

State of the States in Services and Supports for Autism Spectrum Disorders (ASD)

Data Collection and Verification Tool *CMS-10362, OMB 0938-NEW*

Pre-Interview Scheduling

Hello my name is _____ and I'm calling from a healthcare research firm located in Washington, D.C., that is conducting a study on behalf of the Centers for Medicare & Medicaid Services (CMS). 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 need among policymakers, key stakeholders as well as families and individuals with Autism Spectrum Disorder (ASD) for information regarding services and supports for people with ASD. Although we have obtained and reviewed data about various services and supports by State, we would like to better understand about how your agency [or office] is helping people with ASD and also have some questions about some of the information we've collected.

Would you be able to set-up an interview time today? We will send you a letter and project description for your reference. Thank you for your time.

Introduction

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 need among policymakers, key stakeholders as well as families and individuals with Autism Spectrum Disorder (ASD) for information regarding services and supports for people with ASD. The purpose of this tool is to assist the research team in capturing Federal and state level information about available supports and services and to communicate through the research team's structured interviews additional information about services available to people with ASD and the public policy issues that affect people with ASD to key stakeholder audiences. We are interviewing multiple staff at each state, because several state agencies have an impact on supports for people with ASD.

Warm-up

- Please tell me a bit about yourself, your job title and your role at [name of State agency/office.]

{Interviewer will record the key contact's name and State agency/program, email, and phone number}

Name of key contact(s) and State Agency/Program:

Key contact(s) Email:

Key contact(s) phone number:

PRA Disclosure Statement

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-NEW. The time required to complete this information collection is estimated to average (1.75 hours per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

Qualitative Questions for Agencies that Manage Services or Work Directly with People with ASD¹

Identification of Persons with ASD and eligibility for services and supports

- Is there a standard definition established in a rule or written statute that defines ASD for your agency or program? If yes, where could we find that definition?
- Does an ASD diagnosis by itself determine eligibility for services?
 Yes
 No [Please describe other diagnoses that are required, such as an intellectual disability].
- Do different services and supports that your agency or program provides have the same eligibility criteria?
 Yes [Please Describe.]
 No

¹ These agencies include Medicaid, developmental disabilities services, vocational rehabilitation, education, early intervention, foster care, juvenile justice, and corrections.

- **[FOR ALL EXCEPT CORRECTIONS AND VOCATIONAL REHABILITATION]**
How does your agency or program promote early identification and diagnosis of people with ASD?
- How does your agency or program promote identification and diagnosis of people with ASD across the lifespan?
- Are you able to identify or track those individuals with ASD who are receiving services and supports by disability type or diagnosis?

Yes
 No

Services and Support for People with ASD

- Does your agency furnish specific programs or services targeted to persons with ASD?
- Tell us about the specific services and supports your state agency or program provides to people with ASD. PROBE: What services and supports does your state agency or program provide to family members or caregivers of people with ASD (leave of absence/respice)?
 - o What are the specific behavioral, medical and cognitive interventions that are covered?
 - o Other?
- When people with Autism Spectrum Disorders (ASD) come to receive services from your program or agency, how do you know whether or not and/or where these individuals received services previously? PROBE: Are data exchanged between state and local service agencies, so that each agency knows the person's service history, such as what has worked and not worked (subject to privacy requirements)?
- Does private insurance cover services for people with ASD? If so, how does private insurance coverage, or the lack thereof, influence the services and supports [your state agency or program] provides?
- How do individuals find out about services and supports that might be available to them? Are there different routes or points of entry that individuals may follow to get information about services and supports available from your agency?
- How does your agency or program attempt to reach populations less likely to be diagnosed with ASD, such as ethnic and racial minorities and low-income individuals?

Interagency Transition and Coordination of Services and Supports

- How do state and local agencies collaborate in their efforts to support people with ASD? PROBE: Please give us one or two examples you think should be shared with others? What would you do to improve collaboration in your state?

- How does transition and/or coordination between services happen for people with Autism Spectrum Disorders for each of the following situations:
 - o Early intervention to school programs,
 - o Interventions in school and intervention in the home,
 - o School to adult services,
 - o Institution to community,
 - o Day programs to employment
 - o Services provided from one agency to services provided by a different agency
 - o Privately funded services to publicly funded services

Training

- Does your agency or program require direct support workers working with people with autism to receive specific training for this population? If yes, which entity is responsible for providing such trainings? PROBE: Which personnel are required to take these trainings? What topics are covered? What type(s) of guidelines are provided?
- What other training opportunities are available, if any, to support workers that specifically serve people with ASD?

General

- Are leisure and recreational opportunities available to accommodate people with ASD in your state?
 - ___ Yes [Please describe.]
 - ___ No
 - o Do you track leisure and recreational activities provided at a county or local level within the state?
- Does your state agency or program have any plans underway to develop new or expanded supports and services in the next two to five years?

Qualitative Questions for State Insurance Agency

- Does your state have a mandate requiring private insurers to pay for treatment of ASD?
 - o If so, what services and supports are included in your state's insurance (or pending) mandate? PROBE: What particular types of services, such as educational and vocational services, are included? What particular settings for services, such as clinic or in-home settings, are defined?

- o What types of limits, if any, are included in your state's insurance (or pending) mandate? PROBE: Age limit? Dollar limit? IF APPLICABLE: Per year? Per lifetime? Length of limit? Any others?
- Do you think that the state or federal mental health parity legislation affected private insurance coverage for treatment of ASD? If so, how?
- Do you anticipate federal health care reform legislation will change private insurance coverage for treatment of ASD? If so, how?

Qualitative Questions for State Public Housing Agency

- What supportive housing options are available for people with disabilities, including ASD?
- Do supportive housing options for people with ASD differ from options for other people with disabilities? If so, how?
- How are people in subsidized housing connected to service programs such as Medicaid or developmental disabilities services?

Quantitative Questions for individuals with Knowledge of Select Federal Data Sources

- For each data source, we note data limitations, caveats and other considerations that users should keep in mind when reviewing the information. Please tell us any concerns you have regarding data quality and any additional considerations that state policy makers, advocates, and providers should keep in mind when using the data from your state.
- Data sources include:
 - o Data Accountability Center "Part B Child Count: 2008" December 18, 2009. Available online at <https://www.ideadata.org/PartBChildCount.asp>.
 - o U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS), OMB #1820-0517: "Part B, Individuals with Disabilities Education Act, Implementation of FAPE Requirements" 2007. Data updated July 15, 2008. Available online at https://www.ideadata.org/arc_toc9.asp.
 - o Data Accountability Center "Table C-13. Number and percentage of infants and toddlers receiving early intervention services under IDEA, Part C, by age and state: Fall 2008" August 2009. Available online at <https://www.ideadata.org/PartCChildCount.asp>.
 - o Thomson Reuters analysis of data from the RSA – 911: Case Summary Report provided by the U.S. Department of Education, Rehabilitation Services Administration
 - o Thomson Reuters analysis of data from the Medicaid Analytic eXtract (MAX)
 - o Centers for Medicare & Medicaid Services "Medicaid Waivers and Demonstrations List" Available online at <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp>
 - o Eiken, Steve and Burwell, Brian "Medicaid HCBS Waiver Expenditures: FY 2003 through FY 2008" Thomson Reuters: November 30, 2009

- o U.S. Social Security Administration
- o Source: K. Charlie Lakin, Sheryl Larson, Pat Salmi, and Naomi Scott
Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008 2009

Quantitative Questions for Agencies that Serve People with Developmental Disabilities, to Obtain Data for ASD Where Federal Data are not Available

- Does your agency collect data regarding the number of people with ASD in state-operated ICF/MR, private ICF/MR, and/or psychiatric facilities?
- If yes, please complete the tables below to the extent possible:

Number of People with ASD Living in Institutional Settings, June 30, 2008

State Operated ICF/MR	Private ICF/MR	State Psychiatric Facilities

- Does the state collect data regarding the number of people with ASD receiving services in intermediate care facilities for people with mental retardation (ICF/MR) and Medicaid HCBS Waiver services by setting size?
- If yes, please complete the tables below to the extent possible:

Number of People with ASD Receiving Medicaid ICF/MR Services by Size of Setting, June 30, 2008

	4 – 6 Beds	7 – 15 Beds	16 or More Beds
Adults (age 21+)			
Children (age 0 – 20)			

Number of People with ASD Receiving Medicaid HCBS Waiver Services by Size of Setting, June 30, 2008

	1 – 3 Beds	4 – 6 Beds	7 – 15 Beds	16 or More Beds
Adults (age 21+)				
Children (age 0 – 20)				

- Does the state collect data regarding the number of people with ASD receiving services in Medicaid home and community-based services (HCBS) waivers by type of housing (e.g., congregate care, foster care or shared living, own home, or family home)?
- If yes, please complete the tables below to the extent possible:

Number of People with ASD Receiving Medicaid HCBS Waiver Services by Type of Setting, June 30, 2008

	Congregate Care	Foster Care or Shared Living	Own Home	Family Home	Total
Adults (age 21+)					
Children (age 0 – 20)					

- Does the state collect data regarding the number of people with ASD receiving day supports by type of service (e.g., day habilitation, prevocational services, and supported employment)?
- If yes, please complete the tables below to the extent possible:

Number of People with ASD Receiving Medicaid ICF/MR or HCBS Waiver Services by Number of People with Disabilities Residing in the Setting, June 30, 2008

Day Habilitation	Prevocational Services	Supported Employment	Total
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- Does the state collect offer non-Medicaid services (i.e., using only state or a combination of state and local funds) for people with ASD and/or other developmental disabilities?
- If yes, please complete the tables below to the extent possible. For each non-Medicaid program, list the services available and the number of people with ASD (or total) served in the most recent year for which data are available.

Services for People with ASD in State or Locally Funded Programs

Services (e.g., respite, grants, supported employment, day habilitation)	People with ASD Served As of June 30, 2008

Quantitative Questions for Other Agencies that Manage Services or Work Directly with People with ASD, Where Federal Data for ASD are not Available²

- Does your agency collect data regarding the number of people receiving services with ASD and/or other cognitive or behavioral conditions such as intellectual disability or mental illness?

² These agencies include early intervention, foster care, juvenile justice, and corrections.

- If yes, please complete the tables below to the extent possible:

Table 1: Number of Adults with ASD or a Co-Occurring Condition, 2008

	In Institutional Settings ³	In Community Settings ⁴
Autism Spectrum Disorder (ASD)		
Intellectual Disability (ID)		
Serious Mental Illness (MI)		
Co-occurring ASD and ID		
Co-occurring ASD and MI		
Co-occurring ASD, ID, and MI		

Table 2: Number of Adults with ASD or a Co-Occurring Condition, 2008

	In Institutional Settings ³	In Community Settings ⁴
Autism Spectrum Disorder (ASD)		
Intellectual Disability (ID)		
Serious Mental Illness (MI)		
Co-occurring ASD and ID		
Co-occurring ASD and MI		
Co-occurring ASD, ID, and MI		

Closing

Before we end, I'd like to give you a chance to share any additional thoughts or comments. Is there anything else you would like to add that you didn't have a chance to say during our discussion today?

Thank you very much for participating in this discussion today. We appreciate your time and willingness to speak with us.

³ Institutional settings include state-operated psychiatric hospitals, prisons, and juvenile justice residential facilities, and group homes for children in the foster care system.

⁴ Community settings include the person's own home, a home with family members, a foster care family home, and (for the corrections and juvenile justice systems) probation or parole.