

Attachment D.
Research Interview Guide

Research (Networks and Grants) Semi-Structured Interview Guide

Thank you for taking the time to speak with me today. My name is [NAME], and I'm a researcher at 2M Research. [INTRODUCE ALL ON THE CALL, IF THIS HAS NOT ALREADY OCCURRED] The purpose of this interview is to obtain some descriptive information about your research and study outcomes for the evaluation of the HRSA Autism CARES Initiative. We will be asking you questions about your activities and accomplishments related to the goals and objectives of Autism CARES. We'll focus on a few key topic areas, including research goals, awareness building, reducing barriers to care, improving systems of care, mentoring and training professionals, and demonstrating sustainability and impact.

[IF RELEVANT] Your program has been completing an annual survey, during which we ask programs to reflect on their activities in the preceding year. For this interview, I'd like you to reflect on the activities your program has completed for your current grant period. This evaluation builds on the previous evaluation, which covered Autism CARES activities and accomplishments through summer 2017. For each set of questions, I'd like you to report on activities or outcomes that have occurred during your current grant period. We understand that you received your most recent grant in [INSERT YEAR HERE]. Is that correct? We'd like you to think about the time since then during our conversation today.

[TOUCH ON BULLETED TOPICS AS NEEDED]

- **Review of additional data sources.** We have already reviewed some quantitative and qualitative data on your program from other sources, including [NAME RELEVANT DOCUMENTS]. The information you share today will supplement the other sources we have reviewed. You may be able to provide additional context or share new information.

[NOTE TO INTERVIEWER: TO THE EXTENT POSSIBLE, TRY TO DIRECT THE CONVERSATION TOWARD NEW INFORMATION OR SUPPLEMENTAL DETAILS THAT ARE NOT ADEQUATELY COVERED IN PROGRESS REPORTS, ETC.]

- **Evaluation results.** The results from this evaluation will be presented in a report that will focus on all grant programs that received funding under the Autism CARES Act.
- **ASD/DD focus.** We understand your program may also work in areas outside of autism spectrum disorder (ASD) and other developmental disabilities (DD). Since this evaluation focuses on Autism CARES funding, when discussing your program's activities and outcomes, please focus on information pertaining to ASD/DD unless otherwise indicated.

Do you have any questions before we begin?

Do I have your permission to record our conversation? The purpose of the recording is to be certain we accurately capture the information you share today. The recording will not be shared with HRSA.

[CONFIRM PERMISSION ONCE RECORDING STARTS]

According to the Paperwork Reduction Act of 1995, an agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0915-0335. The time required to complete this information collection is estimated to average 60 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.

INTRODUCTION

To begin, I'd first like to ask about the goals of your **[PROGRAM/NETWORK]**.

1. We understand that you have previously reported your goals and objectives in your performance progress reports. We are interested in hearing about what you think are your **[PROGRAM'S/NETWORK'S]** top three goals with regard to the HRSA Autism CARES Initiative?

CONTRIBUTING TO RESEARCH

Next, I'd like to discuss your **[PROGRAM'S/NETWORK'S]** overall activities related to research. Later we'll discuss more on how your **[PROGRAM'S/NETWORK'S]** activities specifically address, for example, awareness building and reducing barriers to care.

2. Thinking about the current grant period (since **[INSERT YEAR OF MOST RECENT GRANT HERE]**), how has your **[PROGRAM/NETWORK]** supported research to advance evidence-based interventions for children and youth with ASD/DD?
3. Are you aware of any of your **[PROGRAM'S/NETWORK'S]** research being translated into clinical practice? If yes, please describe. **[IF NEEDED]** Translating research into practice could include utilizing research to inform evidence-based practice.
4. Can you describe the ways parents and/or families were involved in your research during the current grant period (since **[INSERT YEAR OF MOST RECENT GRANT HERE]**)?
 - a. What contributions did they make?
 - b. What, if anything, did you change as a result of parent or family input?
5. Have you experienced any challenges publishing research?
 - a. If so, how were those challenges addressed or resolved?
6. In general, where do you think your research activities have had the most impact or have been the most successful?
7. What do you see as major gaps in ASD/DD research, if any?

INCREASING AWARENESS

Now, I'd like to learn about ways your **[PROGRAM/NETWORK]** may be helping to increase awareness and disseminate information about ASD/DD to a broad range of audiences. This is in addition to the formal training you provide to trainees within your program. **[IF RESPONDENT ASKS FOR CLARIFICATION]**. For example, in the past, grantees have disseminated "Learn the Signs. Act Early" materials to families, provided continuing education courses to various kinds of professionals, or disseminated findings from their research. You may have different examples.

8. How has your **[PROGRAM/NETWORK]** increased awareness of ASD/DD among maternal and child health professionals, providers, and/or researchers?
9. How has your **[PROGRAM/NETWORK]** increased public awareness of ASD/DD?

10. **[NETWORK ONLY]: [IF NOT ALREADY DISCUSSED]** Can you describe how validated evaluation tools have been disseminated to other researchers, providers, or the public?
11. Did your **[PROGRAM/NETWORK]** face any challenges with respect to awareness building or dissemination of information?
 - a. What strategies were implemented to overcome challenges to awareness building or dissemination of information? Were there any lessons learned?
12. In general, where do you think these awareness-building or dissemination efforts you've described have had the most impact or been the most successful during the most recent grant period?

REDUCING BARRIERS TO CARE, IMPROVING SYSTEMS OF CARE

Next, I'd like to talk about activities related to reducing barriers and improving systems of care that have occurred since **[INSERT YEAR OF MOST RECENT GRANT HERE]**. By systems of care, I mean the full continuum of care for individuals with ASD/DD including screening, diagnosis, intervention, treatment, and transition, etc. We recognize there may be some overlap between this objective and the others, so feel free to recall earlier examples, if you like.

13. Since receiving your most recent grant in **[INSERT YEAR HERE]**, how has your **[PROGRAM/NETWORK]** worked to improve the quality of care for children and youth with ASD/DD?
14. **[IF NEEDED]** What (other) efforts has your **[PROGRAM/NETWORK]** undertaken to build systems of care that improve capacity or are coordinated, comprehensive, and community-based?
15. Telehealth can be an important tool for improving access to quality health care, especially for underserved populations. Please describe how your **[PROGRAM/NETWORK]** has utilized telehealth to improve systems of care in the most recent grant period. **[IF NEEDED]** Telehealth is defined as the use of electronic information and telecommunication technologies (such as videoconferencing, phone text, audioconferencing) to support long-distance clinical health care, patient and professional health-related education, public health, and health administration.
 - a. **[PROBE]** How does your research examine the role of telehealth in access to health care and/or improving health care services?
16. Please describe how your **[PROGRAM/NETWORK]** has used tele-education or e-learning in the most recent grant period. **[IF NEEDED]** Tele-education or e-learning is defined as the use of electronic information and telecommunication technologies (such as videoconferencing or audioconferencing) to support long-distance learning. Tele-education is a subset of telehealth.
 - a. **[PROBE]** Has tele-education or e-learning been used by your **[PROGRAM/NETWORK]** for training? If yes, please describe
17. In general, where do you think your efforts to reduce barriers and improve systems of care have had the most impact or been the most successful? What efforts have been made, or what

efforts do you think are needed, to ensure any advances to improve systems of care and reduce barriers are sustainable?

- a. **[PROBE]** How has your program/Network worked to reduce health disparities and promote health equity for children and youth with ASD/DD?

MENTORING AND TRAINING PROFESSIONALS

We understand that developing leaders in ASD/DD is key to enhancing evidence-based interventions and practices. The next questions address your research activities related to training new investigators.

18. Could you tell me about your **[PROGRAM'S/NETWORK'S]** process for developing and mentoring new ASD/DD investigators? **[IF NEEDED]** This could include efforts to support small research projects from junior investigators, webinars targeting new investigators, new investigators serving as co-authors, and graduate students and/or postdoctoral fellows on projects.
19. Is there any particular study **[MENTIONED IN THE RESEARCH QUANTITATIVE DATA COLLECTION FORM, IF COMPLETED]** that includes findings you want to highlight or emphasize as we write about the successes of your **[PROGRAM/NETWORK]**?
 - a. **[PROBE]** Why does this stand out as particularly important to you?

ADDRESSING ASD/DD ACROSS THE LIFESPAN, INCLUDING TRANSITION FROM YOUTH TO ADULTHOOD

As part of our discussion on improvement of systems of care, we will now touch on how you have addressed ASD/DD across the lifespan.

20. How has your **[PROGRAM/NETWORK]** worked to address health outcomes for individuals with ASD/DD across their lifespan? This could include the transition from youth to adulthood and/or other points throughout the lifespan.
 - a. Research
 - b. Information dissemination
 - c. Development of evidence-based or consensus-based guidelines and screening tools
 - d. Other areas
21. How has the passing of the Autism CARES Act of 2019 impacted your activities during the most recent grant period?
22. **[IF NEEDED]** What strategies have you found to be successful in improving services and support across the lifespan for those with ASD/DD, and what factors have facilitated their success?
23. **[IF NEEDED]** What major challenges remain to improving services and support for those with ASD/DD across the lifespan?

[NETWORK ONLY; IF THE RESEARCH NETWORK QUANTITATIVE DATA COLLECTION FORM INDICATED GUIDELINES HAVE BEEN DEVELOPED] DEVELOPING GUIDELINES FOR ASD/DD INTERVENTIONS

The next questions ask about guidelines developed or validated by your Network. You indicated on the Research Network Quantitative Data Collection Form that your Research Network developed guidelines.

24. **[NETWORK ONLY] [IF NOT ALREADY STATED]** Can you describe your Research Network's guideline development process?
25. **[NETWORK ONLY]** Can you describe how your Research Network's guidelines have been disseminated to other researchers, providers, or the public?

SUSTAINABILITY AND IMPACT OF FUNDING

Next, I will be discussing sustainability and the impact this funding had on your activities and research.

26. To what extent do you feel the changes set in motion through your grant will be sustained following the end of the grant? **[PROBE FOR COLLABORATIONS AND/OR PARTNERSHIPS]**
 - a. **[IF RELEVANT]** Which activities will continue? Which will end?
27. **[GRANT ONLY]** Do you believe your program's research could sustain itself without Autism CARES funding?
 - a. Why or why not?
28. **[GRANT ONLY]** What would you say is the single most important accomplishment of your program with the support of the Autism CARES grant?
 - a. What has the grant support allowed you to do that you could not have done otherwise?
29. **[GRANT ONLY]** What efforts have been made, or what efforts do you think are needed, to ensure any advances achieved are sustainable?
30. **[NETWORK ONLY] [IF NOT ALREADY MENTIONED]** Please tell us more about how successful your partnerships have been among key stakeholders. LEND? DBP? Collaborating Research Entities (CRE)?

[PROBE] Are these new partnerships, or partnerships that were in place prior to your most recent grant in **[INSERT YEAR HERE]**?

[PROBE] We understand your network includes **[NUMBER]** CREs. Can you describe the role of the CREs in the dissemination efforts of the network?

OVERARCHING QUESTIONS

Now I have a few overarching questions about your activities and some final questions about the broad impact of your program.

31. Thinking about all the activities we've discussed today, where would you say you've faced the biggest challenges? What barriers have gotten in the way of your progress?

[PROBE] What have been your main challenges related to research? Promoting evidence-based guidelines for interventions? Increasing awareness? Addressing ASD/DD across the lifespan, including transition to adulthood? Training?

32. How, if at all, has your **[PROGRAM/NETWORK]** evaluated the activities we've discussed today?

- a. How have you evaluated your activities related to research? Promoting evidence-based guidelines for interventions? Increasing awareness? Addressing ASD/DD across the lifespan, including transition to adulthood? Training?
- b. Do you have any initial results from these evaluations that you could describe today?

FINAL QUESTIONS

[NETWORK ONLY] [INTERVIEWER: ASK CLARIFYING QUESTIONS FROM THE CORRESPONDING TABLE(S) IN THE RESEARCH NETWORK QUANTITATIVE DATA COLLECTION FORM BEFORE ASKING THE FOLLOWING QUESTIONS.]

[PLACEHOLDER FOR QUESTIONS YOU MAY HAVE FROM PROGRESS REPORTS/OTHER DATA SOURCES FOR WHICH YOU WOULD LIKE MORE DETAIL]

33. Is there anything else you would like to share about your program at this time?

34. Is there anything else you would like to add that I did not ask about?

That concludes my questions for you. Thank you very much for speaking with me.