AUTISM MEDICAID WAIVER PROGRAMS: FEDERAL AND STATE PERSPECTIVES

May 7, 2009

Presented by AUCD with support through the AUCD Autism Special Interest Group (SIG) and the Cooperative Agreements with the National Center on Birth Defects and Developmental Disabilities (NCBDDDD) at the Centers for Disease Control and Prevention (CDC) and Maternal Child Health Bureau (MCHB) at the Health Services and Resources Administration (HRSA)
WEBINAR AGENDA

I. Welcome & Introduction – Sue Lin and Jennifer Bogin, AUCD

II. Presentation:

Autism Medicaid Waiver Programs: Federal and State Perspectives

Moderator:
- Dr. Cathy Pratt - Director of the Indiana Resource Center for Autism

Speakers:
- Ellen Blackwell, Centers for Medicare and Medicaid Services
- Pia Newman, Assistant Director, Pennsylvania Bureau of Autism Services
- Beth Wroblewski, Director, Bureau of Long-Term Support

III. Question and Answer
AUCD NETWORK AND AUTISM INITIATIVES

- University Centers for Excellence in Developmental Disabilities (UCEDD)
- Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
- Intellectual and Developmental Disabilities Research Centers (IDDRC)
AUCD NETWORK AUTISM INITIATIVES

Act Early Regional Summits Project

- Supported by the Learn the Signs. Act Early. Campaign at NCBDDD, CDC & the Combating Autism Act Initiative (CAAI) at MCHB, HRSA

- Enhances the capacity of states to create collaborative systems change in:
  - Early identification and screening
  - Diagnosis and evidence-based interventions
  - Service coordination for children with autism spectrum disorder and related developmental disabilities
AUCD NETWORK AUTISM INITIATIVES

- Supported by the MCHB’s Combating Autism Act Initiative
- Provides technical assistance to LEND interdisciplinary training programs
  - To better train professionals
  - To utilize valid and reliable screening tools for diagnosis
  - To provide evidence-based interventions for children with ASD and other developmental disabilities
WEBINAR GUIDELINES

- All participants lines will be MUTED during the presentation
- Operator will facilitate the Q&A session
- Participants may submit questions online during presentation through Go To Webinar text box at any time
Medicaid Home and Community Based Services Waivers

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Title XIX of the Social Security Act

Medicaid

- Established in 1965 as a companion program to Medicare
- Federal-State partnership
- Serves about 59M adults and children
- Augments Medicare for about 8M people
- Total Medicaid spending in 2007 = $312B
- Funding is provided jointly based on State per capita income, recalculated each year
- Title V of the American Recovery and Reinvestment Act provides for temporary increases in the Federal share through 2010
The Beginning of Medicaid

- Mostly covered primary/acute health care services
- Long-term care limited to Skilled Nursing Facility (SNF) services – nursing homes
- Institutional bias - eventual addition of community-based services---home health, personal care, home and community-based services (HCBS)
Medicaid in Brief

- States determine their own unique programs
- Each State operates a State plan outlining the nature and scope of services
- Medicaid mandates some services, States elect optional coverage
- States choose eligibility groups, services, payment levels, provider qualifications
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
- HCBS for Elderly/Disabled
- Program for All-Inclusive Care for the Elderly (PACE)
Waivers

• There are several different types of waivers in the Medicaid statute
• Title XIX permits the Secretary of Health & Human Services to waive certain provisions required under the regular Medicaid State plan:

- Comparability (amount, duration, & scope)
- Statewideness
- Income and resource requirements
- Freedom of choice of all willing and qualified providers
Section 1915(c) of the Act

- Allows for States to provide home and community-based services (HCBS) to people who would otherwise require institutional care in a Nursing Facility (NF), Intermediate Care Facility for the Mentally Retarded (ICFs/MR) or Hospital.
- Is the major tool for meeting rising demand for long-term services and supports.
- States may waive comparability, statewideness, and income & resources for the medically needy.
- HCBS are optional Medicaid services.
Services Authorized by Section 1915(c) of the Act

- 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, and Clinic Services
- Other services necessary 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
Section 1915(c) Waiver Operation

- States apply to CMS for approval to operate a waiver
- CMS approves for a period of 3 (initial) or 5 years (renewal)
- Approved HCBS waivers must be administered under the direction of the State Medicaid Agency
- Waiver may be renewed by CMS at the request of the State, for subsequent 5 year periods
- Waiver may not include services available through the Individuals with Disabilities Education Act or Section 110 of the Rehabilitation Act of 1973
Waiver Operation (continued)

• Individuals must be in the waiver target population
• Individuals who meet the target criteria must meet institutional Level of Care criteria
• Medicaid does not pay for room & board
• Waivers are “cost neutral,” e.g. HCBS costs must be less than institutional care costs
• States specify the number of individuals served per year
• Limits on the number a State plans to serve may result in a waiting list, which must be administered fairly
• States may set an individual cost limit or aggregate limit
• Services in the waiver must be available to all enrolled
How Can Self-Direction Options in HCBS Waivers Benefit People with ASD?

- Many States have included self-direction options in their HCBS waivers
- 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 reduce costs & increase satisfaction with services
Quality in HCBS Waivers

- States must have an Quality Management Strategy, with elements embedded throughout the HCBS waiver application.

- States must meet waiver assurances: Level of Care, Individual Plans, Qualified Providers, Health & Welfare, Administrative Authority, & Financial Accountability.
HCBS Facts

- Approximately 350 active HCBS waivers
- Over 1,000,000 participants
- 2006 HCBS Waiver Spending: more than $25 B
- At least 7.5% of total Medicaid spending
- 24% of all Medicaid long-term services spending
- 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 100 HCBS waivers could include people with ASD
- Most States have waiting lists for HCBS waivers
- Waiver services are not portable from State to State
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
- Montana – approved 2008, serves about 50 children

*Pennsylvania – 1915(a) contract*
CMS Regional Offices

Region I (Boston) - CT, ME, MA, NH, RI, VT
Region II (New York) - NJ, NY, Puerto Rico, Virgin Islands
Region III (Philadelphia) - DE, DC, MD, PA, VA, WV
Region IV (Atlanta) - AL, FL, GA, KY, MS, NJ, SC, TN
Region V (Chicago) - IL, IN, MI, MN, OH, WI
Region VI (Dallas) - AR, LA, NM, OK, TX
Region VII (Kansas City) - IA, KS, MO, NE
Region VIII (Denver) - CO, MT, ND, SC, UT, WY
Region IX - (San Francisco) AZ, CA, HI, NV, American Samoa, N. Mariana Islands, Guam
Region X (Seattle) - AK, ID, OR, WA
What Does the Future Hold?

- Most people with ASD need services & supports throughout their lives
- Most States are facing 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
- The increased funding provided through ARRA will assist States burdened by the recession
- The nation’s economic situation will have implications for ASD services, and services to all citizens with disabilities
Autism Medicaid Waiver Programs: Federal and State Perspectives

Pennsylvania Department of Public Welfare
Bureau of Autism Services
Pia Newman
Assistant Director
Background

- PA is a MR state
- Legislation enacted in 1966 creating the Office of Mental Retardation in the Department of Public Welfare (state Medicaid agency).
- No adult services specific to autism
- **Autism Task Force – 2004 Key Recommendations**
  - Create an Office of Disability within the state Medicaid agency with a Bureau of Autism Spectrum Disorders.
  - Develop an autism-specific Medicaid waiver.
Background

Convergence of Circumstances:

– Secretary of DPW, Estelle Richman
– State Rep. Dennis O’Brien
– Critical mass of attention and public awareness

Resulted in:

– The office of Mental Retardation to become the Office of Developmental Programs with a Bureau of Autism Services
– Submission of the Adult Autism Waiver
Background

Waiver developed: 2006-2007

Submitted to CMS: March 2008

Approved by CMS: May 2008

Effective Date: July 1, 2008
Framework

- Bureau of Autism Services is housed within the Office of Developmental Programs (ODP) [previously the Office of Mental Retardation (OMR)]. ODP administers all ID waivers in PA.

- The Adult Autism Waiver is administered directly by the Bureau of Autism Services.

- Other DD waivers are administered through counties or Administrative Entities.

- PA is the only state with an Adult ONLY Autism Waiver.
Current goals and objectives

- Implementation Phase:
  - Still developing processes and procedures
  - Hiring staff
  - Balancing manpower with needs

- Enrolling additional providers of all services in all counties to allow for meaningful choice

- Expanding Public Awareness
  - Enrolling consumers
    (Capacity for 200)
  - Recruiting Providers

- Add participant directed services
- Efficacy Study
- Expand Capacity
Outcomes

Who are we serving?

Eligibility Criteria
- Diagnosis of an ASD.
- Age 21 and older.
- ICF/ORC or ICF/MR level of care.
- Priority given to those not receiving ongoing state funded community-based services
- MA enrolled (300% of FBR)

Location: **Statewide**

Statewide rates for services

Autism-specific training incorporated into provider qualifications

Provider Training
Outcomes

Providing Services:

– Participant chooses a Supports Coordinator (SC)
– SC conducts assessments (SIB-R, Parent Stress, Quality of Life)
– SC calls team meeting
– Team decides what services are needed based on the needs of the participant
  • Assessment driven
  • Evidence based
  • Tracking outcomes

Services include:

– Behavioral Specialist Services
– Temporary Crisis
Challenges/ Lessons Learned

Would do differently:
– Hire staff earlier
– Do ongoing targeted outreach

Challenges:
– This waiver is a brand new service paradigm.
– Every programmatic and operational component was designed from scratch.
– Much is unknown about the needs of adults with autism.

Lessons Learned:
– Everything takes longer than you think. A lot longer!
– Writing the waiver and getting approved from CMS was the easy part!
– Its hard to be first!
Autism Medicaid Waiver Programs: Federal and State Perspectives

Wisconsin
May 2009
Background

- Intensive In-Home autism Treatment Services are part of a broader Children’s Long-Term Support System Initiative.
- There are three CLTS Waivers operated as one system:
  - developmental disabilities (DD)
  - severe emotional disturbance (SED)
  - physical disabilities (PD)
- The CLTS Waivers started Jan. 1, 2004
Current Waiver Capacity

• Children are eligible up to age 22, or 18 years of age in areas where the adult system has moved to Family Care
• 3,756 children receive services through the CLTS Waivers
• This includes 2,034 children who have received or are currently receiving (743) intensive in-home autism treatment services.
History

• CLTS Waivers maximize federal funds using the substantial investment of state funds: Family Support and Community Options Programs, as well as local funding

• Flexible, family-directed CLTS Waivers

• Intensive Autism Services added after direction from CMS that the state could no longer fund these habilitative services as HealthCheck – Other
Framework: Eligibility

• To be eligible, a child must meet:
  – Level of Care, as determined by BLTS
  – Comprehensive Children’s Long-Term Support Functional Screen
  – A Disability Determination by Social Security
  – Financial Eligibility
  – Additional criteria for Intensive In-Home Autism Treatment slot
Framework: Autism Tx Criteria

• Verified Diagnosis of Autism Spectrum Disorder
• One year commitment from family to participate in intensive services
• Qualified provider ready to start serving
• Child under 8 years of age
• Child has not already had 3 years of intensive in-home autism from any source
Framework: Waiver Services

- Adaptive Aids
- Child Care & Foster Care Services*
- Communication Aids
- Consumer and Family-Directed Supports
- Consumer and Family Education and Training
- Counseling and Therapeutic Resources
- Daily Living Skills Training
- Day Services

- Home Modifications
- Intensive In-Home Autism Treatment Services*
- Personal Emergency Response Systems
- Respite Care
- Specialized Medical and Therapeutic Supplies
- Specialized Transportation
- Support and Service Coordination
- Supported Employment
- Supportive Home Care
Framework

Overall framework of system:

County Waiver Agencies as an extension of state Medicaid Agency – Department of Health Services

State oversight of policy, quality and fiscal management

State eligibility/level of care and service plan review and approval
Current goals and objectives

Children with disabilities and their families will pursue their unique hopes and dreams with assistance that:

• Is family-designed and controlled,
• Is individualized and seamless,
• Lasts as long as needed, and
• Involves a variety of community partners.
Current goals and objectives

• Children’s Redesign:
  – Consensus regarding key aspects.
  – Partnerships with Families, Advocates, Counties and State.
  – Coordination with Medicaid.
  – Secured CLTS Waivers.
  – Implemented Functional Screen.
  – Piloted Systems Change.
  – Secretary- Appointed Advisory Committee.
Redesign Focus

A Foundation for A System of Long-Term Support issued in December 1998 provided the blueprint for a redesigned CLTS system addressing five key areas:

- Access
- Choice
- Coordination
- Quality
- Funding
Redesign Next Steps

• Include increased in flexibility, choice and resources; decrease in costs to the system; and expand availability of services to eligible children and families.

• Develop and implement an infrastructure that will provide information, assistance, advocacy, and access to supports and services that are responsive to the unique needs of children and families with long-term support needs.

• Consistent with the concepts developed by the Children’s Long-Term Support Council and the report, *A Foundation for A System of Long-Term Support For Wisconsin Children and Families.*
Challenges/ Lessons Learned

• Speed of transitioning services from the State Medicaid System to the Waiver.

• Adequate staff and timelines for implementing new programs and system change.

• A true shift to family-centered and family-directed services.
Useful Links
Children’s Redesign Paper:
http://dhs.wisconsin.gov/ltcare/OtherLinks/Childrens/chldren-gen.htm

Autism Transition Policy

Autism Services Rights and Responsibilities
http://dhs.wisconsin.gov/forms1/F2/F20911.pdf

Medicaid Waiver Manual
http://dhs.wisconsin.gov/bdds/waivermanual/index.htm
Contact Information

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Question and Answer