Attachment C.

Training Interview Guide

Training (LEND and DBP) Semi-Structured Interview Guide

Thank you for taking the time to speak with me today. My name is [NAME], and I'm a researcher at 2M 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 [LEND/DBP] program's activities and outcomes for the evaluation of the HRSA Autism CARES 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 topic areas, including training, awareness building, research, improving systems of care, sustainability, and impact of funding.

[IF RELEVANT] Your program has been completing an annual survey during which we ask programs to reflect on their activities in the preceding year. For this interview, I'd like you to reflect on the activities your program has completed for your current grant period. This evaluation builds on the previous evaluation, which covered Autism CARES activities and accomplishments through summer 2017. For each set of questions, I'd like you to report on activities or outcomes that have occurred during your current grant period. We understand that you received your most recent grant in [INSERT YEAR HERE]. Is that correct? We'd like you to think about the time since then during our conversation today.

[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 will 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 DIRECT THE CONVERSATION TOWARD NEW INFORMATION OR SUPPLEMENTAL DETAILS THAT ARE NOT ADEQUATELY COVERED IN PROGRESS REPORTS, ETC.]

- **Evaluation results.** The results from this evaluation will be presented in a report that will focus on all grant programs that received funding under the Autism CARES Act.

- **ASD/DD focus.** We understand your program may also work in areas outside of autism spectrum disorder (ASD) and other developmental disabilities (DD). Since this evaluation focuses on Autism CARES funding, when discussing your program's activities and outcomes, please focus on information pertaining to ASD/DD unless otherwise indicated.

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 HRSA.

[CONFIRM PERMISSION ONCE RECORDING STARTS]

According to the Paperwork Reduction Act of 1995, an agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0915-0335. The time required to complete this information collection is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information.

TRAINING

For the first set of questions, I'd like to talk about the training your program provides.

[INTERVIEWER MAY SUMMARIZE OR ASK ABOUT THE PROGRAM'S SPECIFIC TRAINING ACTIVITIES AS DESCRIBED IN PROGRESS REPORTS, ETC.]

1. We understand that you have previously reported your goals and objectives in your performance progress reports. We are interested in hearing about what you think are your program's top three goals with regard to the HRSA Autism CARES Initiative.

2. How would you describe the diversity of your faculty and trainees (racial and ethnic diversity, geographic diversity, **[LEND ONLY]** disciplinary diversity)?

    [NOTE TO INTERVIEWER: SOME GRANTEES MAY HAVE IN THEIR PROGRAMS PEOPLE WITH DISABILITIES WHO DO NOT DISCLOSE THEIR STATUS, AND MANY PROGRAMS DO NOT WANT TO MAKE THEM DISCLOSE.]

3. Have you made any substantial changes to your training program during your current grant period? If so, what have been the biggest changes to your program since **[INSERT YEAR OF MOST RECENT GRANT HERE]**?

4. **[DBP ONLY]** How do family members contribute to the training program and interface with the fellows and trainees? How have the fellows and trainees responded?

5. **[DBP ONLY]** How do self-advocates contribute to the training program and interface with the fellows and trainees? How have the fellows and trainees responded?

6. **[LEND ONLY; IF NOT ALREADY DISCUSSED]** How, if at all, has the curriculum changed during your current grant period (since **[INSERT YEAR OF MOST RECENT GRANT HERE]**)?

    a. **[LEND ONLY]** Has the didactic curriculum been modified to include any new content, especially content specific to ASD/DD?

    [PROBE] Valid and reliable screening and diagnostic tools? Interventions? Treatment of ASD/DD across the lifespan, including transition to adulthood?

7. **[IF NOT ALREADY DISCUSSED]** Have you incorporated any new training opportunities that focus specifically on screening tools, diagnostic instruments, or interventions, particularly for ASD/DD?

    [PROBE] Instruments covered? Type of activities to address youth transitioning to adulthood? Types of activities to address screening, diagnostic, intervention, and treatment of ASD/DD across the lifespan? Audience?

    a. Have the clinical opportunities for trainees changed? Are there any new clinical opportunities in hospital-based settings, schools, or other community settings? Are there any clinical opportunities that are no longer available?

    b. **[LEND ONLY]** Have there been any other new hands-on or observational training opportunities? Specifically, have there been community-based opportunities outside of strictly clinical settings? These opportunities may include, for example, observing services being provided to children with ASD/DD or their participation in a social skills group.

8. What are some of the ways your program prepares trainees to become leaders in their fields?

    a. **[IF NOT ALREADY DISCUSSED]** Has this component of your program, meaning the way your program prepares trainees to become leaders in their fields, changed at all during your current grant period? If yes, how so?

9. To what extent has your program emphasized policy in its training activities during your current grant period? How does your program prepare trainees for policy-related work?

    [PROBE] What do trainees learn about this aspect of **[LEND/DBP]**? How have the Autism CARES **[LEND/DBP]** grants impacted this component of training?

10. In what ways has your program engaged family members and self-advocates in the training process? **[IF NEEDED]** For example, family members and self-advocates may serve as trainees, faculty members, advisors, teachers, research partners, or in other capacities. **[IF OTHER CAPACITIES ARE SPECIFIED]** Can you please describe these other types of involvement?

    a. What sort of training do you provide to family trainees and self-advocate trainees?

11. Which of your training activities have been particularly effective in improving early identification and intervention for ASD/DD?

    a. Do you believe there has been an improvement in the early identification of ASD/DD in children and youth as a result of these activities? Please describe how these activities have improved the early identification of ASD/DD manifestations in children and youth. What factors do you think facilitated their success?

12. **[DBP ONLY]** In the past, grantees emphasized the central role developmental-behavioral pediatricians play in providing coordination of care for individuals with ASD/DD and their families. To what extent has your program taught about coordination of care in its training activities?

    [PROBE] What do trainees learn about this aspect of DBP? How has your most recent Autism CARES DBP grant affected this component of training (since your most recent grant in **[INSERT YEAR HERE])**?

13. Thinking about all the training activities you've described, what would you say has been the most important contribution of the Autism CARES **[LEND/DBP]** funding?

INCREASING AWARENESS

Now I'd like to learn about ways your program may be helping to increase awareness by disseminating information about ASD/DD to a broad range of audiences. This is in addition to the formal training you provide to **[PROFESSIONALS/TRAINEES]** within your program. **[IF RESPONDENT ASKS FOR CLARIFICATION]** For example, in the past, grantees have disseminated "Learn the Signs. Act Early" materials to families, provided continuing education courses to various kinds of professionals, or disseminated findings from their research. You may have different examples.

14. How has your program increased awareness of ASD/DD among maternal and child health professionals, providers, and/or researchers?

15. How has your program increased public awareness of ASD/DD?

16. **[IF NOT ALREADY DISCUSSED]** What roles do trainees play in efforts to raise awareness about ASD/DD? **[IF NEEDED]** This could be awareness among professionals, providers, researchers, and/or the public.

17. In general, where do you think these awareness-building efforts you've described have had the most impact or been the most successful?

> *[PROBE]* Have there been demographic groups for which the message has been successful, particular events with good turnout and satisfaction, or types of communication strategies that have worked well?

18. **[IF NOT ALREADY DISCUSSED]** Have you seen any changes in practices or attitudes as a result of your awareness-building efforts? These could be changes in practices or attitudes among your trainees, families, or other groups with whom your trainees may work. If yes, please describe. How are these changes measured?

CONTRIBUTING TO RESEARCH

Next, I'd like to talk about your program's research activities, specifically any activities related to ASD/DD that your program has engaged in since the time of your most recent grant in **[INSERT YEAR HERE].**

19. To what extent are your **[LEND/DBP]** faculty members or trainees currently involved in planning or conducting any research studies related to ASD/DD?

20. **[LEND]** Can you tell me what you think are the most significant studies related to ASD/DD that have been conducted by LEND faculty or trainees during the current grant period?

    [DBP] Can you tell me what you think are the most significant studies related to ASD/DD that have been supported in some way by the Autism CARES DBP funding during the current grant period?

    > *[FOR EACH STUDY DESCRIBED, PROBE]*

    a. What is being investigated, and who is doing the research?

    b. **[LEND]** 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)?

       [DBP] How will the results be disseminated?

    c. **[LEND]** How is the research being funded? Does Autism CARES funding support these efforts?

       [DBP] How might the results be used (e.g., will they provide evidence about an intervention's effectiveness)? How has your program translated research into practice?

21. **[IF NOT ALREADY DISCUSSED]** How are trainees involved in research? In what capacity? What sort of training do they receive in conducting research and in the research process?

22. With whom does your program collaborate on research projects?

[PROBE] Other departments in the university? Local hospitals? Schools? Other MCHB grantees such as Autism CARES-funded research programs (Research Networks, R40s)?

    a. **[IF NOT ALREADY DISCUSSED]** How have your program's research activities focused on translating research into practice?

23. In general, where have your research activities had the most impact or have been the most successful?

REDUCING BARRIERS TO CARE, IMPROVING SYSTEMS OF CARE

Next, I'd like to talk about activities related to reducing barriers and improving systems of care. By systems of care, I mean the full continuum of care for individuals with ASD/DD, including screening, diagnosis, intervention, treatment, and transition. We recognize there may be some overlap between this objective and the others, so feel free to recall earlier examples if you like.

24. What have been some of the most significant barriers to ASD/DD care in your community/state that you have identified in the most recent grant period (since your most recent grant in **[INSERT YEAR HERE]**)?

    a. What opportunities have existed to address these barriers?

    b. What resources are needed?

    c. Can you describe any improvements you have seen?

25. In the most recent grant period, how has your program worked to improve the quality of care for children and youth with ASD/DD?

26. **[IF NOT ALREADY DISCUSSED]** How has your program supported or promoted timely referral and enrollment in early intervention services for children and youth with ASD/DD?

27. **[IF NEEDED]** What (other) efforts has your program undertaken to build systems of care that improve capacity or are coordinated, comprehensive, and community-based?

    a. Has your program made any efforts to enhance transition-related systems of care? If so, please describe.

28. Has your 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? If yes, please describe. Are these new partnerships, or are they partnerships or collaborations that were in place prior to your most recent grant in **[INSERT YEAR HERE]**)?

    a. **[IF NOT ALREADY ANSWERED]** How have you worked with State Title V or other MCH programs or agencies?

    b. Have you partnered with schools, community-based organizations, or other local entities?

    c. Have you partnered with other MCHB grantees, such as other DBPs, LENDs, Research Networks, States, or National Resource Centers?

29. In general, where do you think your efforts to reduce barriers and improve systems of care have had the most impact or have been the most successful? What efforts have been made, or what efforts do you think are needed, to ensure any advances achieved are sustainable?

    a. *[PROBE]* How has your program/Network worked to reduce health disparities and promote health equity for children and youth with ASD/DD?

30. Telehealth can be an important tool for improving access to quality health care, especially for underserved populations. Please describe how your program has utilized telehealth to improve systems of care in the most recent grant period. **[IF NEEDED]** Telehealth is defined as the use of electronic information and telecommunication technologies (such as videoconferencing, phone text, audioconferencing) to support long-distance clinical healthcare, patient and professional health-related education, public health, and health administration.

    a. *[PROBE]* Is telehealth used by your program for clinical visits, consultation, or training? If yes, please describe.

31. Please describe how your program has used tele-education or e-learning in the most recent grant period. **[IF NEEDED]** Tele-education or e-learning is defined as the use of electronic information and telecommunication technologies (such as videoconferencing or audioconferencing) to support long-distance learning. Tele-education is a subset of telehealth.

NATIONAL RESOURCE CENTERS

The national resource centers are also being evaluated as part of this study. First, I have a few questions about your interactions with the Interdisciplinary Technical Assistance Center (ITAC), which is operated by the Association of University Centers on Disabilities (AUCD). After we discuss ITAC, I'll then ask a few questions about the State Public Health Autism Resource Center (SPHARC). Please feel free to share any details you think are relevant. If you don't have any information to share, that's okay. Just let me know.

32. In your most recent grant period, has your program received support/technical assistance from ITAC (AUCD)?

    a. If so, was this help provided in response to specific challenges you had? Please describe these challenges.

    b. In what ways did ITAC (AUCD) help you address these specific challenges?

33. Can you think of any other examples of things ITAC (AUCD) is doing especially well? Are there ways they could improve or better support your program?

I also have a few questions about your interactions with SPHARC, which is operated by the Association of Maternal and Child Health Programs (AMCHP).

34. In your most recent grant period, has your program received support/technical assistance from SPHARC (AMCHP)?

    a. If so, was this help provided in response to specific challenges you had? Please describe these challenges.

    b. In what ways did SPHARC (AMCHP) help you address these specific challenges?

35. Can you think of any other examples of things SPHARC (AMCHP) is doing especially well? Are there ways they could improve or better support your program?

ADDRESSING ASD/DD ACROSS THE LIFESPAN, INCLUDING TRANSITION FROM YOUTH TO ADULTHOOD

As part of our discussion on improvement of systems of care, we will now touch on how your program has addressed ASD/DD across the lifespan.

36. How has your program worked to address health outcomes for individuals with ASD/DD across their lifespans? This could include the transition from youth to adulthood and/or other points throughout the lifespan.

    a. Information dissemination

    b. Development of evidence-based or consensus-based guidelines and screening tools

    c. Research

    d. Other areas

37. What strategies have you found to be successful in improving services and support across the lifespan for those with ASD/DD, and what factors have facilitated their success?

38. What major challenges remain to improving services and support for those with ASD/DD across the lifespan?

39. How has the passing of the Autism CARES Act of 2019 impacted your activities during the most recent grant period?

OVERARCHING QUESTIONS

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

40. You have previously indicated on your **[PROGRESS REPORTS, SURVEYS]** that your program primarily focuses on **[SHARE THE ACTIVITIES THAT RESPONDENT HAS LISTED IN OTHER DATA SOURCES]**. Today, you have shared with us about **[ACTIVITIES THAT ALREADY HAVE SUFFICIENT INFORMATION GATHERED FROM EARLIER IN THE INTERVIEW]**, but we'd also like to hear more about **[ACTIVITIES LIST THAT INTERVIEWER THINKS NEED MORE PROBING/INFORMATION]**. Could you please describe the types of activities you believe have been particularly successful? What factors do you think made them successful? **[IF NOT ALREADY DISCUSSED]** How have these activities been influenced by HRSA Autism CARES funding?

41. Thinking about all the activities we've discussed today, where would you say you've faced the biggest challenges? What barriers have gotten in the way of your progress?

    [PROBE] What have been your main challenges related to training professionals? Increasing awareness? Research? Promoting evidence-based guidelines for interventions? Systems of care? Addressing ASD/DD across the lifespan, including transition to adulthood?

42. How, if at all, has your program evaluated the activities we've discussed today?

a. How have you evaluated your activities related to training professionals? Increasing awareness? Research? Promoting evidence-based guidelines for interventions? Systems of care? Addressing ASD/DD across the lifespan, including transition to adulthood?

b. Do you have any initial results from these evaluations that you could describe today?

SUSTAINABILITY AND IMPACT OF FUNDING

43. To what extent do you feel the changes set in motion through your grant will be sustained following the end of the grant? *[PROBE FOR COLLABORATIONS AND/OR PARTNERSHIPS]*

a. **[IF RELEVANT]** Which activities will continue? Which will end?

44. What would you say is your program's single most important accomplishment with the support of the Autism CARES **[LEND/DBP]** grant? What has the grant allowed you to do that you could not have done otherwise?

FINAL QUESTIONS

[PLACEHOLDER FOR QUESTIONS YOU MAY HAVE FROM PROGRESS REPORTS/OTHER DATA SOURCES FOR WHICH YOU WOULD LIKE MORE DETAIL]

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

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

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