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AUTISM TREATMENT

INTRODUCTION

The number of children being diagnosed with autism spectrum disorders* (ASD) in the United States has increased significantly in recent years. Since the early 1990s, special education programs have been required to report how many children receive services for ASD. The number of children ages 6-21 years

receiving services for autism increased 754 percent, from 22,664 in 1994 to 193,637 in 2005.

Similar increases have occurred in Wisconsin. In 2000, 2,130 or 1.70 percent of children ages 3-21 who received special education services in the state were diagnosed with autism. In 2007, the number of children increased to 5,635 or 4.38 percent (see Table 1).

Table 1: Children with Autism in Wisconsin for 1999-2000 and 2006-2007

Age	1999-2000	2006-2007
3 to 5	306	593
6 to 11	1,206	2,722
12 to 17	525	2,067
18 to 21	93	253
6 to 21	1,824	5,042
3 to 21	2,130	5,635

Source: Reported by the State of Wisconsin in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Programs.

It is still a subject of debate whether cases of autism are actually increasing or health care providers are simply getting better at diagnosing the disorder. What is clear is that increased prevalence coupled with expensive treatment costs is putting mounting financial pressure on families and government.

This brief provides background on ASD, major issues of debate, and what is being done on the federal and state levels to address the national surge in autism cases. In Wisconsin, the 2007-08 Legislature took up the issue of increased funding options for the treatment of ASD. The two competing bills that were introduced did not pass.

BACKGROUND

What are the Autism Spectrum Disorders?

Autism spectrum disorder is the term widely used by professionals to refer to children with autism and related disorders. It is not a specific diagnosis, but an umbrella term under which specific diagnoses are defined. The disorders range from a severe form, called autism or autistic disorder, 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

*In this brief, ASD is used to refer to autism or autistic disorder; Asperger's syndrome; and pervasive developmental disorder-not otherwise specified (PDD-NOS). The terms ASD and autism are used interchangeably.

called pervasive developmental disorder-not otherwise specified (PDD-NOS).

ASD is characterized by varying degrees of impairment in verbal and nonverbal communication skills, and social interactions and by repetitive behaviors or interests. Children

with ASD often have unusual responses to sensory experiences, such as certain sounds or the way objects look. Each of these symptoms ranges from mild to severe, and are present in each individual child differently (see Table 2).

Table 2: Differences in Infants With and Without Autism

Infants with Autism	Normal Infants
<p>Communication Avoid eye contact Seem deaf Start developing language, then abruptly stop talking</p>	<p>Study mother’s face Easily stimulated by sounds Keep adding to vocabulary and grammatical usage</p>
<p>Social relationships Appear unaware of others Attack others without provocation</p>	<p>Cry when mother leaves the room; anxious with strangers Get upset when hungry or frustrated Recognize familiar faces and smile</p>
<p>Exploration of environment Fixate on single item or activity Practice strange actions like rocking or hand-flapping Sniff or lick toys Show no sensitivity to burns or bruises; engage in self-mutilation</p>	<p>Move from one engrossing object or activity to another Use body purposefully to reach or acquire objects Explore and play with toys Seek pleasure and avoid pain</p>

Source: National Institutes of Mental Health.

Signs and symptoms of ASD begin before age three and last throughout life. In some children, hints of problems may be apparent from birth. In most cases, problems in communication and social skills become more noticeable as a child lags further behind other children of the same age. ASD occurs in all racial, ethnic and socioeconomic groups, but is four times more likely to occur in boys than girls.

Autism is the most common ASD. According to the Centers for Disease Control and Prevention (CDC), autism affects an estimated 1 in 150 births nationally, impacting as many as 1.5 million individuals. Growing at a rate of 10-17 percent per year, it is estimated that the prevalence of autism could reach 4 million Americans in the next decade. What differentiates autism from other disorders and/or conditions is substantial impairment in social interaction. Currently, it is not known what causes autism and related disorders.

Diagnosis

There are no medical tests that can be performed to indicate the presence of ASD. Professionals rely on behavioral characteristics to make a diagnosis. A positive diagnosis of ASD indicates that qualitative impairments exist in at least one of the following three areas: communication, socialization, and restricted behavior in a range of interests and activities.

Diagnosis of ASD is a two-stage process. The first stage involves developmental screening during “well child” check-ups. Several screening instruments have been developed to gather information quickly about a child’s social and communicative development within medical settings. Among them are the *Checklist of Autism in Toddlers* (CHAT), a modified version of CHAT, the *Screening Tool for Autism in Two-Year-Olds* (STAT), and the *Social Communication Questionnaire* (SCQ) for chil-

dren 4 years of age and older. Screening instruments do not provide individual diagnoses, but serve to assess the need for referral for possible diagnosis of ASD.

If further evaluation is indicated from the “well child” check-up, a comprehensive evaluation is conducted by a multidisciplinary team made up of a psychologist, a neurologist, a psychiatrist, a speech therapist, or other professionals who diagnose children with ASD. Parents and teachers are often included, as they have first-hand accounts of the child’s behavior. The team has the responsibility of thoroughly evaluating a child and assessing his or her unique strengths and weaknesses through a series of tests, interviews, and observations to determine a formal diagnosis.

Treatment Options

While there is not yet a cure for ASD, early detection and treatment can greatly improve symptoms and development. Many experts believe that intensive in-home therapy, or Applied Behavioral Analysis (ABA), is the most effective and proven treatment available for children with ASD. ABA was first developed in the 1960s by psychologist Ivar Lovaas and his colleagues at the University of California in Los Angeles. The intensive, one-on-one therapy is delivered by trained professionals at the child’s home and is most effective if started as soon as a disability has been identified, usually by the time the child turns four years old.

Treatment is individualized to each child’s developmental needs with the goal of building a range of important communication, social, and learning skills, while reducing challenging behaviors typically found in children diagnosed with ASD. An effective treatment program builds on the child’s interests, offers a predictable schedule, teaches tasks as a series of simple steps, actively engages the child’s attention in highly structured activities, and provides regular reinforcement of behavior.

Data is recorded on a continual basis and used by a lead therapist to develop a curriculum that is individualized to correspond with each child’s needs and strengths.

While treatment is expensive and can cost anywhere from \$30,000 to \$70,000 per year, depending on how many hours of direct service are provided, some states have estimated that early intervention will result in cost savings of \$1 million over an individual’s lifetime because of a reduced need for ongoing services.

Once children with ASD reach school age, they are eligible for services under the Individuals with Disabilities Education Act (IDEA). Speech therapists, behavioral therapists, physical therapists, psychologists, and social workers are available to provide school-based, individualized, special education for children with ASD.

ISSUES OF DEBATE

Causes of ASD

Given the range of the disorders and the fact that no two children with ASD are alike, there exist many theories and opinions on what causes autism. In the past few years, research has led to agreement on at least two key issues. First, autism has a genetic component. Twin and family studies have suggested an underlying genetic vulnerability to ASD in that children with autistic people in their families are more likely than other children to be autistic.

Second, it is generally accepted that ASD is caused by abnormalities in the brain. MRI studies have shown that autistic brains are functionally and structurally different from normal brains. Researchers are investigating a number of theories, including the link between heredity, genetics, and medical problems. While research findings indicate a strong genetic component, it is likely that environmental, immunologic, and metabolic factors

also influence the development of the disorders.

One of the more controversial issues surrounding the causes of autism is whether or not there exists a link between autism and certain childhood vaccines, particularly the measles-mumps-rubella (MMR) vaccine and vaccines with thimerosal, a preservative that contains small amounts of mercury. Although children's vaccines have been free of thimerosal since 2001 and extensive studies have failed to show a link between autism and vaccines, the controversy about childhood vaccines continues.

Other research is focusing on the role of the environment. Some findings have shown that children with ASD have a metabolic impairment that reduces their ability to rid their bodies of heavy metals and other toxins. Build up of these toxins, which are more prevalent in today's environment, can lead to brain and nervous system damage and developmental delays.

Overall, research has revealed the complexity of ASD and that there is no single, known cause for ASD. It is unlikely that any one factor – vaccines, genetics, or environmental toxins – is the cause of autism.

Is Autism on the Rise?

Another issue of debate is whether the rise in autism represents a true increase in prevalence or if there is simply an increased awareness of ASD among physicians, parents, and school officials. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the standard handbook of psychiatrists, has broadened the definition of autism in recent years to include milder variants. In the past, these individuals may have been overlooked. Older studies may have also dismissed as mentally retarded individuals who would now be considered autistic.

NATIONAL EFFORTS

While it remains to be seen what causes autism and why cases of autism have increased so rapidly in recent years, much is being done on the federal and state levels to address the prevalence of ASD.

Federal Legislation

The Children's Health Act of 2000 was the major impetus for nationwide movement toward expanding autism research and monitoring efforts. The act created the Interagency Autism Coordinating Committee (IACC) comprised of representatives from the National Institutes of Health (NIH) and the CDC.

IACC established eight network centers, called Studies to Advance Autism Research and Treatment (STAART), and 10 "centers of excellence," known as the Collaborative Programs of Excellence in Autism (CPEA). The centers, based at nationally recognized research universities and medical institutes across the country, serve to promote research and monitoring efforts related to causes, diagnosis, early detection, prevention, and treatment of autism.

To further support autism efforts, the Combating Autism Act was enacted in 2006, providing nearly \$1 billion over five years for ASD and developmental disabilities research, screening, treatment, and education through fiscal year 2011. The 2008 Expanding the Promise for Individuals with Autism Act is the most recent federal legislation in response to the rising rates of autism. It provides approximately \$83 million in fiscal year 2008 to improve access to comprehensive treatments, interventions, and services for individuals with ASD and their families.

The Waisman Center

The Waisman Center at the University of Wisconsin-Madison is one institution that has played a large role in national autism research.

The center was awarded \$1.6 million by NIH to participate in the multi-institutional STAART project that investigates the underlying neurobiological aspects of autism, the development of children with the disorder, the impact on families with autistic children, and the effects of various interventions.

The Waisman Center is one of 11 sites in the nation currently participating in the Autism and Developmental Disorders Monitoring Network (ADDM Network), a tracking study funded by the CDC. The goal of the ADDM Network is to provide comparable, population-based estimates of the prevalence of autism in different sites over time.

The most recent autism project at the Waisman Center is related to autism education. The center, in collaboration with the Wisconsin Department of Public Instruction (DPI) and the Department of Health Services (DHS), is participating in a project to implement and study teaching practices proven to be effective for students with autism. The project will coordinate and collect data from three school districts and one early childhood program in the state, establishing one classroom as a model site at each location for evidence-based autism education practices.

The project is spearheaded by the National Professional Development Center on Autism Spectrum Disorders, a multiuniversity center that promotes the use of evidence-based practice for children and adolescents with ASD. The Waisman Center at the University of Wisconsin-Madison, the FPG Child Development Institute at the University of North Carolina, and the M.I.N.D. Institute at the University of California-Davis are the three universities that make up the national center.

WISCONSIN PROGRAMS

While much is being done on the national

level, states have the responsibility of addressing the individual needs of children and families who reside in their state. Wisconsin has, historically, been one of the more generous states in providing access to services for children with ASD.

State Medical Assistance Program (1994-2004)

Wisconsin began covering intensive in-home behavioral treatment in 1994 under the state's fee-for-service Medical Assistance (MA) program after a family of a child with autism claimed that the state must cover the service as an early and periodic screening, diagnosis, and treatment (EPSDT) benefit. In a fee-for-service program, providers bill MA directly for all services provided. Reimbursement for allowable services is then paid by DHS, formally known as the Department of Health and Family Services (DHFS), up to the maximum reimbursement rate.

Referred to as HealthCheck in Wisconsin, EPSDT is required under federal law for all MA enrollees under 21 and requires comprehensive screenings throughout a child's life. Under this benefit, children with ASD received 20 to 35 hours of direct, intensive in-home treatment a week. MA only covered services for children who began receiving the benefit before 12 years of age. It did not cover the services once the child reached his or her sixteenth birthday.

In 1993-94, DHFS paid approximately \$2,400 to serve one child with intensive, in-home autism services. By the end of fiscal year 2001-02, when ASD was covered by the state MA program, more than 1,000 children were receiving the benefit, and expenditures totaled approximately \$31.8 million at an average cost of \$30,000 per child (see Table 3).

Table 3: State Spending on Intensive In-Home Treatment, 1994-2002 (in dollars)

State fiscal year	Spending per recipient	Number of recipients	Total spending on in-home autism treatment
1994	\$2,363	1	\$2,363
1995	5,810	35	203,355
1996	15,539	70	1,087,714
1997	22,417	113	2,533,151
1998	29,255	222	6,494,569
1999	34,370	435	14,950,778
2000	35,221	641	22,576,748
2001	31,338	838	26,261,240
2002	29,545	1,073	31,701,663

Source: Compiled from Wisconsin Department of Health and Family Services data.

CLTS Waiver Program (2004-present)

In April 2003, a directive from the Centers for Medicare and Medicaid Services (CMS), a federal agency within the U.S. Department of Health and Human Services, notified the State of Wisconsin that the existing in-home treatment would no longer be reimbursable under the state’s MA plan, resulting in the loss of all federal matching funds. The state was given an option to continue claiming the federal Medicaid dollars through Children’s Long-Term Support (CLTS) Home and Community-Based Waivers. Federal funding would pay for about 60 percent of the program.

The state’s transition to using CLTS waivers to provide treatment services to children with ASD was not without controversy. In the initial 2003-05 biennial budget, Governor Jim Doyle proposed to eliminate funding for intensive in-home treatment services altogether, citing that the state could not afford to pay for the services given the projected budget deficit. If services were to continue at the same levels, the state would be paying nearly \$40 million over two years.

The proposal was met with strong disapproval from the autism advocacy community. After negotiations with parents, professionals, and educators, the governor’s proposal to allocate \$26.5 million for the biennium and apply for the federal waiver program was approved

by the legislature. The CLTS waivers have been providing treatment services to children with ASD since 2004. The program was reauthorized for an additional five years in November 2006.

To qualify for the CLTS waivers, a verified diagnosis of autism, Asperger’s syndrome, or PDD-NOS from a qualified clinician is necessary. A child must also be a Wisconsin resident for at least six months. The waivers provide up to three years of intensive in-home services to children eight years old or younger. Intensive services are available for a minimum of 20 hours and a maximum of 35 hours per week including travel time. The program also provides a range of on-going services to older children and those who have completed the 3-year intensive phase.

DHFS was appropriated an amount sufficient to allow 250 children per year to begin intensive in-home services beginning with fiscal year 2003-04. The department indicates there were 627 children receiving intensive in-home treatment services as of December 31, 2007, and 1,132 receiving ongoing services.

With the increase in the number of children being diagnosed with ASD, additional funding has been deemed necessary to continue providing quality services at the current level. At the end of 2007, 366 children were waiting for services under the CLTS waivers due to insufficient funding.

Other Initiatives

Governor Doyle led two initiatives to address the rise in autism in Wisconsin: the Task Force on Autism and the Autism Advisory Council.

The Task Force on Autism was convened in 2004 to respond to the needs of parents of children with ASD. The task force met from May 2004 to September 2004, and was comprised of 10 members appointed by the governor and representatives of various state agencies involved with the regulation and administration of services for individuals with ASD. It produced a final report identifying problems with the current system and outlining policy recommendations for solutions.

The following year, Governor Doyle established an Autism Advisory Council to advise DHS on developing a statewide support system for individuals with ASD and addressing key issues outlined by the Task Force on Autism's final report. The council has met continuously since 2005 and is made up of 13 members appointed by the governor, a majority of whom are parents of children with ASD. Also included are public members, providers, local government officials, and professionals with an interest in autism.

2007-08 LEGISLATION

As states continue to struggle with the rising costs of funding autism services for children, some have opted to mandate health insurance coverage for ASD. A mandated benefit is a law that requires a health insurance policy or health plan to cover specific providers, procedures, benefits, or people.

Many insurance companies argue that most medically related treatments are already covered for autism, and because autism is an individually based disorder, there is often no clear standard of care for determining the appropriate therapy. As a result, autism generally falls into a disability

category needing long-term care, not health insurance.

In Wisconsin, legislation related to health insurance coverage of treatment for ASD was first introduced as part of the governor's 2007-09 budget proposal. It was reintroduced as a separate bill during the 2007-08 legislative session.

Two Competing Plans

2007 Senate Bill 178 was introduced in May 2007 by Senators Robson, Wirch, and others and cosponsored by Representatives Hixson, Benedict, and others. The bill required health insurance policies and self-insured governmental and school district health plans to provide coverage of treatment for ASD, defined in the bill as:

“autism disorder, Asperger's syndrome, or Pervasive developmental disorder not otherwise specified.”

In order to be covered by the mandate, treatment must be provided by 1) a psychologist, 2) a psychiatrist, 3) a social worker licensed to practice psychotherapy, or 4) a paraprofessional practicing under one of the above professionals. An amended version of the bill passed the Senate on February 27, 2008, by a vote of 25 to 8. The adopted amendment added speech language pathologists to the list of providers.

Senate Bill 178 was heavily debated in the Assembly on February 28, reflecting the divergent views on how best to deal with the growing numbers of autistic children waiting for treatment. Rather than taking up Senate Bill 178, the Assembly introduced a new bill that would increase funding for the existing autism waiver program, rather than mandate health insurance coverage.

Assembly Bill 901 was introduced on February 28, 2008, by Representatives Newcomer and Petersen. The bill increased a general purpose revenue appropriation to DHS by

\$6,060,000 in fiscal year 2008-09 for the autism benefit under the CLTS waiver program. The funding increase would serve children diagnosed with ASD who are currently on the state-wide waiting list.

The bill also directed DHS to develop and periodically update an informational brochure for parents or guardians of autistic children that must be distributed to local educational agencies and physicians. On March 5, the Assembly passed AB-901, 55 to 39. The bill was sent to the Senate, but was not acted upon before the Senate adjourned on March 21.

Disagreement over the way in which the state should provide services to a growing number of children with ASD prevented any legislation from passing. Opponents of the health insurance mandate believed Senate Bill 178 is both more expensive and less effective at getting children with ASD off the waiting list. They argued that, with the high costs of intensive in-home treatment services, health insurance rates will likely rise. This increase in the cost of health insurance might deter employers, particularly small businesses, or individuals from the market. Leaving more uninsured or underinsured citizens who will utilize government services in the state shifts the burden of cost to taxpayers.

Proponents of Senate Bill 178 see mandated insurance coverage as an opportunity to reduce costs covered by MA. Recognizing that the state cannot keep up with the demand for treatment alone, supporters believe that more children will be reached by shifting some of the costs to the private sector. Families with greater financial resources are more likely to have comprehensive health insurance, leaving more spaces open in the federal waiver program for families who do not have insurance. Supporters of the insurance mandate see Assembly Bill 901 as a "band-aid" to the problem, and not a long term solution.

The State Commissioner of Insurance submitted a "social and financial report" on the health insurance mandate for ASD coverage, pursuant to Section 601.423, Wisconsin Statutes, on June 6, 2008. The report outlines the social and financial impact of mandating health insurance coverage for ASD in Wisconsin. The report can be viewed on their Web site.

OTHER STATES

According to the National Conference of State Legislatures, at least 25 states require insurance coverage for individuals with autism. Six of these states enacted such legislation during the 2007-08 legislative session. Arizona, Florida, and Pennsylvania enacted legislation providing coverage for autism; Connecticut, Louisiana, and South Carolina enacted legislation modifying their existing statutes that provide for coverage of autism.

FOR MORE INFORMATION

For more information on ASD, see National Institutes of Health publication at: www.nimh.nih.gov/health/publications/autism/nimhautismspectrum.pdf

For more information on intensive, in-home autism services under Wisconsin's Medical Assistance Program, see Legislative Fiscal Bureau Budget Paper #392 at: www.legis.wi.gov/lfb/2003-05budget/2003-05BudgetPapers/392.pdf

For more information on CLTS Home and Community-Based Waivers, see Department of Health Services Web site at: <http://dhs.wisconsin.gov/bdds/clts/index.htm>

For more information on autism-related activities at the Waisman Center, see: www.waisman.wisc.edu/news/autism02.html

View a copy of 2007 Senate Bill 178 at: www.legis.state.wi.us/2007/data/SB-178.pdf

View a copy of 2007 Assembly Bill 901 at:
www.legis.state.wi.us/2007/data/AB-901.pdf

For more information on Senate Bill 178, see Social and Financial Report of the Office of the Commissioner of Insurance at:
www.oci.wi.gov/finimpct/sfisb178.pdf

A report on "Wisconsin's Medicaid Waiver Autism Services" by La Follette School of Public Affairs students:
www.lafollette.wisc.edu/publications/workshops/2003-2004/pa869/2004-Autism.pdf

The Governor's Task Force on Autism Final Report:
<http://dhs.wisconsin.gov/bdds/clts/autism/taskforce/finalrep.pdf>

Autism Advisory Council Web site:
<http://dhs.wisconsin.gov/bdds/clts/autism/council/index.htm>

Federal Legislation

Children's Health Act of 2000:
www.cdc.gov/ncbddd/autism/federal/congressionalactivities.htm

Combating Autism Act:
www.whitehouse.gov/news/releases/2006/12/20061219-3.html

2008 Expanding the Promise for Individuals with Autism Act:
www.aucd.org/template/page.cfm?id=311