

OMB control number:
Expiration Date:

Interview Protocol for LEND/DBP Programs

Respondent ID#:	Interviewer:
Respondent Title:	Note Taker:
Date & Time of Interview:	Recorded (Y/N):

Introduction and Verbal Consent

Thank you for taking the time to speak with us today. My name is [interviewer name] and I'm a researcher at [Westat/Westat Insight]. I'm joined on the call by [names/affiliations of other team members, if applicable] and [note taker name, if applicable], who will be taking notes during the call.

We are part of a team hired by the Maternal and Child Health Bureau (MCHB) at HRSA to evaluate the Autism CARES (Collaboration, Accountability, Research, Education, and Support) Act Initiative. The purpose of today's interview is to learn about your program's activities and experiences – including accomplishments and challenges – and understand the data collected by your program.

We will focus on the following key topic areas—

- ▶ Your training and research activities, barriers to care in your community, health equity and topics related to transitions across the lifespan, building awareness and disseminating information about autism/DD, collaboration with the Interdisciplinary Technical Assistance Center, and the impact of COVID-19 on your training program.

If you have any questions about your rights as a research participant, you may contact Westat's Human Subjects Protections office. Would you like that phone number? [IF YES:] Please call 1-888-920-7631 and leave a message with your full name and the name of this project, "Autism CARES Act Initiative Evaluation."

[Continuing grantees] I would like you to focus on activities or outcomes that have occurred since the fall of 2020. This evaluation builds on the previous evaluation, which covered Autism CARES activities and accomplishments through roughly summer 2020.

With your permission, we would like to audio record the interview for note-taking purposes. Other project team members may listen to the recording later, but we will store the recording on a secure directory and delete it after preparing summaries of the interviews. Would it be okay to record the call?

[If verbal agreement received, begin recording.]

Do you have any questions before we begin?

Interviewee Introduction

Could you start by introducing yourself/yourselves with your name and role(s)/responsibility(ies)?

Training Activities

We would like to start by talking about the training your program provides.

1. [New grantees] How have you incorporated content on autism/DD into your curriculum?
 - a. What specific topics are covered?
 - b. Do you have training opportunities that focus specifically on screening tools, diagnostic instruments, or interventions for autism/DD?
 - i. Instruments covered? Type of training? Audience?
2. [Continuing grantees] How, if at all, has your curriculum changed since the fall 2020?
 - a. Have you modified your curriculum to include any new content?
 - i. Screening tools, diagnostic instruments, or interventions for autism/DD
3. How have you incorporated content on transition and life-span related topics into your curriculum?
4. Has content on transition and life-span been incorporated into other elements of the program (e.g. research, TA/outreach, or for DBP, clinical activities)?
 - a. What strategies have you used to incorporate adult-focused providers to improve transition and adult services?
5. How has your training curriculum been modified to include any new content, especially content related to diversity, equity, inclusion, and accessibility (DEIA)? (e.g., incorporating principles from Universal Design for Learning, intersectionality, environmental adaptations, etc.)?
 - a. Who has attended these trainings?
 - b. How frequently do you conduct trainings on DEIA-centered topics?
 - c. What other emerging topics have you covered in your curriculum? (For example, cultural and linguistic responsiveness, quality improvement and evidence-based practice, person-/family-centered care)
6. [New grantees] What clinical opportunities do you offer to trainees? What are the settings for clinical training (hospital-based, schools, other community settings)?
 - a. Are there other hands-on or observational training opportunities? For example, other community-based opportunities, outside of strictly clinical settings?
 - b. Are any practicum sites in historically underserved communities?
7. [Continuing grantees] Have the clinical opportunities you offer to trainees changed since fall 2020?
 - a. Any new clinical opportunities or settings?
 - b. Are there other hands-on or observational training opportunities? For example, other community-based opportunities, outside of strictly clinical settings?
 - c. Are any practicum sites in historically underserved communities?
8. Do you collaborate with other LEND programs or other organizations around training? [Examples] Regional LEND collaborations, interstate LEND training, UCEDDs. What advantages do these collaborations provide?

9. [New grantees] What are some of the ways your program prepares trainees to become leaders in their field?
 - a. Do they participate in academic, clinical, public health practice, or public policy and advocacy activities after completing the program?
10. To what extent has your program engaged family members and self-advocates in the training process as faculty members, trainees, and other capacities?
 - a. What sort of training do you provide to family trainees and self-advocate trainees?
11. How has incorporating individuals with lived experience as trainees and faculty improved understanding of transition and lifespan-related topics?
12. In general, where would you say your training efforts have had the greatest impact or been the most successful? What factors do you think facilitated their success?
 - a. What activities have been particularly effective in reaching the goal of early identification and intervention for Autism/DD?

Equity

13. How would you describe the diversity of your faculty and trainees (racial and ethnic diversity, geographic diversity, disciplinary diversity)?
 - a. What is their demographic makeup (e.g., what is their race, and/or ethnicity)?
 - b. What disciplines do they represent?
 - c. What is the geographic diversity of faculty and trainees (e.g., are most rural, urban)?
14. What strategies do you use to recruit and engage diverse trainees and faculty?
 - a. How have these helped you obtain more diverse candidates?
 - b. How have you raised awareness of training and employment opportunities within your program?
15. To what extent has your program reached children from historically underserved or marginalized communities 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?
 - b. Any preliminary results you may have observed from these activities?
 - c. Has your program developed/used innovative models of care, such as telehealth or tele-education to expand the reach to underserved populations?

Systems of Care

Now we would like to talk about how your program has monitored changes in access to screening, diagnosis, and community-based services and supports since fall 2020.

16. What are the most significant gaps related to screening, diagnosis, and treatment of autism/DD your [area/region/State/communities you serve]? (insurance/coverage for needed services, shortage of parent/patient navigators, screening for females)
 - a. What are the most efficient ways to address these gaps?
 - i. Who is best positioned to do the work? What organizations or individuals can best address these barriers?
 - ii. What resources are needed?
17. Are there gaps in services for individuals with autism/DDs, such as in insurance, housing, employment, or transportation?
 - b. What are the most efficient ways to address these gaps?
 - i. Who is best positioned to do the work? What organizations or individuals can best address these barriers?
 - ii. What resources are needed?
18. What changes have you seen, if any, in children's access to care or services since fall 2020?
 - a. How are you tracking these changes?
 - b. Is there any evidence that access to early screening and diagnostic services or services has improved since fall 2020?
19. Have you seen changes in the age at which children are diagnosed with autism/DD?

What is the direction of the change?

 - a. Over what period of time have you seen these changes take place?
 - b. What are the reasons for the changes? For example, are they environmental, systematic, budgetary, or equity focused)?
20. Has your program provided technical assistance or collaborated with state and local partners (such as State agencies, schools, family groups, Title V agencies, and community-based organizations) to improve the system of care for children and families in your area [*if continuing grantee*] since fall 2020?
 - a. Please describe these activities.
 - b. Has your program provided continuing education to medical practices or other providers to improve the services they offer to children with autism/DDs and their families [*if continuing grantee*] since fall 2020?
21. What other efforts has your program undertaken to build or improve systems of care [*if continuing grantee*] since fall 2020? For example, collaborations with clinical providers or state policymakers?
22. [*If not already mentioned*] Has your program developed resources or collaborated with other organizations to assist children with autism/DDs and their families through the transition to adulthood?
 - a. Where do you think your efforts to reduce barriers and improve systems of care have had the most impact or been the most successful?

- b. What efforts have been made, or what efforts do you think are needed, to ensure any advances achieved are sustainable?

Increasing Awareness

Next, we would like to learn about ways your program may be helping to increase awareness and disseminate information about autism/DDs to the community and providers. This is in addition to conducting and publishing research and the formal training you provide to trainees within your program. For example, disseminating materials to families, providing continuing education courses to various kinds of professionals, or disseminating findings from research.

- 23. Can you tell us about your program's efforts to increase awareness of autism and developmental disabilities? [*If continuing grantee*] Please focus on efforts undertaken between fall 2020 and now.

[*For each effort described, ask*]

- a. What types of audiences/professional fields did you target (e.g., practicing pediatricians aiming to get the latest information on screening, rural health care providers, social workers, educators; adult providers for pediatric patients transitioning to adult care)?
- b. What topics/content areas did these efforts focus on?

[*probe if needed*]

- i. Did any cover screening and evaluation tools, including those that can be used in telehealth?
 - ii. Did any cover dissemination of new/revised evidence-based curricula, products, training approaches, research findings, or project results?
 - iii. Did any cover resources and systems of care?
 - c. What were the primary communication strategies used (e.g., dissemination of print materials, Webinars, PSAs, conferences)?
 - d. Were there any dissemination strategies that you tried that did not work?
 - e. What roles do trainees play in efforts to raise awareness about autism/DDs?
- 24. [*If not already covered*] How, if at all, have your program's awareness activities targeted or focused on—
 - a. Increasing understanding of lived experiences of people with autism/DD and their families?
 - b. Transition to adulthood for people with autism/DDs?
 - 25. Approximately how many activities have you initiated and how many people have you reached [*if continuing grantee*] since fall 2020?
 - 26. Where do you think your awareness-building efforts have had the most impact or been the most successful? (e.g. demographics where message has been successful, particular events with good turnout and satisfaction, types of communication strategies that have worked well)
 - a. Have you seen any changes in practices or attitudes as a result of your awareness efforts?
 - b. How are these changes measured?

Research

Next, I would like to talk about opportunities your trainees have to participate in research.

27. To what extent are your trainees currently involved in planning or conducting research studies related to autism/DDs?
 - a. Which trainees are involved in research studies (e.g. long-term)?
28. Can you tell us about the research related to autism/DDs that has been conducted by [LEND/DBP] faculty or trainees [*if continuing grantee*] since fall 2020?
[*For each study described, probe. If necessary, probe on most significant*]
 - a. What is being investigated, and who is doing the research?
 - i. What are the topics? What is the population of study?
 - b. What is the anticipated impact of the results/how might the results be used (e.g., will they provide evidence about an intervention's effectiveness)?
29. How are trainees involved in research? In what capacity? What sort of training do they receive in conducting research and the research process?
30. With whom do you collaborate on research projects?
 - a. Other departments in the university? Local hospitals? Schools? Other MCHB grantees such as other CARES-funded research programs (Research networks, R40s)?
31. Where have your research activities had the most impact or been the most successful?

Resource and Coordinating 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 Training Resource Center (ITRC), which is run by the Association of University Centers on Disabilities (AUCD).

24. How have you interacted with AUCD since fall 2020?
 - a. Have you attended any conferences they hosted (e.g., annual meeting, LEND directors meeting)? Do you receive emails from them? Have you participated in a Webinar or held other types of meetings with their staff?
25. What kinds of support, if any, has AUCD provided to your program under Autism CARES? How did this help you meet your objectives?
 - a. Did they provide technical assistance in any form?
 - b. Did they identify, produce, or disseminate information that contributed to your success?
 - i. For example, have you viewed any webinars or used anything from the training toolbox? Do you receive any newsletters from AUCD? Attended any conferences?
 - c. Did they conduct data analysis or data management? Provide training on NIRS (the National Information Reporting System)?

- d. How have they helped promote involvement of people with lived experience (i.e., family members and self-advocates)?
 - e. Have they facilitated any collaboration with other grantees or organizations to help share effective practices or address emerging issues (e.g., supported LEND and DBP workshops)?
 - f. Have they helped you form partnerships with Federal agencies and organizations related to the autism/DD community?
26. How effective were these efforts?
27. What kinds of support, if any, has AUCD provided to your program under Autism CARES related to promoting diversity, equity, inclusion, and accessibility? What kinds of support have they provided related to promoting health equity?
- 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? For example, have you viewed any webinars or used anything from the training toolbox? Do you receive any newsletters from AUCD?
 - d. How satisfied are you with the support you receive from AUCD?
 - e. Is there support you needed but did not get?
28. Can you think of any other examples of things AUCD is doing especially well? What about ways they could improve or better support your program?

COVID

Finally, I'd like to find out how the COVID-19 pandemic affected your program.

29. *[For continuing grantees funded before COVID-19]* What changes did your training program have to make in response to the pandemic that impacted training of autism/DD providers?
- a. Topics covered in the curriculum
 - b. Populations involved in the program
 - c. Training methods used
 - d. Timeline of the training activities
 - e. Management and operations of the program (e.g., virtual meetings in lieu of in-person meetings)
30. *[For continuing grantees funded before COVID-19]* What positive and negative effect(s) did these changes have on the training programs?
31. *[For continuing grantees funded before COVID-19]* How, if at all, is your training program planning to continue any of the changes made because of COVID-19?
32. How, if at all, have you modified your training program due to COVID-19?
33. How has COVID-19 positively or negatively impacted access to screening, diagnosis, and entry into services?

Wrap up

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

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

Thank you very much for speaking with us today. If you have questions about this interview or additional information you would like to share, please reach out to Katherine Flaherty (KatherineFlaherty@westat.com) or Carla Bozzolo (cbozzolo@insightpolicyresearch.com)