

**ATTACHMENT D:
RESEARCH NETWORK SEMI-STRUCTURED INTERVIEW PROTOCOL**

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SEMI-STRUCTURED INTERVIEW GUIDE
AUTISM INTERVENTION RESEARCH NETWORKS

The purpose of this interview is to obtain descriptive information about your activities and outcomes for the evaluation of MCHB's Combating Autism Act Initiative. Today, we will be asking you questions on several topic areas related to the objectives of the Combating Autism Act Initiative.

Note: This guide is divided into five domains, one for each CAAI 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 guide will be adapted to the activities for a particular grantee. Each discussion will also build on the information that has already been obtained during reviews of program documents.

Review Data Collection Form (15 min)

In this section, the questions will be tailored to the particular grantee's information obtained from the survey form. Each discussion will also build on the information that has already been obtained during reviews of program documents.

I'm going to start by reviewing the information on the data collection form that you sent to us on MONTH, DAY. Do you have it with you or can you pull it up for reference? [If longer than a week], Are there any updates to it?

Studies

You have noted that you are working on [INSERT NUMBER] studies. Is our understanding accurate? [ASK ANY REMAINING QUESTIONS ABOUT THE PURPOSE OF THE STUDIES] Are there any other studies you are working on that are funded as part of your CAAI grant?

- [INSERT NUMBER] of these are studies that have continued from the last grant period, correct?
- o [INSERT NUMBER] of these use leveraged funds from other sources? Which sources?
- Can you describe whether and how your research studies target underserved populations?
 - o Which populations?
- What steps, if any, did you take/are you taking to ensure the participation of underserved and minority populations, in the design and execution of study protocols?

Tools/Measures

You have noted that you are working on [INSERT NUMBER] tools or measures. Is our understanding accurate? [ASK ANY REMAINING QUESTIONS ABOUT THE PURPOSE OF THE TOOLS OR MEASURES]

- [INSERT NUMBER] of these are tools/measures that have continued from the last grant period, correct?
- [INSERT NUMBER] of these have been released, is that correct?

Guidelines

You have noted that you are working on [INSERT NUMBER] guidelines. Is our understanding accurate? [ASK ANY REMAINING QUESTIONS ABOUT THE PURPOSE OF THE GUIDELINES]

- [INSERT NUMBER] of these are guidelines that have continued from the last grant period, correct?
- [INSERT NUMBER] of these have been released, is that correct?

Conduct Research Leading To Evidence-Based ASD Interventions (15 min)

We understand that your grant has focused on research that addresses the [physical/behavioral/developmental] health needs of children and adolescents with ASD.

Tell me a little bit about the network's processes. What strategies do you use to develop and fund or obtain funding for research concepts and proposals?

Probes:

- How successful have these strategies been in conducting your research?
 - What worked best?
 - What would you change? [look for Successes/positive aspects – shortcomings and negative aspects]
- Have you had any challenges in publishing the research?
- Thinking about the development of the research products, what are some of the challenges you have faced?
- 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?

Develop and Validate Tools for ASD Intervention (8 min). [NOTE: Skip this section for DBPNet]

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

Develop Guidelines for ASD Interventions (7 min) [Note: Skip this section for DBPNet]

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

Disseminate Findings and Network Activities (15 min)

We understand that your Network has also focused on dissemination of information for health professionals and families impacted by ASD and other DD. This will help to increase awareness about improving health and well-being of children and adolescents with ASD and their families. Tell me a little about this work.

- What are the challenges that the Network has faced with respect to dissemination?
- [If not already discussed]: What kind of **materials** have been developed?
 - Who are the intended audiences?
 - How have the materials been disseminated?
- While not a grant requirement, some grantees are also working on raising awareness with other interested parties, such as parents. To what extent has the Network engaged in raising public awareness?

Probes:

- What kinds of training, information sharing, and other sessions have you held geared towards health professionals? What have been the contents of those sessions? Format of that training or information-sharing (e.g. monthly teleconference?)
- What other sorts of community outreach and educational sessions have you held? Content of those sessions? Frequency? Audience?
- [For AIR-P]: [If not already discussed], tell me about the monthly webinar activities. How successful were these efforts?

Collaborations

We understand that your Network includes [INSERT NUMBER] Collaborating Research Entities (CREs). These are the sites where the research is being conducted, typically the institutions of your co-Investigators. Can you describe the role of the CREs in the dissemination efforts of the Network?

Probes:

- How effective were they in these activities?
- How do they collaborate with one another to develop, conduct, and disseminate the research?

- In the course of your grant period, have you formed any collaborations or partnerships with State agencies, schools or social service agencies, community-based organizations, or other organizations?
 - Nature of these collaborations? [Note: AIR-B CRE's each have an implementing site, AIR-P CRE's each have a clinic which may or may not be part of their institutional affiliation]

Probes:

- How successful have these partnerships been?
- Have you done any collaborating with LEND/DBP programs to implement training and education based on research findings, tools, and guidelines? Collaborations with other CAAI grantees? [If so,] How have you coordinated with them?
- Have you done any collaborating 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?
- 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?
- [For AIR-B]: What about collaborating with schools themselves, other than conducting the research?

Grand Rounds, Presentations, Conferences, Speeches

To build awareness, you have also [*describe our understanding of ground rounds, speeches and presentations*]. Is our understanding accurate? Is there anything else to add?

Other Outreach Activities

To build awareness, you have also [*describe our understanding of their other outreach activities not already mentioned*]. Is our understanding accurate? Is there anything else to add?

- How effective do you feel the website has been in disseminating information?
 - How often do you update the website?
 - How do you measure use of the information on the website?
 -
- Any other dissemination or awareness-building efforts we haven't already mentioned?
- Which efforts have been most successful and why?

Develop New Investigators (15 min)

Tell me about your process for developing and mentoring new ASD investigators.

Probes:

- 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.
- How successful have these recruiting and mentoring strategies been?

Promote Implementation of Practices/Improved Care (15 min)

One key goal of the CAAI is to transfer network findings into practice settings and communities, and to promote the implementation of evidence-based practices that will result in improved care. How specifically has the Network promoted translation of your research into clinical practice and/or school settings?

Probes:

- What specific steps have been taken to work with medical or behavioral care providers to implement the research or to incorporate the research into the medical educational curriculum? What progress was made?
- What about working with schools and educational staff in practices that improve school services?
- [AIR-P and AIR-B only]: After the guidelines and tools were released, what was your expectation on timing for adoption? Have these expectations been met?
- Have any of the Network's efforts addressed service barriers for minority and underserved populations? [Probe: awareness of research] If yes, please explain.
 - What progress was made to reducing barriers?
 - How effective were these activities?

Sustainability

- What strategies, if any, were implemented to sustain the Network after the federal grant period ends?

Probes:

- Which activities will continue? Which will end?
- For those activities that will continue, what will be the source of funding?

Wrap Up (5 min)

- What was the most important contribution(s) of the CAAI funding to date?

Probes:

- Have you met your initial goals or objectives for your research studies?
 - If yes, how do you know?
 - If not, why not?

Any findings you'd like to highlight in particular at this point? Or a particular study, guideline, or tool?

Is there anything that we haven't covered?

Thank you for your time. We greatly appreciate your assistance.