

Autism CARES Act Initiative Evaluation: Survey of Research Networks and Programs

Introduction

Thank you for participating in our Survey of Autism CARES Autism and DD Research Networks and Programs. We value your input! Our team at Westat Insight is conducting this survey under contract with the Health Resources and Services Administration Maternal and Child Health Bureau. We expect this survey to take 15 to 20 minutes. For all the data we collect for analysis, we will use unique survey identifiers—not respondent names and will keep your responses confidential. Any published reports will summarize the results in the aggregate and will not include individual responses. This survey seeks to collect information about your research topics, dissemination activities, and efforts to engage diverse audiences. The information collected from this survey will help guide our interview discussions that will follow.

If you have questions about this survey or how we will use the information you provide, please contact Project Director Katherine Flaherty (KatherineFlaherty@westat.com) or Deputy Project Director Carla Bozzolo (cbozzolo@insightpolicyresearch.com).

Grantee Institution & Principal Investigator _____

Grant program:

- Autism Intervention Research Network on Physical Health (AIR-P)
- Autism Intervention Research Network on Behavioral Health (AIR-B)
- Healthy Weight Research Network (HW-RN)
- Developmental Behavioral Pediatrics Research Network (DBPNet)
- Autism Secondary Data Analysis Research Program (Autism SDAR)
- Autism Field-Initiated Innovative Research Studies Program (Autism FIRST)
- Autism Single Investigator Innovation Program (Autism SIIP)

1. *Has your autism and DD research generated evidence in any of the following areas? Please check all that apply:*

- Transitions
- Risk factors and/or life course factors
- Health and wellbeing, including clinical improvements and quality of life
- Other. Please specify: _____

2. *For your research on transition-aged populations, did you include any of the following topics in your research during this project period? Please check all that apply:*

- Transition from pediatric to adult healthcare

- Transition from adolescence to adulthood
- Transition between education settings (e.g., middle school to high school, community college, four-year universities, vocational schools)
- Transition from dependent to independent living situation
- Transition from unemployment to employment
- Other. Please specify: _____

3. *What key groups did your program engage during this project period? Please check all that apply:*

- Researchers
- Clinicians/Healthcare professionals (pediatric and adult)
- Educators
- Individuals with autism and DD
- Family members of individuals with autism and DD
- Policymakers
- General public
- Other. Please specify: _____

4. *How have your research findings promoted health equity:*

By health equity we mean, “the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.” (<https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>)

Please check all that apply:

- By engaging or including community organizations and/or members experiencing health disparities
- By research prioritization and implementation of health equity topics
- By incorporating health equity in the research methods used, including the analytic plan
- By dissemination or translation of research findings related to health equity
- Other. Please specify: _____

5. *Which historically underserved and/or marginalized populations has your program included in your research during this project period?*

By underserved and/or marginalized populations we mean people who experience discrimination of any kind and encounter barriers (e.g., racial, ethnic, gender, sexual orientation, economic, cultural, and/or linguistics) to accessing public health and health care services.

Please check all that apply:

- Low-income populations
- Racial and/or ethnic minorities
- Individuals living in rural areas
- Other. Please specify: _____

6. Please list, if any, the existing datasets and/or administrative records you have used to conduct your research that were designed to improve the health and wellbeing of individuals with autism and DD:

7. How many junior or new investigators did your program mentor and/or train in the field of autism and DD research since the fall 2020? _____

8. During this current grant period, how many peer-reviewed articles have you published on effective interventions and guidelines to improve the health and wellbeing (physical and mental) of individuals with autism and DD across the lifespan? _____

9. How many products (other than peer-reviewed publications) about autism and DD did you publish or disseminate since fall 2020? _____

Products could include lay summaries of research publications, toolkits, guidelines, conference policy briefs, fact sheets presentations, reports, infographics, web postings, printed electronic materials, or similar materials.

10. What types of products did these include? Please check all that apply:

- Peer-review publications
- Lay summary of research publications
- Toolkits
- Guidelines
- Conference presentations
- Policy briefs
- Fact sheets
- Reports
- Infographics
- Web postings
- Printed electronic materials (e.g., briefs, newsletters, toolkits)
- Other. Please specify: _____

11. What audiences did you target for dissemination of these products? Please check all that apply:

- Researchers
- Clinicians/Healthcare professionals
- Educators
- Individuals with autism and DD
- Family members of individuals with autism and DD
- Policymakers
- General public
- Businesses
- Colleges and universities
- Other. Please specify: _____

12. Finally, is there any other additional information that you would like to share with us?

Thank you again!