

The Coverage of Autism Services in Pennsylvania

Introduction

Approximately 21,300 children with autism reside in Pennsylvania¹. Autism spectrum disorders are biomedical brain disorders characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests². Since there is no cure, individuals with autism have extensive health and support needs to control symptoms, such as behavioral interventions, medications and medical services.

The services that are used to treat autism are extremely expensive. For example, one expert estimates that children with autism can incur medical care costs that exceed \$29,000 per person per year, while non-medical care costs can exceed \$38,000 per person per year³. The cost of these services can be covered by paying out of pocket, qualifying for publicly-financed Medical Assistance (Medicaid) coverage, having private insurance, or relying on some combination of the three. Some individuals with autism might receive “uncompensated care,” which is care for which no reimbursement is made. With the financial stress of paying for services out of pocket, families primarily rely on insurance coverage to obtain autism services.

Medical Assistance Benefits

Individuals who meet the eligibility requirements for Medical Assistance are able to receive all medically necessary services, including inpatient, outpatient hospital, and physician care, and laboratory and x-ray services⁴. For children with autism, Medical Assistance offers “wraparound services” that supplement the other traditionally covered health care services. Wraparound services address behavioral health needs and are intended to help autistic children function with greater independence in their daily environments⁵. Services to teach independence can occur anywhere that a child needs them, including play-dates, community outings and recreation facilities⁶. Wraparound services include: prescriptions, neuropsychological evaluations, supplements, transportation to medical appointments,

diapers and speech, physical and occupational therapies⁷.

ELIGIBILITY REQUIREMENTS FOR CHILDREN WITH AUTISM

Children with autism can qualify for Medical Assistance by either meeting an income requirement or having a disability determination.

Any child in Pennsylvania whose family income falls within a specified limit for his/her age group is eligible for Medical Assistance. There is no asset limit. Income limits are as follows: family income under 185 percent of the federal poverty level (FPL) for children under age one; family income under 133 percent FPL for children age one to five; and family income under 100 percent FPL for children age six through 18. Title IV-E adoptive or foster children qualify for Medical Assistance regardless of family income.

Children can also qualify for Medical Assistance in Pennsylvania if they meet the Social Security Administration (SSA) definition of disability, regardless of the family’s income or assets¹. An individual under age 18 is considered “disabled” under SSA standards if he or she has a medically determinable physical or mental impairment which results in marked and severe functional limitations and can either be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months⁸.

In addition, the SSA has specific requirements for establishing that a child is autistic. These requirements include: qualitative deficits in the development of reciprocal social interaction; qualitative deficits in verbal and nonverbal communication and in imaginative activity; and markedly restricted repertoire of activities and interests⁹.

¹ Under the Medical Assistance medically needy eligibility category, states have the option to provide Medical Assistance coverage to children under 21 who are still students. This also includes disabled persons. Pennsylvania has a medically needy program, so autistic children between the ages of 18 and 21 may have extended Medical Assistance eligibility.

To demonstrate that the SSA requirements are met, the records for children ages 1 to 3 must show at least one of the following: 1) gross or fine motor development at a level generally acquired by children no more than one-half the child's chronological age; 2) cognitive/ communicative function at a level generally acquired by children no more than one-half the child's chronological age; 3) social function at a level generally acquired by children no more than one-half the child's chronological age; or 4) attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in two or more areas covered by 1, 2, or 3.

For children ages 3 to 18, a claimant's records must document marked impairment in of two of the following age-appropriate functions: 1) cognitive/ communicative; 2) social; 3) personal; or 4) maintaining concentration, persistence, or pace.

The Pennsylvania Department of Public Welfare (DPW) estimates that Medical Assistance serves 13,800 children with autism annually, reaching about 60 percent of children with autism in the state¹⁰. Approximately 54 percent of autistic children served by Medical Assistance are eligible through the child income category and the balance through disability determinations¹¹.

ELIGIBILITY REQUIREMENTS FOR ADULTS WITH AUTISM

Adults with autism, including those who were covered by Medical Assistance when they were children, must reestablish eligibility for the program by meeting disability standards set by the SSA, having an income at or below 100 percent of the FPL, and having assets valued at less than \$2,000ⁱⁱ.

On May 14, 2008, the Centers for Medicare and Medicaid Services approved a Medicaid waiver for Pennsylvania that extends coverage for adults with autism by providing home and community-based services¹². This is the first Medicaid waiver in the country that focuses specifically on autistic adults. To be eligible for services under the waiver, which will be administered by DPW's Bureau of Autism Services, an individual must be 21 years or older and a resident of Pennsylvania, and meet functional and

financial eligibility criteria¹³. The functional criteria are: (1) having a diagnosis of autism spectrum disorder, childhood disintegrative disorder¹⁴, pervasive developmental disorder-not otherwise specified¹⁵, or Rett disorder as determined by a licensed psychologist or physician¹⁶, and (2) being at risk of institutionalization or of an intermediate care facility. The income limit is 300 percent of the federal benefit rate¹⁷ (\$1,911 for 2008) and the asset limit is \$8,000ⁱⁱⁱ. Services covered by the autism waiver include assistive technology, behavioral specialist services, community inclusion, community transition services, counseling, environmental modifications, family counseling, family training, job assessment and placement, nutritional counseling, residential habitation, respite, supported employment, temporary crisis services, supports coordination, therapies (occupational and speech language pathology) and transitional work services¹⁸. Each waiver enrollee will have an individualized service plan. DPW intends to submit a waiver amendment to add participant-directed services at a later date. DPW estimates that the waiver will serve 200 individuals at a cost of \$20 million a year¹⁹.

Mandated Private Insurance Benefits

In the past, most private insurance plans did not cover certain services needed to treat autism. For many children in Pennsylvania, private insurance paid for their regular medical care costs and Medical Assistance paid for services related to autism. The cost to Medical Assistance for paying for autism services for children covered with private insurance is relatively high and continues to increase. Furthermore, some children covered by Medical Assistance had problems obtaining autism services because various providers refused to accept the reimbursement rate paid by the program. To address the access-cost issues, the Pennsylvania legislature passed the Autism Insurance Act of 2008 to mandate private insurance coverage of autism services for children.

The Autism Insurance Act of 2008 requires private insurers^{iv} in Pennsylvania to pay for the

ⁱⁱ Please see the waivers section of this article for additional Medical Assistance eligibility requirements for adults.

ⁱⁱⁱ Parental income and assets do not count towards eligibility requirements.

^{iv} The employer-sponsored group health insurance policy needs to have at least 51 employees. Also, a policy is excluded if it is "self-

diagnosis and treatment of autism spectrum disorders for individuals under 21 years of age^v. Required services include: diagnostic assessments of autism spectrum disorders, prescription medications, psychiatrist services, psychological services, applied behavioral analysis, rehabilitative care and speech, and occupational and physical therapy. The coverage is capped at \$36,000 per individual per year. For children enrolled in Medical Assistance, the program will cover the costs that exceed the limit. The cap will be adjusted annually based on the rate of inflation.

Conclusion

Assessment and services are needed early in an individual's life and for an extended period of time to mitigate behavioral and cognitive issues associated with autism. Services that manage autism are expensive because of their duration and extent. The Commonwealth of Pennsylvania has been consistently more generous and creative in assuring that individuals with autism receive medical services by: covering all disabled children regardless of family income or assets through Medical Assistance, covering a richer set of benefits under its disability eligibility category, creating a Medical Assistance waiver to allow autistic adults to obtain services to stay in the community and passing the Autism Insurance Act of 2008 that mandates private insurance coverage of autism treatment for children. However, given the limitations in the supply of services, difficulties remain in accessing necessary care.

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¹ Pennsylvania Health Care Cost Containment Council. 2008. "Mandated Benefits Review by the Pennsylvania Health Care Cost Containment Council: House Bill 1150 Autism Spectrum Disorders."

²http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

³ Ganz, Michael L. 2006. "The Costs of Autism." In *Understanding Autism: From Basic Neuroscience to Treatment*, Steven O. Moldin and John L. R. Rubenstein. CRC Press.

insured" or the Employee Retirement Income Security Act (ERISA).

^v The Autism Insurance Act of 2008 does not apply to Medical Assistance because it is not private insurance.

⁴ Pennsylvania Medicaid Eligibility Handbook. Healthy Beginnings, 318.12 Benefits

⁵ Information provided by the Pennsylvania Department of Public Welfare to the PMPC.

⁶ Frequently Asked Questions About Autism (Internet). Pennsylvania Department of Public Welfare (cited September 2, 2008). Available from <http://www.dpw.state.pa.us/ServicesPrograms/Autism/AutismRsrc/003677882.htm>

⁷ Information provided by the Pennsylvania Department of Public Welfare to the PMPC.

⁸ Social Security Child Disability Starter Kit Fact Sheet (Internet). Social Security (cited September 2, 2008). Available from http://www.socialsecurity.gov/disability/disability_starter_kits_child_factsheet.htm#disability

⁹ Listing 112.10 - Social Security Administration Blue Book listing for Autism in Children

¹⁰ Pennsylvania Health Care Cost Containment Council. 2008. "Mandated Benefits Review by the Pennsylvania Health Care Cost Containment Council: House Bill 1150 Autism Spectrum Disorders."

¹¹ Pennsylvania Health Care Cost Containment Council. 2008. "Mandated Benefits Review by the Pennsylvania Health Care Cost Containment Council: House Bill 1150 Autism Spectrum Disorders."

¹² Autism Waiver (Internet). Pennsylvania Department of Public Welfare (cited September 2, 2008). Available from <http://www.dpw.state.pa.us/ServicesPrograms/Autism/News/2008NewsAnnouncements/003677257.htm>

¹³ Autism Waiver: Consumer Frequently Asked Questions and Answers (Internet). Pennsylvania Department of Public Welfare (cited September 2, 2008). Available from <http://www.dpw.state.pa.us/ServicesPrograms/Autism/News/2008NewsAnnouncements/003677744.htm>

¹⁴ Diagnostic and Statistical Manual of Mental Disorders, 4th edition, 1994. Diagnostic criteria for 299.10 Childhood Disintegrative Disorder.

¹⁵ Diagnostic and Statistical Manual of Mental Disorders, 4th edition, 1994. Diagnostic criteria for 299.80 Pervasive Developmental Disorder Not Otherwise Specified.

¹⁶ Diagnostic and Statistical Manual of Mental Disorders, 4th edition, 1994. Diagnostic criteria for 299.80 Rett's Disorder.

¹⁷ Autism Waiver: Consumer Frequently Asked Questions and Answers (Internet). Pennsylvania Department of Public Welfare (cited September 2, 2008). Available from <http://www.dpw.state.pa.us/ServicesPrograms/Autism/News/2008NewsAnnouncements/003677744.htm>

¹⁸ Autism Waiver: Consumer Frequently Asked Questions and Answers (Internet). Pennsylvania Department of Public Welfare (cited September 2, 2008). Available from <http://www.dpw.state.pa.us/ServicesPrograms/Autism/News/2008NewsAnnouncements/003677744.htm>

¹⁹ Information provided by the Pennsylvania Department of Public Welfare to the PMPC.