Autism Spectrum Disorders Services in the United States

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A Brief History of Services

- Mid 1800s-1940s – Large, mostly rural custodial institutions for people with disabilities emerge and grow
- 1920s – every State has at least one large institution
- 1950s – Supreme Court orders changes to education system that establish rights for children with disabilities
- 1960s – Awareness that institutional conditions were dehumanizing and warehouse-like, inception of Medicaid, parents form advocacy groups

1970s

- Institutional reform, Congress creates Intermediate Care Facilities for the Mentally Retarded (ICFs/MR)
- Community-based services alternatives emerge
- Congress passes the Education for All Handicapped Children Act (EHA)
- Employment opportunities grow

1980s to the Present

- Institutional closings continue and accelerate
- Family support receives recognition
- Congress adds home and community based services (HCBS) to Medicaid statute
- Americans with Disabilities Act
- The Olmstead Decision
- Assistive technology options
- Development of self-advocacy
- Person-centered, self-directed service opportunities increase

Major Funding Streams for Autism Spectrum Disorder (ASD) Services

- Family
- Private
- Government (Federal, State, local)
  - Education
  - Social Security
  - Medicaid
  - Medicare
  - Child Welfare
  - Justice (Corrections)

The Special Education System

- 1973 – Section 504 of the Rehabilitative Services Act
- 1975 - EHA reauthorized in 2004 as the Individuals with Disabilities Education Improvement Act (IDEA 2004)
- IDEA authorizes formula grants to States and discretionary grants to institutions of higher education & other nonprofits for demonstrations, training, other programs

IDEA

- Requires States provide a free appropriate public education (FAPE) in the Least Restrictive Environment (LRE) for children with disabilities ages 3-21 (Part B) and
- Early intervention services (Part C) for disabled infants and toddlers birth-age two, and their families

Part C of IDEA/0-3 years

- Each State's governor designates a lead agency, usually the State's health & human services or education arm
- A multi disciplinary team (parents/professionals) develops the Individual Family Service Plan (IFSP)
- IFSP includes needed services, defines goals, criteria for progress
- IFSP identifies a service coordinator

Part B of IDEA/3-21 Years

- Local Education Agencies (school districts) implement programs
- Requires that FAPE be provided in the LRE
- Some States serve children beyond age 21
- Autism added as a disability category in 1990

Free and Appropriate Public Education

- Designed to meet a particular child's unique needs
- Provides access to the general curriculum
- Provides the child with an education that prepares for employment, further education, and independent living

Least Restrictive Environment

- IDEA requires that "…removal of children with disabilities from the regular education environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily"

Where Are Children with ASD Educated?

- Special classrooms in regular or home schools
- General education classrooms for all or part of the school day
- Center-based programs
- Private schools
- Home

The Individualized Education Plan (IEP)

- Describes measurable annual goals, both functional and academic
- Team includes parents and professionals
- Outlines the child's supplementary aids and services
- May require extended school year services
- Mandates that transition needs be addressed at age 16
- Must be reviewed regularly
- Is constructed to enable a child to receive educational benefits

Section 504 of the Rehabilitation Act of 1973

- Civil rights statute that prohibits discrimination in public and private programs that receive Federal assistance
- Administered by the Office for Civil Rights/Department of Education
- Covers qualified students with disabilities attending schools

Section 504 (continued)

- Students must have a physical or mental impairment that substantially limits one or more major life activities
- School districts must provide FAPE
- Provides some children and young adults not eligible under IDEA with services
- LEA writes a “504 plan”

Americans with Disabilities Act (1990)

- Administered by the Department of Justice
- Gives civil rights protections to people with disabilities, with focus on participation and access
- Guarantees equal opportunity in public accommodations, State/local government, commercial facilities, and transportation

The Olmstead Decision

- 1999 Supreme Court ruling
- Concerned two institutionalized Georgia women seeking community care
- Interpreted the ADA to mean that States must provide services in the most integrated setting
- Spurred Federal action to assist States in providing health, transportation, housing, education, and other social supports in community settings to people with disabilities

Private Health Insurance for Children with ASD

- Coverage often limited to medical services
- Some insurance companies may deny coverage based on an ASD diagnosis
- Most coverage debates are aimed at “Applied Behavioral Analysis” (ABA) treatment, and speech and occupational therapies
- ABA is a treatment philosophy that includes certain services and supports designed for a particular child
- Some States require private insurers to cover ABA treatment: AZ, TX, LA, MN, FL, SC, IN, PA*
- ABA treatment covered by insurers typically has maximum yearly or lifetime benefits

*Source: Autism Speaks

Supplemental Security Income

- Social Security disability benefits are different from Supplemental Security Income (SSI) benefits
- Most people with ASD receive SSI benefits
- SSI benefits are paid monthly to low-income disabled children and adults
- Disability definition/qualification is very complex

SSI (continued)

- Impairment listing for ASD is at 20 Code of Federal Regulations 404, Subpart P, Appendix 1
- Many SSI recipients are also eligible for food stamps
- Most SSI recipients also qualify for Medicaid
- The 2008 monthly individual benefit is $637/month
- The resource limit for an individual is $2000

Medicaid

- Title XIX of the Social Security Act (Act)
- Established in 1965 as a companion to Medicare
- Medicaid provides health and Long Term Care (LTC) services
- Joint Federal/State entitlement program
- States determine their own unique programs
- Some services are mandatory, others optional

Medicaid (continued)

- Each State operates a State plan
- States select eligibility groups, services, payment levels, providers
- States must specify amount, duration & scope of each covered service
- Services must be medically necessary
- States define medical necessity
- Generally, services must be available Statewide

Medicaid (continued)

- States may not place limits on services or deny/reduce coverage due to a particular illness or condition
- States may request that the Secretary of the Department of Health & Human Services grant “waivers,” which can change comparability, availability, income and resource requirements, and limit provider choice

Federal Medical Assistance Percentage (FMAP)

- Calculated each year by the HHS Secretary
- Based on rolling three year per capita income data for each State and the United States as a whole
- Minimum 50% match rate, maximum 83%
- Highest 2009 FMAP (70%+): AR, KY, LA, MS, NM, SC, UT, WV
- Most States receive about 50% FMAP
- Certain populations & services subject to different match rates (American Indian, administrative costs, family planning)

Medicaid Benefits

MANDATORY

- Physician services
- Laboratory & x-ray
- Inpatient hospital
- Outpatient hospital
- EPSDT
- Family planning
- Rural and federally-qualified health centers
- Nurse-midwife services
- NF services for adults
- 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

School Services & Medicaid

- Section 1903(c) of the Act (1988) clarifies that Medicaid must pay for covered services in a child's IFSP or IEP before education sources
- Services must be "regular" State plan services [Section 1905(a) of the Act]
- Services may be delivered in school settings according to Medicaid rules

The Early & Periodic Diagnostic, Screening, & Treatment Service (EPSDT)

- Included in the original Medicaid law
- Covers screening, vision, dental, hearing, physical, and mental health services, whether or not the services are in the approved State plan
- Required benefit for all "categorically needy" children (poverty-level income, receive SSI, or receive Federal foster care or adoption assistance)
- For children birth to age 21

Medicaid Eligibility

- People must be in a group covered by the individual State's program
- Financial & non-financial criteria apply
- Some groups are mandatory, others optional
- Almost all groups include people who are:
  - Aged, blind, or disabled
  - Under 21
  - Pregnant
  - Parent/caretaker of a child

Dual Eligibility

- Some people with ASD could be dually eligible for Medicare/Medicaid
- Medicare pays for physician/hospital care, Medicaid pays for LTC
- About 8 million people - most costly and frail in both programs
- About half live in Nursing Facilities
- Most have annual incomes <$10,000/year
- Represent about 40% Medicaid costs, 25% Medicare costs

Waiver Authorities in Medicaid

- Section 1915(b) – managed care services, selective contracting
- Section 1915 (c) – home and community-based services (HCBS)
- Section 1115 demonstrations (AZ, VT, HI)

Section 1915(c) Waivers

- Added to the Medicaid statute in 1981
- HCBS are now the foundation of LTC for poor, disabled and elderly citizens
- Provide community alternatives to institutional care for children & adults
- Undergoing gradual addition of self-directed services opportunities
- HCBS are optional

What Statutory Services May Be Included in a HCBS Waiver?

- Case Management
- Homemaker Home Health Aide
- Personal Care
- Adult Day Health
- Habilitation
- Respite Care
- Services for individuals with chronic mental illness: Day Treatment, Partial Hospitalization, Psychosocial Rehabilitation, Clinic Services
- “Other” services to avoid institutionalization

What Other Services Might Help a Person with ASD?

Some examples:

- Assistive technology
- Behavior management
- Day Program
- Supportive employment
- Dental
- Family/caregiver training
- Independent living skills training
- Nutritional counseling
- Community transition

How Do States Operate HCBS Waivers?

- State must apply to the Centers for Medicare & Medicaid Services (CMS)
- Waivers are approved for 3, then 5 years
- Waivers must offer an alternative to institutionalization, e.g. people must be at institutional Level of Care (LoC) - [Nursing Facility, Hospital, Intermediate Care Facility for the Mentally Retarded (ICF/MR)]

ICFs/MR

- To participate in a HCBS waiver, a person with ASD must meet LoC
- LoC for people with ASD is typically an ICF/MR
- A person must be able to choose between an ICF/MR and HCBS
- ICFs/MR serve people with mental retardation or related conditions

ICFs/MR

- Congress added the optional ICF benefit in 1967, following reports about dismal conditions in large institutions
- About 6,400 ICFs/MR in the United States
- Most are privately owned
- Most ICFs/MR are small - <9 beds
- Most clients are served in large ICFs/MR (9+beds)
- Alaska has no ICFs
- Average cost of an ICF/MR is about $118,000/year per person

Institutions for Mental Disease (IMDs)

- IMDs are a “hospital, NF, or other institution with more than 16 beds…providing diagnosis, treatment, or care of persons with mental diseases”
- Medicaid does not cover IMD services for people ages 22-64 (IMD exclusion)
- Children 0-21 may receive services in Psychiatric Residential Treatment Facilities (PRTFs)

More About HCBS Waivers

- Waivers cannot include services available through IDEA or The Rehabilitation Act of 1973 (vocational services)
- States must include quality requirements
- Medicaid does not pay for room and board
- It must cost the State less to support people through HCBS than it does to provide institutional services – “cost neutrality”

HCBS Waivers (continued)

- States must define a target group (Aged/Disabled, Mental Retardation or Developmental Disability, Mental Illness)
- States must specify how many people will be served each year
- States may establish waiting lists that are based on objective criteria and applied consistently
- Services in a particular waiver that includes people with ASD may not meet every need

Today's 1915(c) Landscape

- Some States use Section 1915(b) waivers concurrent with Section 1915(c) waivers to use managed care delivery systems for HCBS
- About 65% of all Medicaid services are delivered through managed care
- About 350 active HCBS waiver programs
- About 100 HCBS waivers could include people with ASD
- Most States have waiting lists for HCBS waivers

Waiting Lists in Maryland for HCBS Waivers Serving People with ASD

- Three waivers – MR/DD, MR/DD-self-directed, and Autism
- About 20,625 on waiting lists
- Only 13,500 can be served
- Four priority categories: crisis resolution (30 days), crisis prevention (1 year), current request, future need
- Average wait time for crisis resolution is 4 years

How Can Self-Direction Benefit People with ASD?

- People with ASD and their families may exercise decision-making authority over HCBS
- Recruiting, hiring, and firing staff are permitted
- Budget authority allows people to pay for their own services
- Self-direction may work better for people not served well by the traditional agency-based model
- Self-direction can save money & increase satisfaction with services
- Room and board costs (rent, food, utilities) are challenging for individuals with only SSI income

What Does Medicaid HCBS Look Like Today?

- HCBS waiver costs are about $28B/year
- About 42% of LTC funding spent on HCBS
- About 58% of LTC funding spent on institutional services
- Total Medicaid LTC spending in 2007 = $101B
- Total Medicaid spending in 2007 = $312B

ASD-Specific HCBS Waivers

- 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

*Pennsylvania – 1915(a) contract, Nebraska concurrent 1915(b)(c), Montana Section 1915(c), Washington Section 1915(c), Iowa SPA, – under review

The Rehabilitation Act of 1973

- Administered by the Rehabilitation Services Administration
- Provides for programs that help people with disabilities achieve employment, independence, and economic goals
- Services could include assessment, counseling, transition, guidance, placement, job-seeking skills, supported employment, job coaching, job accommodations, skills training, college training, mobility equipment, driver training, vehicle/home modifications

What Does the Future Hold?

- Most people with ASD need services & supports throughout their lives
- About half the States are facing significant budget shortfalls and slower than anticipated revenue growth
- Rising unemployment increases Medicaid rolls
- States are continuing to use HCBS and managed care options to achieve integrated LTC savings
- An uncertain economy will have implications for ASD services, and services to all citizens with disabilities