

**Health Resources and Services Administration
Maternal and Child Health Bureau**

Autism CARES Act Evaluation

OMB Control No. 0915-0335

**Request for Clearance,
Supporting Statement,
and Data Collection Instruments**

Part

B. Collection of Information Employing Statistical Methods

B.1. **Respondent Universe and Sampling Methods**

The respondent universe for the collection of data is all grantees receiving Health Resources and Services Administration (HRSA) grant support under the Autism CARES Act of 2014 as follows:

- Fifty-three Leadership Education in Neurodevelopmental Disabilities (LEND) grantees
- Ten Developmental-Behavioral Pediatrics (DBP) training program grantees
- Twenty-seven Research program grantees
 - o Five Research Networks (one focused on physical/medical health; one focused on behavioral, mental, social, and/or cognitive health; one focused on developmental pediatrics; one focused on the needs of adolescents and young adults with ASD/DDs during times of transition; and one focused on overweight and obesity risks among individuals with ASD/DDs)
 - o Ten R40 Maternal and Child Health Research multiyear grantees
 - o Twelve R40 Secondary Data Analysis Studies (known as SDAS) grantees
- Nine State Implementation program grantees
- Four State Innovation in Care Integration grantees
- Two Resource Centers (these centers provide technical assistance and disseminate information to the grant programs)

Because of the small number and unique nature of each grant program, a census of all programs will be conducted. The findings will not be generalized beyond the respondents.

B.2. Procedures for the Collection of Information

Information will be collected from each grantee in several ways. First, each grantee will submit specific program performance measures annually to the HRSA program officer. These measures have already been cleared through OMB. Second, information in the form of qualitative data will be garnered from semistructured interviews with the principal investigator or project director from each grant program. Third, grantee project directors for select grant programs (i.e., Research Networks) will complete study questionnaires that provide detailed quantitative information about project implementation.

The interviews will provide data pertaining to the grantees' implementation activities (e.g., training of MCH providers) and the intermediate results of those activities (e.g., screening/evaluation of underserved children by trained fellows or faculty), which are expected to lead to the long-term goal of early screening, early diagnosis, and early treatment of individuals with ASD/DDs.

The study is designed to measure the grantees' progress in meeting MCHB's objectives under the Autism CARES Act, which include increasing awareness of ASD/DDs, training professionals to use valid, reliable, screening and diagnostic tools; providing evidence-based interventions for ASD/DDs; supporting research to advance evidence-based or consensus-based guidelines for interventions; improving the overall system of services for ASD/DDs; and reducing barriers to screening and diagnosis.

Table B.1 provides a crosswalk of each of the research questions and objectives by data source. Each protocol referenced in this table is included in full as attachments C through K.

Table B.1. Research Question and Objective by Data Source

Research Question	Data Source				
	DBP Interview	LEND Interview	Research Network/R40 Interview and Questionnaire	State Interviews	Resource Center Interviews
Train professionals					
How have Autism CARES Act grantees contributed to the training of professionals who can provide services for children and youth with ASD/DDs?					
a. Who receives ASD/DD training from Autism CARES grantees? What are trainees' key characteristics, and how have grantees contributed to a diverse and interdisciplinary field of professionals?	X	X	X	X	
b. How have LEND and DBP grantees enhanced the didactic and clinical training opportunities related to ASD/DDs?	X	X			
c. How have LEND and DBP grantees prepared trainees for ASD/DD leadership positions?	X	X			
d. How have Autism CARES grantees collaborated with one another and with other stakeholders to provide ASD/DD training?			X	X	X
e. What training strategies have Autism CARES grantees found to be successful, and what factors have facilitated their success?	X	X	X	X	
f. What major barriers prevent the training of professionals who can provide services for children and youth with ASD/DDs? What challenges have Autism CARES grantees faced in overcoming these barriers?	X	X	X	X	
g. How have Autism CARES grantees evaluated their own efforts to train professionals, and what were their evaluation results?	X	X			
Increase awareness and disseminate information					
How have Autism CARES grantees increased awareness of ASD/DDs and/or disseminated related information?					
a. Who are the target audiences for Autism CARES grantees' ASD/DD awareness and dissemination efforts? What main messages do Autism CARES grantees convey to these audiences?	X	X	X	X	X
b. How are Autism CARES grantees targeting their awareness and dissemination efforts to appropriate audiences?	X	X	X	X	X

Research Question	Data Source				
	DBP Interview	LEND Interview	Research Network/R40 Interview and Questionnaire	State Interviews	Resource Center Interviews
c. What are Autism CARES grantees' primary modes of ASD/DD awareness outreach and dissemination (e.g., conferences, Webinars, campaigns)?	X	X	X	X	
d. What products, actions, or initiatives have resulted from Autism CARES grantees' efforts to increase awareness of ASD/DDs and/or disseminate related information?	X	X	X	X	
e.					
f. How have Autism CARES grantees collaborated with one another and with other stakeholders to increase awareness of ASD/DDs and/or disseminate related information?			X	X	X
g. What awareness and dissemination strategies have Autism CARES grantees found to be successful, and what factors have facilitated their success?	X	X	X	X	
h. What major awareness and/or dissemination gaps remain? What challenges have Autism CARES grantees faced in bridging these gaps?	X	X	X	X	X
i. How have Autism CARES grantees evaluated their own efforts to increase awareness of ASD/DDs and/or disseminate related information, and what were their evaluation results?	X	X	X	X	X
Contribute to research, develop evidence-based guidelines and screening tools					
How have Autism CARES grantees contributed to ASD/DD research?					
a. What ASD/DD-related research topics are Autism CARES grantees pursuing, and what are the products of this research?	X	X	X		
b. How have Research Program grantees contributed to evidence-based or consensus-based ASD/DD guidelines, tools, and interventions?			X		
c. How have Autism CARES grantees mentored and developed new investigators in the ASD/DD field?	X	X	X		
d. How have Autism CARES grantees collaborated with one	X	X	X		X

Research Question	Data Source				
	DBP Interview	LEND Interview	Research Network/R40 Interview and Questionnaire	State Interviews	Resource Center Interviews
another and with other stakeholders on ASD/DD research?					
e. What major research gaps remain, and what challenges have Autism CARES grantees faced in addressing these research gaps?	X	X	X		
f. What strategies have Autism CARES grantees found to be successful in promoting the uptake of new research or the transfer of new findings into practice, and what factors have facilitated their success?	X	X	X	X	
g. What barriers prevent the uptake of new research or the transfer of new findings into practice, and what challenges have Autism CARES grantees faced in addressing these barriers?			X	X	X
h. How have Autism CARES grantees evaluated their own efforts to contribute to ASD/DD research, and what were their evaluation results?	X	X	X		
Reduce barriers to screening and diagnosis, improve systems of care					
What efforts did Autism CARES grantees undertake to reduce barriers to care¹ for children and youth with ASD/DDs? What efforts did they undertake to improve systems of care for this population?					
a. How have Autism CARES grantees' activities addressed needs of underserved populations with ASD/DDs?	X	X	X	X	
b. How have Autism CARES grantees collaborated with one another and with other stakeholders to reduce barriers to care and/or improve systems of care for children and youth with ASD/DDs?	X	X		X	X
c. What strategies have Autism CARES grantees found to be successful in reducing barriers to screening and diagnosis and improving systems of care, and what factors have facilitated their success?	X	X	X	X	
d. What major barriers to care do children and youth with	X	X		X	

¹ The word “care” encompasses the full continuum of care for individuals with ASD/DDs (screening, diagnosis, intervention, treatment, transition, etc.)

Research Question	Data Source				
	DBP Interview	LEND Interview	Research Network/R40 Interview and Questionnaire	State Interviews	Resource Center Interviews
ASD/DDs face? What challenges have Autism CARES grantees faced in addressing these barriers?					
e. How have Autism CARES grantees evaluated their own efforts to reduce barriers to screening and diagnosis and improve systems of care, and what were their evaluation results?	X	X	X	X	
Identify needs and develop services for youth transitioning to adulthood					
What efforts did Autism CARES grantees undertake to identify needs and develop services and supports for young adults with ASD/DDs transitioning to adulthood? How have they helped families and communities with transition issues?					
a. How have Autism CARES grantees incorporated the issue of transition into their efforts to train professionals, increase awareness and disseminate information, contribute to research and develop evidence-based or consensus-based guidelines and screening tools, support transitions, and facilitate collaboration?	X	X	X	X	
b. What strategies have Autism CARES grantees found to be successful in improving services and supports for young adults transitioning to adulthood, and what factors have facilitated their success?			X	X	
c. What major challenges remain to improving services and supports for young adults transitioning to adulthood? What challenges have Autism CARES grantees faced in addressing these issues?	X	X	X	X	
d. How have Autism CARES grantees evaluated their own efforts to support the transition to adulthood for young adults with ASD/DDs and their families, and what were their evaluation results?		X	X	X	
National Resource Centers: Facilitate collaboration					
How have National Resource Centers supported Autism CARES grantees (e.g., providing technical assistance, facilitating collaboration, convening Autism CARES grantees, collecting and managing data, producing and disseminating resources, providing a central resource center)?					
a. What strategies have resources centers found to be successful in serving grantees, and what factors have					X

Research Question	Data Source				
	DBP Interview	LEND Interview	Research Network/R40 Interview and Questionnaire	State Interviews	Resource Center Interviews
facilitated their success?					
b. What major challenges do resource centers face in serving grantees? What challenges do Autism CARES grantees face in using resource center services? How have resource centers and Autism CARES grantees worked to overcome these challenges?					X
c. How have resource centers evaluated their own efforts to support Autism CARES grantees, and what were their evaluation results?					X
Buzzwords/Key Concepts					
1. Collaboration	X	X	X		
2. Cultural and linguistic competency	X	X	X	X	
3. Families	X	X	X	X	
4. Family-centered care	X	X	X	X	
5. Interdisciplinary care and collaboration	X	X	X		
6. Leadership (advocacy)	X	X			
7. Medical homes	X	X	X	X	
8. Translating research into practice			X		
9. Underserved populations (rural and minority)	X	X	X	X	

B.3. Methods to Maximize Response Rates and the Issue of Nonresponse

All grantees of the HRSA grant-funded programs involved in Autism CARES are required, as a condition of their grants, to provide the requested information to HRSA and to participate in an interview with the research contractor, so nonresponse will not be an issue. HRSA will provide that information to Insight Policy Research (the contractor).

B.4. Tests of Procedures

The semistructured interview protocols were used in the previous data collection effort (OMB 0915 0335) and have been updated to streamline the questions and improve clarity. While the attached versions have not been pretested, all procedures were developed with input from the HRSA Project Officers and HRSA grantees and were based on previous successful efforts. The protocols were designed with this input in mind and follow a standard approach to ensure high-quality data are obtained across all grant programs.

B.5. Consultants

No additional consultants are envisioned for data collection or data analysis.