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Testimony on Senate Bill 178
Senate Committee on Public Health, Senior Issues, Long Term Care and Privacy
Thursday, May 31, 2007 411 South, State Capitol

Thank you, Chairman Carpenter and Committee Members, for holding this public hearing today.

As I am sure you will hear from the people gathered here today, the impact of autism on families in Wisconsin is an extremely important issue. It is encouraging to see this committee move quickly on legislation that will improve the quality of life for these families.

SB 178 would provide insurance coverage for families with children affected by autism. According to the CDC one out of every 192 children in Wisconsin is affected by autism.

Perhaps you know the parents, grandparents, siblings of a person with autism. Or you know a person affected by the disorder. Or you know a teacher or other childcare worker who works with these children. A child with autism lives in my neighborhood. I go to church with a family whose child has Autism. A few weeks ago, a constituent came to my office and told me of the frustrations, heartbreaks and problems she endures as the parent of an autistic son. She told me of the financial difficulty this disorder has caused her family. We need to make sure that the struggles that she and other families touched by autism, do not include financial worries as well.

The Brookings Institute places the cost of treatment in excess of $50,000 per year with minimal coverage by insurance or government programs. With other increases in health care costs this burden on working families leads to lack of treatment. Research provided through the National Research Council has shown that early intervention can help an individual show an improvement in IQ, communication, learning and appropriate social behavior.

Providing early treatment would save us money in our special education system. According to the DPI in 2004-05 there were approximately 4,300 students with autism receiving special education services in Wisconsin. As stated before, early intervention leads to a lessened need for specialized curriculum as the child gets older saving our precious tax dollars.

In closing, I urge you to move this legislation forward and provide insurance coverage for autism spectrum disorders as several other states have done – so that families can concentrate on providing the best care for these children and so that these children can have a better chance at a normal and more successful life. Thank you again for the opportunity to speak here today. I am happy to answer any questions, but would also note the others here today to testify who can speak more directly to the need for this legislation and its impact on working families.

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Date: May 31, 2007

To: Sen. Tim Carpenter, Chair
Senate Committee on Public Health, Senior Issues, Long-Term Care & Privacy

From: Mari Frederick, Chair

Re: SB 178: Support for Health Insurance Coverage of Treatment for Autism Spectrum Disorders

The Wisconsin Council on Developmental Disabilities is mandated under federal law to advise the legislature on issues impacting people with developmental disabilities. Children on the autism spectrum are included in the Council's constituency.

The Council strongly supports SB 178 for the following reasons:

- Autism spectrum disorders are biologically based. Children with these disorders should be covered by health insurance just as children with brain tumors or cancer are covered.

- Children with suspected autism spectrum disorders are more likely to be screened and diagnosed if evaluation and treatment by professionals are covered services.

- If private insurance covered these services, Medicaid funds could be concentrated on long-term care.

The Council would support an amendment to SB 178 expanding coverage to children with other developmental disabilities. They would also benefit from health insurance coverage of psychiatrists, psychologists, and other professionals.

Thank you for your consideration of this testimony. If you have any questions, feel free to contact Jennifer Ondrejka, Executive Director, at 266-1166 or ondrejm@dhfs.state.wi.us.

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Testimony before the
Senate Committee on Public Health, Senior Issues, Long-Term Care & Privacy
on
Thursday, May 31, 2007, 9:30 am
Room 411 South, Capitol

Presented by
State Senator Judy Robson, 15th District

In support of SB 178, Autism Insurance Coverage

Thank you all for coming today to this public hearing on a bill to ensure that all persons with autism, especially our young children, receive the care they need to grow and lead healthy, happy lives.

I introduced Senate Bill 178 after the Joint Finance Committee removed an identical provision from the Governor's budget bill. When I learned that this provision might not be included for consideration in the state budget, I acted immediately to have it drafted as a separate bill. I wanted to make sure that regardless of what happens in the budget process, this initiative can move forward on the strength of its own merits.

And move forward it has! Since this bill was introduced on May 5, the issue has been ignited a storm of attention. For example, it has been the topic of numerous newspaper, radio and TV reports. I personally have received petitions listing the names of more than 1000 persons who support the bill. And in my office alone, we have received well over 50 letters and emails of support and I know the other legislators are getting the similar expressions of support.

As you know, this bill will require individual and group health insurance policies and plans to cover the cost of treatment for insured persons with autism, Asperger's syndrome or other pervasive developmental disorders.

As a registered nurse, I firmly believe that autism-related conditions should be covered by health insurance policies. If autism treatment services are covered by insurance in Wisconsin, as they are in other states like Kentucky and Indiana, more individuals with autism will be able to receive the treatment necessary to help them function to the best of their ability.

Why do we need to cover children with autism? This disorder is becoming increasingly prevalent. A recent national report from the U.S. Center for Disease Control and Prevention found that about 1 in 150 children have autism. In Wisconsin, the rate was slightly lower at about 1 in 192, but that still makes it a very serious concern.

In addition, research shows that intensive behavioral treatment programs begun when children are in their toddler years have a 50% rate of success, making it possible for these children to enter a regular school setting at an age-appropriate grade with no need for costly special education.

You've all heard the expression that something is a "win-win" situation. The effort to secure health insurance coverage for persons with autism is even better. It is a "win-win-win."

First, it helps get early intervention care to children when the treatment is most effective.

Second, it can relieve some of the pressure on the waiting lists for the state-funded Wisconsin Early Autism Program. This outstanding program has served more than 2,500 children with autism since is started in 1995. But the waiting lists are long and the process of even getting on the waiting list is very challenging.

Third, it saves taxpayer dollars that will otherwise need to be spent on special education programs in our schools and for long-term care services as these children grow into adulthood.

I can think of few legislative proposals that come honestly rise to this "win-win-win" standard.

The care of vulnerable children, especially those most in need and who face great challenges as they grow up, should know no political boundaries. I hope all of my Democratic and Republican colleagues will stand up and be counted in support of giving these children the care and treatment they need <u>and</u> giving their families the peace of mind they deserve.

Thank you for your dedication to these children and their families.

To:	Chairperson Tim Carpenter Members of the Senate Committee on Public Health, Senior Issues, Long Term Care and Privacy
From:	R.J. Pirlot, Wisconsin Manufacturers & Commerce Steve Baas, Metropolitan Milwaukee Association of Commerce Bill Smith, National Federation of Independent Business Dave Storey, Wisconsin Merchants Federation Matt Hauser, Wisconsin Petroleum Marketers & Convenience Store Association Peter Hanson, Wisconsin Restaurant Association Michelle Kussow, Wisconsin Grocers Association Mary Ann Gerrald, Wisconsin Automobile & Truck Dealers Association
Date:	May 31, 2007
Subject:	**Opposition to Senate Bill 178**, relating to health insurance coverage for autism spectrum disorders.

SB 178 mandates all fully-insured employers to pay for the cost of treating autism, Asperger's syndrome and "pervasive developmental disorder not otherwise specified." SB 178 mandates coverage for treatment by a psychiatrist, psychologist, social worker licensed to practice psychology, or a paraprofessional practicing under the supervision of one of the aforementioned providers.

SB 178 Will Raise Health Care Costs, Jeopardizing Affordability

Government insurance mandates inevitably lead to higher health care insurance costs, meaning employers and employees will have to pay more for health insurance coverage. As health care insurance costs go up, typically the hardest hit are Wisconsin's small businesses and their employees.

Rising health care costs are already forcing Wisconsin employers to shift health care cost increases to their employees, reduce health care coverage, or both. SB 178 will make the affordability problem worse.

SB 178 Will Jeopardize Access to Health Care Insurance

As health care insurance costs rise, fewer and fewer individuals and businesses can afford to insure. An increase in premium costs to employers will have a negative impact on the number of people insured in Wisconsin. Only 26 percent of the Wisconsin population will be affected by SB 178—the population that depends on state-regulated health insurance plans for their coverage. This population is declining as health care costs rise. The additional cost represented in SB 178 will reduce the insured population further.

Wisconsin businesses and their employees are already struggling to help pay for employee health care benefits. SB 178 will make the access problem worse.

Health Care Costs Are Rising and Hurt Economic Development

Rising health care insurance costs are a major concern for businesses, big and small, as they strive to stay competitive. Rising health care costs undermine the ability of Wisconsin companies to offer health care benefits and, significantly, impede their ability to create and retain good-paying jobs in Wisconsin. Again, SB 178 will make the access and affordability problems worse.

My name is Judy Endow. I have a master's degree in Social Work, have raised three children and am employed full time as an autism consultant. I am also a person who has autism. I do have health insurance from my workplace. It does not cover many things that are medically necessary due to my autism and thus, I have huge medical expenses every year, even though I am basically a healthy person.

For example, due to sensory issues I must be put to sleep for most routine medical procedures at both the doctor and dentist office, including blood tests, ~~mammograms~~ xrays and getting my teeth cleaned. This costs several hundreds of dollars of out of pocket expenses just to get annual physical checkups. If the checkups are necessary then why doesn't private insurance pay for all people to get them? Medical Assistance covers these expenses. I have skipped many years of preventative health checkups just because I could not afford the out-of-pocket expense not covered by insurance.

I cannot help it that the neurology of my autism makes my skin and teeth extremely sensitive or that my body cannot hold still when people are attempting to perform medical procedures. I am not electing to have this extra expense. For me, it is a medical necessity and it is not covered by my insurance. I understand that if I had medical assistance these things would be covered - at least both the dentist and doctor office have told me so. Why is it that a person with autism who works at a job and has health insurance cannot have medically necessary procedures covered by that insurance?

I also pay hundreds of dollars out of pocket each year to purchase services that are medically necessary for me such as deep tissue massage that allows my neurology to stay regulated so that I can work. If I could afford the price I would be able to maintain better regulation. For me, I can at least get by because I have several friends who donate time weekly to help me with sensory regulation as I cannot afford to purchase any of the ongoing Occupational Therapy kinds of treatments that are helpful to me on a regular basis. Others with autism are not so lucky.

As a society we have agreed that it is wrong to discriminate. We would not think of saying that it is ok for a health insurance company to NOT cover medical expenses for a person because they are Black or Jewish. So then, why is it ok for an insurance company to NOT cover expenses for person who is autistic? Why is it preferable for an autistic person to have the state medical assistance insurance rather than private insurance?

I am an extremely lucky person in that even though I have autism, I am also able to carry on a professional life and am able to pay for some medical services and have friends who are willing to fill in, affording me with "free OT therapies" that, though they are not of medical standards never-the-less enable me to maintain my ability to function as a gainfully employed human being. Others with autism are not so lucky.

Why are therapies that help a person with autism maintain gainful employment NOT seen as medically necessary and not covered by private insurance? It's great to have a job and to have health insurance, but it would really be nice if the insurance would cover things that, though optional for most folks, are medically necessary for me and for others with autism spectrum disorders.

Hello, I am Molly Immendorf. I am the president of the Autism Society of Greater Madison and I am the parent of a 10 year old son named Will who has autism spectrum disorder. Thank you for requiring that insurance companies here in Wisconsin cover autism-related services through SB 178. For far too many years, medically necessary treatments have been denied by insurance companies because the neurological disorder autism has been specifically excluded. Prior to Will's diagnosis, he was receiving speech therapy though our insurance plan. After diagnosis, speech therapy was no longer covered because he was non-verbal due to autism.

Fortunately, Will received occupational, physical and speech therapy as well as behavioral therapy, which are all covered by Wisconsin's Katie Beckett program and more recently the Children's Long Term Support Waiver. He continues to gain skills and has gone from being non-verbal at the time of diagnosis to a boy who will tell you all you ever wanted to know about computers and AT&T.

As president of the local autism society chapter, I meet parents of newly diagnosed children who are facing up to an 18 month wait for a slot in the CLTS waiver. One of the reasons my son and others have improved so much is that he received timely, intensive early intervention. Parents of newly diagnosed children are rightly worried about the long delay in receiving treatment for their young children.

Although the CLTS waiver is beneficial for many, it is flawed. In addition to the extremely long wait for a slot, there are age limits and it is not consistently managed across the state. Additionally, there are many individuals with autism who are older and not receiving medically necessary therapy because there is no insurance coverage.

Recently, I was called by a mother whose son with autism was denied coverage for an official medical diagnosis by a licensed psychologist. Her son will be a 2007 graduate from high school and plans to attend college. He was able to be included in his primary and secondary schools because he was receiving support due to his educational diagnosis of autism. However that diagnosis was not sufficient for the university to provide disability services for him. They require a medical diagnosis. But the insurance plan for this family would not cover the visit to the diagnostician. This family will have to spend thousands of dollars to have a medical diagnosis for their son.

Savvy parents and physicians are sometimes successful in getting insurance coverage, but the autism diagnosis cannot be mentioned in the referral. If the insurance company gets a inkling that the individual has autism, the referral will most likely be denied. It is happening again and again in our state.

In my opinion, any individual covered by an insurance plan should qualify for therapies if their physician deems them to be medically necessary. Why should a stroke or accident victim qualify for speech therapy and not a child with autism?

Please support the passage of SB178. The autism community in Wisconsin is counting on you.

Sincerely,

Margaret (Molly) Immendorf
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WISCONSIN
SPEECH-LANGUAGE PATHOLOGY
and AUDIOLOGY PROFESSIONAL ASSOCIATION

Date: May 31, 2007

To: Members of the Senate Committee on Public Health, Senior Issues, Long-Term Care, and Privacy

From: The Wisconsin Speech-Language Pathology and Audiology Professional Association (WSHA-P)

Re: Senate Bill 178 relating to health insurance coverage of treatment for autism spectrum disorders

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The Wisconsin Speech-Language Pathology and Audiology Professional Association (WSHA-P) supports insurance coverage of treatment for autism spectrum disorders. The association asks that you include the profession of speech/language pathology as a provider of treatment for an autism spectrum disorder under SB 178. Speech-Language therapy is an existing treatment for children with autism and is an integral part of the services available for children with autism.

Autism is a complex disorder with very obvious behavior and communication deficits. The inter-relatedness of behaviors and communication are difficult if not impossible to separate. Difficulties communicating can result in negative behaviors. Negative behaviors impact the child's ability to acquire communication skills.

Behavior therapy is vital to address a variety of behavioral difficulties presented by children with autism that often stand in the way of participation in more "mainstream" intervention strategies. Communication deficits range from not initiating any form of communication in order to convey a want, need or idea to disorders of word use and comprehension. An SLP best addresses these deficits because of our education, training, and professional experience.

An SLP has completed a master's level (or doctorate) in Communication Sciences and Disorders. Many have also completed a nine-month fellowship and have passed a national examination. These SLPs are licensed by the State and are nationally certified by the American Speech-Language and Hearing Association (ASHA).

In many circumstances, children who are receiving intensive behavior therapy services are being denied for speech/language therapy services by their insurance companies on the basis of duplication of services. While these two providers may be treating the same child, the focus of the intervention and the skills and training of those providing the services are very different. Speech/Language Pathologists focus on identifying and improving the child's ability to communicate wants, needs, and ideas in the most functional way as possible for that individual child.

WSHA-P requests that the services of an SLP for children on the autism spectrum disorder be considered within the realm of services that should be covered by health insurance under Senate Bill 178.

*I am here in support of Bill 178. This bill is necessary not only to provide treatment for people that are affected by autism today. But for all of the children that will be diagnosed in the years to come. With no known cause and 1 out of every 94 boys being diagnosed this could easily strike your family or the family of your children or grandchildren.

*It is unfortunate that a child has to wait days or weeks to be treated, it is appalling to know in this state they must wait months or years. In a country, that prides itself on "No child Left Behind" Wisconsin is doing just that.

*I know that many of you ran your campaigns on keeping health insurance affordable, and to support a bill that may result in an increase in insurance premiums would go against just that. But I challenge you to go to your constinutates and tell them that you found away today to put a band-aid on a pail with multiple leaks, and that is to discriminate against children and adults with autism. A solution to the health care cost crisis is not to discriminate and I would believe most people in the communities you represent would feel the same way.

* We do not know if this increase will result in a loss of coverage for some. We do know that thousands of Wisconsin families would benefit from this bill. My husband was a small business owner forced to seek other employment not because we could not afford our health insurance premiums, but because no one would even insure our son regardless of the cost.

*Our son is denied insurance not only for intensive treatment and related therapies, but also for all medical bills and prescriptions that have nothing to do with his autism. If my son goes the doctor for a cold, the taxpayers pay for it, when I refill his prescription that is $225 a month, that has nothing to do with his autism, the taxpayers pay for it.

*Many feel this is not an insurance company's responsibility but the states. But keep in mind that not all people qualify for government assistance. Even though they have the autism diagnosis and are in need of medical attention, they are not considered severe enough by the states requirements for Medicaid or the Waiver. These families are left with no affordable treatment options. They must rely primarily on the public schools, whose objective is to teach children, not treat medical conditions.

*For those of you who feel the expense of treating such a small group of people is not fair to those not directly effected I would argue that autism in this day and age does not affect less than 1% of the population, it affects MOST of the population. All of the members of my family are affected by my sons autism, it will affect the budget of the school district my son will attend, it will affect the taxpayers who may be forced to pay for his life long care, it affects the lives of people that will be forced to move from this state in the best interest of their child as well as the families that will decide not to relocate here due to lack of insurance coverage options. It will also impact the autistic service providers in this state. How can the state encourage the top autism providers to stay or want to come help our children when they could easily practice in a state where receiving payment in not an issue.

*Medicaid cannot possibly keep up with the needs of these children and adults at the rate they are being diagnosed. I have already heard the stories first hand of how it has become harder to qualify for services and how services are more easily taken away from kids that are progressing, dumping them onto the already drained public schools to deal with.

*I ask you to place a mandate on insurance companies to do the right thing. You can help save these children, you can provide relief and hope to thousands of families around Wisconsin, you can help redirect Medicaid money to so many other people that are in need, you can help take some of the responsible and expense off the school systems to treat these children, and you can give working adults with autism something they have always been denied the right to have. Therefore, I ask you to please do the right thing and support Bill 178.