



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

Presentation to the Interagency Autism Coordinating
Committee (IACC)

April 11, 2011

Project Purpose

- To address the growing need among federal and state policymakers and stakeholders for accurate and comprehensive state-level information about available services and supports for people with ASD

Overall Research Goal

- Collect and compile qualitative and quantitative data on existing programs and policies for the following topics subject to data availability:
 - ▶ Corrections
 - ▶ Developmental Disability Services
 - ▶ Early Intervention
 - ▶ Education
 - ▶ Insurance
 - ▶ Medicaid
 - ▶ Mental Health
 - ▶ Public Health
 - ▶ Vocational Rehabilitation

Overview of Presentation

- Summary of 2009-2010 Progress
- Quantitative Data Findings
- Open Research Questions

2009-2010 Research Activities

- Convened Technical Advisory Panel (TAP)
- Developed Data Collection Instruments
- Discussions with Autism Organizations
- Submitted PRA/OMB Package
 - ▶ 60-day Public Comment Period began on March 25, 2011

TAP Members

- Tec Chapman, former Deputy Director, Division of MRDD, Missouri Department of Mental Health
- Peter Gerhardt, Organization for Autism Research
- George Jesien, Association of University Centers on Disabilities
- K. Charlie Lakin, Project Director, Research and Training Center on Community Living
- Cathy Pratt, Director of the Indiana Resource Center for Autism at the Indiana Institute on Disability/Indiana University
- Denis Rozell, Easter Seals
- Paul Shattuck, Washington University Saint Louis – George Warren Brown School of Social Work
- Nina Wall-Cote, Director of the Bureau of Autism Services in the Pennsylvania Department of Public Welfare

Quantitative Data Summary

- The research team collected data from public programs that identify beneficiaries with ASD. Programs that do not identify people by diagnosis were not included.
- This portion of the presentation includes:
 - ▶ Data regarding the number of people with ASD served in each program
 - ▶ Notable findings that may be interest to the IACC
 - ▶ Explanatory information regarding state variation and limitations in data availability

Number of People with ASD (CY 2008 unless otherwise noted)

- Special Education (IDEA Part B): 335,963 as of October 1, 2008
- Medicaid: 144,811 in CY 2007
- Supplemental Security Income (SSI): 135,934
- Social Security Disability Insurance (SSDI): 30,296
- Vocational Rehabilitation: 5,906

Notable Findings

- ASD was less likely to be reported for Hispanic, African-American, and American Indian and Alaska Native individuals
- More than half of adults with ASD receiving Medicaid also received Medicare (dually eligible individuals)
- 82% of Medicaid participants with ASD received at least one prescription drug
- 33% of participants received anti-psychotic medications

State Variation in People Served

- For each program, the percentage of beneficiaries with ASD varied at least 5-fold
- States with a high percentage of people served with ASD in one program were more likely to report a high percentage in other programs
- Within each program, states with a low percentage of beneficiaries with ASD were more likely to report a high percentage of beneficiaries with an intellectual disability (ID)

Data Availability Limitations

- Data in the report likely under-represent people with ASD for several reasons, including:
 - ▶ Data for people with ASD and another condition may be reported under the other condition
 - ▶ States have flexibility in providing guidance for IDEA reporting by ASD and other categories
 - ▶ The Medicaid data source does not include all services

Open Research Questions

- What are the top three public policy priorities that need to be addressed by Federal and State agencies to improve the delivery of needed services and supports to people with ASD and their families?
- Within the current context of declining state revenues, what recommendations do you have to improve service and support outcomes for people with ASD who may be receiving supports for the first time?
- What data would be most useful in a State of the States report?

Moving Forward

- Please submit any comments and responses to the open research questions to:
 - ▶ autism@Impolicyresearch.com

Thank you for your time and interest.