

# Autism CARES Act Initiative Evaluation: Research Programs Interview Protocol

Respondent ID#:	Interviewer:
Respondent Title:	Note Taker:
Date & Time of Interview:	Recorded (Y/N):

## Introduction and Verbal Consent

Thank you for taking the time to speak with us today. My name is [interviewer name] and I'm a researcher at [Westat/Westat Insight]. I'm joined on the call by [names/affiliations of other team members, if applicable] and [note taker name, if applicable], who will be taking notes during the call.

We are part of a team hired by the Maternal and Child Health Bureau (MCHB) to evaluate the Autism CARES (Collaboration, Accountability, Research, Education, and Support) Act Initiative. The purpose of today's interview is to learn about your program's activities and experiences, including accomplishments and challenges, and understand the data collected by your program.

In the interview, I will focus on—

- ▶ Your autism and developmental disabilities (DD)-focused research studies and activities, awareness and dissemination, health equity and disparities, transitions across the lifespan, and impacts of the COVID-19 public health emergency (PHE) on program operations.

If you have any questions about your rights as a research participant, you may contact Westat's Human Subjects Protections office. Would you like that phone number? [IF YES:] Please call 1-888-920-7631 and leave a message with your full name and the name of this project, "Autism CARES Act Initiative Evaluation."

With your permission, we would like to audio record the interview for note-taking purposes. Other project team members may listen to the recording later, but we will store the recording on a secure directory and delete it after preparing summaries of the interviews. Would it be okay to record the call?

[If verbal agreement received, begin recording.]

Do you have any questions before we begin?

## Interviewee Introduction

Could you start by introducing yourself/yourselves with your name(s) and role(s)/responsibility(ies)?

## Research to Improve Health and Wellbeing of Individuals with Autism and Developmental Disabilities Across the Lifespan

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Our first set of questions focus on your autism and DD research aimed at improving the health and wellbeing of individuals with autism and DD across the lifespan. For all the following questions, we would like to focus on research studies completed or under development since the fall of 2020.

1. In your response to Question 1 of the survey, you indicated publishing X number of research studies. We would like to get copies of the publication abstract(s). Would you please email the abstracts to Carla Bozzolo at [cbozzolo@insightpolicyresearch.com](mailto:cbozzolo@insightpolicyresearch.com)
2. Please describe how your research has helped to improve the health and wellbeing of individuals with autism and DD.
  - a. **[SIIP/ATRP only:]** Specifically, how has your research advanced evidence on social determinants and risk factors associated with healthy life outcomes?
  - b. **[SIIP/ADLP only:]** Specifically, how has your research improved understanding of early life origins, signs, and indicators of autism/DD and their comorbidities?
3. What has your program done to foster collaborations between key groups working to advance research studies and/or activities to improve the health and wellbeing of individuals with autism and DD? Key groups could be community partners, other researchers, healthcare professionals, educators, policymakers, or those with lived experience of autism and DD.
4. In your response to Question 2 of the survey, you indicated that your research generated evidence in *[list]* area(s). *(Answer options for question 2: Transitions; Risk factors and/or life course factors; Health and wellbeing, including clinical improvements and quality of life; Other)*

Could you please elaborate on your research findings?
5. What knowledge gaps, if any, have been filled by your research? What knowledge gaps, if any, remain?
  - a. Gaps among certain historically underserved or marginalized populations?
  - b. Gaps regarding certain risk factors or signs of autism or other DD?
  - c. Gaps regarding certain social determinants or risk factors associated with healthy life outcomes?
  - d. Gaps in activities promoting healthy weight among individuals with autism and DD?
  - e. Gaps in activities promoting scientific collaboration and infrastructure building?
6. How have your research findings been translated and disseminated to promote changes in practice, programs, and/or policies (e.g., through toolkits, guidelines, fact sheets, etc.)?
7. On survey question 5, you noted your research findings have promoted health equity by *[list actions/strategies noted]*. *(Answer options for question 3: By engaging or including community organizations and/or members experiencing health disparities; By research prioritization and implementation of health equity topics; By dissemination or translation of research findings related to health equity; Other)*

Can you tell me more about these activities or strategies [probe: challenges, mitigation strategies, strategies that were particularly effective]?

[If needed: We use the Health Resources & Services Administration’s definition of health equity: “The absence of disparities or avoidable differences among socioeconomic and demographic groups or geographical areas in health status and health outcomes such as disease, disability, or mortality.”]

8. How has your research incorporated lived experience of individuals with autism and DD and/or their families?
9. In your response to Question 7 of the survey, you noted using existing datasets and administrative records in your research that were designed to improve the health and wellbeing of individuals with autism or other DD. What issues relevant to MCH populations have emerged from research using those datasets and/or records?

## **Awareness of Autism and Developmental Disabilities**

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Now we would like to ask you how your program has increased awareness of autism and DD.

10. In your response to Question 9 on the survey, you indicated X number of published products, such as lay summaries of research publications, guidelines, reports, infographic, web postings, etc. Do you have similar products that are currently being developed but not yet published?
  - a. [If yes:] Can you tell us what types of products these include?
  - b. [If yes:] What subjects or topics do these products focus on?
11. Which dissemination products, actions, and/or initiatives have been most effective in increasing awareness of autism and DD?
12. Which dissemination products, actions, and/or initiatives have been least effective?
13. In your response to survey question 11, you selected one or more audiences for dissemination of products focused on learning about autism or other DD. (*Answer options for question 8: Researchers, Clinical/healthcare professionals, Educators, Individuals with autism or other DD, Family members of individuals with autism or other DD, Policymakers, General public, Other*)

How do you measure the reach of your products’ dissemination among those audiences?

  - a. How have these dissemination efforts promoted understanding of autism or other DD indicators and comorbidities?
  - b. How have these dissemination efforts helped to advance knowledge and awareness around social determinants and risk factors associated with healthy life outcomes among individuals with autism?
  - c. How have these dissemination efforts helped to advance the evidence base of information on the health of children, adolescents, and young adults with autism or other DD, and in particular, ways to address the needs of historically underserved or marginalized populations?
  - d. How have these dissemination efforts identified existing and emerging issues for MCH populations?
  - e. [ How have these dissemination efforts promoted healthy weight among individuals with autism and DD?

## **Reducing Health Disparities and Increasing Health Equity**

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We'd like to transition now into asking about how your programs include populations that have been historically underserved or marginalized.

14. In your response to the survey question 6, you indicated that your program included the following historically underserved or marginalized populations: *[list populations]*. (Answer options for question 9: *Low-income populations, Racial and/or ethnic minorities, Individuals living in rural areas, Other*)
15. Could you please elaborate on the strategies/activities that your program implemented to help address health disparities among these populations? (Probe: *Which strategies/activities have been most effective? Which have been least effective?*)
  - a. **[HWRN only:]** What research activities has the network implemented to promote healthy weight among individuals with autism and DD in historically underserved or marginalized populations?
16. How has your research program evaluated their efforts to address disparities and advance health equity in screening, diagnosis, and systems of care?
17. What have been your greatest challenges [or lessons learned] in your efforts to engage historically underserved or marginalized individuals and address health disparities?
18. What have you done to recruit diverse participants in research studies from historically underserved or marginalized populations? Improving Transitions and Care Across the Lifespan

We're now going to turn to some specific questions about how your programs included transition-focused topics.

19. In your response to survey question 3, you indicated that your research included the following topics on transition-aged populations: *[list topics]*. (Answer options for question 10: *Transition from pediatric to adult healthcare, Transition from adolescence to adulthood, Transition between education settings, Transition from dependent to independent living situation, Transition from unemployment to employment, Other*)
  - a. Could you please elaborate on these topics? [Probe: *How did you choose these topics?*]
20. How has your program engaged with other programs and/or with other key stakeholders who are focused on transition to adulthood for people with autism and DD? Identifying Changes Made by CARES Programs Because of COVID-19

Our last section includes a few questions about how COVID-19 impacted your program's implementation and the changes you needed to make because of it. I'd like to keep the discussion focused more on the impact of COVID-19 on your program than the impact on individuals with autism and DD.

21. What changes, pivots, or adaptations, did your programs make/implement to overcome challenges because of COVID-19? [Probes: *Topics covered? Populations targeted? Strategies used? Dissemination products? Timeline of activities? Management and operations of the program?*]
22. Which COVID-19-driven changes, pivots, or adaptations, if any, had positive effects on your programs?
23. Which COVID-19-driven changes, pivots, or adaptations, if any, had negative effects on your programs?

24. Will you continue any changes made because of COVID-19 or revert to your original plans when implementing program activities?

## **Wrap-up**

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25. Is there anything we have not covered that you would like to share?

Thank you very much for speaking with us today. If you have questions about this interview or additional information you would like to share, please reach out to Katherine Flaherty ([KatherineFlaherty@westat.com](mailto:KatherineFlaherty@westat.com)) or Carla Bozzolo ([cbozzolo@insightpolicyresearch.com](mailto:cbozzolo@insightpolicyresearch.com))