

SUPPORTING STATEMENT

**CMS-10362
OMB 0938-NEW**

Autism Spectrum Disorders (ASD): State of the States Services and
Supports for People with ASD

Centers for Medicare & Medicaid Services (CMS)

A. Background

Federal data suggest that an estimated one of every 110 children has Autism Spectrum Disorders (ASD).¹ The high prevalence of ASD and the work of autism advocates have raised awareness among Federal and State policymakers regarding the importance of effective services specific to the needs of this population. As the number of people identified with ASD has grown, so has demand for services and supports tailored to their specific needs. States have an important public policy role in serving people with ASD. States operate disparate systems that provide publicly funded services for people with developmental disabilities including ASD (e.g., Medicaid, Education, Vocational Rehabilitation). States also enact policy decisions that affect the privately funded support that people with ASD receive, such as requiring health insurers to cover certain services that can improve the function of some children with ASD.

Given the key role States play, measuring unique and disparate State activity is a critical step in encouraging improved policies and supports. Currently there is no comprehensive, nationwide summary of State services for people with ASD and policies related to people with ASD. In the most thorough attempt released to date, Easter Seals has produced state-specific profiles regarding autism that include special education data and information regarding insurance mandates and other legislative activities. However, these profiles do not present data from public programs other than special education, and do not consistently capture supports in programs that are not specifically aimed at people with ASD (such as programs that serve people with many types of developmental disabilities, including ASD).²

Note that additional follow-up after the data collection is completed is not anticipated.

Centers for Disease Control “Autism Overview,” accessed online August 2009 at ¹
<http://www.cdc.gov/ncbddd/autism>

Easter Seals “2009 State Autism Profiles” February 2009, accessed online August 2009 at ²
http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles

B. Justification

1. Need and Legal Basis

The Centers for Medicare & Medicaid Services (CMS) has contracted with L&M Policy Research (L&M) and its partners, Thomson Reuters, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to address the growing need among Federal and State policymakers and stakeholders for accurate and comprehensive information regarding available services and supports for people with ASD.

In order to guide the data collection in all 50 states and the District of Columbia, the research team has drafted a semi-structured interview guide that focuses on current services for people with ASD, policies for people with ASD and funding and utilization of public supports for people with ASD (see Attachment A). The team proposes collecting data from following State-level offices and departments, such as:

- Corrections
- Developmental Disability Services
- Early Intervention
- Education
- Insurance Commissioner
- Medicaid
- Mental Health
- Public Health
- Employment – Vocational Rehabilitation

The L&M team's partners, Thomson Reuters and NASDDDS, have established contacts within each state for this project. The initial approach to the data collection will be to reach out to the key contacts identified, in consultation with the CMS Contracting Officer's Technical Representative (COTR), by Thomson Reuters and NASDDDS within each agency. We may also rely on the research team technical advisory panel (TAP) participants to provide us with key contacts. A two-person team will conduct the interviews. All interviews will be audio taped to assist with note taking. The team anticipates that based on the nine different agencies listed above, a total of up to 459 respondents may be reached.

A qualitative data collection tool that includes questions for individuals about knowledge of National and Federal Data Sources (quantitative methodology) will be used to capture the information about services and supports for people with ASD (see Attachment A).

We propose conducting these interviews beginning in June 2011 in order to meet project deadlines and report to the Interagency Autism Coordinating Committee (IACC), whose 2010 Strategic Plan has given priority to understanding services and supports for people with ASD (see Attachment B).

2. Information Users

The information that is collected in the interviews will be used to communicate additional information about services available to people with ASD and the public policy issues that affect people with ASD to key stakeholder audiences, including those who follow the activities of the Interagency Autism Coordinating Committee (IACC). The IACC publishes a Strategic Plan for ASD research each year that is much anticipated by ASD stakeholders: <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>

The format of this report will include data tables from various state programs and narrative about the data being presented based on the interviews with state agency staff. We propose interviewing multiple staff in each state because several state agencies have an impact on services and supports for people with ASD.

Each participant will take part in one interview session. Once the interview data are collected, they will be analyzed. A process of qualitative analysis will be used to identify common themes across multiple topic areas. Notes and audio recordings will be reviewed to insure that no biases were introduced (e.g., from leading questions) and that alternate interpretations of the data are considered.

3. Use of Improved Information Technology

This data collection will utilize digital recording technology to collect, store, and manage the interview data. Participants will respond verbally to guiding questions.

4. Efforts to Identify Duplication

The Strategic Plan set forth by the IACC review of the literature shows differences in policies, resources and organizations for providing supports and services to people with ASD. In addition, the IACC reports people with ASD and their families require assistance navigating complex service systems to find the most appropriate services and supports and that information about these publicly funded services and supports are lacking.

Currently, there is no comprehensive, nationwide summary of State services for people with ASD and policies related to people with ASD. In the most thorough attempt released to date, Easter Seals has produced state-specific profiles regarding autism that include special education data and information regarding insurance mandates and other legislative activities. However, these profiles do not present data from public programs other than special education, and do not consistently capture supports in programs that are not specifically targeted to people with ASD (such as programs that serve people with many types of developmental disabilities, including ASD).³

While prior research provides general information regarding the differences in state policies to provide supports and services, this additional research is needed to detail the services and supports provided by each state.

Easter Seals "2009 State Autism Profiles" February 2009, accessed online August 2009 at ³
http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles

5. Involvement of Small Entities

This data collection does not involve or impact small businesses or other small entities.

6. Consequences if Information Collected Less Frequently

This is a one-time data collection.

7. Special Circumstances

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

8. Federal Register Notice and Outside Consultations

8.a. Federal Register Notice

The 60-day Federal Register notice published on March 25, 2011 (76 FR 16790). No comments were received.

CMS has committed itself to conducting an assessment of existing programs and supports for people with ASD. In addition, the Agency intends to present findings to the Interagency Autism Coordinating Committee (IACC), whose 2010 Strategic Plan has given priority to understanding services and supports for people with ASD.

8.b. Outside Consultations

A Technical Advisory Panel (TAP) has been convened by CMS's contractor as research and advisory partners, providing ongoing advice and direction throughout the course of the project. The role of the TAP has been and will continue to be to provide input into key research tasks. This advisory panel consists of representatives from academic institutions and State agency offices that understand the current landscape of services and supports for people with ASD.

9. Payments/Gifts to Respondents

No payments or gifts will be made to respondents.

10. Assurance of Confidentiality

Individuals and organizations will be assured of the confidentiality of their replies under Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). They will be told the purposes for which the information is collected and that, in accordance with this statute, any identifiable information about them will not be used or disclosed for any other purpose.

Individuals and organizations contacted will be further assured of the confidentiality of their replies under 42 U.S.C. 1306, and 20 CFR 401 and 4225 U.S.C.552a (Privacy Act of 1974). In instances where respondent identity is needed, the information collection will fully comply with all respects of the Privacy Act.

Only the principal investigator and research staff necessary to conduct research will have access to the data. All electronic files are password and encryption protected. All activities

stated in this project will be performed in concordance with the Health Insurance Portability and Accountability Act (HIPPA) Privacy Rule, 45 CFR Parts 160 and 164. Informed consent will be obtained from all who participate in the semi-structured interviews.

11. Questions of a Sensitive Nature

Interviews will be conducted by an individual interviewer and will focus on soliciting insights into the availability of services and supports to people with ASD. There are no questions in the data collection tool concerning sexuality, religious beliefs or other matters. If however, interviewees who wish to review their responses prior to reporting the information will be given the opportunity to do so.

12. Estimates of Annualized Burden Hours and Costs

Exhibit 1 shows the estimated annualized burden hours for the respondent's time to participate in this project. The pre-scheduling interview call and/or email will be experienced by all participants and is expected to take approximately 15 minutes to complete. Discussions will last about 1.5 hours. The total burden for each participant is estimated to be 1.75 hours.

Exhibit 1 also shows the estimated annualized cost burden for the respondent's time to participate in the project. Because we anticipate that about 25 percent of interviews will include two respondents as the respondent originally contacted may invite a colleague to join the call, the estimated cost burden is multiplied by 1.25. The total hours is estimated to be 803.25 (459 responses x 1.74 hr/response) and the total cost is estimated to be \$ 37,893 (\$37.74/hr x 1.75 hr x 1.25 x 459 responses).

Exhibit 1. Estimated annualized cost burden

Data Collection Mode	Number of respondents	Total burden hours	Average hourly wage rate*	Adjustment for Possible Additional Respondent	Total cost burden
Semi-structured interviews with key state agency or program staff	459 (Representative(s) from 9 key agencies across 50 states and DC)	1.75	\$37.74	1.25	\$37,893

* Key state agency/program staff average hourly wage based on the mean hourly wage estimate of all state government management occupations from the May 2009 National Industry-Specific Occupational Employment and Wage Estimates, U.S. Department of Labor, Bureau of Labor Statistics.

13. Estimates of Annualized Respondent Capital and Maintenance Costs

There are no direct costs to respondents other than their time to participate in the study.

14. Estimates of Annualized Cost to the Government

Exhibit 2 shows the estimated cost to the Federal government for this 18-month project – not anticipating the need for additional follow-up under the current contract. The total cost is \$349,927 – work/costs that are all associated with the purchasing services of a contractor. This amount includes all direct and indirect costs of the design, data collection, analysis (non-statistical), and reporting phase of the study.

Exhibit 2. Estimated Cost

Cost Component	Total Estimated Cost
Project Development	\$41,076
Data Collection Activities/Data Processing and Analysis	\$151,402
Reporting of Results	\$100,499
Project Management	\$56,951
Total	\$349,927

15. Changes in Hour Burden

This is a new collection of information.

16. Time Schedule, Publication and Analysis, and Public Reporting Plans

No publications are planned under this contract. Exhibit 3 details the project's time schedule.

Exhibit 3. Timeline of Key Events following Receipt of OMB Clearance

Key Events	Timeline
Receive OMB clearance	To be determined
Conduct interviews	Immediately after receipt of OMB clearance, through October 2011
Analysis and generation of preliminary report.	DRAFT: December 2011 FINAL: January 2012
Analysis and generation of final report.	DRAFT: January 2012
State of the State Profile	January 2012

17. Exemption for Display of Expiration Date

CMS does not seek this exemption.

Attachments:

Attachment A – Data Collection Tool

Attachment B – Interagency Autism Coordinating Committee (IACC) 2010 Strategic Plan