

**INTERVIEW GUIDE FOR STATE INNOVATION IN  
CARE INTEGRATION GRANTEE PROJECT  
DIRECTORS  
(2016 AWARDEES)**

# Interview Guide for State Innovation in Care Integration Grantee Project Directors (2016 Awardees)

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**T**hank 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 Innovation in Care Integration grant activities and outcomes for the evaluation of MCHB's Autism CARES (or Collaboration, Accountability, Research, Education, and Support) Act Initiative. I will be asking you questions about your activities and accomplishments related to the goals and objectives of Autism CARES. I'll focus on a few key topics such as reducing barriers to screening, referral, and diagnosis; improving systems of care; awareness building; 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.** We have already reviewed some quantitative and qualitative data on your program from other sources, including [name relevant documents]. The information you share today can 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 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 Integration in Care Integration 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 have occurred since the start of your grant.

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. Reducing Barriers to Screening, Referral, and Diagnosis

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A key objective of the State Innovation in Care Integration grants is to improve access to appropriate screening, referral, diagnosis, care coordination, and services.

1. Prior to your grant, what were some of the barriers that prevented timely screening, referral, and diagnostic evaluation of children suspected of having autism spectrum disorder (ASD) or a related developmental disability (DD)?
  - a. What strategies have been used to—
    - i. Increase the proportion of children identified as at risk for ASD and referred for diagnostic evaluation?
    - ii. Increase the proportion of children with ASD who are enrolled in services before 37 months of age?
    - iii. Increase the number of at-risk children referred to early intervention programs and specialists for comprehensive evaluation? What do you view as your greatest successes in this area?
  - b. What barriers persist?
2. [Probe] (If not reported in the noncompeting grant application) Are you on target to meet your goals with respect to—
  - a. Increasing the proportion of children identified as at risk for ASD and referred for diagnostic evaluation?
  - b. Increasing enrollment of children with ASD in services before 37 months of age?
  - c. Increasing the number of at-risk children referred to early intervention programs and specialists for comprehensive evaluation?
3. Although this may not be a focus of your efforts, please tell me about any grant activities 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. What have been your major successes and challenges with regard to training professionals?
4. In what ways have you engaged parents in increasing their knowledge and skills?
  - 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?
5. Are there other training activities you would like to tell me about?
6. Can you describe any efforts to collaborate with other MCHB grant programs, such as LEND or DBP, on reducing barriers to screening, diagnosis, and services?
7. In general, what feedback have you received on your training and awareness-building efforts?

## B. Improving Systems of Care

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*[Note to interviewer, goals in this area: By August 31, 2019, increase the proportion of children and youth with ASD and other DDs within the State and their families by 25 percent over baseline who report increased knowledge, skill, ability, and self-efficacy in family-centered care. All grantees of this funding opportunity will participate in a community of learners and implement quality improvement activities. Grantees should also use innovative, evidence-informed strategies to improve access to a coordinated, comprehensive system of services for children and youth with ASD/DDs. Each evidence-informed strategy must include family engagement activities to ensure partnership between ASD/DD families and providers.]*

8. What steps have been taken to ensure that children with ASD/DDs and their families have access to a coordinated, comprehensive system of services for children and youth with ASD/DDs?
  - a. Can you describe any activities aimed at improving family engagement and promoting partnerships between ASD/DD families and providers?
  - b. Has your grant used shared resources, such as community networks and health teams of area health education centers, to support care coordination and case management?
  - c. Has your grant used telemedicine to—
    - i. Facilitate ASD/DD diagnosis or treatment?
    - ii. Increase access to medical and nonmedical ASD/DD providers in medically underserved communities?
    - iii. Facilitate cross-system coordination, integration, and data sharing between and among providers and families?
9. Please describe any successes and challenges your team has encountered in using any of the aforementioned strategies.

*[Probes: What strategies seem most effective in improving access to a coordinated, comprehensive system of services for children with ASD/DDs and their families? What specific improvements would you attribute to that strategy?]*

*[Note to interviewer: The grantees have goals related to components of family engagement activities. Family engagement activities should address the continuum of needs and work at multiple levels to ensure children and youth with ASD/DDs and their families receive the level of participation best for them. The levels of engagement can be in direct care, organizational design, and/or governance and policymaking. The continuum of engagement can be in consultation, involvement and/or partnership, and shared leadership. Each grantee is expected to incorporate the appropriate family engagement activity that supports the chosen strategy.]*

10. How has your grant promoted family engagement in governance and policymaking? In what ways, if any, has engagement of family members helped facilitate system-level improvements?

11. How has your grant promoted partnerships between individuals and family members of children with ASD and their providers? Is there any evidence of improvements in access or quality of care resulting from such partnerships?
12. 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?

## C. Awareness Building

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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.

13. While I understand this may not be a focus of your current activities under this grant, can you describe any efforts of your grant to respond to that need?  
[If State is doing work in this area] Who are the target audiences of the outreach efforts?
  - a. Are there specific subgroups that still need to be targeted to improve their awareness of developmental milestones?
  - b. Please describe the communication strategies used (e.g., dissemination of print materials, Webinars, PSAs) and which strategies seem to be most effective.
  - c. What do you view as your greatest successes in this area?
  - d. What barriers are you facing in building public awareness?

## D. Transition From Youth to Adulthood

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14. 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 that are 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?
15. 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

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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.

16. 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?
17. Have you requested technical assistance to help you meet a particular challenge or objective? Please describe.
18. Did this technical assistance help you meet your objective? How?
19. [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?
20. 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 SPHARC could improve or better support your program?

## F. Overarching Questions, Wrap-up

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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

21. [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?

22. 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?
23. 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 addressed already] How have you been evaluating your transition-related efforts?

### ***Sustainability and Long-Term Impact of Funding***

24. 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?
  - a. [If relevant] Which activities will continue? Which will end?
25. What would you say is your program's single most important accomplishment with the support of the Autism CARES grant?

### ***Final Questions***

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

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

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