: Kim Dormer
Performance Period: 7/1/2020-6/30/2022
Level of Funding:
Project Goal: To identify optimal policies and incentives that can be rapidly deployed during future pandemics to minimize losses and inequity in distribution of losses.
Specific Aims: We will use linear programming to characterize an intertemporal, international societal optimization problem, examining how different policies impact outcomes and evaluating disparities therein. We will consider a series of scenarios where national policy makers adopt different initial combinations of non-pharmaceutical policies, dependent on actions of other nations. We will develop national profiles with potential interventions and a mapping to expected outcomes. For each scenario we will: optimize the set of adopted interventions in each nation, given national and global outcome preferences, identify the impact of national and international policies on the magnitude and distribution of expected payoffs, design incentive mechanisms to better align policy responses to minimize equity weighted health losses. We will validate our approach using data generated during the COVID-19 pandemic to assess how observed outcomes align with the expected payoff as predicted in our model. (Vanness role: co-investigator; policy economic evaluation)
Overlap: None

CONSULTING
Apriori Bayesian Consulting, LLC
Ongoing Academic: 0.9 Summer: 0.3
Role (Managing Member and Consultant)
Provides ad hoc health economics and outcomes research consulting services to the following clients:
Medical Decision Modeling Inc., New York University.
Overlap: None

Other Support
Lee, Brian

NINDS 1R01NS107607-01A1, 6/1/19 – 4/30/23

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

The goal of this project is to study whether anti-seizure medications during pregnancy influence risk of autism.

Role: PI (co-PIs: Magnusson, Rai). 30% effort. Total amount: USD

Commonwealth of Pennsylvania, Department of Human Services, Office of Developmental Programs, Bureau of Autism Services, 0.6 calendar months
"Autism Services, Education, Resources, and Training Collaborative (ASERT)."
The goal of this project is to improve access to autism resources in Pennsylvania.
Role: Co-I (PI: Shea)

Department of Defense, 7/1/20-6/30/23
"Community participation, service needs, and health outcomes among adults with autism"

Role: Co-I (PI: Shea). 0.8 calendar months. Total amount:

Pennsylvania Department of Health CURE grant, 6/1/20-6/30/21

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

Role: PI. 0.6 calendar months. Total amount:

Other Support
Salzer, Mark

ONGOING

90RT0521 (Salzer) **09/30/18-09/29/23**
NIDILRR/Administration for Community Living
Temple University RRTC on Community Living and Participation of Individuals with Psychiatric Disabilities
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.

90IFRE0029-01-00 (Ostrow) **9/30/19-9/29/22**
NIDILRR/Administration for Community Living
Career Outcomes of Certified Peer Specialist with Psychiatric Disabilities
Dr. Salzer is an investigator on a longitudinal study of the early careers of Certified Peer Specialists trained in five states around the country. The study is primarily focused on their employment experiences.

90RTHF0004 (Cook) **09/29/20-09/29/25**
NIDILRR/Administration for Community Living
Rehabilitation Research and Training Center (RRTC) on Health and Function of People with Psychiatric Disabilities
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.

AR190018 (Shea) **7/1/20 – 6/30/23**
Department of Defense/Drexel University (Prime)
Community Participation, Service Needs, and Health Outcomes among Adults with ASD
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.

Drexel ASERT (Salzer) **07/1/16 – 6/30/21**
PA Dept of Public Welfare/Drexel University (Prime)
Autism Services, Education, Resources, & Training Collaborative
Dr. Salzer provides input to Drexel colleagues, and is engaged in various activities, on policy issues in response to requests from the PA Department of Public Welfare.

K08MH116101 (PI: Thomas) **4/1/19 – 3/31/22**
NIH/DHHS
Facilitating Emerging Adult Engagement in Evidence-Based Treatment for Early Psychosis through peer-Delivered Decision Support
Primary mentor on this K-Award with the following specific aims: 1) to understand decision-making needs pertinent to early CSC engagement in order to develop a peer-delivered decision support intervention (Study 1), and 2) to perform a preliminary evaluation of the peer-delivered decision support intervention in order to inform and support an R01 study (Study 2).

No Contract # (Song) **4/15/20 – 4/14/22**
Eagles Autism Foundation
Getting Out There: Identifying Community Participation Experiences and Preferences among Adults with Autism Spectrum Disorder
Dr. Salzer serves as the primary mentor for Dr. Wei Song on this series of studies examining factors influencing the participation of autistic adults using a large, cross-sectional database gathered in Pennsylvania.

No contract # (PI: Salzer) **1/1/19-06/30/21**
Eastpointe
Eastpointe Technical Assistance
Dr. Salzer leads technical assistance and training efforts in NC to assist in the promotion of community inclusion policies, programs, and practices.

90IFRE0018 (PI: Pearl) **09/30/18-09/29/21**
NIDILRR/Administration for Community Living/Penn State (Prime)
Increasing Community Participation In Young Adults With Autism Living In Rural Communities
Dr. Salzer serves as an investigator on this study to develop pilot data on the effectiveness of an intervention called "Participation of Adults with Autism in Rural Communities" (PAARC), for families of young adults with ASD living in rural areas to increase community participation of young adults with ASD, will be assessed through the following hypotheses: compared to an active control group, participants in PAARC 1) will report engagement in a higher number of days participating in community activities and 2) will report increased variation of community activities.

90IFRE0018 (PI: Pfeiffer) **09/30/18-09/29/21**
NIDILRR/Administration for Community Living
Peer-delivered travel training for adults on the autism spectrum
Dr. Salzer is an investigator on an exploratory study to develop and implement a peer-mediated transportation training program. A pilot study will be conducted to estimate potential outcome benefits for the intervention necessary for making decisions about the utility of seeking RO1-

level funding with the following hypotheses: a) Individuals receiving travel training interventions will increase self-efficacy and percentage of attendance to employment services over time. b) Individuals receiving travel training will require less support for transportation and improved work performance over time. c) Individuals with more support services and symptoms of ASD will require higher dosing amounts of travel training intervention.

H79SM063321 10/1/2017 – 9/30/2021 (NCE)
SAMHSA/Mental Health Partnerships (Prime)
Homeless2Home: Data Collection and Performance Assessment Associated with A Peer Support Re-Integration Program for Women with SMI Leaving Corrections
Dr. Salzer is the lead evaluator for a subcontract to the Mental Health Partnerships to implement a peer-delivered intervention for women leaving the Riverside Correctional Institute in Philadelphia. Dr. Salzer is responsible for coordinating with MHASP in conducting interviews at release/entry into the intervention, 6-months, and discharge from the intervention using the standard GPRA tool and data entry system that is required as part of SAMHSA proposals. Temple University will also be responsible for additional data collection as required from SAMHSA and select local performance measurement efforts as specified in the grant proposal.

FY21-CHMBG-TEMPLE (PI: Salzer) 05/1/18-06/30/21
State of Delaware DSAMH
Training and Technical Assistance on Community Inclusion
Dr. Salzer leads technical assistance and training efforts in DE to assist in the promotion of community inclusion policies, programs, and practices, with a particular focus on Peer Centers in the state.

COMPLETED (Past Three Years)

90RTCP0001 (Salzer) 09/30/13-09/29/19 (NCE)
NIDILRR/Administration for Community Living
Temple University RRTC on Community Living and Participation of Individuals with Psychiatric Disabilities
Dr. Salzer has been PI of this federally-funded Center since 2003. The Center has the mission is to advance 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.

H79SM063380 (PI: McCurdy) 04/01/18-09/29/20
SAMHSA/Project HOME (Prime)
H4 Initiative: Housing, Healthcare, Healing and Hope
Dr. Salzer served as the Program Evaluator for the "H4 Initiative: Housing, Healthcare, Healing, and Hope" program, which connected individuals experiencing long-term homelessness with housing a housing resources.

90RT5039-01-01 (Pfeiffer) **10/1/15 – 9/30/19**
NIDILRR/Administration for Community Living/University of Minnesota (Prime)
Rehabilitation Research and Training Center on Home and Community Based Services Outcomes Measurement
Dr. Salzer served as an investigator and advising to The RRTC on Home and Community Based Services Outcome Measurement that had the overall aim of enhancing measurement of outcomes associated with HCBS programs.

H133G140040 (Salzer) **10/1/15 – 9/30/18 (NCE)**
NIDILRR/Dept. of Education
Identifying enabling environments affecting adults with psychiatric disabilities
Dr. Salzer was PI of this study to generate knowledge about enabling environments that affect individuals who experience psychiatric disabilities using Global Position System (GPS) and Geographic Information Systems technologies.

HC-1610-26006 (PI: Halpern) **10/1/17 – 6/30/19**
National MS Society
What are the barriers preventing access to rehabilitation services, particularly maintenance services among people with MS and what are some of the potential solutions to these barriers?
Dr. Salzer served as an investigator on a study aimed at understanding barriers preventing access to rehabilitation services for people with MS.

R34MH101364 (PI: Cook) **7/1/14-6/30/19**
NIH/University of Illinois (Prime)
½-Multisite Study of Self-Directed Care for People with Serious Mental Illness
Dr. Salzer contributed to the conceptualization and implementation of the research project including the selection of research measures, definition of inclusion and exclusion criteria, recruitment of study subjects, assessment of model fidelity, training of intervention staff, delivery of the intervention being tested, execution of statistical analysis, and interpretation of results.