R40 MCH Autism Intervention Research Program Grantees Interview Protocol

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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 and study 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. We’ll focus on the following main topic areas:

1. Conduct research leading to evidence-based ASD interventions.
2. Disseminate information and increase awareness.

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.

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.*]

[Notes: This guide is divided into two domains, one for each CARES goal associated with the R40 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 according to the activities of a particular grantee. Each discussion will also build on the information that has already been obtained during reviews of program documents.]

[*Prior to the interview, we will send a document with a profile of the grant program containing information we pulled from applications and progress reports. Prior to this interview, each grantee will read through the profile, verify the information, and make corrections or additions where necessary*.]

Thank you for reviewing the research summary we sent you. Gaining your feedback ahead of time helps us ensure a good sense of your study. Still, our understanding of your research could be enhanced by hearing about it from you, in your own words.

1. Conduct Research Leading to Evidence-Based ASD Interventions

The first section of this interview is about the MCHB objective to conduct research leading to evidence-based ASD interventions.

1. We understand your grant has focused on research leading to improvements in interventions that address the health of children and adolescents with ASD and other DDs.

[*Read brief study description.*]. Is our understanding accurate?

1. [If not already discussed] How would you best articulate your goals for conducting this research?
2. Can you tell me if these goals were reached?
3. [Probe] If yes, how do you know? If not, why not?
4. Could you describe any challenges in achieving the study goals?
5. Any challenges you faced implementing this research?
6. Was the study completed by the end of the grant period?

[*See column D in R40 Interview database*.]

1. How would you describe the type of research conducted?
2. [Probe] Intervention research? Other? What was the primary focus?
3. What populations did this research focus on? Were you able to reach your target population(s)?
4. Was there a focus on underserved populations?
5. Specifically, Hispanic, African-American, low-income, or rural populations
6. Was cultural competency addressed in any way for this study?
7. Did this study consult families, parents, or people with ASD/DDs over the course of the study?
8. At which points in the study (i.e., study design, implementation, interpretation of results)?
9. This is the last question about your research process. As you know, we are using this information to report on your grant activities; however, we are reporting on the activities of all grantees who received funding through the R40 mechanism.

Could you describe the most significant findings from your research, or those findings you think we should highlight in the report, which speak to the value of the research and its impact?

1. Disseminate Information to Health Professionals and the Public

The next part of our interview is about the products of your research and dissemination of those findings to health professionals and the public.

1. I can see from your report that you have [X] total products related to this research. Could you briefly describe those products?
2. Publications
3. Conference presentations: are all listed scientific conference presentations?
4. Toolkits: please describe. Are they publicly available? Could you share with us?
5. Measures: please describe. Are they publicly available? Could you share with us?

i. Validated? Plans to validate? Piloted?

1. Guidelines developed (not expected, just checking)
2. Piloted? Released? Endorsed?
3. What dissemination efforts or activities of these products have been or will be conducted?
4. What types of health professionals or population groups were (or will be) the target audience for your dissemination efforts?
5. [If dissemination was conducted] Which dissemination efforts have been most successful and why?
6. What are the challenges associated with disseminating your particular study information?
7. What types of things do you hope could happen as a result of your research in this area?
8. Wrap-Up
9. Is there anything we haven’t covered?

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

Public Burden Statement:  An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.  The OMB control number for this project is 0915-XXXX.  Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 10C-03I, Rockville, Maryland, 20857.