

# Autism, Medicaid, and Early Intervention

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Group**

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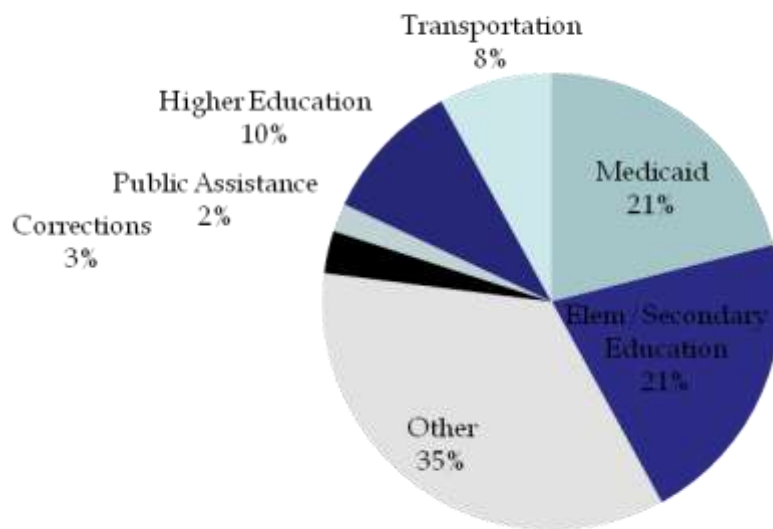
OSEP National Early Childhood Conference

## Today's Fiscal Environment

- State finances declined in 2009, expected to continue through 2012
- 43 States reduced approved budgets in 2009, compared to three States in 2007, and 13 States in 2008
- Historically, State economic recovery following a recession takes several years

# State General Fund Spending

Total State Spending (estimated) 2009



# Medicaid and the Children's Health Insurance Program (CHIP)

- Insure about 1/3 of all children in the U.S., most from low income families
- Children represent about half all Medicaid beneficiaries
- 29M in Medicaid, 8M in CHIP
- A child is not eligible for Medicaid may be eligible for CHIP, an optional Federal allotment program with fixed funding
- Medicaid and CHIP represent the safety net for American children during hard economic times

# How is Medicaid Faring?

- Medicaid enrollment has increased nearly 8 percent nationally in 2009
- American Recovery and Reinvestment Act (ARRA) funding has preserved eligibility and slowed cuts
- Most States have made changes to their Medicaid programs to address funding shortfalls
- Long-term services and supports (LTSS) expansion has stalled
- States continue to use technology, care coordination, managed care delivery systems, and quality initiatives to manage costs

# Medicaid Support of Education Services

- **1965.** The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Service
- **1975.** The Education for All Handicapped Children Act (now IDEA 2004)
- **1988.** Section 1903(c) of the Social Security Act (Act) – Medicaid payment for services included in a child's IFSP (or IEP)

# Medicaid Rules

- There is no service category in Medicaid entitled “school-based services,” or “early intervention services,” or “IFSP” services
- Services must be included in Section 1905(a) of the Act
- Early intervention services covered by Medicaid must be defined in terms of Medicaid’s statutory and regulatory requirements, including provider qualifications
- The IFSP may only serve to determine medical necessity if members of the team are qualified to make the decision in accordance with their scope of practice
- IFSPs may contain non-Medicaid services

# Section 1905(a) Regular State Plan Services

## MANDATORY

- Physician services
- Laboratory & x-ray
- Inpatient hospital
- Outpatient hospital
- EPSDT
- Family planning
- Rural and federally-qualified health centers
- Nurse-midwife services
- Nursing Facility services
- Home health

## OPTIONAL

- Dental services
- Therapies -  
PT/OT/Speech/Audiology
- Prosthetic devices, glasses
- Case management
- Clinic services
- Personal care, self-directed personal care
- Hospice
- ICFs/MR
- PRTF (psychiatric) for children <21
- Rehabilitative services
- Home & Community Based Services for the Elderly and Disabled
- Program for All-Inclusive Care for the Elderly (PACE)

## Where Are People with Autism Spectrum Disorders (ASD) in Medicaid/CHIP?

- It is difficult to extract meaningful data about people with ASDs, even from the Medicaid Statistical Information System (MSIS)
- CMS has some evidence indicating more male Medicaid beneficiaries than females are diagnosed with an ASD (ICD-9 code)
- About 6.2% of Medicaid home and community-based services (HCBS) recipients in a 2006 report, using Medicaid data from six States, were identified with an ASD
- States have more information than CMS
- Many adults with ASDs remain undiagnosed, or misdiagnosed

# Medicaid Section 1915(c) HCBS Waivers

- Permit States to provide HCBS to people who would otherwise require Nursing Facility (NF), Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) or hospital Level of Care (LoC)
- Are the major tool for meeting rising demand for LTSS
- Serve diverse target groups, including children with ASD
- Include gradual addition of participant-direction of services
- Cannot duplicate services included in a child's IFSP

# HCBS Waivers for People with ASD

- Indiana – approved 1990 – serves about 600 people
- Maryland – approved 2000 – serves about 900 children
- Wisconsin – approved 2003, serves about 3,000 people
- Colorado – approved 2005, serves about 160 children
- South Carolina – approved 2006, serves about 600 children
- Maine – approved 2007 – serves about 2,000 people
- Massachusetts – approved 2007, serves about 80 children
- Kansas – approved 2008, serves about 50 children
- Pennsylvania – approved 2008, serves about 200 adults
- Montana – approved 2008, serves about 50 children
- Missouri – approved 2009, will serve about 175 children
  
- \*Pennsylvania also operates a managed care program for 200 adults with ASD

# CMS' Autism Task Orders

- Environmental Scan – ASD Services and Supports
- Focused Review of Nine States
- Model Services and Supports for Children and Adults with ASD
- “State of the States” for People with ASD

# Agencies in the Department of Health & Human Services (HHS) Involved in ASD Issues

- Administration for Children and Families (ACF)
- Agency for Health Care Research and Quality (ARHQ)
- Centers for Medicare and Medicaid Services (CMS)
- Centers for Disease Control and Prevention (CDC)
- Health Resources and Services Administration (HRSA)
- HHS Office on Disability
- Substance Abuse and Mental Health Services Administration (SAMHSA)
- National Institutes of Health (NIH):
  - National Institute of Mental Health
  - National Institute of Child Health and Human Development
  - National Institute of Neurological Disorders and Stroke
  - National Institute on Deafness and Other Communication Disorders
  - National Institute of Environmental Health Sciences

# The Interagency Autism Coordinating Committee

- Administration for Children and Families (ACF)
- Centers for Medicare and Medicaid Services (CMS)
- Centers for Disease Control and Prevention (CDC)
- Health Resources & Services Administration (HRSA)
- National Institutes of Health (NIH)
- HHS Office on Disability
- Substance Abuse & Mental Health Services Administration (SAMHSA)
- Department of Education (ED)
- Autism Society of America
- Adult with ASD
- Coalition for Safe Minds
- Autism Science Foundation
- Parent of a Child with an ASD

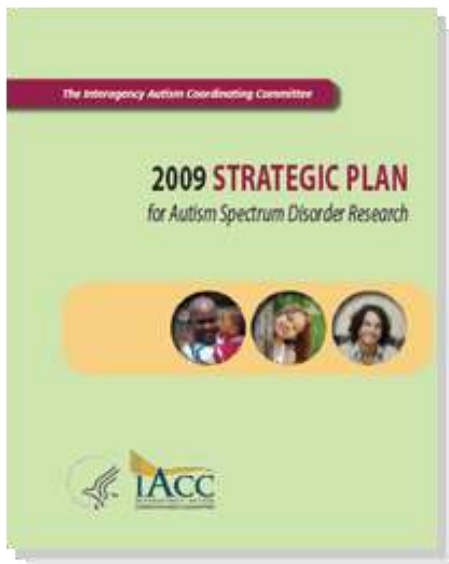


# What Does the IACC Do for People with ASD?

- Develops, annually updates, and submits to Congress a strategic plan for ASD research
- Compiles an annual summary of ASD research advances
- Makes recommendations to the HHS Secretary for changes to ASD activities, and solicits public participation

# IACC Activities

- Facilities exchange among members
- Coordinates ASD-related programs
- Helps increase public understanding of member agencies' ASD activities
- IACC Website: [www.iacc.hhs.gov](http://www.iacc.hhs.gov)
- IACC Webcast archive:  
<http://videocase.nih.gov/default.asp>
- IACC e-mail subscription:  
[IACCPublicInquires@mail.nih.gov](mailto:IACCPublicInquires@mail.nih.gov)
- IACC Tweets: [www.twitter.com/IACC](http://www.twitter.com/IACC) Autism



- When Should I Be Concerned?
- How Can I Understand What Is Happening?
- What Caused This To Happen and Can It Be Prevented?
- Which Treatments and Interventions Will Help?
- Where Can I turn for Services?
- What Does the Future Hold?



# IACC Presentation October, 2009 – “The evidence-base for ABA and other psychosocial interventions”

## Tony Charman –Centre for Research in Autism and Education

### What Do We Know?

- There is emerging and increasing evidence for social-communication and behavioral approaches
- Early intervention should focus on the core deficits/needs:
  - Managing behavior
  - Enhancing Social Interaction
  - Enhancing (non-verbal communication skills)
- Parent training approaches educate and empower at a time when they are seeking guidance
- However, effectiveness is very variable in every trial
- Some children make great gains, others less so

### What Do We Need?

- A fair-minded approach to evaluating the evidence
- Better dissemination of the existing evidence base
- More large-scale randomized controlled trials
- Identification of the effective elements of interventions
- Evidence of how interventions might work differently in different settings
  - Training parents, working in preschool
- Recognition that one size does not fit all
  - Can we really identify “what works for whom?”
- Improved access to appropriately trained professionals and services
  - As the evidence builds, so will the demand

# The Community Living Initiative

- HHS Office on Disability's (OD) dynamic partnership between Federal agencies
- 2009 marked the 10<sup>th</sup> anniversary of the Supreme Court's *Olmstead v. L.C.* Decision
- The Secretary formed a Coordinating Council, and the OD has established workgroups (Services, Housing, Workforce, Communications, Data/Quality)
- Stakeholder dialogues will be held across the U.S. to help craft the Administration's agenda to improve Federal programs and support the efforts of State and local governments to include people with disabilities fully in their communities

# Technical Assistance for ASD

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