



# State of Wisconsin / OFFICE OF THE COMMISSIONER OF INSURANCE

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June 6, 2008

Senator Russ Decker  
Senate Majority Leader  
Room 122 South, State Capitol  
P.O. Box 7882  
Madison, WI 53707-7882

Representative Michael Huebsch  
Speaker of the Assembly  
Room 211 West, State Capitol  
P.O. Box 8952  
Madison, WI 53708

Dear Senator Decker and Representative Huebsch:

Pursuant to s. 601.423, Wis. Stats., I am submitting a social and financial report on Assembly Bill 417, relating to health insurance coverage of treatment for autism spectrum disorders.

### **Current Wisconsin Law**

Current law does not require disability insurance policies or municipal/governmental self-insured health plans to cover treatment of autism spectrum disorders.

### **Assembly Bill 417**

Assembly Bill 417 creates Sec. 632.895 (15) Wis. Stats. The bill requires every disability insurance policy (with some exceptions) and every self-insured health plan of the state or a county, city, town, village, or school district to provide coverage of treatment for an autism spectrum disorder.

Assembly Bill 417 defines "autism spectrum disorder" as:

- Autism disorder;
- Asperger's syndrome;
- Pervasive developmental disorder not otherwise specified.

Treatment must be provided by the following in order to be covered by the mandate:

- Psychiatrists;
- Psychologists;
- Social Workers certified or licensed to practice psychotherapy;
- Paraprofessionals working under the supervision of a Psychiatrist, Psychologist or Social Worker licensed to practice psychotherapy; or
- Professionals working under the supervision of an outpatient mental health clinic.

The required coverage may be subject to any limitations, exclusions and cost-sharing provisions that apply generally under the health insurance policy or self-insured governmental or school district health plan.

### **Autism Spectrum Disorders**

Autism Spectrum Disorders (ASD) range from a severe form, called autistic disorder (autism) to a milder form, Asperger's syndrome. If a child has symptoms of either of these disorders, but does not meet the specific criteria for either, the diagnosis is called pervasive developmental disorder not otherwise specified (PDD-NOS).<sup>1</sup>

All children with ASD demonstrate impaired social interaction, problems with verbal and nonverbal communication and repetitive behaviors and interests.<sup>2</sup> These symptoms can range from mild to severe.

The Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition (DSM-IV), published by the American Psychiatric Association, provides diagnostic criteria for autistic disorder. These criteria are listed in an attachment to this report.

According to the National Institute of Neurological Disorders and Stroke, children with autism have a higher than normal risk for certain co-existing conditions including fragile X, tuberous sclerosis, epileptic seizures, Tourette syndrome, learning disabilities and attention deficit disorder.

While there is no cure for autism, there are therapies and behavioral interventions designed to remedy specific symptoms.<sup>3</sup> Educational and behavioral interventions use highly structured and intensive skill oriented training sessions to help children develop social and language skills.<sup>4</sup> Medication may be prescribed to manage symptoms of anxiety, depression and to treat severe behavioral problems.<sup>5</sup>

Early intensive behavioral treatment has been successfully used as a means to improving cognitive, language, adaptive, social and academic functioning in children with ASD. In the 1970s, University of California, Los Angeles (UCLA) researcher Dr. O. Ivar Lovaas worked with children under age 4 using a 40 hour a week curriculum emphasizing language development, social interaction and school integration skills.<sup>6 7</sup> After a few years of treatment, 47% of the experimental group (9 of 19 children) were reported to have achieved "normal functioning."<sup>8</sup>

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<sup>1</sup> Strock, Margaret (2004). *Autism Spectrum Disorders (Pervasive Developmental Disorders)*. NIH Publication No. NIH-04-5511, National Institute of Mental Health, National Institutes of Health, U.S. Department of Health and Human Services, Bethesda, MD, 40pp. <http://www.nimh.nih.gov/publicat/autism.cfm>

<sup>2</sup> Ibid.

<sup>3</sup> National Institute of Neurological Disorders and Stroke (April 2006 publication updated July 31, 2007). *Autism Fact Sheet*. NIH Publication No. 06-1877, National Institute of Health, U.S. Department of Health and Human Services, Bethesda, MD, [http://www.ninds.nih.gov/disorders/autism/detail\\_autism.htm](http://www.ninds.nih.gov/disorders/autism/detail_autism.htm)

<sup>4</sup> Ibid.

<sup>5</sup> Ibid.

<sup>6</sup> The National Autistic Society. Lovaas. <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=528&a=3345>

<sup>7</sup> Glen O. Sallows and Tamlynn D. Graupner (2005). Intensive Behavioral Treatment for Children with Autism: Four-Year Outcome and Predictors. *American Journal on Mental Retardation Volume 110, Number 6, 417.*

<sup>8</sup> Ibid.

A study published in 2005 replicated the parameters of the early intensive behavioral treatment developed at UCLA and found that 11 of 23 children (48%) showed rapid learning, achieved Full Scale IQs in the average range and, at age 7, were succeeding in first or second grade classes.<sup>9</sup>

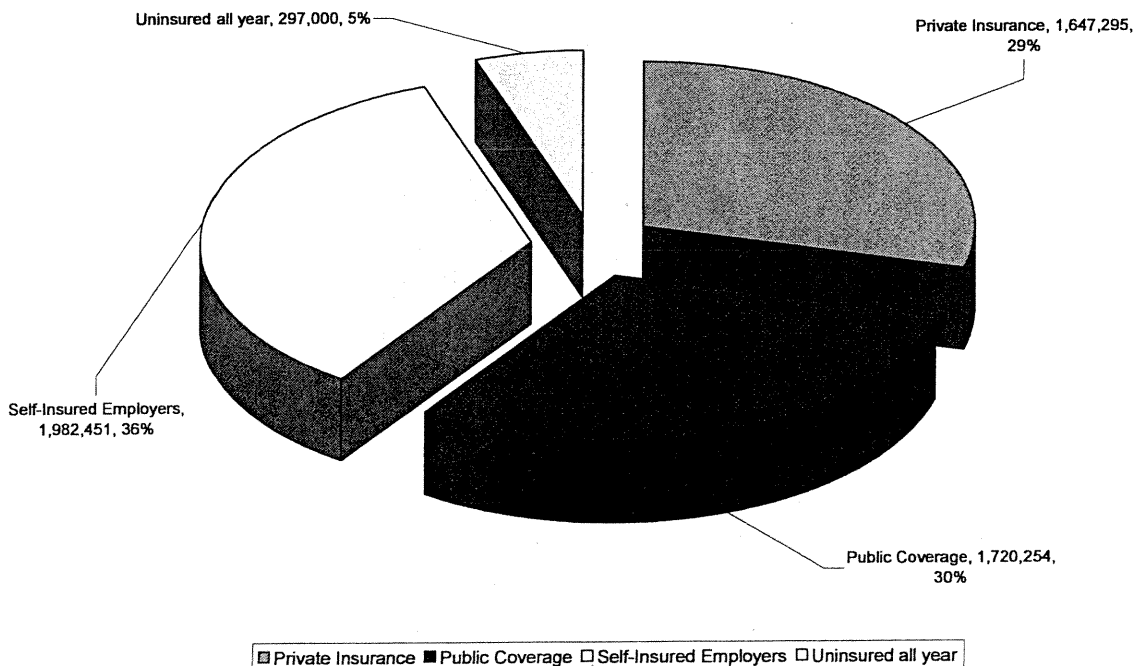
**Social Impact Factors**

Private insurance

Fully insured health insurance products cover approximately 1.65 million state residents,<sup>10</sup> representing approximately 29% of the population. This mandate expands coverage for those individuals.

Individuals who are members of groups whose benefit plans are self-funded are exempt from state regulation by the Employee Retirement and Income Security Act of 1974 (ERISA) and will not be affected by AB 417. It is unknown whether there would be any indirect impact with unregulated self-funded plans if AB 417 were to become law. For example, market pressures may result in a company choosing to provide coverage mandated under the bill as a way to attract new employees. Self-funded plans provide health coverage to approximately 36% of Wisconsin’s population.

**Wisconsin Health Coverage 2006**



<sup>9</sup> Ibid.

<sup>10</sup> Office of the Commissioner of Insurance (July 2006). *Health Insurance Coverage in Wisconsin* (PI-094 R 07/2006) p. 15. Madison, WI.

## Prevalence

The Centers for Disease Control and Prevention (CDC) measured autism prevalence rates among eight-year-olds in 14 communities around the nation, including 10 counties in southeast and south central Wisconsin. The Wisconsin counties included Kenosha, Racine, Milwaukee, Ozaukee, Waukesha, Jefferson, Rock, Dane, Green and Walworth. The report, issued on February 9, 2007, found an autism prevalence rate of 1 out of every 150 children. State specific data indicates a total prevalence of ASDs among Wisconsin eight year olds at 5.2 per 1,000, or .52%.<sup>11</sup> Unlike most other states participating in the study, the method of data collection used for Wisconsin did not include information from special education records.

School enrollment is often used as a measure of the growing prevalence of ASD. The number of children ages 6 through 21 diagnosed with autism receiving services under the Individuals with Disabilities Education Act increased more than 500 percent, from 20,000 in 1993 to almost 120,000 in 2002.<sup>12</sup> The number of children in Wisconsin public schools who were diagnosed with Autism grew from 1,052 in 1997 to 5,085 in 2005.

It is unclear to what extent the increased prevalence of ASDs is due to broadened diagnostic criteria and how much is due to a true increase in the number of people who have autism and related disorders. University of Wisconsin Researcher Paul Shattuck, for example, published an article arguing “diagnostic substitution” as a possible explanation for the increase in autism’s administrative prevalence.<sup>13</sup> The basic premise behind “diagnostic substitution” is that the same child who might have received some other disability label 15 years ago is now identified with autism because of shifting referral and diagnostic practices.<sup>14</sup> The study found that the growing administrative prevalence of autism from 1994-2003 was associated with corresponding declines in the usage of other diagnostic categories, such as mental retardation and learning disability.<sup>15</sup> As a result, the study concluded special education trends should not be used to support claims of an autism epidemic.<sup>16</sup>

Data regarding the prevalence of ASD in adults is unavailable.

## Access to Services: Special Education

Once children with ASD enroll in school, they are eligible for services under the Individuals with Disability Education Act. A wide range of services can be made available for children with ASD including those provided by: speech therapists,

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<sup>11</sup> Rice, Catherine, PhD (2007). Surveillance Summaries, Prevalence of autism spectrum disorders-Autism and developmental disabilities monitoring network, 14 sites United States, 2002. Centers for Disease Control and Prevention February 9, 2007, 56(SS01); 12-28. Washington, D.C.

<sup>12</sup> United States Government Accountability Office (January 2005). Special Education, Children with Autism. Report to the chairman and ranking minority member, Subcommittee on Human Rights and Wellness, Committee on Government Reform, House of Representatives. GAO-05-2220. Washington, D.C.

<sup>13</sup> Shattuck, Paul, PhD (2006). *The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education* Pediatrics 2006; 117;1028-1037

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

behavioral therapists, occupational therapists, physical therapists, psychologists and social workers.<sup>17</sup>

It is uncertain whether some of the treatment services provided by the professionals listed in AB 417, including intensive behavioral treatment services, might fall under a health insurance policy's exclusions for educational services. AB 417 allows insurers to enforce any exclusions and cost-sharing provisions that generally apply in their policies. Services provided by school social workers and psychologists for example, may be argued to be excluded as educational services. An example of exclusion language included in a health insurance policy is as follows:

“Any services, supplies or equipment that are required to be provided by a public school district or state or local educational agency pursuant to the requirements of the federal individuals with Disabilities Education Act, 20 U.S. C. 1401 et. seq. as amended or any state or local law(s) and regulations(s) which implement such Act (regardless of whether the service is actually provided by the public school district or educational agency.)”

Language of this nature may exclude treatment services mandated in the bill from coverage, even if a child is unable to access services through the educational system due unavailability.

#### Access to Services: Children's Long-Term Support Home and Community-Based Medicaid Waivers (CLTS Waivers)

The CLTS Waivers have been providing treatment services to children with ASD since 2004. These waivers were reauthorized for 5 years in November 2006. According to information provided by the Department of Health and Family Services (DHFS), a child with ASD qualifies for services under the CLTS Waivers based on several factors, including his or her income and assets (separate from their parents). A verified diagnosis of autism, Asperger's or PDD-NOS from a qualified clinician is also necessary to receive ASD treatment services under the CLTS Waiver. Among other things, a child must also be referred to the state for services prior to the age of 8, be a Wisconsin resident for at least 6 months and must indicate he or she has not received 3 years of intensive in home treatment services from any funding source.

Intensive in home treatment services are provided under the CLTS Waivers for a minimum of 1 year and a maximum of 3 years. This entails approximately 20-35 hours of face to face treatment time each week. Further information regarding criteria for these services and provider qualifications under the CLTS Waivers can be found in attachment II of this report.

Upon completion of the intensive services, children transition to on-going services which include any of the services offered under the waivers, including but not limited

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<sup>17</sup> United States Government Accountability Office (January 2005). Special Education, Children with Autism. Report to the chairman and ranking minority member, Subcommittee on Human Rights and Wellness, Committee on Government Reform, House of Representatives. *GAO-05-2220*. Washington, D.C.

to, counseling and therapeutic services, daily living skills training, day services and communication aids.<sup>18</sup>

The DHFS indicates there were 627 children receiving intensive in home treatment services as of December 31, 2007 and 1,132 receiving ongoing services. As of December 31, 2007, 366 children were waiting for services under the CLTS Waivers due to insufficient funding. It is estimated that children coming on to the list as of this writing will wait well over a year for funding.

Information provided by DHFS indicates 1,094 families receiving autism treatment services under the CLTS waiver have access to health care coverage outside of the program. OCI has determined that 123 of these families are covered by private health insurance and thus impacted by AB 417. 648 families listed with health care coverage did not have enough additional information for OCI to determine whether their coverage is private insurance or self funded. To the extent coverage is provided by private insurers, not self insured plans, AB 417 will result in greater cost sharing for services between private insurers and the waivers (the waiver program being the payer of last resort). Given the average lifetime maximum for most group health insurance policies is \$2.0 million, private insurance will supplant state funds for most treatment expenses. Deductibles and co-payments will be eligible for coverage through Medicaid. As a result, some children will leave the state program and others will significantly reduce their reliance on state funds. This assumes intensive behavioral and ongoing treatment services are not excluded by a health insurance policy's educational or other exclusion.

As fewer state funds are required to serve those currently in the program, more funds will be available to serve children on the state waiting list. AB 417 will allow state waiver dollars to go further in meeting treatment needs for those who have no other resource but the state.

As previously mentioned, 29% of state residents have private health insurance coverage. Assuming 29% of the children currently receiving intensive in home behavioral treatment under the CLTS waivers have access to private health insurance coverage (not self funded), we can estimate that 182 children will leave the waiver program or rely on those funds at a significantly reduced level. Making the same assumption for those children receiving ongoing services, we can estimate 328 children will have access to private coverage and may leave the program. An equal number of children leaving the waiver program are expected to move from the waiting list into the CLTS waiver program.

AB 417 will result in children accessing treatment services sooner than under current law. Children on the state waiting list with employer sponsored or individual health insurance coverage will have immediate access to services and will likely leave the waiting list, allowing children with no private insurance coverage (or those covered by self funded plans) to move from the list into CLTS waiver services more quickly. Through reducing the amount of time between an ASD diagnosis and access to

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<sup>18</sup> Department of Health and Family Services (July 2006). *Medicaid Home and Community Based Waivers Manual* Chapter IV Pages IV-10 to IV-13.

treatment services, AB 417 may result in positive treatment results that would not have otherwise been realized.

AB 417 would increase access to treatment services for ASD children with private insurance coverage who are not in the CLTS waiver programs and are not on the waiting list for services. This group is not anticipated to be very large as there are many safety nets in place to ensure families are aware of the state program. Physicians, day care providers and educators are a few examples.

As indicated by DHFS, educational services and any CLTS Waiver services are coordinated such that identified goals and approaches for attaining those goals are linked across settings.

#### Access to Services: Adults

AB 417 increases access to services for adults with ASD who have private health insurance coverage. As mentioned earlier, information available on adults with autism is incomplete. It is unknown how many adults with ASD have private health insurance coverage. Few adults with ASD are employed and carry their own insurance; however some are covered under their parent's policies as dependents. Another unknown is the extent to which adults with ASD utilize services provided by the professionals listed in AB 417. Dr. Peter Gerhardt, President of the Organization for Autism Research and an expert on adults with Autism, indicates there are adults who need access to the resources offered by professionals covered in AB 417; but at a lower intensity than younger children.

#### Increased Utilization of Services

AB 417 is expected to increase utilization of treatment services due to the fact that there are children in Wisconsin currently unable to access Autism treatment services provided by the professionals defined in the bill.

It is unknown whether AB 417 will increase ASD diagnosis, and thus utilization of treatment services, as a way to avoid mental health treatment coverage limitations.

### **Financial Impact**

#### Cost to Insurers

Wisconsin has long benefited from a healthy and competitive insurance market. The state currently has one of the lowest uninsured rates in the country, with 5% of residents having no health insurance coverage in 2006<sup>19</sup>. Insurers and business groups argue that mandated coverage of specific benefits can lead to expensive health

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<sup>19</sup> Office of the Commissioner of Insurance (July 2006). *Health Insurance Coverage in Wisconsin* (PI-094 R 07/2006) p. 15. Madison, WI

insurance products, making it difficult for businesses to afford coverage for their employees. Wisconsin mandates coverage for 24 health related benefits.<sup>20</sup>

Advocates for children with autism argue that early diagnosis and intervention are critical to positive treatment outcomes. To date, behavior approaches for addressing the delays and deficits common in autism have been recognized as effective treatment methods.<sup>21</sup> Intensive behavioral treatment costs can reach or exceed \$50,000 a year.<sup>22</sup> Some estimates place the cost closer to \$32,000 each year from age 3 to age 7.<sup>23</sup> Wisconsin advocates cite a cost of \$60,000 per year for the first two years and \$25,000 to \$30,000 per year for the final two years. The state, through the CLTS waivers, estimates it pays \$40,000 annually per child.

The Census Bureau estimates there are approximately 339,983 Wisconsin resident children under the age of five. It is unknown how many of these children are covered by private health insurance policies, however, using the established level of 29% (figure 1) of residents with private health insurance would translate to 98,595 children under the age of five with private health care coverage. Applying an autism prevalence rate of .52% yields 513 children in the correct age group to benefit from intensive behavioral therapy that also have private health insurance coverage. Using the estimate of \$40,000 a year for intensive behavioral treatment, the mandate would cost the private insurance industry in Wisconsin approximately \$20.4 million annually to cover intensive in-home behavioral treatment services. This is in relation to the approximately \$8 billion in health insurance premium collected by insurers annually in this state. Using the established figure of 1.6 million privately insured Wisconsin residents, we can estimate the mandate will cost \$1.06 per privately insured person, per month.

It is important to note that this analysis primarily centers on children expected to participate in and have private insurance coverage for intensive in-home behavioral treatment. The mandate proposed under AB 417 does not limit coverage to any specific age group or a particular type of therapy. Rather, the proposal requires coverage of the treatment for autism spectrum disorders if treatment is provided by the professionals listed in the bill. There is insufficient data regarding the number of adults with ASDs and private insurance coverage.

The Council for Affordable Health Insurance looked at ten state mandates relating to coverage for autism treatment services and found the estimated cost experience to be under 1%. It is important to bear in mind that mandates differ across the ten states, with some containing more limitations than others.

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<sup>20</sup> Office of the Commissioner of Insurance (January 2007). Fact Sheet on Mandated Benefits in Health Insurance Policies (PI-019 R 01/2007). Madison, WI.

<sup>21</sup> Glen O. Sallows and Tamlynn D. Graupner (2005). Intensive Behavioral Treatment for Children with Autism: Four-Year Outcome and Predictors. *American Journal on Mental Retardation* Volume 110, Number 6, 417.

<sup>22</sup> The Brookings Institution (2006). Conference Report: Autism and Hope. The Brookings Institution and the Help Group, January 2006.

<sup>23</sup> Michael Ganz, MS, PhD. (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Arch Pediatrics and Adolescent Magazine* April 2007.



There are twenty states with insurance laws mandating coverage related to autism. Some require coverage for treatment services through their laws mandating coverage for mental health services and others have stand alone laws specific to coverage for autism related services.

<b>Mental Health</b>	<b>Specific Law</b>
California	Indiana
Iowa	Georgia
Connecticut	Kentucky
Illinois	Maryland
Kansas	New York
Louisiana	Tennessee
Maine	South Carolina
Montana	Arizona
New Hampshire	
New Jersey	
Virginia	
Texas	

(Source: Connecticut Office of Legislative Research December 27, 2006 Report: "Insurance Coverage for Autism")

\*The South Carolina mandate passed on June 7, 2007 and will take effect July 1, 2008.

\*The Arizona mandate was signed into law on March 21, 2008 and will take effect July 2009.

Health insurance industry representatives serving Wisconsin residents, for the most part, indicate information is unavailable regarding the expected financial impact of AB 417 on health plans.

An insurer providing services to Wisconsin residents estimates the per member per month (pm/pm) premium impact for members of an HMO point of service plan to be between \$1.46 and \$2.04. This company believes the cost will near the high end of the range or may exceed the range based on a number of factors including the broad definition of autism used in the bill and the requirement of coverage for services provided by paraprofessionals.

The Kentucky Office of Insurance compiled data indicating the total pm/pm cost of their autism treatment mandate in calendar year 2005 was \$0.02. It is important to note that the Kentucky mandate is much more restrictive than what is proposed in AB 417, in that it establishes a maximum \$500.00 per month per covered child from 2 through 21 years of age.

Aetna provided claim information regarding their experience in covering autism treatment services in Connecticut and New Jersey. Treatment services include behavior management, psychological testing, behavior analysis, behavior modification, evaluation of speech and physical and occupational therapy. In both states, treatment services for autism are mandated under the state mental health parity laws.

#### New Jersey:

- Aetna found approximately \$50,000 of costs associated with autism treatment services for their fully insured (FI) HMO members age 2-6 (38,298 total), in calendar year 2006.
- Aetna's total FI HMO membership in New Jersey is 610,803. This results in a pm/pm impact of \$0.007.

#### Connecticut:

- Aetna found approximately \$4,052 of costs associated with autism treatment services for their FI HMO members age 2-6 (4,166 total), in calendar year 2006.
- Aetna's total FI HMO membership in Connecticut is 91,786. This results in a pm/pm impact of \$0.004.

An insurer covering the following services under the Maryland mandate indicates paying \$27,519 in 2006 with a pm/pm impact of \$0.008:

- Developmental Assessment and Therapy;
- Evaluation and Management;
- Hearing/Speech/Language Assessment and Therapy;
- Medical Therapy: Behavior;
- Medical Therapy: Psychiatric;
- Physical and Occupational Therapy; and
- Psychodiagnostic Assessment and Therapy.

An insurer providing the following services under the Virginia mandate indicates paying \$3,269 in 2006 with a pm/pm impact of \$0.002:

- Behavioral Assessment and Therapy;
- Developmental Assessment and Therapy;
- Evaluation and Management; and
- Psychodiagnostic Assessment and Therapy.

#### Cost Avoidance

Michael Ganz of the Harvard School of Public Health published an article estimating the lifetime cost to care for a person with autism to be \$3.2 million and the annual societal cost to care for all people with autism to be \$35 billion.<sup>24</sup>

The high cost of intensive behavioral treatment coupled with state waiting lists often delay treatment access after an ASD diagnosis. Some argue this delay jeopardizes a child's ability to gain improvements and reach "normal functioning." It is thought younger children with ASD may have more behavioral and neural plasticity than older children and may not have fallen as far behind their peers; allowing them to "catch up"

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<sup>24</sup> Michael Ganz, MS, PhD (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Arch Pediatrics and Adolescent Magazine* April 2007.

more so than older children.<sup>25</sup> AB 417 will allow some children access to treatment earlier and at a more intense level than would have been realized without the mandate. For an unknown few, AB 417 will provide access to treatment when none would have been available at all. Assuming improved outcomes resulting from early, unlimited access to treatment, AB 417 may lead to future cost savings in the areas of special education services, medical needs, long term care support and lost productivity of people with ASD and their parents.

#### *Special Education*

- According to the January 2005 U.S. Government Accountability Office (GAO) report, *Special Education: Children with Autism*, the estimated average annual expenditure of educating a child with autism were generally greater than those of educating a child with other disabilities in public school settings. In 1999-2000 average per pupil expenditures for children with autism was \$18,000 annually.<sup>26</sup>
- Total lifetime special education costs for a person with ASD is estimated to be \$150,483.<sup>27</sup>
- State specific per pupil expenditure information is unavailable.

#### *Medical Expenses*

- A Kaiser Foundation study published in the journal *Pediatrics* compared the utilization and costs of medical services for children with and without ASDs.
  - The average annual estimated cost of health care for children with ASDs was 3 times the cost for children without ASDs (\$2,757 vs \$892).<sup>28</sup>
- Lifetime physician and dental costs for a person with ASD are estimated to be \$42,259.<sup>29</sup>

#### *Long Term Care Support*

- Total lifetime costs for adult care are estimated to be \$662,192.<sup>30</sup>
  - Ranging from \$25,000 at ages 23-27 years to around \$7,000 at ages 63 to 66 years.<sup>31</sup>

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<sup>25</sup> Svein Eikeseth, Tristram Smith, Erik Jahr and Sigmund Eldevik (2002). Intensive Behavioral Treatment at School for 4-to-7-Year Old Children with Autism. *Behavior Modification Volume 26 No. 1* January 2002 49-68.

<sup>26</sup> United States Government Accountability Office (January 2005). Special Education, Children with Autism. Report to the chairman and ranking minority member, Subcommittee on Human Rights and Wellness, Committee on Government Reform, House of Representatives. *GAO-05-2220*. Washington, D.C.

<sup>27</sup> Michael Ganz, MS, PhD (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Arch Pediatrics and Adolescent Magazine* April 2007.

<sup>28</sup> Lisa Croen, et. al. (2006). A Comparison of Health Care Utilization and Costs of Children with and without Autism Spectrum Disorders in a Large Group-Model Health Plan. Kaiser Foundation. *Pediatrics 2006 Volume 118; 1203-1211*

<sup>29</sup> Michael Ganz, MS, PhD (2007). The Lifetime Distribution of the Incremental Societal Costs of Autism. *Arch Pediatrics and Adolescent Magazine* April 2007.

<sup>30</sup> Ibid.

<sup>31</sup> Ibid.

*Lost Productivity*

- Lifetime productivity losses for those with autism are estimated to be \$971,072 and for the parents of autistic individuals losses are estimated to be \$904,595.<sup>32</sup>

In preparing this report, the following organizations and state agencies were contacted:

- The University of Wisconsin Madison, Department of Population Health Sciences;
- Aetna;
- Department of Health and Family Services;
- Department of Public Instruction;
- Kentucky Department of Insurance; and
- The Wisconsin Association of Health Plans.

Please contact **Eileen Mallow at 266-7843** or **Jennifer Stegall at 267-7911** if you have any questions regarding this report.

Sincerely,

  
Sean Dilweg  
Commissioner

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<sup>32</sup> Ibid.

## Autism FAQ - Definition of Autism

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The following is from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM IV):

### DIAGNOSTIC CRITERIA FOR 299.00 AUTISTIC DISORDER

A. A total of six (or more) items from (1), (2), and (3); with at least two from (1), and one each from (2) and (3)

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

- a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
- b) failure to develop peer relationships appropriate to developmental level
- c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
- d) lack of social or emotional reciprocity ( note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids )

(2) qualitative impairments in communication as manifested by at least one of the following:

- a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- c) stereotyped and repetitive use of language or idiosyncratic language
- d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

- a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- b) apparently inflexible adherence to specific, nonfunctional

routines or rituals

c) stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements)

d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

(1) social interaction

(2) language as used in social communication

(3) symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

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## **INTENSIVE IN-HOME TREATMENT FOR CHILDREN WITH AUTISM, ASPERGER'S OR PERVASIVE DEVELOPMENTAL DISORDER**

### **SPC 512**

Applies to CLTS (SED, DD only)

#### **DEFINITION**

The provision of treatment oriented behavioral services provided by qualified professionals to children diagnosed with Autism, Asperger's and Pervasive Developmental Disorders (NOS) per the DSM IV and their families. This service may consist of a variety of therapeutic approaches that can be implemented with the intent to enhance behavior, communication, and social skills. The intent of the treatment is to develop and improve health, welfare, and effective functioning in the home and community.

Any service provided may not also be covered under the Medicaid state plan.

#### **SERVICE REQUIREMENTS/LIMITATIONS/EXCLUSIONS**

1. Only those services not reimbursable under the State Medicaid Plan will be reimbursable using waiver funds.
2. The cost of travel time may be included in the rate paid to the provider of this service.
3. Any treatment that is to be funded by the waiver under this service must be directly related to an individual child's therapeutic goals.
4. A variety of behaviorally based therapy models consistent with best practice and research on effectiveness will be permitted under this waiver service.
5. This service is limited to children who, through an independent evaluation, meet the required diagnostic and functional criteria per the DSM IV before starting services.
6. Services must start before the child reaches age eight years, unless a variance has been granted by the Department of Health and Family Services.
7. Intensive levels of services are defined as a range of 20 to 35 hours of face-to-face contacts per week. Individual plan hours may vary. Individual hours are established

by discussions with the child's team including, providers, the child's family, and the county.

8. Services are provided in the child's home on a face-to-face basis with the child.
9. Once children have had three years of intensive services, or at such time that they are not making progress towards outcomes at the intensive level of service, they will transition to other home and community-based services waiver supports and services. Variances to this three year-limit may be requested and are subject to the approval of the Department of Health and Family Services
10. Intensive services must be coordinated with other relevant services, such as educational services through the public schools, Medicaid card covered services, and private supports and services.
11. The use of the intensive in-home autism service is exclusive of the other home and community-based waiver services.
12. For additional policies concerning this service (SPC 512) please refer to Appendix E.

## STANDARDS

### A. Provider Team Composition

The in-home intensive treatment team consists of:

#### 1. Lead therapist

A provider who has the following credentials and experience **MUST** lead the in-home intensive treatment team. The lead therapist must present written evidence of the following requirements, prior to the provision of services:

- a. A doctoral degree in psychology, or a medical degree from an accredited educational institution;
- b. Actively licensed by a state board of examiners of psychiatry or is a licensed psychologist who is listed or eligible to be listed in the National Register of Health Care Providers in Psychology;
- c. Has completed 1500 hours of training or supervised experience in the application of behaviorally based therapy models consistent with best practice and research on effectiveness, for children with an autistic disorder, Asperger's disorder or pervasive developmental disorder (NOS); and



- d. At least two years of experience as an independent practitioner, and as a supervisor of less experienced clinicians.

2. Senior therapist

- a. The senior therapist must be a certified psychotherapy provider, with a master's degree in one of the behavioral sciences who has at least 400 hours of training or supervised experience in the use of behaviorally based therapy models consistent with best practice and research on effectiveness for children with an autistic disorder, Asperger's disorder or pervasive developmental disorder (NOS); in addition to, or as part of their 3000 hours of training/supervision; OR
- b. A bachelor's degree in a human services discipline and at least 2,000 hours of training or supervised experience in the use of behaviorally based therapy models consistent with best practice and research on effectiveness for children with an autistic disorder, Asperger's disorder or pervasive developmental disorder (NOS).

3. Line staff

- a. Line staff must be at least 18 years old and a high school graduate.
- b. Line staff must have obtained at least 30 hours of direct supervised experience in the use of behaviorally based therapy models consistent with best practice and research on effectiveness, for children with an autistic disorder, Asperger's disorder or pervasive developmental disorder (NOS); OR have at least 160 hours working in any setting with children with Autism Spectrum Disorders prior to the provision of services.
- c. The lead therapist and the child's family will recruit all staff with careful consideration given to background checks and compatibility.
- d. Line staff must work under the direction of the lead therapist and the senior therapist.
- e. Line staff must be oriented to the specific outcomes and approach for provision of services for an individual child.
- f. Line staff must be directly supervised during their initial visit with a child.

## B. Team Roles

The lead therapist assesses the child and develops the intensive treatment plan based upon the child's individual needs. The senior therapist then provides the ongoing supervision of the implementation of the treatment plan; this includes training and supervision of the line staff, training for the family to review the child's progress and develop an intervention plan for the next week. Line staff implement the discrete trials. Families also follow through on discrete trial activities, although these hours are not billable to the waiver. The lead therapist monitors progress on at least a monthly basis and more frequently if needed to address issues with the child's outcomes.

Discrete trials are an operant conditioning technique, which includes the introduction of a particular activity with a specific desired outcome for a child. The child receives positive reinforcement for properly completing the task.

### 1. Lead therapist

On teams with a senior therapist: Following the initial training session, the lead therapist trains and directs the team by conferring with the Senior Therapist at least weekly in person or by telephone and by working with the child in person and with the Senior Therapist and one or more line staff at least every two months.

On teams without a senior therapist: Following the initial training session, the lead therapist trains and directs the team by working with the child in the home and the line staff at least weekly.

### 2. Senior therapist

The senior therapist is an extension of the lead therapist and works with the child, the child's family, and other team members in the home a minimum of two hours weekly. The senior therapist confers with the lead therapist at least weekly in person or by telephone and implements any changes in the treatment plan that might result from the conference and, works with the child, the child's family, and line staff to assure that the treatment plan is being followed accurately.

### 3. Line staff

Line staff are trained by the lead therapist and senior therapist and directly supervised by the senior therapist and/or lead therapist to implement the treatment plan. The lead therapist is responsible to assure that line staff follow the treatment plan and provide good quality safe care.

The line staff documents the nature and scope of the services, as directed by the lead therapist and/or senior therapist, provided during each session with the child.

Line staff may accompany children to community-based activities that are intended to facilitate generalization of the behavior principles being covered in the in-home sessions and/or as transition to school, day care, and other community settings. Community-based activities without therapeutic intent are not covered; therefore, any community-based activities must be clearly documented with purpose, time spent and measurable goals in the individualized treatment plan of the child.

4. Family involvement:

The families of children receiving intensive in-home services are vital members of the in-home autism therapy team. They must be involved in the initial training session and must remain involved at a sufficient level to initiate intensive in-home treatment, reinforce behavior and implement therapeutic goals as developed by the treatment team.

#### **DOCUMENTATION**

1. The lead therapist shall provide a written progress report to the child's service coordinator and family at least every six months.
2. All of the services provided must be clearly documented in the child's chart by one of the team members present. Documentation must include location of service, time spent and team members present.
3. For billing purposes, the provider records must support, in case notes, time logs or other forms of documentation, the units of service billed.