Attachment E.

State Systems Interview Guide

State Systems 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 **[INNOVATIONS IN CARE COORDINATION FOR CHILDREN AND YOUTH WITH ASD/DD]** grant 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 topics such as reducing barriers to care, improving systems of care, building awareness, training professionals, contributing to research, and demonstrating sustainability.

[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 THE 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 that 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.]

INCREASING AWARENESS

First, we'd like to learn about way your program may be increasing awareness in a broad range of audiences. We'll first discuss increasing awareness among professionals, providers, and/or researchers and then ask about your program's efforts to increase public awareness. **[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 grantees have disseminated findings from their research. You may have different examples.

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

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

3. 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?

REDUCING BARRIERS TO CARE, IMPROVING SYSTEMS OF CARE

A key objective of the **[INNOVATIONS IN CARE COORDINATION FOR CHILDREN AND YOUTH WITH ASD/DD]** grants is to improve access to appropriate screening, referral, diagnosis, care coordination, and services.

4. Prior to this most recent grant (before **[INSERT YEAR HERE]**), what were some of the barriers that prevented timely screening, referral, and diagnostic evaluation of children suspected of having ASD/DD?

   a. How did your grant (since **[INSERT YEAR HERE]**) set out to address those barriers?

   b. What efforts have been most successful to reducing barriers and why?

   c. Can you describe any improvements you have seen?

   d. What barriers persist?

5. **[IF NOT ALREADY DISCUSSED]** What strategies have been used to increase the proportion of children identified as at risk for ASD/DD and referred for diagnostic evaluation?

   a. What do you view as your program's greatest successes in this area?

6. **[IF NOT ALREADY DISCUSSED]** What strategies have been used to increase the proportion of children with ASD/DD who are enrolled in services before 37 months of age?

   a. What do you view as your program's greatest successes in this area?

7. **[IF NOT ALREADY DISCUSSED]** What strategies have been used to increase the number of at-risk children referred to early intervention programs and specialists for comprehensive evaluation?

   a. What do you view as your program's greatest successes in this area?

8. **[IF NOT ALREADY DISCUSSED]** How has your program worked to improve access to care for children and youth with ASD/DD?

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

9. **[IF NOT ALREADY DISCUSSED]** What steps have been taken to ensure that children and youth with ASD/DD and their families have access to a coordinated, comprehensive system of services for children and youth with ASD/DD?

10. How has your program worked to improve the quality of care for children and youth with ASD/DD?

11. What steps have been taken to ensure children and youth with ASD/DD and their families have access to a medical home?

    a. Can you describe any training activities aimed at helping medical practices become a medical home for patients?

    b. Can you describe any efforts to assess the degree to which those medical practices have succeeded in providing a standard of care consistent with the medical home model?

    c. Thinking about the goal of ensuring that children and youth with ASD/DD have access to a medical home, where do you think the most progress has been made? What role has your grant played in that progress?

12. Can you describe any activities aimed at improving family engagement and promoting partnerships between ASD/DD families and providers? Is there any evidence of improvements in access or quality of care resulting from such partnerships?

13. Has your grant used shared resources, such as community networks and health teams from area health education centers, to support care coordination and case management?

14. 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 to support long-distance clinical health care, 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.

15. 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.

16. 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 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 maternal and child health programs or agencies?

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

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

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.

18. 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

19. 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?

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

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

TRAINING

22. Although this may not be a focus of your efforts, please tell me about any grant activities (since **[INSERT YEAR HERE]**) related to training professionals in the use of evidence-based screening tools and referral procedures.

    [INTERVIEWER NOTE: FOCUS ON GATHERING MORE DETAILS ABOUT IMPLEMENTATION OF LEARNING COLLABORATIVES OR QUALITY IMPROVEMENT PROJECTS IF THE NARRATIVE DOES NOT PROVIDE SUFFICIENT DETAILS.]

    a. How has your program provided education, training, and technical assistance to providers and/or community-based organizations through a learning community?

    b. What have been your major successes and challenges with regard to training professionals?

23. How has your program supported or coordinated the enhancement of leadership capacity among providers and other stakeholders in the ASD/DD field?

    [PROBE] At the local, state, and/or national levels?

24. In what ways has your program engaged parents in increasing their knowledge and skills?

    a. How has your program worked to increase family navigation services to improve communication between families and primary and specialty providers?

    b. Do parents receive training on becoming a partner in shared decision making with their child's provider?

25. Are there other training activities you would like to tell me about?

CONTRIBUTING TO RESEARCH

Next, I'd like to discuss with you about your program's overall activities related to research.

26. Thinking about the current grant period (since **[INSERT YEAR OF MOST RECENT GRANT HERE]**), how has your program, if at all, supported research to advance evidence-based interventions for children and youth with ASD/DD?

27. How has your program used evidence-based interventions to support the translation of research into practice? **[IF NEEDED]** Translating research into practice could include utilizing research to inform evidence-based practice.

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.

25. In your most recent grant period (since **[INSERT YEAR OF MOST RECENT GRANT HERE]**), 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?

26. 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).

27. 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 your program had? Please describe these challenges.

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

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

OVERARCHING QUESTIONS

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

29. You have previously indicated on your **[PROGRESS REPORTS, SURVEYS]** that your program primarily focuses on **[SHARE THE ACTIVITIES THAT RESPONDENT HAS SHARED 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 LISTED 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?

30. 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?

31. How, if at all, has your program evaluated the activities we've discussed today?
    a. How have you evaluated your activities related to increasing awareness? Systems of care? Transition to adulthood? ASD across the lifespan? Research? Training?

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

SUSTAINABILITY AND IMPACT OF FUNDING

32. To what extent do you feel that 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?

33. What would you say is your program's single most important accomplishment with the support of the Autism CARES grant? **[IF NEEDED]** Please describe the ways your work toward these goals has improved the lives of children and youth and/or families affected by ASD/DD.

FINAL QUESTIONS

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

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

35. 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.