

**INTERVIEW GUIDE FOR STATE
IMPLEMENTATION GRANTEE PROJECT
DIRECTORS (2013-2014 AWARDEES)**

Interview Guide for State Implementation Grantee Project Directors (2013-2014 Awardees)

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 State Implementation grant 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 awareness building; reducing barriers to screening, referral, and diagnosis through training; improving systems of care; and transition from youth to adulthood. The latter is a new reporting requirement for MCHB and will be a theme throughout our discussions today.

Touch on bulleted topics as needed

- ▶ **Review of additional data sources.** In addition to the quantitative data collection tool you have recently filled out for us, we have reviewed data on your program from progress reports and DGIS data. The information I collect today is intended to supplement the data we have already 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 State Implementation grantees. The second is a larger, more detailed report that will focus on all MCHB 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 occurred during the second and third years of your grant (i.e., since approximately fall 2014.)

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. Awareness Building

To start, I'd like to ask you a few questions about grant-funded activities intended to raise awareness of autism spectrum disorder and other developmental disabilities (ASD/DDs).

1. When the authorizing legislation was first passed in 2006, it called on HHS to increase public awareness of developmental milestones by providing information and education on ASD and other DDs.
 - a. Can you describe any efforts of your grant to respond to that need?
 - b. Who were the target audiences of these outreach efforts?
 - c. Are there specific subgroups that still need to be targeted to improve their awareness of developmental milestones?
2. What roles, if any, have partners played in dissemination of ASD-related information and community outreach?
3. Please describe the communication strategies used (e.g., dissemination of print materials, Webinars, PSAs) and which strategies seem to be most effective.
4. Have any of your awareness-building activities focused specifically on reducing disparities in screening rates, diagnostic referrals, or early intervention services? Please explain.
5. Have any of your efforts focused on raising awareness about transition services, either where families can find such services or the need to develop more comprehensive transition services for young adults with ASD/DDs?
6. To what extent would you say your grant has successfully achieved what it set out to accomplish with respect to raising awareness of ASD and other DDs?
 - a. What work remains to be done?

B. Reducing Barriers to Screening, Referral, and Diagnosis Through Training

A key objective of the State Implementation grants is to increase the number of children with ASD/DDs who are identified by 24 months of age, receive first evaluation by 36 months of age, and are enrolled in intervention services by 48 months of age.

7. Prior to your grant, what were some of the barriers that prevented timely screening, referral, and diagnostic evaluation of children suspected of having ASD or a related DD?
 - a. How did your grant set out to address those barriers? Can you describe any improvements you have seen?

[Probe, if not reported in the noncompeting continuation application] For example, have you seen an increase in the number of children and youth with ASD/DDs who are identified by 24 months of age? What about the number of children who receive their first evaluation by 36 months of age? The number of children enrolled in intervention services by 48 months of age?]
8. Please tell me about any grant activities related to training professionals in the use of evidence-based screening tools and referral procedures.

[Interviewer: Focus on gathering more details about implementation of learning collaboratives or quality improvement projects if the narrative does not provide sufficient details.]

- a. What have been your major successes and challenges with regard to training professionals?
9. In what ways have you engaged parents in training?
 - a. Do parents serve as family navigators for other families with a newly diagnosed child?
 - b. Do parents work on quality improvement teams that engage pediatric practices in ongoing training?
 - c. Do parents receive training on becoming a partner with their child's provider in shared decisionmaking?
 10. Are there other training activities you would like to tell me about?
 11. Can you describe any efforts to collaborate with other MCHB grant programs such as LEND or DBP on training-related initiatives? How did your training efforts complement the training offered through LEND or other professional training programs?
 12. Can you describe any aspects of the training that focused on—
 - a. Cultural competency?
 - b. Coordination of care?
 - c. Family-centered care?
 13. In general, what feedback have you received on your training and awareness-building efforts?

C. Improving Systems of Care

[Note to interviewer: Includes efforts to increase access to medical homes or improve the organization and capacity of community-based services so they are easy for families to use. Such efforts increase the number of families who feel comfortable as partners in shared decisionmaking with their children's providers and any efforts related to transition-support services.]

14. What steps have been taken to ensure children with ASD/DDs and their families have access to a medical home?
 - a. Can you describe any training activities aimed at helping practices become a medical home for patients?
 - b. Can you describe any efforts to assess the degree to which those practices have succeeded in providing a standard of care consistent with the medical home model?
 - c. Thinking about the goal of ensuring that children with ASD/DDs 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?

15. How has your grant addressed the need for community-based services that are organized for easy use by families?
 - a. Prior to your grant, what would you say was the most significant challenge for families seeking services (e.g., lack of local services necessitating travel, lack of coordination across different service systems, inadequate capacity at the local level to meet the needs of children with ASD/DDs)?
 - b. What specific challenges did your grant aim to address? Have you seen evidence of progress? Please explain.
 - c. How has your grant engaged families in planning and implementing grant activities?
16. How, if at all, have you collaborated with Autism CARES grantees or other stakeholders to improve systems of care for individuals and families with ASD/DDs?
17. [If not already discussed] Please discuss your approach to meeting the grant objective pertaining to shared decisionmaking between parents and providers and helping more parents feel comfortable with that role.

D. Transition From Youth to Adulthood

18. Although the grant guidance does not include specific objectives related to transition-support services, large numbers of individuals with ASD are approaching adulthood and will continue to need comprehensive and coordinated support services well into the future. Can you describe any grant activities focused on issues related to transition?
 - a. Has there been a needs assessment to identify services most in demand?
 - b. Have any grant activities involved dissemination of transition-related resource materials to families and pediatric practices?
19. What strategies have you found to be particularly successful in improving services and supports for young adults transitioning to adulthood?
 - a. What major barriers still remain?

E. SPHARC

We are also evaluating the contributions of the resource centers funded through Autism CARES. As you know, the State Public Health Autism Resource Center, or SPHARC, provides technical assistance to support State grantees and Title V programs. SPHARC also organizes a peer-to-peer exchange program that facilitates cross-State learning. Other SPHARC activities include bimonthly technical assistance calls, archived Webinars, and a comprehensive Web-based resource library.

20. Can you describe any SPHARC resources you have taken advantage of at some point in your grant?
 - a. Have you used the listserv to communicate with other grantees?
 - b. Are you aware of the learning modules available on the SPHARC Web site? Have you accessed any of the materials available through those modules?

- c. Have you participated in or viewed any of the technical assistance Webinars?
 - d. Have you tapped into the peer-to-peer exchange program in any way?
21. Have you requested technical assistance to help you meet a particular challenge or objective? Please describe.
22. Did this technical assistance help you to meet your objective? How?
23. [If not already covered] In what ways has SPHARC facilitated collaboration between your team and other State grantees and other organizations and entities focused on children with ASD and other DDs?
24. Are there other ways SPHARC has contributed to the success of your grant or the collective success of Autism CARES grantees?
- a. What about ways they could improve or better support your program?

F. 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 grant.

General Questions

25. [If not already covered, check for adequate coverage of the “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)
 - i. How were these activities influenced by Autism CARES funding?
26. 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?

27. In reviewing your noncompeting continuation application, I saw that you conducted evaluation activities [describe evaluation activities and results]. Do you have any updates or additional results you'd like to share?
- a. [If not already addressed] How have you been evaluating your transition-related efforts?

Sustainability and Long-Term Impact of Funding

28. 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?
- a. [If relevant] Which activities will continue? Which will end?
29. What would you say is the single most important accomplishment of your program with the support of the Autism CARES grant?

Final Questions

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

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

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