

Interview Protocol for State Systems Grant Program

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 am 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) 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.

In the interview, we will focus on the following topics related to autism and developmental disabilities:

- ▶ Your autism- and DD-focused activities, awareness and dissemination, health equity and disparities, transitions across the lifespan, support you have received from the resource center, and impacts of the COVID-19 public health emergency on your program.

If you have any questions about your rights as a participant in this evaluation, 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."]

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/yourselfs with your name(s) and role(s)/responsibility(ies)?

Program Objectives

As you know, the State Innovations in Care Coordination for Children and Youth with Autism/DD Program (State Systems) has five main objectives. **Each objective targets 25% increases in their progress by the end of the current grant period that includes September 2019 to August 2023.**

We would like to talk with you about your progress toward the each of objectives and sustainability efforts you have undertaken to further improve or continue the progress made.

[Refer to responses to the objectives in the survey]

Objective 1: Increase the number of children with or at risk for autism/DD in medically underserved areas receiving family navigation services.

1. Are you on track to achieving this goal by August 2024?
2. What have been the major barriers and facilitators to achieving this objective?
3. What steps have you taken to address the sustainability of these efforts?
4. What would help to improve progress and sustainability of these efforts?

Objective 2: Increase the number of families of children with or at risk for autism/DD reporting self-efficacy in navigating the system of care and services.

1. Are you on track to achieving this goal by August 2024?
2. What have been the major barriers and facilitators to achieving this objective?
3. What steps have you taken to address the sustainability of these efforts?
4. What would help to improve progress and sustainability of these efforts?

Objective 3: Increase in the number of children with or at risk for autism/DD receiving referrals to both comprehensive developmental evaluations and early intervention services before 3 years of age.

5. Are you on track to achieving this goal by August 2024?
6. What have been the major barriers and facilitators to achieving this objective?
7. What steps have you taken to address the sustainability of these efforts?
8. What would help to improve progress and sustainability of these efforts?

Objective 4: Increase in the number of children in medically underserved areas enrolled in community-based services and supports before 3 years of age.

9. Are you on track to achieving this goal by August 2024?
10. What have been the major barriers and facilitators to achieving this objective?
11. What steps have you taken to address the sustainability of these efforts?

12. What would help to improve progress and sustainability of these efforts?

Objective 5: Increase the percent of providers implementing care coordination for children in targeted medically underserved areas and populations.

13. Are you on track to achieving this goal by August 2024?
14. What have been the major barriers and facilitators to achieving this objective?
15. What steps have you taken to address the sustainability of these efforts?
16. What would help to improve progress and sustainability of these efforts?

Systems of Care

Now we would like to ask you about your program's strategies for improving systems of care for children with autism/DD and their families.

A. Partner Sites

We understand that the State System programs are expected to recruit a minimum of five primary care sites as partners to implement family navigation, and that these sites should be in populations that have been historically underserved or marginalized.

[Refer to the sites - #'s and names and locations - listed in the progress reports for the following questions]

17. How did you choose your sites? (For example, populations served, specific services provided, location)
18. For what underserved populations, do each of the sites provide care?
19. How are you measuring the impact of these partnerships?
20. What opportunities and challenges have you encountered in working with the primary care sites?

B. Family Navigation

Next, I'm going to ask about your family navigation activities at your partner sites.

21. **On a scale from 1 -5 (with 1 having the least impact and 5 having the most impact)** how do you think the family navigation services at your partners sites have affected the following:
 - a. Strengthening partnership between the families and clinicians providing care to children with or at risk for autism/DD _____
 - b. Improving family awareness of resources and services for their children _____
 - c. Reducing delays in accessing specialty and sub-specialty services _____
 - d. Minimizing barriers to accessing community-based services _____
 - e. Helping with coordination of care between multiple providers _____
 - f. Promoting care that is culturally and linguistically competent _____

22. How do you assess the effects of family navigation services on families? (For example, conversations with families, family services, program data)?
 23. Besides navigation, are there other ways your program engages with families?
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C. Learning community

Next, we would now like to ask about learning communities.

24. Do you have a learning community for your program? (Y/N) _____

[If yes]:

- a. When did you establish your learning community? (MM/YY) ___/___
- b. Have many times has your learning community met since it began?
- c. Who participates in the learning community? (For example, primary care, specialty care and community-based providers, families)
- d. What is the average number of attendees at each learning community session?
- e. What topics have you covered in your learning community sessions?
- f. How has your learning community contributed to your program and services for children with autism/DD and their families?
- g. How do you assess the effectiveness of your learning community? (For example, attendance, evaluations)

D. Transitions, Health Equity, and Sustainability

We next want to ask you about a few other topics related to your program – transitions, health equity, and sustainability.

25. Did your project use grant funds to address transition? (Y/N)

[If yes]

26. Did your program address transitions from:
 - a. Pediatric to adult health care
 - b. What challenges has your area/state encountered in transitioning pediatric patients with autism/DD to adult care?
 - c. Transition across settings and providers
 - d. Other transitions (such as transitions from adolescence to adulthood)
27. In addition to the programs and services described above that target underserved populations, has your program used other strategies or implemented other activities to address health equity?
28. What steps have you taken to ensure the sustainability of your program?

Increasing Awareness of Autism/DD

When the Autism CARES legislation was first passed in 2006, there was a focus on increasing public awareness about autism and other DDs. While we understand this may not be a focus of your current activities in your **current grant period (September 2019 – August 2023)** under this grant, we wanted to explore your activities to increase awareness **during the current grant period**.

29. What activities did your program conduct to increase awareness? (For example, webinars, social media postings, journal articles, other written materials, participation in conferences or community events)
 - a. What topics did you cover in your program activities to increase awareness? (For example, developmental milestones, family navigation, timely referrals, community-based services, care coordination)
 - b. Who were your target audiences of the awareness efforts? (For example, families, medical providers – pediatric and adult providers, public)
30. Which of your activities to increase awareness do you think were the most effective? Why do you think they were the most effective?
31. Which of your activities to increase awareness do you think were the least effective? Why do you think they were the least effective?
32. What barriers has your program faced in building public awareness?
33. What barriers has your program faced in building awareness in the medical community?

State Public Health Coordinating Center for Autism

Now we would like to ask you about the State Public Health Coordinating Center for Autism (formerly known as SPHARC) and the support and resources you have received **during the current grant period**.

34. What support and resources from the coordinating center have you used?
 - a. Listserv to communicate with other grantees
 - b. Participation in grantee affinity groups
 - c. Learning modules available on the center's website
 - d. Technical assistance webinars
 - e. Peer-to-peer exchange program
 - f. Other
35. Have you requested technical assistance (TA) to help you meet a particular challenge or objective?
[If yes]:
 36. Please describe the TA.
 37. How did this technical assistance help you meet your objectives?

38. In what ways has the coordinating center facilitated collaboration between your team and other State System grantees and other organizations and entities focused on children with autism and other DDs?

COVID-19

The last area we would like to cover with you is the affect of COVID-19 on your program.

39. Did you have to make any changes in your program in the following areas because of COVID-19?
- Topics covered
 - Populations targeted/served
 - Strategies used
 - Dissemination (e.g., presentations at conferences)
 - Timeline of activities
 - Program management and operations (For example, virtual meetings replaced in-person meetings)
 - Other (Describe) _____
40. For those changes made, please describe the specific changes made.
41. What effect did any changes you made have on your program?
- What were positive effects experienced?
 - What were negative effects experienced?
42. What did you learn from the pandemic that will positively impact how you work in the future?
43. Have you continued/planned to continue any changes you made because of COVID?

Wrap-up

44. Is there anything we have not covered that you would like to share?

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)