

**DEVELOPMENTAL BEHAVIORAL PEDIATRICS
(DBP) INTERVIEW PROTOCOL**

DBP Interview Protocol

Thank you for taking the time to speak with me today. My name is [name], and I'm a researcher at Insight Policy Research. The purpose of this interview is to obtain some descriptive information about your DBP program's activities and outcomes for the evaluation of MCHB's Autism CARES (or Collaboration, Accountability, Research, Education, and Support) Act 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 topics including training, awareness building, research, 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 their transition to adulthood because this is a new reporting requirement for MCHB.

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 can 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 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 DBP grantees. The second is a larger, more detailed report that will focus 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 roughly summer 2014. For each set of questions, I'd like you to report on activities or outcomes that have occurred since approximately fall 2014.
- ▶ **ASD and other developmental disabilities (DDs) focus.** I know your program works on DDs other than ASD. I am interested in hearing about activities related to both ASD and other DDs.
- ▶ **CARES Funding.** I know your program has funding from various sources, and it can be challenging to separate out the contributions of each. Because this evaluation focuses on Autism CARES funding, please try to focus on activities supported by your Autism CARES DBP training grant 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.]

A. Training

For this set of questions, I'd like to talk about some of the ways the Autism CARES funding has influenced the training your program provides.

[Interviewer may customize this section as a reminder to probe on the program's specific training activities as described in progress reports, etc.]

1. As I mentioned before, we are interested in how the grants have influenced your program since fall 2014. How has the continued Autism CARES funding influenced the training your program offers?
 - a. Has the funding influenced your program's training capacity (e.g., enabling you to support a larger number of trainees)?
 - b. Has the funding changed the clinical opportunities available to trainees?
 - c. Has the funding changed the training opportunities in community settings for trainees? What kinds of activities have been added, and where do they take place?
 - d. To what extent has your program engaged family members in the training process? To what extent has your program engaged self-advocates/people with disabilities in the training process? To what extent are these efforts supported by the Autism CARES DBP training grant?
2. [If not already covered] Has the number of long-term trainees changed since fall 2014?
 - a. What about the number of medium- or short-term trainees? Have the types of medium- or short-term trainees changed as a result of the Autism CARES DBP training grant (e.g., trainees from new disciplines, more community practitioners)?
3. How would you describe the diversity of your faculty and trainees (racial and ethnic diversity, geographic diversity, disciplinary diversity)? Has the Autism CARES DBP training grant affected this in any way?
4. How, if at all, has the curriculum changed since fall 2014?
 - a. Has the didactic curriculum been modified to include any new content, especially content specific to ASD?
 - b. [Probe] Transition to adulthood? Valid and reliable screening and diagnostic tools? Interventions?
5. [If not already covered] Have you incorporated any new training opportunities that focus specifically on screening tools, diagnostic instruments, or interventions, particularly for ASD?
 - a. [Probe] Instruments covered? Type of training? Audience?
6. [If not already covered] Have you incorporated any new training opportunities that focus specifically on transition to adulthood, particularly for ASD?
 - a. [Probe] Type of training? Audience?

7. In the past, grantees emphasized the central role developmental-behavioral pediatricians play in providing coordination of care for individuals with ASD/DDs and their families. To what extent has your program emphasized providing coordination of care in its training activities?
 - a. [Probe] How do trainees learn about this aspect of DBP? How have the Autism CARES DBP grants affected this component of training?
8. To what extent has your program emphasized advocacy in its training activities since fall 2014? How does your program prepare trainees for advocacy-related work?
 - a. [Probe] How do trainees learn about this aspect of DBP? How have the Autism CARES DBP grants impacted this component of training?
9. I understand DBP programs aim to prepare trainees to take on leadership roles following their training. What are some of the ways your program prepares trainees to become leaders in their field? Has this component of the program changed at all with the Autism CARES DBP funding? Anything new since fall 2014?
10. Thinking about all the training activities you've described, what would you say has been the most important contribution of the Autism CARES DBP funding?
11. Which of your training activities have been particularly effective in reaching the goal of early identification and intervention for ASD? What factors do you think facilitated their success?

B. Contributing to Research

Next I'd like to talk about your program's research activities, particularly any activities related to ASD.

12. To what extent are your DBP faculty members or trainees currently involved in planning or conducting any research studies related to ASD/DDs?
13. Can you tell me a bit about some of the most significant studies related to ASD/DDs that have been supported in some way by the Autism CARES DBP funding since fall 2014?

[For each study described, probe]

 - a. What is being investigated, and who is doing the research?
 - b. How will the results be disseminated?
 - c. How might the results be used (e.g., will they provide evidence about an intervention's effectiveness)?
 - d. Did any partnerships or collaborations contribute to these activities? What about partnerships or collaborations with other MCHB-funded programs (LEND, SIGs, Research Networks)?
14. [If not already discussed] Are trainees involved in research? In what capacity? What training do they receive in conducting research and the research process?

15. [If not already discussed] Has your program undertaken or planned to undertake any other research activities focused on translating research into practice? [Probe] Such as developing guidelines for practice?
16. Thinking about all the research activities you've described, what would you say is the most significant contribution of the Autism CARES DBP funding to your research activities?

Increasing Awareness

Now I'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. This is in addition to the formal training you provide to professionals within your program.

17. Can you tell me about a few of your program's key efforts to increase ASD/DD awareness since fall 2014, particularly those activities touched by the Autism CARES funding?
[For each effort described, probe]
 - a. What types of audiences/professional fields were targeted (e.g., practicing pediatricians aiming to get the latest information on screening, rural health care providers, social workers, educators)?
 - b. Approximately how many professionals did you reach?
 - c. What topics/content areas did these efforts focus on (e.g., early signs and symptoms, evidence-based screening tools, DSM 5 changes, transition issues and services)?
 - d. What was the primary communication strategy used (e.g., dissemination of print materials, Webinars, PSAs, conferences)?
 - e. How did the Autism CARES funding impact these activities?
18. [If not already covered] What awareness-building activities, if any, focused on transition to adulthood?
19. Thinking about all the awareness-building activities you've described, what would you say is the most significant contribution of the Autism CARES DBP grant funding?
 - a. Have you seen any changes in practices or attitudes as a result of your awareness efforts? How are these changes measured?

C. Reducing Barriers and Improving Systems of Care

Next I'd like to talk about activities related to reducing barriers and improving systems of care.

20. What are the most significant barriers to care in your community? What opportunities exist to address these barriers?
 - a. Who is best positioned to do the work? What organizations or individuals can best address those barriers?
 - b. What resources are needed?

- c. Which of these barriers, if any, has your program specifically been working to address since fall 2014? What strategies are you using to address them? How has the Autism CARES DBP funding influenced these activities?
- 21. What changes have you seen, if any, in children's and young adults' access to care?
 - a. How, if at all, are these changes tracked?
 - b. Is there any evidence of improved access to early screening and diagnostic services? Of improved access to transition services?
- 22. To what extent has your program reached children and young adults from underserved populations with respect to screening, diagnostic, intervention, or transition issues?
 - a. Have you developed or carried out any specific plans to reduce barriers to care among underserved children? [Probe] Any preliminary results you may have observed from these activities?
 - b. Has your program developed/used innovative models of care, such as telehealth or tele-education to expand the reach to underserved populations?
- 23. Has your DBP program formed any partnerships or collaborations to improve systems of care, such as to provide training or technical assistance, raise awareness, or provide other services?
 - a. [If not already answered] How have you worked with State Title V or other agencies?
 - b. What about partnerships with schools, community-based organizations, or other local entities?
 - c. What about partnerships with other MCHB grantees, such as LENDs, research networks, or State Implementation grantees?
- 24. [If needed] What (other) efforts has your program undertaken to improve systems of care? [Probe] Efforts that improve capacity of community providers, coordinate services in the community, etc.?
 - a. What about efforts to enhance transition-related systems of care?
- 25. [If not already discussed] Are there any additional success stories or lessons learned that you'd like to share regarding reducing barriers and improving systems of care?
- 26. Thinking about all the "systems of care" activities you have described today, what do you think has been the most significant contribution of the Autism CARES DBP funding?
 - a. What activities or strategies have been particularly effective? What factors do you think facilitated their success? What would you say is your biggest contribution to improving systems of care?

D. National Resource Centers

The national resource centers are also being evaluated as part of this study. I have a few brief questions about your interactions with the Interdisciplinary Technical Assistance Center (ITAC), which is run by the

Association of University Centers on Disabilities (AUCD). Please feel free to share any details you think are relevant. If you don't have any information to share, that's OK. Just let me know.

27. How have you interacted with ITAC (AUCD) since fall 2014? [Probe] Did you go to a conference they hosted? Do you receive emails from them? Have you participated in a Webinar or held other types of meetings with their staff?
28. What kinds of support, if any, has ITAC (AUCD) provided to your program under Autism CARES? How did this help you to meet your objectives?
 - a. Did they provide technical assistance in any form?
 - b. Did they facilitate any collaboration with other grantees or organizations?
 - c. Did they disseminate or produce information that contributed to your success?
 - d. Did they help you address any specific challenges?
29. Can you think of any other examples of things ITAC (AUCD) is doing especially well? What about ways they could improve or better support your program?

E. Overarching Questions, Wrap-up

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

General Questions

30. [If not already covered; check for adequate coverage of "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)

[Include how these activities were influenced by Autism CARES DBP funding.]

31. 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 training? Research? Awareness? Systems of care? Transition-related services?

32. How, if at all, has your program evaluated the activities we have discussed today?
- Have you evaluated your activities related to training? Research? Awareness? Systems of care?
 - Do you have any initial results to share from these self-evaluations?

Overarching Autism CARES Goals

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

Sustainability and Long-Term Impact of Funding

35. 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?
- [If relevant] Which activities will continue? Which will end?
36. What would you say is your program's single most important accomplishment with the support of the Autism CARES DBP grant? What has it allowed you to do that you could not have done otherwise?
- Your program has been receiving Autism CARES DBP funding for [X] years now. How do you think this funding has affected your training program in the long term?

Final Questions

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

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

1. 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.