

Health Resources and Services Administration/Maternal and Child Health Bureau Combating Autism Act Initiative Data Collection

A. Justification

1. Circumstances of Information Collection

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 through the Combating Autism Act of 2006 (CAA)¹. The purpose of this information collection is to describe the progress made by HRSA/MCHB's CAA-funded grant programs in implementing the provisions of the Act.

Background

In response to the growing need for research and resources devoted to ASD and other DD, the U.S. Congress passed the CAA in 2006 to authorize federal programs to combat ASD and other DD through research, screening, intervention, and education.

The CAA provides funding for several agencies to engage in various autism-related activities. These agencies and activities are described below.

- **National Institutes of Health (NIH)** conducts research on causes, diagnosis, early detection and treatment of ASD and other DD through the Centers of Excellence.
- **Centers for Disease Control and Prevention (CDC)** conducts research and surveillance activities related to ASD and other DD, including collection of state-level epidemiologic data.
- **Health Resources and Services Administration (HRSA)** implements a network of programs dedicated to training professionals, conducting research on physical and behavioral interventions for ASD and other DD, and improving State systems of care.

HRSA/MCHB Initiatives

HRSA's activities under this legislation are delegated to the Maternal and Child Health Bureau (MCHB). MCHB administers a broad range of programs that promote and support the health of mothers and children, and their families. Many of MCHB's discretionary grant programs target specific populations, such as low-income, racial and ethnic minority, rural, children with special health care needs, families, as well as populations with particular medical conditions. In addition, MCHB provides grant support for programs that build maternal and child health

¹ Public Law 109-416§42 U.S.C.§1. A copy of the legislation can be found in Attachment A.

services capacity such as training health professionals, developing standards of care, and increasing assessment, planning and quality assurance capabilities.

Under the authority of the CAA, MCHB developed the Combating Autism Act Initiative (CAAI). The overall goal of this Initiative is to enable all children to reach their full potential by developing a system of services that includes:

1. Screening children as early as possible for ASD and other DD;
2. Conducting early, interdisciplinary clinical evaluations to confirm or rule out ASD and other DD; and
3. If a diagnosis is confirmed, providing early, evidence-based interventions.

Additionally, in alignment with guidance from the legislation, the CAAI specifies five objectives:

1. Increase public/provider awareness of ASD and other DD;
2. Reduce barriers to screening and diagnosis;
3. Support research on evidence-based interventions for ASD and other DD;
4. Promote the development of evidence-based guidelines and tested/validated intervention tools; and
5. Train professionals to use valid and reliable screening tools, to confirm or rule out a diagnosis of ASD/DD and to provide evidence-based interventions.

HRSA/MCHB's contribution to achieving these five goals includes funding for three separate grant programs focusing on training, research and improving state systems of care. Each program is briefly described below.

Training Programs

- Leadership Education in Neurodevelopmental Disabilities (LEND) training programs: Thirty-four existing grantees received additional funding of approximately \$200,000 each year while five new LEND programs were established and funded at a level of approximately \$550,000 each per year.
- Developmental Behavioral Pediatrics (DBP) training programs: Six existing grantees received additional funding of approximately \$50,000 per year.

Research Programs

- Autism Intervention Research (AIR) Networks: Two autism intervention networks focus on intervention research, guideline development and information dissemination. One network is focused on physical/medical health intervention research (AIR-P, with \$4 million per year) while the other is focused on behavioral, mental, social, and/or cognitive health intervention research (AIR-B, with \$2 million per year).
- R40 MCH Autism Intervention Research Program: In 2009, five R40 MCH Autism grantees were funded for two years to support research on evidence-based interventions to improve the health and well-being of children and adolescents with ASD and other DD. Each grant award is no more than \$400,000 per year.
- R40 MCH Autism Intervention Secondary Data Analysis Studies (SDAS) Program: The program's goals are to support research on evidence-based interventions to improve the health and well-being of children and adolescents with ASD and other DD, utilizing the exclusive analysis of existing secondary data. Each grantee award is no more than \$100,000 per year. In 2009, MCHB funded two grantees under the SDAS Program for one year.

Improving State Systems of Care

- State Implementation Grants: Nine grantees implement state autism plans and develop models for systems of services for children with ASD and other DD. Each grantee receives funding of approximately \$300,000 each year.

Use of Information for Policy and Program Objectives

The Combating Autism Act mandated that the Secretary of the Department of Health and Human Services (DHHS) provide to the Congress an interagency report documenting the progress of HRSA/MCHB, NIH and CDC in implementing the provisions of this Act. For HRSA's part, the agency has hired a contractor to assess and report on the progress of the three separate grant programs funded through MCHB's Combating Autism Act Initiative. This progress report requires data collection from these grant programs on their activities since receiving the supplemental grant funds. The data will be used by MCHB and by Congress to make decisions about future funding of these programs, and to assess program priorities.

2. Purpose and Use of the Information

The data will be obtained through grantee performance measures, semi-structured interviews and questionnaires. The grantee performance measures have all been cleared through the Discretionary Grants Information System (DGIS) OMB number 0915-0298. Examples of the performance measures that will be obtained for each grant program are listed below, followed by descriptions of the data collection instruments for which OMB approval is being sought.

Training Programs (LEND and DBP)

DGIS Performance Measure 39 (OMB # 0915-0298): The percent of participants in MCHB long-term training programs who are from underrepresented groups. Data for this performance measure will be obtained from the LEND and DBP grantees that received CAA funding.

LEND Semi-structured interview protocol (Attachment B):

LEND Directors and/or LEND program staff will be asked to answer questions about their CAA grant-funded activities pertaining to the following areas: training professionals to use valid and reliable screening and diagnostic tools for ASD and other DD; reducing barriers to screening and diagnosis of ASD and other DD; increasing awareness of ASD and other DD among trainees, and providers; and contributing to research on evidence-based practices. These data will be collected through telephone interviews.

DBP Semi-structured interview protocol (Attachment C):

DBP Directors will be asked to answer questions about their CAA grant-funded activities and accomplishments pertaining to each of the following areas: training professionals to use valid and reliable screening and diagnostic tools for ASD and other DD; reducing barriers to screening and diagnosis of ASD and other DD; increasing awareness of ASD and other DD; translating evidence-based research into practice; and training professionals to provide advocacy, counseling and coordination of care. These data will be collected through telephone interviews.

Research Programs

DGIS Performance Measure # 3 (OMB # 0915-0298): The percent of completed MCHB supported projects publishing findings in peer-reviewed journals.

Research Network semi-structured interview protocol (Attachment D):

Principal Investigators will be asked about their research activities pertaining to evidence-based interventions for ASD and other DD, their efforts to test and validate tools used for ASD interventions, their development of evidence-based treatment guidelines and their efforts to disseminate their research findings, their evidence-based guidelines for treating ASD and other DD as well as information about validated intervention tools. Additional questions will focus on how the Research Network's work may be addressing barriers to service for underserved populations.

Research Network Questionnaire (Attachment E):

This form will collect information about the number of research proposals developed and funded by the network, the network's progress in validating intervention tools and developing evidence-based guidelines for their implementation, the methods used to disseminate information about ASD interventions and the outcomes of those dissemination efforts (e.g., number of training sessions, number of outreach sessions). This form will also

ask the Principal Investigators to describe any collaborations or partnerships they have formed with other agencies or entities, and their efforts to serve minority and underserved populations.

R40 Autism Intervention Research Program Questionnaire (Attachment F): This form will be used to collect information from the R40 programs that received two-year grants. Grantees will be asked to describe the primary focus of their data collection, including the target population and the study findings, along with information about any articles or publications that are being prepared, submitted, or that have been accepted for publication.

R40 Secondary Data Analysis Studies (SDAS) Program Questionnaire (Attachment G): The SDAS program grantees will be asked to briefly describe the secondary data they are using in their research, the study population and the main findings.

Improving State Systems of Care

DGIS Performance Measure #23 (OMB # 0915-0298): The degree to which grantees have assisted States in increasing the percentage of children who are screened early and continuously for special health care needs and linked to medical homes, appropriate follow-up, and early intervention.

State Systems of Care semi-structured interview protocol (Attachment H):

Grantees will be asked to describe: their efforts to build awareness of ASD and other DD among target populations and more specifically, their use of CDC Learn the Signs, Act Early materials; their efforts to address service barriers, including activities related to screening, medical homes, and referral systems; training initiatives; and activities related to infrastructure building.

Network Questionnaire (Attachment I):

This instrument will collect information about the partnerships that the State grantee has established with other organizations under the grant, as part of a Network Analysis. Each grantee will be asked to list each organizational partner and to describe the nature of their partnership (e.g., frequency of communication, collaboration).

This information collection request seeks approval for the four semi-structured interview protocols (Attachments A through D) and the four questionnaires (Attachments E through I). The semi-structured interviews will be conducted one time only, by telephone. The questionnaires will be collected once, via fax or email.

The interviews and questionnaires will gather information about the activities that each grant program has implemented with their CAAI funding during the three year grant period. More specifically, the questionnaires will collect information about particular products or accomplishments (e.g., papers accepted for publication, or formal partnerships established) whereas the interviews will capture more in-depth information about each grant program's activities, their challenges and successes, and any commonalities achieved across programs (e.g., collaborative efforts between LEND programs and State Systems of Care grantees). This

information will be used to identify the mechanisms the grant programs are using to meet the overall goal and objectives of the Combating Autism Act Initiative, authorized under the Combating Autism Act, and to assess their progress in implementing those mechanisms.

Who will use the information?

The information gathered through this data collection effort is needed to inform the DHHS' Inter-agency Report to Congress, which requires "a description of the progress made in implementing the provisions of the Combating Autism Act of 2006." (For full list of the legislative requirements, see Appendix A).

3. Use of Improved Information Technology

The data collection forms for which we are requesting approval will be collected electronically or by phone. The questionnaires to be submitted by the Research and the State Systems of Care programs will be submitted via email or fax, and all semi-structured interviews will be conducted by phone.

4. Efforts to Identify Duplication

There are no other HRSA/MCHB data collection activities that are measuring the progress of CAAI grantees in meeting the objectives of the Combating Autism Act. The information being collected is not available elsewhere and the data collection has not taken place previously.

5. Involvement of Small Entities

This activity does not impact small entities.

6. Consequences if Information Collected Less Frequently

The information will be collected one time only. If the data are not collected, HRSA and the DHHS will not have sufficient information to provide the mandated Report to Congress.

7. Consistency with the Guidelines in 5 CFR 1320.5(d)(2)

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

8. Consultation Outside of the Agency

The notice required by 5 CFR 1320.8(d) was published in the *Federal Register* on November 3, 2009, Volume 74, Number 211, page 56839-56840. The 30-day Federal Register notice published on May 4, 2010, Volume 75, Number 85, page 23772-23773. No comments were received.

In December 2008, we presented the logic models and research questions to a total of 8 grantees, (two per grant program) at the annual grantee meeting and requested their feedback. Following that meeting, we revised the research questions and asked the same individuals to comment on the revisions, with special attention to the clarity of the questions, the anticipated length of time it would take to answer them and ways we could reduce the response burden. The questions were finalized on the basis of their comments.

Contact information for three of the grantees that provided feedback are below:

LEND:

Nathan Blum, MD
The Children's Hospital of Philadelphia
34th Street and Civic Center Boulevard
Philadelphia, Pa. 19104
Phone: 215-590-7681

DBP:

Leonard Rappaport, MD
Children's Hospital, Boston
300 Longwood Avenue
Fegan-10
Boston MA 02115
Phone: 617-355-7030

Research Networks:

Connie Kasari
Graduate School of Education & Information Studies, UCLA
760 Westwood Plaza
Los Angeles, CA, 90025
Phone: 310 825 4321

9. Compensation of Respondents

Respondents will not be remunerated or compensated.

10. Assurance of Confidentiality

No personally identifiable information will be collected. Only program data will be collected, which is aggregate in nature.

11. Questions of a Sensitive Nature

There are no questions of a sensitive nature.

12. Estimates of Annualized Hour Burden

The burden estimates for respondents are shown in Table 1. We plan to interview the Principal Investigator or Project Director from each grant program, along with 5 additional staff members, for a total of 6 respondents per grant program. The questionnaires for the Research Programs and the State Systems of Care grant programs will be completed by each Principal Investigator/Project Director for these programs.

Wage rates were determined based on May 2008 national industry-specific occupational and wage estimates from the Bureau of Labor Statistics. For the Training and Research Program grantees, the wage rate reflects the national estimate for a Medical Scientist. For the Improving Systems of Care Programs, the wage rate is based on national estimates for an Administrative Service manager.

Table 1. Estimated Hour and Cost Burden of the Data Collection

Grant Program	No. of Respondents	No. of Responses per Respondent	Total Responses	Hours per Response	Total Hour Burden	Wage Rate	Total Hour Cost
LEND	39	6	234	.75	175.5	39.36	\$6907.68
DBP	6	6	36	.75	27	39.36	\$1062.72
State Implementation Program	9	6	54	.75	40.5	\$38.22	\$1547.91
Research Program	9	6	54	.75	40.5	\$39.36	\$1594.08
Total	63		378		283.5		\$11,112.39

13. Estimates of Annualized Cost Burden to Respondents

There are no capital or startup costs associated with data collection.

14. Estimates of Annualized Cost to the Government

The total cost to the Government include the cost of all data collection and analysis activities. The total estimated cost is approximately \$1,100,000 for the three year contract.

15. Changes in Burden

This is a new collection activity.

16. Time Schedule, Publication, and Reporting Plans

All data must be collected by March 2011 to ensure inclusion in the 2011 Report to Congress. The proposed schedule for the information collection is show below in Table 2.

Table 2. Estimated Time Schedule for Data Collection, Analysis and Publication

Activity	Time Schedule
Develop data collection tools	June, 2009
Receive OMB approval	Estimated July 2010
Interviews scheduled and conducted	October, 2010-March, 2011
Questionnaires administered and collected <ul style="list-style-type: none"> • Research Network Questionnaire • R40 AIR Program Questionnaire • R40 SDAS Questionnaire • Network Questionnaire 	January 2011
Data Analysis	April, 2011
Final Report to HRSA	June 30, 2011
Final Report to Congress	August 30, 2011

Final reports will be submitted to HRSA/MCHB in June 2011. Additionally, the results will be published in a Report to Congress in August 2011.

17. Exception for Display of Expiration Date

All data collection materials will display the OMB expiration date.

18. Certifications

HRSA certifies that the collection of information encompassed by this request complies with 5 CFR 1320.9 and the related provision of 5 CFR 1320.8(b)(3).

ATTACHMENTS TO SUPPORTING STATEMENT

- Attachment A: Public Law 109-416§42 U.S.C.§1
- Attachment B: LEND Semi-structured interview protocol
- Attachment C: DBP Semi-structured interview protocol
- Attachment D: Research Network Semi-structured interview protocol
- Attachment E: Research Network Questionnaire
- Attachment F: R40 Autism Intervention Research Program Questionnaire
- Attachment G: R40 Secondary Data Analysis Studies (SDAS) Program Questionnaire
- Attachment H: State Implementation Grant Program semi-structured interview protocol
- Attachment I: Network Questionnaire

