

Supporting Statement A

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

Autism CARES Act Evaluation

OMB Control No. XXXX-XXXX

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

Terms of Clearance: None

A. Justification

1. Circumstances Making the Collection of Information Necessary

In compliance with Section 3506(c)(2)(A) of the Paperwork Reduction Act of 1995, the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) is requesting Office of Management and Budget (OMB) approval to collect information from grantees funded under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 (P.L. 116–60) (attachment A). The purpose of this information collection is to describe the accomplishments of the grant programs implementing the provisions of the Autism CARES Act.

Background

Autism is a neurodevelopmental condition. The American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (5th edition) identifies the diagnostic criteria for autism as including persistent impairments in social interaction, such as difficulties in social skills and nonverbal communications; difficulty in developing, maintaining, and understanding implicit social norms regarding relationships with others; and restricted, repetitive patterns of behavior, such as repetitive motor movements, inflexibility with regard to routines, restricted interests, and unusual reactions to sensory input. In response to the growing need for resources devoted to autism and other developmental disabilities (DDs), the U.S. Congress passed legislation to ensure support for research, services, prevalence tracking, and other government activities would be in place to address the dramatic rise of autism/DDs.

MCHB Initiatives

MCHB's mission is to improve the health and well-being of America's mothers, children, and families. MCHB administers a broad range of programs that promote and support the health of mothers and children and their families. Many of the bureau's discretionary grant programs target specific populations, such as those with low incomes, those representing racial and ethnic minorities, individuals living in rural and underserved areas, children with special healthcare needs, families, and populations with particular medical conditions. MCHB provides grant support for programs that build maternal and child health services capacity, such as training health professionals; improving services and access to care; and increasing assessment, planning, and quality assurance capabilities.

Autism CARES Act Programs

The overall goal of MCHB's Autism CARES Act programs is to enable all infants, children, and adolescents with autism/DDs, or those with predictive factors for autism/DDs to reach their full potential by developing a system of services with the following objectives:

1. Screen children as early as possible for autism/DDs.
2. Conduct early, interdisciplinary, clinical evaluations to confirm or rule out autism/DDs.
3. Provide early, evidence-based interventions when a diagnosis is confirmed.
4. Increase public/provider awareness of autism/DDs.
5. Reduce barriers to screening and diagnosis of autism/DDs.
6. Support research on evidence-based interventions for autism/DDs.

7. Promote the development of evidence-based guidelines and tested/validated intervention tools for autism/DDs.
8. Train professionals to use valid and reliable screening tools to confirm or rule out a diagnosis of autism/DD and to provide evidence-based interventions.
9. Build system capacity to provide coordinated, comprehensive, and community-based care for children and youth with autism/DDs.

To achieve these objectives, MCHB funds programs in three areas: research, State systems, and training. The program funds 12 programs and 95 awardees as described below.

Research Programs

Two types of research programs are in place: networks and individual grants.

Research Networks: Four Research Networks advance the evidence base on effective interventions for individuals with autism/DDs, develop guidelines, and disseminate information.

The **Autism Intervention Research Network on Physical Health (AIR-P)** focuses on improving the physical health and well-being of individuals with autism across the lifespan.

Through its interdisciplinary, multisite network, AIR-P supports innovative life course intervention research that promotes optimal health and well-being of individuals with autism.

The areas of focus include primary care services and quality; community-based lifestyle interventions; gender, sexuality, and reproductive health; health systems and services; neurology; and genetics.

The **Autism Intervention Research Network on Behavioral Health (AIR-B)** focuses on improving the behavioral, mental, social, and/or cognitive health of individuals with autism/DDs

and developing evidence-based interventions, treatments, and tools. The AIR-B network conducts multisite research to develop evidence-based autism interventions, treatments, and tools. This program uses community-based, participatory research methods to ensure parents and providers can effectively implement evidence-based interventions at home and at school. AIR-B recruits participants from diverse racial/ethnic, rural, and socioeconomic groups and conducts studies in underresourced settings.

The **Developmental-Behavioral Pediatrics Research Network** (known as DBPNet) promotes and coordinates research activities in developmental, behavioral, and psychosocial aspects of pediatric care. The network focuses efforts on (1) providing an infrastructure to support rapid scientific discovery; (2) conducting ongoing, interactive, and collaborative activities among network members; (3) leveraging innovative research projects and network capacity to compete for grant opportunities from other Federal agencies or private foundations; and (4) fostering research and mentorship opportunities for young or new investigators.

The **Research Network on Promoting Healthy Weight Among Children With Autism/DDs** (HW-RN) works to advance the evidence base for the prevention and treatment of obesity and enhance healthy weight in this high-risk group. HW-RN is an interdisciplinary research network that leads and promotes coordinated research activities related to promoting healthy weight among children and youth with autism/DDs, with an emphasis on reaching underserved and underrepresented communities.

Individual Research Grants: MCHB supports 11 research grants composed of the following:

- Two **Autism Single Investigator Innovation Programs** (Autism SIIP): the Autism Transitions Research Project and Autism Longitudinal Data Project

The goal of the Autism SIIP program is to support empirical research and advance the evidence base on interventions and investigate barriers to screening, diagnosis, and receipt of evidence-based autism/DD interventions to improve the health and well-being of children and adolescents with autism, with a special focus on addressing the needs of underserved populations.

- Two **Autism Field-Initiated Innovative Research Studies Program** (Autism FIRST) grantees

The goal of the Autism FIRST program is to support research on interventions intended to develop and test ways to effectively tailor services, supports, and interventions to individual and family strengths, needs, and challenges and identify services and supports that mediate or moderate relations between family stresses and outcomes for children, adolescents, and young adults with autism/DDs.

- Seven **Autism Secondary Data Analysis Research Program** (Autism SDAR) grantees (funded for a period of 1 year)

The purpose of the MCH SDAR program is to support applied maternal and child health (MCH) research that uses secondary analysis of available national datasets and/or administrative records to improve the health and well-being of MCH populations.

State Systems

State Innovations in Care Coordination Grant: Five States were awarded Innovations in Care Coordination Grants in September 2019, and a new cohort of five grantees is expected to be awarded in 2023. The State Systems grants provide grantees with the funding needed to implement family navigation and provider training in medically underserved areas to improve access to coordinated and integrated care for children with autism/DDs.

The State Systems grantees are supported by the State Public Health Coordinating Center for Autism. Funded through a cooperative agreement with MCHB, the Center provides technical assistance to the State System grantees and other State entities such as Title V programs and serves as a comprehensive web-based resource center for the State programs.

Training Programs

Two types of training programs are in place: ***Leadership Education in Neurodevelopmental and Related Disabilities (LEND) and Developmental-Behavioral Pediatrics (DBP) training programs.***

Sixty LEND programs have been established, with the following primary objectives:

- Provide high-quality interdisciplinary training to health and related professionals from diverse disciplines.
- Prepare those professionals to assume leadership roles in their respective disciplines.
- Provide interdisciplinary services and care to children with special healthcare needs and their families.

LEND funding was designed primarily to support the training of professionals who can provide screening, diagnostic evaluation, and evidence-based intervention for individuals with autism/DDs. Several LEND programs also contribute to the evidence base for autism identification and treatment through participation in research. Consistent with MCHB's mission, LEND grantees have the related objective of improving the overall system of services available to children with autism/DDs and their families.

Twelve DBP programs receive Autism CARES funds to enhance the behavioral, psychosocial, and developmental aspects of pediatric care. The primary objectives of DBP follow:

- Support and prepare developmental-behavioral pediatric fellows for leadership positions in teaching, research, and clinical care.
- Provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and expertise.

The training programs are supported by the Interdisciplinary Training Resource Center (ITRC) on Autism and Developmental Disabilities. One grantee received funding to serve as the technical assistance and resource center to the LEND and DBP grantees.

Use of Information for Policy and Program Objectives

The Autism CARES Act mandates that the U.S. Department of Health and Human Services (HHS) provide to Congress an interagency report documenting the progress of Federal agencies, including HRSA MCHB in implementing the provisions of this act. HRSA MCHB hired a contractor to assess and report on the progress of the programs funded through the Autism CARES Act and determine the long-term and collective impact of these programs on improving

the health and well-being of individuals with autism/DDs. Therefore, the contractor will collect relevant data from MCHB-funded grantees. This information will assist HRSA MCHB and Congress in assessing ongoing program priorities.

2. Purpose and Use of Information Collection

The purpose of this project is to design and implement a comprehensive evaluation of the MCHB Autism CARES Act Initiative programs. The data will be used as follows:

- Conduct performance monitoring of the programs.
- Provide credible and rigorous evidence of program effectiveness.
- Meet program needs for accountability, decision making, and quality assurance.
- Strengthen the evidence base for best practices.

Data collection instruments will include (1) surveys with the Research and State Systems grantees and (2) interview guides with all grantees (Research, State Systems, Training, and Resource Centers). Through the surveys, we will collect quantitative data on program activities and publications. Through the interviews, we will collect detailed qualitative data about the program activities and perceptions of successes, challenges, and barriers.

The evaluation team will conduct individual or group semi-structured, in-depth interviews with the program directors and other grantee team members (if the program directors select additional team members for interviews). The data collection activities are summarized in table A.1.

Information collected in the surveys will include quantitative data not included in available secondary sources. Through the interviews, the team will draw on the survey data and collect new, unique qualitative data about the programs.

Table A.1. Overview of Data Collection Activities

Instrument	Respondent Category	Mode	Length (in Minutes)	Number of Respondent	Frequency of Data Collection
Research survey	Individual and Group research grants	Survey	30	16	1
Research interview guides	Individual & Group research grants	Interview	60	16	1
State Systems survey	State Systems	Survey	30	5	1
State Systems interview guide for individual grantees	State Systems	Interview	60	5	1
State Systems interview guide for State coordinating center	State Systems	Interview	60	1	1
Training interview guide for individual grantees	Training	Interview	60	72	1
Training interview guide for resource center	Training	Interview	60	1	1

3. Use of Improved Information Technology and Burden Reduction

The State Systems Grantee Survey (attachment D) will be emailed as a Word document for grantees to complete. The survey is brief with no skip patterns and can be easily completed via Word document over email. The Research Grantee Survey (attachment B) will be programmed into a web-based platform to include a “save and continue” option to enable respondents to save their responses and continue the survey later. The survey includes skip logic, so the grantees will answer only questions that pertain to the evaluation questions relevant to their specific program areas, thus minimizing respondent burden. Grantee representatives who have not completed the

survey will be contacted via telephone and offered the opportunity to complete the survey via telephone with a trained interviewer. All semi-structured interviews (attachments C, D, E, F, and G) will be conducted by telephone.

4. Efforts to Identify Duplication and Use of Similar Information

No other MCHB data collection activities are available that measure the impact and progress of the Autism CARES Act programs in meeting their objectives. The surveys and interviews in this package will include only information not available through other sources such as the MCHB DGIS data and grantee reports. The surveys and interview guides will not be duplicative but will collect complementary information and address any gaps in other data collection tools MCHB uses.

5. Impact on Small Businesses or Other Small Entities

This activity does not impact small businesses or other small entities.

6. Consequences of Collecting the Information Less Frequently

The information collected with the surveys and the semi-structured interviews will be conducted one time. If the data are not collected, HRSA and HHS will not have adequate information to provide the mandated Report to Congress.

7. Special Circumstances Relating to the Guideline of 5 CFR 1320.5

This data collection request is fully consistent with the guidelines in 5 CFR 1320.5(d)(2).

8. Comments in Response to the Federal Register Notice/Outside Consultation

Section 8A:

A 60-day *Federal Register* Notice was published in the *Federal Register* on March 21, 2023: Vol. 88, No. 54, pp. 16995–16996. The purpose is to obtain input on the availability of data, clarity of instructions, and information to be collected. The instruments were reviewed by the persons listed in table A.2, which shows names, affiliations and titles, and contact information.

Table A.2. Persons Consulted on Data Collection Instruments

Name	Affiliated Entity	Title	Contact Information (Telephone, Email)
Margaret L. Bauman, M.D.	Boston University School of Medicine; Integrated Center for Child Development Subject Matter Expert	Child Neurologist and Associate Professor	617.658.5600 mbauman@iccdpartners.org
Karen Kuhlthau, Ph.D.	Harvard Medical School; Massachusetts General Hospital and MassGeneral Hospital for Children Subject Matter Expert	Associate Professor of Pediatrics and Associate Sociologist	617.724.2842 kkuhlthau@mgh.harvard.edu
Leticia Manning	HRSA	Public Health Analyst and Contracting Officer’s Representative	301.443.8335 LManning@hrsa.gov
Lauren Ramos	HRSA	Director, Division of Maternal and Child Health (MCH) Workforce Development	301-443-6091 LRamos@hrsa.gov
Hae Young Park	HRSA	Deputy Director, Division of MCH Workforce Development	301-443-2127 HPark@hrsa.gov
Robyn Schulhof	HRSA	Senior Public Health Analyst	301.443.0258 RSchulhof@hrsa.gov

Name	Affiliated Entity	Title	Contact Information (Telephone, Email)
Rita Maldonado	HRSA	Public Health Analyst	301-443-3622 RMaldonado@hrsa.gov
Deborah Shelef	HRSA	Public Health Analyst	240-460-5221 DShelef@hrsa.gov

9. Explanation of Any Payment/Gift to Respondents

Respondents will not be remunerated or compensated.

10. Assurance of Confidentiality Provided to Respondents

No personally identifiable information will be collected. Only program data will be collected.

11. Justification for Sensitive Questions

There are no questions of a sensitive nature.

12. Estimates of Hour Burden Including Annualized Hourly Costs

The burden estimates for respondents appear in table A.3. Burden is defined as the time expended by persons to generate, maintain, retain, disclose, or provide the information requested. This includes the time needed to review instructions and develop, acquire, install, and use technology and systems for the purpose of collecting, validating, and verifying information, processing and maintaining information, and disclosing and providing information. Burden also includes time to train personnel and to be able to respond to a collection of information; search data sources, complete and review the collection of information, and transmit or otherwise disclose the information. These estimates are based on previous experience with instruments in prior OMB submissions. Participants may include the project director and principal investigator from each grant program.

Wage rates are based on May 2021 national occupational and wage estimates from the Bureau of Labor Statistics. For the Research program LEND and DBP interviews with principal investigators, the cost estimates are based on the mean hourly wage for a social scientist. For the

interviews with the ITRC, the cost estimates are based on the national mean hourly wage for a medical scientist. For the State Systems survey and interviews with State Systems program principal investigators and the State Public Health Autism Resource Center, the cost estimates are based on the national mean hourly wage for a medical and health services manager. For the Research program survey, the cost estimates are based on the national mean hourly wage for a social science research assistant.

Table A.3. Estimated Total Hour and Cost Burden of the Data Collection

Grant Program/Form Name	Number of Respondents	Average Number of Responses per Respondent	Total Responses	Average Hours per Response	Total Hour Burden	Wage Rate	Total Hour Cost
Research: Survey	16	1	16	0.5	8	\$27.13	\$217.04
Research: Interview guide	16	1	16	1.5	24	\$43.70	\$1,048.80
State Systems: Survey for State innovation grants	5	1	5	0.5	2.5	\$57.61	\$144.03
State Systems: Interview guide for State innovation grants	5	1	5	1.5	7.5	\$57.61	\$432.08
State Systems: Interview guide for State coordinating center	1	1	1	1.5	1.5	\$57.61	\$86.42
Training: Interview guide for individual training grantees	72	1	72	1.5	108	\$43.70	\$4,719.60
Training: Interview Guide for Resource Center	1	1	2	1.5	3	\$50.02	\$150.06
Total Across 3 Years	116	-	116	-	154.5		\$6,798.02

13. Estimates of Other Total Annual Cost Burden to Respondents or Record

Keepers/Capital Costs

No capital or startup costs are associated with data collection.

14. Annualized Cost to Federal Government

The cost to the Federal Government for collecting these data is estimated to be the portion of the Evaluation Team's 3-year evaluation contract that is devoted to the primary data collection and analysis efforts related to the surveys and interviews, which is approximately \$437,542. The cost is also estimated to include approximately 20 percent of the Federal Project Officer's time (estimated for an O-4 PHS Commissioned Officer), which is approximately \$18,542.88¹ annually. The total annualized cost to the Federal Government is approximately \$456,084.88.

15. Explanation of Program Changes or Adjustments

The overall burden has decreased since the last OMB submission. The previous data collection collected survey data (in addition to interview data) from all grantees, whereas this revised data collection will only administer surveys to the State Systems and Research grantees. For the training programs, the evaluation team will use available data from the National Information and Reporting System instead of administering surveys. The data collection also has been streamlined. In the previous OMB package, a separate quantitative data collection form for the Research grantees was used to capture standardized details related to each study and publication. The necessary information collected in that form will be captured in the survey, such as capturing standardized details about each of their studies and publications (e.g., number of studies with families as participants). These changes result in fewer burden hours estimated across the primary data collection activities.

16. Plans for Tabulation and Publication and Project Time Schedule

a. Analysis of Grantee Survey Data

¹ Annual cost is based on annual salary of a O-4 PHS Commission Officer with 6 years of experience (\$92,714.40).

The analysis of Grantee Survey quantitative data will be aggregated annually and presented in table format. It will include descriptive statistics such as means, frequency distributions, and cross-tabulations for each research question, separately by program area.

b. Analysis of Semi-Structured Interview Data

The purpose of the qualitative analysis is to supplement the information obtained through the annual Grantee Survey and expand on the descriptive information described above. The qualitative analysis will result in narrative summaries and illustrative quotes that describe the activities the grantees engaged in.

The interviews will be coded in a qualitative analysis software (NVivo). Analysts from the evaluation study team will examine the coded data to identify themes specifically focused on the evaluation questions.

The proposed schedule for the data collection, analysis, and reporting requirements appears in table A.4.

Table A.4. Estimated Time Schedule for Data Collection, Analysis, and Reporting Requirements

Activity	Time Schedule
Update data collection tools	January 2022–September 2022
Receive OMB approval	June 2023–July 2023 (anticipated)
Grantee surveys administered	1 month after obtaining OMB approval/or as soon as Option Year 1 begins if approval is obtained sooner than October 1, 2023.
Interviews scheduled and conducted	1 month after obtaining OMB approval/or as soon as Option Year 1 begins if approval is obtained sooner than October 1, 2023.
Data analysis	Spring 2023–summer 2025
Annual interim evaluation reports to HRSA	May 2024, May 2025
Annual data placemats to HRSA	June 2023, June 2024, June 2025
Annual evaluation reports to HRSA	September 2023, September 2024, September 2025

c. Integration of Quantitative and Qualitative Data

Synthesizing the quantitative and qualitative results will be important to answer the evaluation questions addressed by the surveys and the semi-structured interview guides. This mixed-methods design will bring together the surveys and interview data to establish interdependent findings from these quantitative and qualitative sources.

Annual interim reports will be submitted to HRSA in September 2023, September 2024, and September 2025. Annual data placemats will be submitted to HRSA in June 2023, June 2024, and June 2025.

17. Reason(s) Display of OMB Expiration Date Is Inappropriate

The OMB number and expiration date will be displayed on every page of every form and instrument.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exemptions to the certification.

Attachments to Supporting Statement A

Attachment A. Autism CARES Act of 2019 (P.L. 116–60)

Attachment B. Research Grantee Survey

Attachment C. Research Grantee Interview Guide

Attachment D. State Systems Grantee Survey

Attachment E. State Systems Grantee Interview Guide

Attachment F. SPHARC Interview Guide

Attachment G. LEND/DBP Interview Guide

Attachment H. ITRC Interview Guide