

**ATTACHMENT E.  
RESEARCH NETWORK INTERVIEW PROTOCOL**

## Research Network Interview Protocol

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**T**hank you for taking the time to speak with me today. My name is [name], and I'm a researcher at Insight Policy 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 network's activities and outcomes for the evaluation of MCHB's Autism CARES (or Collaboration, Accountability, Research, Education, and Support) Act Initiative. I will be asking you questions about your activities and accomplishments related to the goals and objectives of Autism CARES. I'll focus on research studies, research products, awareness building, collaborating, developing new investigators, and improving systems of care.

Throughout our discussion, I will also be asking you about activities related to supporting youth with autism spectrum disorder (ASD) during times of transition because this is a new reporting requirement for MCHB focus.

### Touch on bulleted topics as needed

- ▶ **Review of additional data sources.** In addition to the quantitative data collection tool you have recently filled out for us, we have also reviewed data on your program from progress reports and DGIS. The information we collect today is intended to supplement the data we have already reviewed. You may be able to provide additional context or share new information.

*[Note to interviewer: To the extent possible, try to focus the conversation on new information or supplemental details that are not adequately covered in the progress reports.]*

- ▶ **Evaluation results.** The results from this evaluation will be presented in two separate documents. The first is a brief (< 10-page) fact sheet summarizing the major activities of the Autism CARES Research Program. The second is a larger, more detailed report on all grant programs that received funding under Autism CARES.
- ▶ **Evaluation period.** This evaluation builds on the previous evaluation, which covered Autism CARES activities and accomplishments through fall 2014. For each set of questions, we'd like you to report on activities or outcomes that have occurred since approximately fall 2014.

*[For HCT-RN and HW-RN, there is no previous evaluation, so instruct to report all activities since first receiving CARES funds.]*

- ▶ **ASD focus.** You or your program may work in areas outside of ASD and other developmental disabilities (DDs) and may receive support from numerous sources. Since this evaluation focuses on Autism CARES funding, please report only on activities pertaining to ASD and DDs that are supported by Autism CARES funding.

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 anyone outside the Insight evaluation team.

*[Confirm permission once recording starts.]*

*[Note: The questions cover eight domains, one for each Autism CARES goal associated with the Research Program grants. The questions in each domain provide the general topics to cover and not all are applicable to all grantees. As a result, the following questions will be adapted to the activities of a particular grantee. Each discussion will also build on the information already obtained from the Autism Research Network Quantitative Data Collection Tool.]*

I'm going to start by reviewing the information on the data collection form you sent to us [date submitted]. Do you have it with you or can you pull it up for reference?

## **A. Conducting Research Leading to Evidence-Based ASD Interventions**

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I'd like to talk about your program's research activities related to ASD and evidence-based or consensus-based practices. This discussion may reference data you provided in tables 1–8 of the data collection form.

Let's start with tables 1 and 2.

*[Interviewer asks clarifying questions about tables 1 and 2 of the data collection form, focusing especially on any discrepancies between the two tables and ongoing studies not yet complete at the end of the funding cycle.]*

*[After asking any clarifying questions about tables 1 and 2, ask all the following questions on topics related to the tables.]*

*[Note to interviewer: Definitions of leveraged and mixed funding are above table 1 on the quantitative tool, for the interviewee's reference. They are also copied below.]*

Leveraged funding is defined as a situation where network funds were used to write proposals for new funding that builds on research projects recently completed or in progress at the time of proposal writing. This is different from mixed funding, which occurs when a study receives supplemental funds from another source (e.g., Autism Speaks).

### **Table 1: Summary of Number, Type, and Status of Studies and Their Financial Support**

1. How did you come up with the number of studies with mixed funding?
2. How did you calculate the dollar amount of funding obtained as a consequence of the Autism CARES funds?

3. Tell me about the network's processes for obtaining funding to support research. What strategies did you use to develop and fund or obtain funding for research concepts and proposals?
  - a. [Probe] How successful have these strategies been in conducting your research? What worked best? What would you change?  
*[Look for successes/positive aspects and shortcomings/negative aspects]*
4. Do you believe the network could sustain itself without Autism CARES funding? Why or why not?

## **Table 2: List of Studies, Their Goals, and Status of Study Activity**

5. Is there any particular study here that includes some finding you want to highlight or emphasize as we write about the successes of your research network?

The next questions relate to tables 3 and 4 and ask about your activities related to underserved populations and your reach to families of children affected by ASD/DDs.

*[Interviewer asks clarifying questions about tables 3 and 4 of the data collection form, especially focusing on any discrepancies between the two tables.]*

6. Can you describe the ways in which parents and families are involved in your research? What contributions did they make? What, if anything, did you change as a result of family input?

*[Ask any necessary clarifying questions related to table 5.]*

The next questions relate to tables 6, 7, and 8 and ask about your publications and presentations.

*[Interviewer asks clarifying questions about tables 6, 7, and 8 of the data collection form, focusing especially on any discrepancies among tables 6, 7, and 8. After asking clarifying questions about tables 6, 7, and 8, ask all the following questions on publications and presentations.]*

7. Is there any publication that includes some finding you particularly want to highlight or emphasize as we write about your research network?
8. Have you experienced any challenges publishing research? If so, how were those challenges addressed or resolved?

Before we move on to the next section, we have two overarching questions about your research experiences with Autism CARES.

9. What do you see as major gaps in ASD/DD research?

10. How, if at all, has your program evaluated its research efforts? Do you have any initial results to report?

## **B. Develop and Validate Tools for ASD Interventions**

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The next questions relate to tables 9 and 10 and ask about tools and outcome measures developed or validated by your network.

*[Interviewer asks clarifying questions about tables 9 and 10 of the data collection form, focusing especially on any discrepancies between the two tables.]*

11. [If not already stated] Can you verify which tools have been endorsed by professional associations?
12. [If not already stated] Can you verify which tools have been disseminated to other researchers, providers, or the public? How?

## **C. Develop Guidelines for ASD Interventions (Only for AIR-P)**

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The next questions relate to tables 11 and 12 and ask about tools and outcome measures developed or validated by your network.

*[Interviewer asks clarifying questions about tables 11 and 12 of the data collection form, focusing especially on any discrepancies between the two tables]*

13. [If not already stated] Can you verify which guidelines have been endorsed by professional associations?
14. [If not already stated] Can you verify which guidelines have been disseminated to other researchers, providers, or the public? How?

## **D. Disseminate Information and Increase Awareness**

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Now we'd like to learn about ways your program may be helping to increase awareness and disseminate information about ASD/DDs to a broad range of audiences.

In table 13, you provided us with information about your materials developed and related dissemination activities. We also asked you about dissemination to three broad audiences: health or school professionals, parents, and communities. We hope to learn more context about the information you provided, so we can tell your story well in the final report.

15. Who were the primary audiences targeted with dissemination efforts? Were they mainly those described in table 13, or are there other, perhaps, more specific audiences?
  - a. What were the main messages for each audience?

16. What were the primary modes of ASD/DD awareness outreach and dissemination (e.g., dissemination of print materials, Webinars, conferences, communication campaigns, teleconference, in-person training)?
  - a. Were any modes of awareness building more effective than others?
17. Has your network produced any products, actions, or initiatives resulting from efforts to increase awareness of ASD/DDs and/or disseminate related information?
  - a. If yes, could you send us any documentation related to these products so we may have them as potential examples to highlight in our reports?
18. How have you evaluated your own success with information dissemination and awareness building (e.g., tracking the number of downloads)?
19. What dissemination strategies have been most successful? Why?
  - a. How effective do you feel your Web site has been in disseminating information?
  - b. How often did you update the Web site?
  - c. How did you measure use of the information on the Web site?
20. Did the network face any challenges with respect to dissemination?
  - a. Did those challenges differ by audience (health care professionals, families)?
  - b. What strategies were devised to overcome dissemination challenges? Were there any lessons learned?
21. In general, where do you think your awareness-building efforts had the most impact or were the most successful?
22. Is there anything related to this dissemination work you would like to highlight in the MCHB report?
23. Is there anything you are particularly proud of that you feel was effective in meeting MCHB objectives?

## **E. Collaborate With CARES Grantees and Others**

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Let's move on to table 14 and discuss collaborative activities of your research network.

*[Note: Potential collaboration partners include State Title V Block Grant and State Children with Special Health Care Needs Program, The National Medical Home Autism Initiative, Family Professional Partnerships, Cultural Competence Program, State Implementation Grants for CSHCN, Health Insurance and Financing, Early and Continuous Screening, Healthy and Ready to Work, State agencies, schools or social service agencies, community-based organizations, or other organizations.]*

[Interviewer will ask clarifying questions about table 14 of the data collection form, before asking the following questions.]

24. Feel free to reference table 14 for this question. How has your program collaborated with other Autism CARES grantees and other stakeholders for any of the following reasons:
  - a. The specific purpose of increasing of ASD/DD awareness and disseminating related information?
  - b. To provide ASD-related technical assistance and training?
  - c. [If not already mentioned] Have you formed any collaborations or partnerships with State agencies, schools or social service agencies, community-based organizations, or other organizations?

[Probe] Nature of these collaborations? [Note: AIR-B collaborating research entities (CREs) each have an implementing site; AIR-P CREs each have a clinic that may or may not be part of the institutional affiliation]

[Probe] How successful have these partnerships been?

[Probe] Have these partnerships or collaborations contributed to the goal of increasing awareness of ASD and other DDs among health professionals, paraprofessionals, family members, or advocates?
25. We understand your network includes [number] CREs. These are the sites where the research is conducted, typically the institutions of your co-investigators. Can you describe the role of the CREs in the dissemination efforts of the network?
  - a. [Probe] How effective were they in these activities?
  - b. [Probe] How do they collaborate with one another to develop, conduct, and disseminate the research?
26. Can you describe any collaborations with LEND/DBP programs to implement training and education based on research findings, tools, and guidelines?
  - a. Any collaborations with other CARES grantees?
  - b. [If so] How have you coordinated with them?
27. Have you collaborated with other departments in your hospital or university to disseminate and implement research findings, tools, and guidelines? [If so] How have you coordinated with them?
28. Did you collaborate/coordinate with other local or State initiatives to develop/deliver family trainings? Family-to-family health information centers? [If so] How have you coordinated with them?
  - a. [For AIR-B] What about collaborating with schools themselves, other than conducting the research?

## F. Develop New Investigators

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The next questions address your network's activities related to training new investigators. We'll start by looking at table 15 in the quantitative tool.

*[Interviewer asks clarifying questions about table 15 of the data collection form before asking the following questions]*

29. Could you tell me about your process for developing and mentoring new ASD investigators?
  - a. [Probe] 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
30. How successful have these recruiting and mentoring strategies been?
31. Finally, can you tell me how, if at all, your program has evaluated its efforts to train professionals? Do you have any initial results to report?

## G. Reducing Barriers and Improving Systems of Care

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One key goal of Autism CARES funding is to transfer research findings into practice settings and communities and to promote the implementation of evidence-based or consensus-based practices that will result in improved care.

*[Interviewer asks clarifying questions about table 15 of the data collection form before asking the following questions.]*

32. How has your program promoted translation of your research into practice as it relates to ASD/DDs? (may include efforts in clinical or school settings, among others)
  - a. Specifically, how has your network achieved translation of research into practice at clinical settings? School-based settings? Community settings?
33. To what extent has this research been translated into policy or practice at the local, regional, or Federal level?
34. Other Autism CARES grantees are focusing on reducing barriers to care for underserved populations and making sure they have swift access to screening, diagnosis, and intervention. Have any of the network's studies or tools addressed service barriers for minority and underserved populations? [Probe awareness of research] If yes, please explain.
  - a. What progress was made to reducing barriers?
  - b. How effective were these activities?

## H. Youth Transition to Adulthood

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35. How has your research network incorporated the issue of transition into efforts in—



- a. Research
  - b. Information dissemination
  - c. Development of evidence-based or consensus-based guidelines and screening tools
36. What strategies have you found to be successful in improving services and supports for young adults transitioning to adulthood, and what factors have facilitated their success?
37. What major challenges remain to improving services and supports for young adults transitioning to adulthood? What challenges have you faced in addressing these issues?
38. How have you evaluated your own efforts to support the transition to adulthood for young adults with ASD/DDs and their families, and what were their evaluation results?

## **I. Overarching Questions, Wrap-Up**

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

### **General Questions**

39. [If not already covered, check for adequate coverage of the “buzzwords”] I want to make sure we cover a few key concepts important to MCHB.
- What can you tell me about your program’s main activities related to—

[Probe on any relevant items]

- a. Transition
- b. Collaboration with other MCHB grantees
- c. Cultural and linguistic competency
- d. Family-centered care
- e. Interdisciplinary care and collaboration
- f. Medical homes
- g. Underserved populations (rural and minority)

[Probe] How were these activities influenced by Autism CARES funding?

- 40. Thinking about all the activities we've discussed today, where would you say you have faced the biggest challenges? What barriers have gotten in the way of your progress?
  - a. [Probe] With regard to research, awareness, systems of care?
- 41. How, if at all, has your program evaluated the activities we have discussed today?
  - a. Have you evaluated your activities related to research, awareness, systems of care?
  - b. Do you have any initial results to share from these self-evaluations?

### ***Overarching Autism CARES Goals***

- 42. What would you say are your main goals with regard to Autism CARES?
- 43. Are there any areas where you fell short of these goals?
  - a. If so, what challenges prevented you from meeting the goal or goals?
  - b. What do you think it would take for you to meet those goals in the future?

### ***Sustainability and Long-Term Impact of Funding***

- 44. To what extent do you feel the changes set in motion through your grant will be sustained following the end of the grant? What strategies, if any, were implemented to sustain your program after the Federal grant period ends?
  - a. [If relevant] Which activities will continue? Which will end?
- 45. What would you say is the single most important accomplishment of your program with the support of the Autism CARES grant? What has the support allowed you to do that you could not have done otherwise?
  - a. Your program has been receiving Autism CARES funding for [X] years now. How do you think this funding has affected your training program in the long term?



## ***Final Questions***

46. Is there anything else you would like to share about your program at this time?
47. Are there any questions I should have asked that I didn't ask?

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

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