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Details:

(FORM UPDATED: 08/11/2010)

**WISCONSIN STATE LEGISLATURE ...
PUBLIC HEARING - COMMITTEE RECORDS**

2009-10

(session year)

Senate

(Assembly, Senate or Joint)

**Committee on ... Public Health, Senior Issues,
Long-Term Care, and Job Creation (SC-PHSILTCJC)**

COMMITTEE NOTICES ...

- Committee Reports ... **CR**
- Executive Sessions ... **ES**
- Public Hearings ... **PH**

INFORMATION COLLECTED BY COMMITTEE FOR AND AGAINST PROPOSAL

- Appointments ... **Appt** (w/Record of Comm. Proceedings)
- Clearinghouse Rules ... **CRule** (w/Record of Comm. Proceedings)
- Hearing Records ... bills and resolutions (w/Record of Comm. Proceedings)
(**ab** = Assembly Bill) (**ar** = Assembly Resolution) (**ajr** = Assembly Joint Resolution)
(**sb** = Senate Bill) (**sr** = Senate Resolution) (**sjr** = Senate Joint Resolution)
- Miscellaneous ... **Misc**

Senate

Record of Committee Proceedings

Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Senate Bill 3

Relating to: health insurance coverage of treatment for autism spectrum disorders.

By Senators Robson, Sullivan, Hansen, Erpenbach, Wirch, Kreitlow, Jauch, Carpenter, Lehman, Lassa, Miller, Decker, Risser and Taylor; cosponsored by Representatives Hixson, Pasch, Benedict, Berceau, A. Ott, Krusick, Shilling, Turner, Young, Radcliffe, Van Akkeren, Kaufert, Sherman, Pocan, Hraychuck, Schneider, Black, Hubler, Jorgensen, Bernard Schaber, Hilgenberg, Sinicki, Hebl, A. Williams and Steinbrink.

January 13, 2009 Referred to Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation.

February 9, 2009 **PUBLIC HEARING HELD**

Present: (5) Senators Carpenter, Coggs, Vinehout, Schultz
and Kapanke.

Absent: (0) None.

Appearances For

- Judy Robson, Madison — Senator
- Kim Hixson, Madison — Rep.
- Sean Dilweg, Madison — Commissioner
- Karen Timberlake, Madison — Secretary, DHS
- Dan Kapanke, LaCrosse — Senator
- Lynn Meshke, DePere
- Bill Binger, Burlington
- Kathleen Woody, Wauwatosa — Dr., Autism Intervention Milwaukee
- Jennifer Krzoska, Muskego
- Michael Krzoska, Muskego
- Nancy Alar, Cottage Grove
- Matt Alar, Madison
- Nicole Busalacchi, Kewaskum
- Billy Mauldin, Madison
- Michelle Brenholt, DeForest
- Kelly Shariff, Manitowoc — Autism Society
- Zachary Shariff, Manitowoc
- Hallie Wiertzema, Richland Center

- Glen Sallows, Madison — Dr.
- Peggy Helm-Quest, Merrimac — Autism Society of Wisconsin
- Liz Doss-Anderson, Madison
- Kelly Brodhagen, Appleton
- Matthew Andrzejewski, Madison
- Julie Poetzel, Menomonee Falls
- Vivian Hazell, Oshkosh
- Julie Heibel, Waunakee
- Jennifer Braunschweig, Onalaska
- Vickie Lewis, Kenosha
- Barb Klug-Sieja, Beaver Dam
- Kim Starr, Madison — Sedona
- William Barreau, Sun Prairie
- Eric Anderson, Madison — Autism Society of Greater Madison
- Matthew Ward, Madison
- Monique Lomax, Madison
- Faith Morledge, Middleton

Appearances Against

- Kevin Petersen, Madison — Rep.
- R.J. Pirlot, Madison — Wisconsin Manufacturers & Commerce
- Bill Smith, Madison — National Federation of Independent Business

Appearances for Information Only

- None.

Registrations For

- Nichole Mazahreh, Monroe
- Robin Connely, Fennmore
- Linda Connely, Fennmore
- Kathlyn Maldegen, Madison
- Renee Tarmutzer, Janesville
- Lori Wing, Verona
- Stephen Seaway, Fort Atkinson — Dr.
- Karrie Erdman, Oconomowa
- Michelle Ellinger, Madison
- Jim Doyle, Madison — Governor
- Amy Masek, Sussex — Wi. Autism Insurance Now
- Al Ott, Madison — Rep.
- Molly Bushman, DeForest
- Emily Vogel, Lake Mills
- Sarah Bowen, Madison — WI. Psychological Assoc.

- Eric Fuhrmen, Waunakee
- Jennifer Kammerud, Madison — WI. Dept. of Public Instruction
- Amy Bushman, DePere
- Linda Anderson, Madison — WI. Occupational Therapy Assoc.
- Sara Diedrick-Kasdorf, Madison — Wi. Counties assoc.
- Mickey Beil, Madison
- David Cullen, Madison — Rep.
- Mark Grapentine, Madison — Wi. Medical Society
- Corrin Ehlke, West Bend
- Nissan Bar-Lev, Fox Point — Autism Society of Wisconsin
- Jennifer Johnson, Denmark
- John Donnelly, Madison — Board for People with Developmental Disabilities
- Ramie Zelenkova, Madison — Easter Seals Southeast Wisconsin
- Ramie Zelenkova, Madison — WI. Speech Language Pathology and Audiology Pro. Assoc.
- Jean Gorski, Brookfield
- Jane Skabtaie, Madison

Registrations Against

- Gary Manke, Madison — WI. Automotive Parts Assoc.
- Gary Manke, Madison — WI. Automotive After Market Assoc.
- David Storey, Madison — WI. Retail Council
- Curt Witynski, Madison — League of Wisconsin Municipalities

Registrations for Information Only

- None.

February 10, 2009

EXECUTIVE SESSION HELD

Present: (5) Senators Carpenter, Coggs, Vinehout, Schultz and Kapanke.

Absent: (0) None.

Moved by Senator Vinehout, seconded by Senator Kapanke that **Senate Substitute Amendment 1** be recommended for adoption.

Ayes: (5) Senators Carpenter, Coggs, Vinehout, Schultz and Kapanke.

Noes: (0) None.

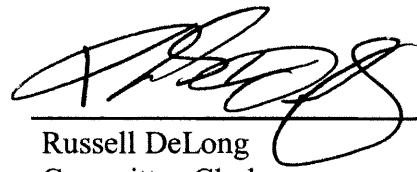
ADOPTION OF SENATE SUBSTITUTE AMENDMENT 1
RECOMMENDED, Ayes 5, Noes 0

Moved by Senator Vinehout, seconded by Senator Kapanke that
Senate Bill 3 be recommended for passage as amended.

Ayes: (5) Senators Carpenter, Coggs, Vinehout,
Schultz and Kapanke.

Noes: (0) None.

PASSAGE AS AMENDED RECOMMENDED, Ayes 5, Noes 0



Russell DeLong
Committee Clerk

Vote Record

Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Date: 2/10/09

Moved by: Vinehout

Seconded by: Kapanke

AB _____ SB 3 _____ Clearinghouse Rule _____
 AJR _____ SJR _____ Appointment _____
 AR _____ SR _____ Other _____

A/S Amdt _____
 A/S Amdt _____ to A/S Amdt _____
 A/S Sub Amdt (1) _____
 A/S Amdt _____ to A/S Sub Amdt _____
 A/S Amdt _____ to A/S Amdt _____ to A/S Sub Amdt _____

Be recommended for:
 Passage Adoption Confirmation Concurrence Indefinite Postponement
 Introduction Rejection Tabling Nonconcurrence

<u>Committee Member</u>	<u>Aye</u>	<u>No</u>	<u>Absent</u>	<u>Not Voting</u>
Senator Tim Carpenter, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Spencer Coggs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Kathleen Vinehout	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Dale Schultz	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Dan Kapanke	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Totals:	<u>5</u>	_____	_____	_____

Motion Carried

Motion Failed

Vote Record

Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Date: 2/10/09

Moved by: Vinehout

Seconded by: Kapanke

AB _____ SB 3 _____ Clearinghouse Rule _____
 AJR _____ SJR _____ Appointment _____
 AR _____ SR _____ Other _____

A/S Amdt _____
 A/S Amdt _____ to A/S Amdt _____
 A/S Sub Amdt _____
 A/S Amdt _____ to A/S Sub Amdt _____
 A/S Amdt _____ to A/S Amdt _____ to A/S Sub Amdt _____

- Be recommended for:
- Passage
 - Adoption
 - Confirmation
 - Concurrence
 - Indefinite Postponement
 - Introduction
 - Rejection
 - Tabling
 - Nonconcurrence

Committee Member

	<u>Aye</u>	<u>No</u>	<u>Absent</u>	<u>Not Voting</u>
Senator Tim Carpenter, Chair	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Spencer Coggs	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Kathleen Vinehout	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Dale Schultz	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Senator Dan Kapanke	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Totals:	<u>5</u>	<u>0</u>	_____	_____

Motion Carried

Motion Failed



Jim Doyle, Governor
Sean Dilweg, Commissioner

Wisconsin.gov

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**Testimony of Commissioner Sean Dilweg
To the Senate Committee on Public Health, Senior Issues, Long-Term Care, and
Job Creation
SSA 1 to SB 3
February 9, 2009**

Chairman Carpenter and Members of the Committee:

Thank you for the opportunity to testify today in support of Senate Substitute Amendment 1 to Senate Bill 3, relating to health insurance coverage of treatment for autism spectrum disorders.

Senate Substitute Amendment 1 goes a long way in ensuring individuals diagnosed with autism get the treatment services they need. Most notably:

- Treatment services must be prescribed by a physician.
 - This ensures a licensed medical professional has assessed an individual's condition and is prescribing necessary treatment.
- Insurers must cover at least \$60,000 for intensive-level services per year with a minimum of 30 to 35 hours of care per week for at least 4 years. \$30,000 in coverage must be provided for post-intensive level treatment.
 - This language reflects the true cost of intensive and post-intensive level services and provides a clear indication to insurers of the expected coverage levels.
- Broad definitions of intensive and post-intensive level treatment are included in the bill with the direction that the Insurance Commissioner further define them.
 - Should this bill pass, I am committed to bringing interested parties to the table in an effort to build consensus around what will specifically be categorized as intensive and post-intensive level treatment.
- Coverage may not be subject to limitations or exclusions, including the limitations on the number of treatment visits.
 - The addition of this language is important to ensure there is a clear indication to insurers that coverage not be limited. Limiting, for example, the number of visits a child can receive from any one of his or

her treatment providers could be detrimental to their progress under a treatment plan.

Financial Impact

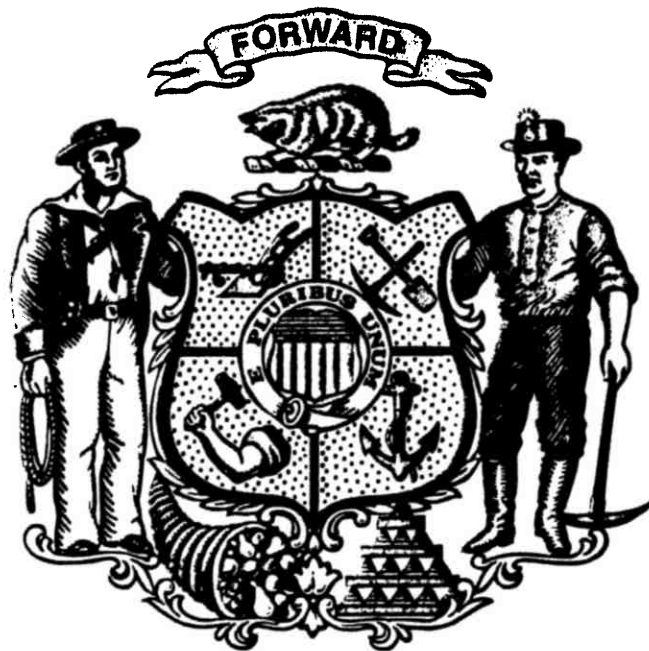
Last session my office prepared a social and financial impact statement for SB 178 which also mandated health insurance coverage of autism treatment services in the same manner as SB 3. With a focus on intensive therapies, it was estimated the mandate would cost the private insurance industry in Wisconsin approximately \$20.4 million annually. This is in relation to the approximately \$8 billion in health insurance premium collected by insurers annually in this state. When considering the 1.6 million privately insured Wisconsin residents, it is estimated the mandate will cost \$1.06 per privately insured person, per month (pm/pm).

In looking at experience in other states, I was able to obtain data from Aetna in 2007 indicating that company experienced only a \$0.007 pm/pm cost when covering services under the New Jersey mandate and \$0.004 pm/pm when covering services in Connecticut. Both mandates related to autism coverage in those states falls under the state's mental health parity laws.

Conclusion

Time is of the essence for children with autism. The key to successful intensive treatment is ensuring children receive it within the first few years of life and immediately after diagnosis. Private insurance coverage is the right thing to do to ensure kids, like those in this room today, have access to services that can afford them an opportunity toward improved cognitive and physical development. Assuming improved outcomes resulting from early access to treatment, SSA 1 to SB 3 will not only lead to improved quality of life for children with Autism but will likely 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.

Thank you Chairman Carpenter and members of the Committee for your consideration of these changes.





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**Senate Committee on Public Health, Senior Issues,
Long-Term Care, and Job Creation**

Testimony in Support of SB-3

Stephen F. Seaman, Ph.D., M.S.
2/9/2009

Mr. Chairman and members of the committee:

Thank you for the opportunity to speak on behalf of SB-3, which would require health insurance policies to cover the cost of treatment of Autism, Asperger's Syndrome and Pervasive Development Disorder Not Otherwise Specified. These three disorders are often referred to as Autism Spectrum Disorders (ASD) as they share many common characteristics. A recent study estimated the prevalence of ASD as approximately 6.0 to 6.5 per 1000 people.

As a psychologist in practice for almost 30 years, I have had the occasion to treat many patients with ASD. They represent a broad range of functioning from college graduates to learning impaired high school dropouts; from married individuals to those with severely impaired social functioning; from those with successful careers to those who have never been able to work; from those who generally function within society to those who are unable to live independently or are even incarcerated due to severe behavioral difficulties that have led to legal offenses. This range is consistent with the range that is generally seen in the ASD population. What this range of people has in common is an impairment of social interaction and communication, along with restricted activities and interests. Essentially, there is an impairment of the ability to perceive and interpret subtle or nonverbal social cues that most of us rely on in our interactions with others. Most of us intuitively understand the emotional state of those we interact with, and are able to recognize their response to us. This ability is impaired for people with ASD.

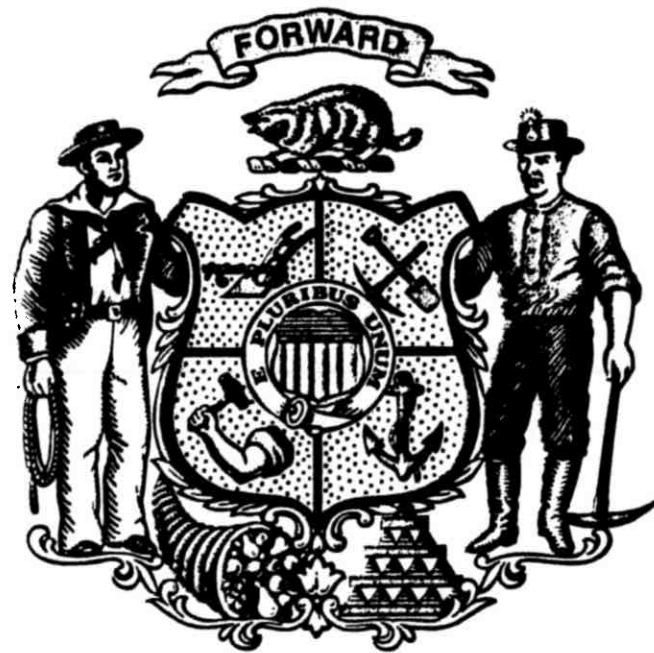
While I cannot say with certainty why ASD has been excluded from coverage by many insurance policies, there may be several reasons. First, while the causes of the disorder are complex and varied, in most cases there is a significant neurological component. Therefore, it has sometimes been viewed as similar to mental retardation, Parkinson's Disease and other neurological conditions that are not amenable to psychological or psychiatric treatment. Second, because each person with an ASD has a unique set of strengths and weaknesses, treatment is best individualized to the needs of that person, making systematic research on the efficacy of treatment more difficult. Third, when

people with an ASD enter treatment, it is usually for treatment of another problem (depression, anxiety, loneliness, anger problems, behavioral problems, job loss). Even though the ASD may be a causal basis for the presenting problem, oftentimes the treatment focuses on the presenting issue, and once that has improved treatment ends.

Cure or remission of symptoms as we might expect in the treatment of depression, anxiety, phobias, panic attack or even bipolar disorder or schizophrenia, is generally not possible for Autism Spectrum Disorders. Nonetheless, some of my most rewarding experiences as a psychologist have been in treating these types of patients, and some of the most important long term impact on functioning has occurred. It is for this reason that I support this bill. The goal of treatment is initially to help both patients and important people in their lives to label and understand what is "wrong." Typically patients and their families recognize that they are "different", or "don't fit in", but don't understand why. The next part of therapy is concrete social skills training, so that the patient can learn a set of "rules" about how to behave and understand the behaviors of others in order to function better in normal social settings, including work and school.

Look Me in the Eye: My Life with Asperger's by John Elder Robison is a fascinating personal discussion of this process. The title reflects one of the skills the author needed to learn: to look the other person in the eye when speaking with them, an innate instinct most of us have, but was missing in him (and many others with ASD). By learning a set of rules or procedures, patients with ASDs can function much more effectively in many aspects of their lives.

Aside from improved quality of life for individuals with Autism, Asperger's or a Pervasive Developmental Disorder, effective treatment is a benefit to the society at large. The incidence of secondary psychiatric disorders which would require treatment (such as depression, anxiety or profound loneliness) is reduced. Behavioral or anger control issues, which can result in job loss, police involvement or incarceration, will be reduced. Finally, some people with ASDs, along with areas of deficit, have areas of unique ability and talent. As a society we can best benefit from the unique contribution that individual might have to offer, if they have learned to manage the areas of deficit.



Testimony before the
Senate Committee on Public Health, Senior Issues, Long-Term Care & Job Creation
on

Monday, February 9, 2009, 10:00 am
Room 411 South, Capitol

Presented by
State Senator Judy Robson, 15th District

In support of SB 3 and SSA 1 to SB 3, Autism Insurance Coverage

Thank you, Sen. Carpenter for holding this hearing on Senate Bill 3.

With the help of this legislation, more Wisconsin children diagnosed with autism will be able to receive the treatment they need to function to their fullest potential.

SB 3 builds on the autism proposal that was considered last session. It passed the Senate on a 25 to 8 vote. And if the bill had been allowed to come to a vote in the Assembly, it likely would have also passed in that house. Both bills require individual and group health insurance policies and self-insured, governmental and school district health plans cover treatment for persons with autism, Asberger's syndrome or other pervasive developmental disorders.

To strengthen this bill, I introduced a substitute amendment which is the result of work with legislators, advocates, the Insurance Commissioner and others to be sure that there is coverage for as many persons as possible.

You have before you a copy of the substitute amendment as well as a Legislative Council memo comparing the bill as introduced and the changes in the substitute amendment.

Briefly, the changes are as follows:

- Defines treatment coverage and hours of covered care. Specifically, it requires coverage levels to be at least \$60,000 for intensive-level services and at least \$30,000 for post-intensive-level services per year per insured person. It also requires a minimum of 30-35 hours of care per week for a minimum duration of four years.
- Defines "intensive-level services" as evidence-based behavioral therapy that is designed to help an individual with autism spectrum disorder overcome the cognitive, social and behavioral deficits associated with that disorder.
- Defines "post-intensive level services" as therapy that occurs after the completion of intensive-level treatment and is designed to sustain and maximize gains made during intensive-level treatment. For those individuals who have not and will not receive intensive-level treatment, post-intensive level therapy may improve their condition.

These definitions ensure that covered autism treatments are based on medically recognized practices.

- Requires a physician's prescription for autism coverage. This change is included so that treatment is overseen and approved by a medical professional, rather than an insurance company's independent analysis as is the case in other states.
- Allow the treatment plan to be revised or reduced by the supervising professional, in consultation with the prescribing physician if it is determined that less treatment is medically appropriate.

- Add speech and language therapists and occupational therapists to the list of qualified providers.
- Grant rulemaking authority to the Office of the Commissioner of Insurance to establish the criteria for qualified providers.

However, all this talk about insurance coverage and legislative votes must not overshadow the real reason we are working to pass this bill.

We are dedicated to this effort because we believe that persons with autism deserve to our respect, our support and our recognition.

Until recently, autism was considered a life-long disability with poor prognosis. Now, with early and appropriate treatment, children can see dramatic improvements.

Even though autism is a recognized medical condition with a DSM code, many insurance companies refuse to provide coverage. In order to get treatment for their child, many families pay out of their pockets – sometimes sacrificing their home, family stability, their hopes and their dreams.

Autism is a growing problem. As many as a half-million Americans under the age of 21 are autistic. That's about 1 in every 150 children who are affected by this disease.

Children with autism in Wisconsin should not have the same access to insurance coverage as in other states. According to the National Conference of State Legislatures (NCSL), at least 25 states require insurance coverage for individuals with autism. Those states include Illinois, Minnesota, South Carolina, Florida, Arizona, Texas, Pennsylvania, Connecticut, Kentucky and Indiana. Wisconsin should join that list.

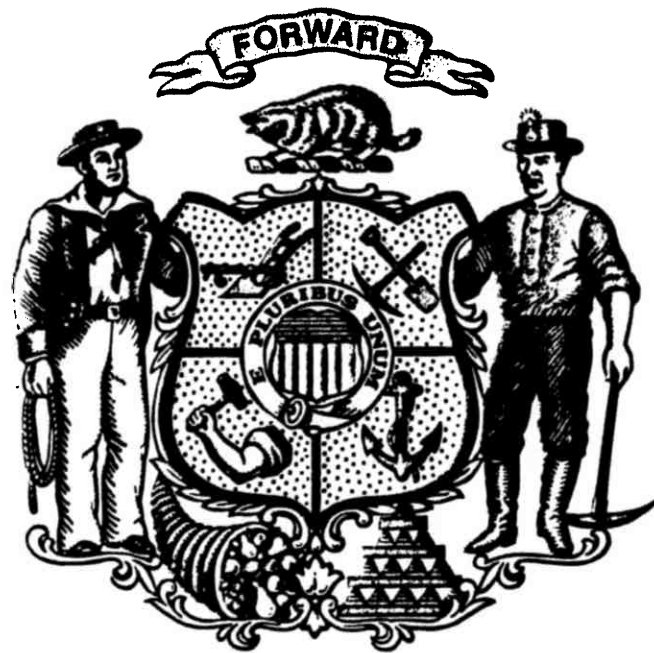
To demonstrate how important early intensive intervention, I would like to share with you a recent personal experience.

Just a few weeks ago, I first learned about Drew Goldsmith. Drew is a 12-year-old student, he is autistic and he is a filmmaker. As a volunteer with the Beloit International Film Festival, I had the pleasure of learning about his short film that will be shown at the Festival later this month.

Entitled "Treasure Diversity," Drew's film is a call for all of us to celebrate every kind of diversity. And that included the diversity known as autism. This is not Drew's first film nor is likely to be his last. He has wanted to make films for as long as he can remember.

While Drew struggles with speech, he has found ways to "speak" with eloquence and heart through his film. In an interview on his website, he said: "It is my profound opinion that those who desire to divide us into high- versus and low-functioning autistics deliver a great disservice to our common quest for true equality."

Drew is not alone. I expect that every parent here today will tell you they want their child with autism to be treated with fairness and dignity. With this bill, we can take a giant step toward that goal.



Statement in favor of Senate Bill 3
February 9, 2009

My name is Eric Anderson, and I'm the President of the Autism Society of Greater Madison. The many people here today are looking to you to bring greater fairness to the citizens of Wisconsin when they utilize their health insurance.

Early diagnosis and treatment of autism is critical to successful outcomes, but proven therapies are often expensive and not covered by insurance in this state. Wisconsin does have a waiver program, but the magnitude of the need overwhelms the available slots, meaning families are left to fend for themselves when timely action is most critical. This forces parents to pay out of pocket and often cripple their financial outlook, or worse, watch their child deteriorate before their eyes. It is unconscionable that any parent should be put in that position.

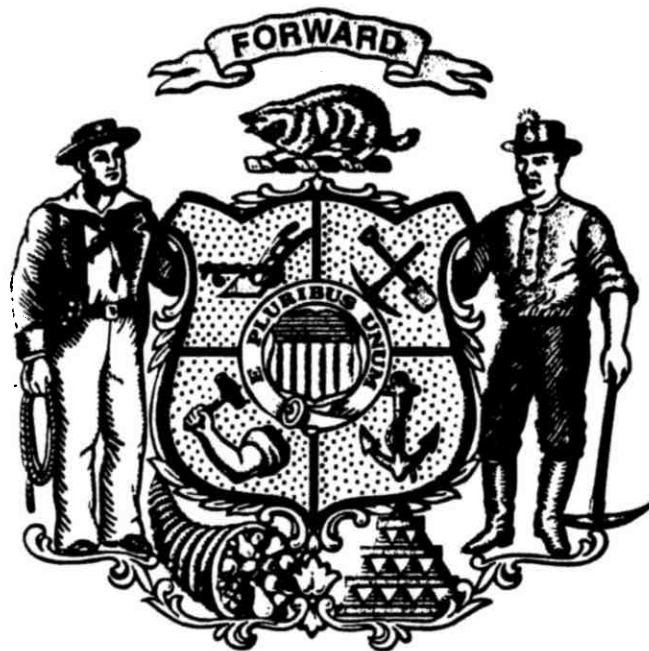
Beyond the early years, people on the autism spectrum face health concerns throughout their lifespan for which insurance denies them coverage. Let's be clear here: autism is a HEALTH problem. Why on earth should it be singled out and not be covered by HEALTH insurance?

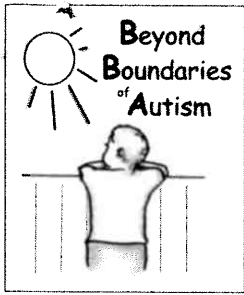
I understand and appreciate the concerns of those who oppose yet another insurance mandate. Passing this bill would increase insurance premiums to private employers. These increased costs are generally a drag on profits or passed along to employees. However, not having a mandate doesn't make health care any cheaper. It just concentrates that cost on an unfortunate few – our most vulnerable citizens. It's also true that with each incremental increase in cost, some will CHOOSE to forego insurance and leave themselves open to the possibility of financial ruin. The key to remember is the whole point behind insurance is risk sharing and risk abatement when an outcome would be catastrophic. This bill allows families confronted with autism to get help in their time of need, the same as families sharing the burden of cancer, diabetes, or other health issues. If others then choose not to abate the potential costs of their health risks, I would say that at least they were given a choice.

When you have a child with autism, the milestones that other parents take for granted are always an open question. From the moment of diagnosis, there's an ongoing question whether our sons or daughters will ever go to college, get married, or hold a steady job, but it doesn't have to be like that. Passing this bill won't eliminate the challenges these families face, but it does remove one of their barriers and provides more equal footing. My son, Carl, will be heading off to college this fall as a National Merit Scholar, and you will see many more such stories if these exceptional children are given the help they need to succeed and become productive citizens.

Wisconsin has a long history of looking out for families, and I know all of you want to do the right thing for all of your constituents. I hope you will choose to correct what the insurance companies have not done and will not do on their own. Thank you.

Eric G. Anderson
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Madison, WI 53705
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(608) 663-7526 x305 (w)





Beyond Boundaries of Autism
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Skaiser_bba@gwicc.org

A program of **Goodwill** NCW
Serving North Central Wisconsin Communities

Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Senator Tim Carpenter (Chair)
Senator Spencer Coggs
Senator Kathleen Vinehout
Senator Dale Schultz
Senator Dan Kapanke

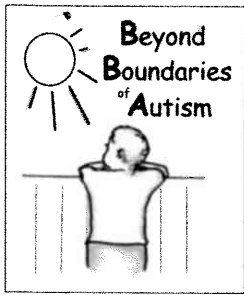
**Public Hearing Senate Bill 3
February 9, 2009**

Relating to: health insurance coverage of treatment for autism spectrum disorders.
By Senators Robson, Sullivan, Hansen, Erpenbach, Wirsch, Kreitlow, Jauch, Carpenter,
Lehman, Lassa, Miller, Decker, Risser and Taylor; cosponsored by Representatives
Hixson, Pasch, Benedict, Berceau, A. Ott, Krusick, Shilling, Turner, Young, Radcliffe,
Van Akkeren, Kaufert, Sherman, Pohan, Hraychuck, Schneider, Black, Hubler,
Jorgensen, Bernard Schaber, Hilgenberg, Sinicki, Hebl, A. Williams and Steinbrink

Request for expansion of SECTION 9 to Include Licensed Professional Counselors

Submitted by:

Vivian Hazell Program Director/Lead Therapist - Beyond Boundaries of Autism



Beyond Boundaries of Autism
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Serving North Central Wisconsin Communities

Request for expansion of SECTION 9 to Include Licensed Professional Counselors

On behalf of Beyond Boundaries of Autism's families and professionals we are asking you to expand the categories of professionals listed in **SECTION 9** to include Licensed Professional Counselors.

As the bill now reads, the following are listed as authorized providers

1. A psychiatrist, as defined in s. 146.34 (1) (h).
2. A person who practices psychology, as described in s. 455.01 (5).
3. A social worker, as defined in s. 252.15 (1) (er), who is certified or licensed to practice psychotherapy, as defined in s. 457.01 (8m).
4. A paraprofessional working under the supervision of a provider listed under subds. 1. to 3.
5. A professional working under the supervision of an outpatient mental health clinic certified under s. 51.038.
6. A speech language pathologist, as defined in s. 459.20 (4).

As we make this request, we firmly believe that the skills of Wisconsin Licensed Professional Counselors, as described below, certainly justify inclusion in this opportunity.

Wisconsin Department of Regulation & Licensing oversees this professional group and describes their expertise as follows:

Professional counseling means applying a combination of human development, rehabilitation and either psychosocial or psychotherapeutic principles, procedures or services that integrate a wellness, pathology and multicultural model of human behavior in order to assist an individual, couple, family, group of individuals, organization, institution or community to achieve mental, emotional, physical, social, moral, educational, spiritual, vocational or career development and adjustment through the life span of the individual, couple, family, group of individuals, organization, institution or community.

No person may practice professional counseling or use the title "professional counselor", "professional rehabilitation counselor", "vocational rehabilitation counselor", or "rehabilitation counselor" or any similar title unless the person is licensed as a professional counselor by the Professional Counselor Section of the examining board.

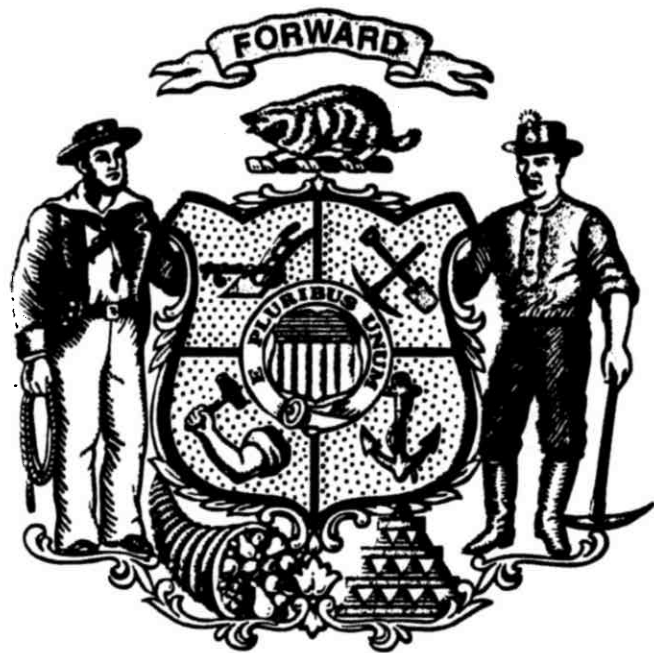
We make this recommendation in light of the great work that professionals with this credential have already been doing on behalf of children with autism under the current waiver system. In addition, the state has invested a great deal of quality oversight of this group and can insure the professional standards as set forth in the regulations. Expanding the bill to include this profession not only expands the talent pool that can serve potential families but also opens an avenue of employment for individuals that have already invested in becoming recognized by the state of Wisconsin as trained and appropriate professionals.

Thank you for consideration of this request.

Respectfully Submitted:

Vivian Hazell LPC

Program Director, Beyond Boundaries of Autism





Date: February 9, 2009

To: Chairperson Carpenter, Members of the Senate Committee on Public Health, Senior Issues, Long-Term Care, and Job Creation

Re: Senate Bill 3, Substitute Amendment 1

The Wisconsin Speech-Language Pathology and Audiology Professional Association (WSHA-P) strongly supports Senate Bill 3 with Senate Substituent Amendment 1, which includes speech-language pathologists as providers of services for individuals diagnosed with autism spectrum disorder. WSHA-P applauds Senator Judy Robson, Representative Kim Hixson, Governor Doyle, legislative co-sponsors, families, and advocacy groups for their dedication to this important issue.

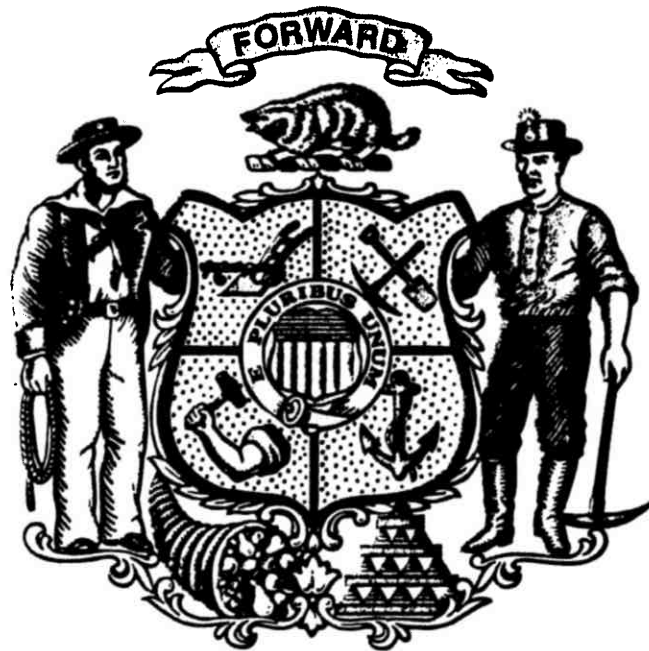
Speech-language pathologists specialize in evaluating and treating infants, children, adolescents, and adults with communication problems. Speech-language pathologists hold masters or doctoral degrees and many have earned national certification through the American Speech-Language-Hearing Association (CCC-SLP or CCC-A).

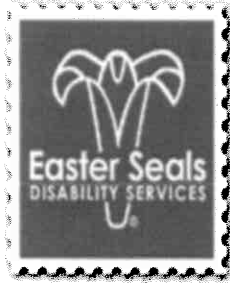
Speech-language pathologists are independent therapy providers, but they often work as part of a team which may include physicians, audiologists, and psychologists. Speech-language pathologists work in a variety of settings including: hospitals, rehabilitation centers, public and private schools, community clinics, adult day care centers, private practice offices, long-term care facilities, and state and federal government agencies. Depending on the specific work setting Wisconsin requires licensure to practice as a speech-language pathologist from the Department of Regulation and Licensing or the Department of Public Instruction.

Communication problems can range from fluency/stuttering disorders to vocal/voice disorders, speech disorders, or language disorders resulting from a variety of causes. Speech-language pathologists work with a variety of patients including individuals with autism spectrum disorder (ASD), cleft palates, learning and physical disabilities, language delay, hearing loss, and eating, swallowing and communication problems following stroke or a traumatic brain injury or disorder, such as Parkinson's disease.

Speech-language pathologists are trained to evaluate how individuals produce speech, how individuals understand language, and how individuals express themselves. All individuals with ASD are challenged in the area of social communication. Thus, many individuals with ASD have difficulty acquiring the form and content of language and/or augmentative and alternative communication systems, and all have needs in acquiring appropriate social use of communication. Given the nature of autism spectrum disorder it is important that a speech-language pathologist play a critical role in screening, diagnosing, and enhancing the social communication development and quality of life of children, adolescents, and adults with ASD.

The Wisconsin Speech-Language Pathology and Audiology Professional Association appreciates the opportunity to provide information on speech-language pathologists and the important role they play in screening for autism spectrum disorder, and of equal importance in enhancing the lives of individuals with autism spectrum disorder.





Date: February 9, 2009
To: Chairperson Carpenter, Members of the Senate Committee on
Public Health, Senior Issues, Long-Term Care, and Job Creation
Re: Senate Bill 3, Substitute Amendment 1

Easter Seals Southeast Wisconsin touches the lives of nearly 10,000 children and adults with disabilities in our state. We have a seventy-five year history of meeting the needs of children and adults with autism and other developmental disabilities. We believe the proper therapy and treatment for individuals with autism will result not just in important personal gains for these individuals, but also have larger societal effects. For each \$1 we spend on early intervention, \$7 is saved in future support costs in special education and Medicaid waiver funds.

Easter Seals Southeast Wisconsin strongly supports Senate Bill 3 with Substitute Amendment 1 to extend health insurance coverage to individuals diagnosed with an autism spectrum disorder. Easter Seals applauds the efforts of Senator Judy Robson, Representative Kim Hixson, Governor Doyle, legislative co-sponsors, families, and advocacy groups to assure the best, most effective treatments are offered to Wisconsin families living with autism.

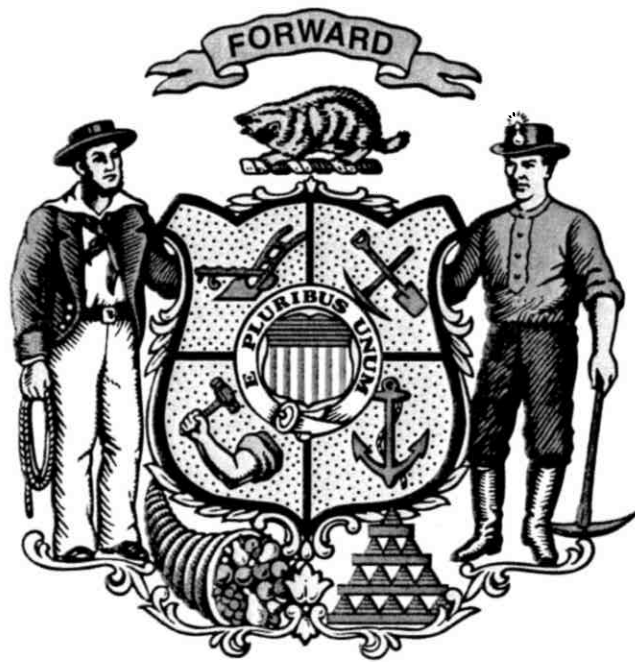
Easter Seals strongly supports the inclusion of licensed speech and occupational therapists as independent service providers. These trained professionals have a long history of delivering services through the Birth to 3 Program and other medical treatment. The inclusion of speech and occupational therapists will also help maintain a reasonable cost structure of services.

Easter Seals strongly supports evidenced-based practices like P.L.A.Y. Project that truly fight autism and its effects. P.L.A.Y. Project is currently part of National Institute for Health study in ten Easter Seals affiliates across the United States. P.L.A.Y. Project is based on Dr. Stanley Greenspan's DIR (developmental, individualized and relationship based) philosophy and Floortime. P.L.A.Y increases engagement in children with autism to develop stronger family and social relationships. In addition, it makes the parents the prime-movers in therapy with the support of a trained P.L.A.Y. consultant.

Easter Seals believes parental choice is key to the success of any treatment. The current waiver system has limited treatment options, which may or may not be right for each child or each family, depending on their own circumstances. Senate Bill 3 with Substitute Amendment 1 will allow families to work with their physician to determine the best therapy for their son or daughter.

Easter Seals is eager to begin serving more children with autism and to combat this horrible epidemic that affects 1:150 children and has even higher rates among boys 1:88.

We are committed to providing hope, help and answers to families in Wisconsin living with autism.



Monday, February 9, 2009

Good morning. I am here today to speak in favor of SB3 which would require group insurance plans to cover individuals with autism spectrum disorder (ASD).

I am the mother of Henry Meshke, a seven-year-old boy with autism and cerebral palsy (CP), both developmental disabilities. We are a solidly middle-class family and we purchase the best private insurance available to us through my husband's employer. Our insurance is very expensive but our twin boys were born 12 weeks early and spent 10 weeks in the neonatal intensive care unit so we recognize the importance of good insurance. We gladly pay the premiums so that our children will have the best healthcare available to them if the need arises.

Sadly, our expensive insurance *does not cover a single service related to my son's autism or CP*. When I say they do not cover a single autism- or CP-related service, let me be very clear about what that means -- it means that despite the fact that we pay more than \$5,000 per year for the best insurance available, that insurance will not cover Henry's in-home therapy. It will not cover Henry's physical therapy. It will not cover Henry's occupational therapy. It will not cover Henry's speech therapy. It will not cover anything remotely related to Henry's autism and you would be amazed at what insurance companies can relate to autism.

If we were to pay out of pocket for the many therapies that have been prescribed for Henry, it would cost us *\$8000 or more per month* just for therapy. We love our son and we want what is best for him but we simply cannot afford to spend in excess of \$50,000 per year for the many therapies he needs. As a result, Henry must settle for the therapy we can afford, not the therapy he truly needs.

Many of the parents and professionals you will hear from today will tell you that we need an autism insurance mandate because we need to eliminate the waiting list for early and intensive therapy. They are absolutely right. It is horrifying to know that parents who have recently received the devastating news of their child's autism diagnosis are then being told their child must wait almost two years for treatment.

I think we can all agree that if this bill passes, it will help to reduce or even eliminate the current waiting list. This is a good thing. However, as the parents of a child who is almost 8 and who no longer receives intensive services, my husband and I are more concerned with two other aspects of this bill.

The first is the fact that this bill addresses the life-span of individuals with autism. I believe that every parent of a child with autism, no matter how high-functioning, looks into their child's future with fear. Why? Because, to date, the primary focus of autism programs here in Wisconsin has been very young children. We seem to have forgotten that these very young children quickly become teens and eventually adults. And as they age, their needs do not disappear, they simply change. We are here today because, regardless of age, not a single one of the 35,000 individuals with autism in the State of Wisconsin receives group insurance reimbursement for their autism-related treatment. Furthermore, even if every one of those

35,000 individuals received early and intensive treatment through existing state-funded programs, 50% or more of them would still never be fully mainstreamed. Unfortunately, like our son, a significant number of them will need life-long services and support. As I said earlier, if private insurance doesn't cover the needs of these individuals, those needs do not simply disappear. In some cases, those needs are ignored but when they cannot be ignored, they are met with taxpayer funding.

Let's be clear about the seriousness of this situation...The autism rate continues to skyrocket with no end in sight. Insurance doesn't cover autism and the taxpayers are left holding the bag. The system as it currently exists is already unable to cope with the needs of individuals with autism as is evidenced by the 2-year waiting list. Surely we should all be asking ourselves, if the situation is so dire now, where will we be in 10 years? Honestly, these are the sort of worries that keep parents like me awake at night.

To me, the solution is simple. If we pass the autism insurance bill now WITH a life-span requirement, not only will we be guaranteeing that many individuals with autism will be off-loaded from state-funded programs to private insurance, we will also be freeing up funds to address the needs of those who require long-term services and support but cannot ever access private insurance.

I know that when the Senate debates the merits of this bill, there will be those who argue that we do not need a life-span component, that it will be enough to simply cover early and intensive treatment. And even if the bill passes with a life-span component, there will be those who lobby the Office of the Commissioner of Insurance to drop it. As the parent of a child who is likely to need long-term services, I beg you not to compromise on this component. The healthcare and treatment needs of teens, young adults and adults with autism may not receive the same attention as the needs of small children with autism, but they are equally as significant and deserve to be included in this legislation. With the proper help early on and strong supports later in life, people of all ages with autism can and do contribute a great deal to their respective communities and to our state. It is only right that this bill protect their rights as well.

The second issue that is near and dear to the hearts of our family is the importance of covering not only behavioral therapy but complimentary therapies such as physical, occupational and speech therapy. I believe the most current language of SB3 specifies coverage for these therapies but I predict there will be those who recommend cutting physical, occupational and speech therapy in an attempt to reduce the scope and cost of the bill. Please do not compromise on this issue as many individuals with autism struggle with motor and language skills. On-going access to qualified therapists can significantly improve their chances at independence and reduce their need for costly supports later in life.

In closing, let me say that my husband and I see SB3 as a cross-road for our state. In the past, Wisconsin has been a leader in providing services to and protecting the rights of individuals with autism. I am sad to say that we have fallen behind. Several dozen states have passed or are currently debating bills similar to the one currently before you. They have already recognized that we have two choices -- we can allow insurance companies to continue posting record profits while shirking their duties or we can demand that they provide the same level of coverage to

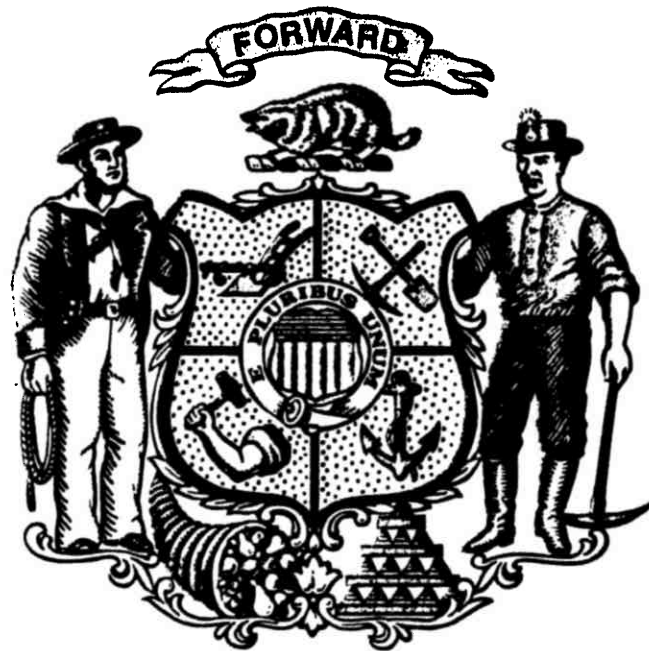
developmentally disabled citizens as they do to everyone else. For our family and other families living with autism, the choice is clear. I hope the same is true for you.

I thank you for your time. I have provided you with a copy of my comments and contact information. I encourage you to contact me if I can answer any questions, clarify any comments or offer you additional insights into the challenges and joys of loving and raising a child with autism.

Lynn Meshke
Mother to Henry Meshke (age 7), autism and CP
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This is our son Henry. He is 7-years-old and has both autism and cerebral palsy. Henry is non-verbal and walks with a walker but he has demonstrated that he is very smart. Despite not speaking, he is quite charming and has a great sense of humor. We would ask that you think about Henry and others like him when you consider this bill. Please remember that although he is 7 now, he will someday be a grown man with significant needs who will benefit from an autism insurance bill that protects his rights throughout life.





Wisconsin

**Statement Before the
Senate Committee on Public Health, Senior Issues, Long Term Care
and Job Creation**

By

**Bill G. Smith
State Director
National Federation of Independent Business
Wisconsin Chapter**

**Monday, February 9, 2009
Senate Bill 3**

Mr. Chairman and members of the Committee, thank you for allowing me to make a brief statement on behalf of small and independent business.

I am not participating in today's hearing to diminish or deny the cost and anguish that comes with the treatment of an autistic child.

However, contrary to the goals of those who favor this legislation, quite the opposite of expanding health insurance coverage to cover the treatments for autistic children could be the net result.

A government mandate to expand insurance coverage has little to do with big insurance companies.

They will sell the coverage. The question is whether small business will be able to afford to buy it.

According to Mercer Health and Benefits, health insurance costs in Wisconsin are already 23% above the national average. Only about 41% of Wisconsin small business employers offer health insurance to their employees, and that percentage is decreasing every year as health insurance plans become less affordable and economic challenges more formidable. Health insurance costs increase for many reasons, but there is no question government mandated coverage's contribute to less coverage or no coverage for many small business owners and their workers.

Testimony by Bill G. Smith, NFIB – continued
Senate Committee on Public Health, Senior Issues, Long Term Care and Job Creation
Page Two

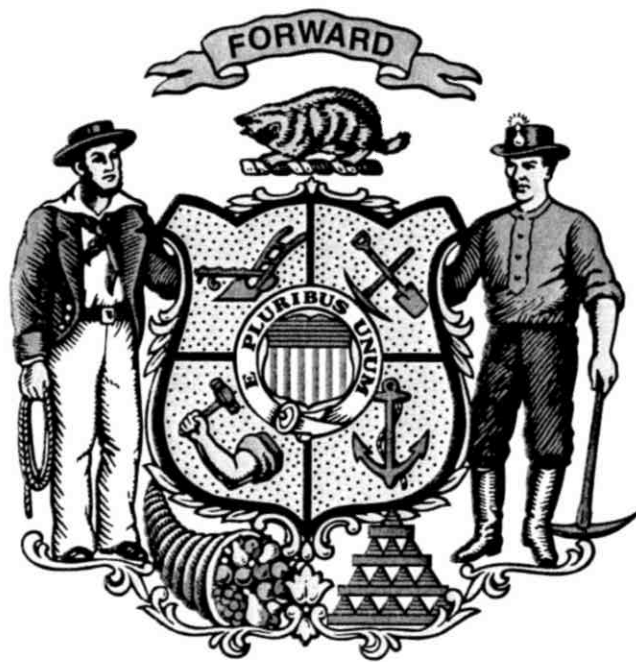
I know the proponents of this legislation argue the impact on cost is minimal. However, studies show a mere 1 percent increase in the cost of a health insurance plan equals over \$36 million in premium costs for those who purchase group health insurance, primarily small employers.

This mandate, at best, Mr. Chairman, will affect only about 26% of Wisconsin citizens in the commercially insured market. Obviously, passage of this legislation will not adequately or efficiently address the concerns of the authors of the bill. In fact, passage of this bill may result in less coverage or even no coverage - but passage will clearly result in higher insurance costs for small business.

Small business owners believe they should have the freedom to structure their plans based on affordability and the needs of their workforce, without mandates by government.

These children need and deserve treatment. However, I urge members of the Committee to examine all the options, and to resist the easy mandate response to this very serious issue. A response that, in the long term, will fail.

It is on behalf of these small business employers that I request a vote against passage of SB 3.



February 9, 2009

SB 3?

My name is Renee Tarnutzer and I am from Janesville. I always thought my son, Alex, would have the same opportunities as every other child – no matter what. Even last November, when we heard the words “Alex has Autism,” my husband and I thought to ourselves, “OK. He’s been through four daycares. We know he’s been struggling. We can manage this. We’ll get him the help he needs and he’ll be OK.” Never in a million years did I think that simply trying to get Alex the help he needs would be one of the biggest battles of my life.


First, we tried to get insurance coverage for the diagnostic appointment and it was denied – a financial blow of five hundred and fifty dollars. Then came the evaluations – also not covered by insurance. We turned to our school district for help. Although they determined his autism will have a “negative impact on his educational performance,” he does not qualify under state guidelines for help. In April we are supposed to have another appointment with the diagnosing pediatrician but we may have to cancel it so that we can put the five hundred dollars toward other therapy sessions that might be more beneficial. Three months after the diagnosis and we are faced with the fact that we are alone financially in this fight.

Alex needs help from an occupational therapist for fine motor and sensory processing and from a psychologist for social skills, rigidity, transitions and aggression. Since he doesn’t qualify for help from the school or for the autism waiver through the state, we are faced with choosing from the therapies that the doctors recommend because we can’t afford all of them. Any help that he gets will be out of our pocket – a very expensive journey.

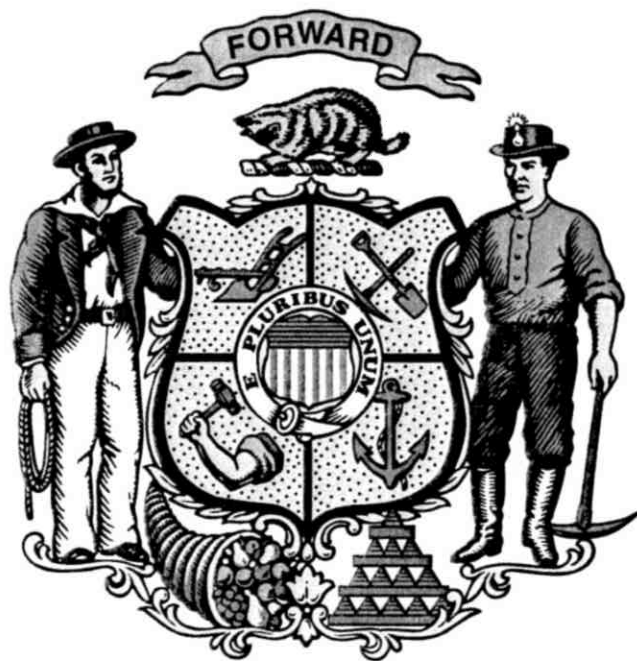
Just imagine knowing that there is help for your child but you cannot provide it for him financially. Imagine the guilt you would feel. And there are many kids out there who need much more therapy than Alex does – and at a much higher price tag.

Alex has high functioning autism and it is treatable – if he gets the help he needs NOW. Unfortunately, Alex will only get as much help as we can financially afford to give him because he does not qualify for help from the outside – not from insurance, not from the autism waiver and not from the school district. Alex, and countless others like him, is falling through the cracks. With the proper treatment, Alex will be a higher functioning adult someday. Without the help of our insurance, though, we will stretch our dollars as far as we can but it still will not help him reach his highest potential.

This is a battle like no other. You already know the facts and figures about Autism. You don’t need to hear them again from me. The fact is that these are our kids. This world is already difficult enough for them as it is. We don’t need to make it more difficult. No child, not mine, not yours, not any child in this state, should be deprived of getting the help that they need for a medical condition. You have the power to change their lives. You need to do the right thing. Pass this bill. Let these kids fight the good fight and help them conquer this battle with Autism.



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State of Wisconsin
Department of Health Services

Jim Doyle, Governor
Karen E. Timberlake, Secretary

SB 3?

Testimony of Secretary Karen Timberlake
Senate Committee on Public Health, Senior Issues, Long-Term Care and Job Creation
February 9, 2009

Good morning Chairman Carpenter and members of the Committee. Thank you for inviting me and thank you for taking up this important legislation.

A similar version of this bill was included in Governor Doyle's biennial budget during the 2007-08 session and was approved by the full Senate. Governor Doyle and we at the Department of Health Services appreciate the past support of the Senate for this important legislation. We are optimistic that this bill will be passed into law and will make treatment for autism spectrum disorders accessible and affordable for more Wisconsin families.

What is Autism?

Autism is a developmental disorder defined by symptoms, appearing before the age of three, which reflect delayed or abnormal development in three areas: language development, social skills, and restricted and repetitive behavior.

The severity of these developmental delays varies widely from child to child. The three most typical diagnoses are autism, Asperger's syndrome, and pervasive developmental disorder not otherwise specified. This range of diagnoses makes up the "autism spectrum." The level and type of treatment needed is directly related to where the child falls along the spectrum.

In recent years the rate of autism spectrum diagnoses has skyrocketed. Currently, 1 out of every 150 children is diagnosed somewhere on the autism spectrum, compared to 4 out of every 10,000 just two decades ago.

Fortunately, the outlook for children with an autism spectrum disorder is better now than ever before. Before the 1990's, children with autism did not receive much help and many of them did not get much better. Now, research – much of it done right here in Wisconsin – shows that with proper treatment, about half of even the more severely affected children can improve enough to succeed in school and live in many respects as typical children do.

During the toddler and preschool years, children are able to learn rapidly. For this reason, children with social and language delays show much greater improvement if they begin treatment before age five and receive intensive treatment (35 to 40 hours per week) during their first few years of life.

Children's Long Term Support Waivers and Autism

Treatment for autism spectrum disorders is very expensive. The State, through the Children's Long-Term Support Medicaid Home and Community-Based Services Waivers, has provided funding for treatment services for children with autism spectrum disorders since 2004. These waivers were reauthorized for 5 years in November 2006, and the State follows a 5-year renewal cycle.

Children in the intensive component of the current waiver program receive one-on-one behavioral treatment only. No other non-treatment services are authorized for children in the intensive phase of the program. Children enrolled in the on-going autism waiver program may continue to pursue behavioral treatment, although fewer hours of treatment are covered. They may also receive other therapy and supportive services intended to sustain and maximize gains made during intensive-level treatment.

As of January 1, 2009, there were 695 children receiving intensive in-home treatment services and 1,276 receiving ongoing treatment and community services under the waivers. There were 335 children waiting for autism services due to funding limitations. It is estimated that children beginning to be served as of January 1, 2009 have waited approximately 12 - 18 months for waiver funding, including the time spent attaining a diagnosis and determining eligibility.

In the year or more that these children wait for an opening in the waiver program, their parents are faced with a difficult choice: spend thousands – frequently tens-of-thousands – of dollars out of their own pockets to pay for treatment, or wait and hope their child doesn't fall further behind. Reports of families selling their homes, taking out second mortgages, taking on second and third jobs, are all too familiar to anyone who has interacted with a family with a child on the autism spectrum.

If SB 3 becomes law, the Department of Health Services estimates that requiring insurers to cover treatment services for autism treatment will allow approximately one-third of the children currently eligible for the waiver program but on the waiting list to access the same level of services through their private insurance.

In addition, a significant number of children currently in the state waiver program will be able to access the same level of care through private insurance. We estimate that 34% of children in the "intensive treatment" program and 11% in the "post intensive" treatment program will be able to access private insurance under SB 3. This will open up additional slots in the waiver program to serve families on the wait list who cannot access private insurance.

With families transitioning from the waiver program and the waiting list to private insurance, we estimate that the entire waiting list will be eliminated by 2011.

Transitioning Children from the Waivers to Insurance Coverage

Passage of SB 3 will require families who are currently being served by the waiver program to transition to private insurance coverage if it is available to them. We understand that many parents currently in the waiver program may wish to stay in the program; however, federal regulations require that Medicaid is the payer of last resort, including Medicaid waiver programs. Families with private insurance that meets the provisions of SB 3 will not be able to access the waiver program.

Children will not be abruptly cut off from the waiver program once SB 3 is signed into law. Children who are eligible for waiver services will continue to receive those services until it has been determined that they have insurance that will fund the service.

DHS will work with local waiver agencies to help identify those waiver participants who may have health insurance. DHS will work with local waiver staff and families to design a plan that assures continuity of service and a smooth transition to treatment covered by insurance. We will develop informational materials that will be distributed to local waiver agencies so that waiver agency staff can help families and their providers smoothly coordinate the process of accessing available insurance coverage for services provided.

SB 3 represents a long-term solution to the problem of the waiver waiting list. Passage of this bill will allow children to access treatment as soon as possible. Autism is a condition that cannot be cured but can be treated successfully. Early diagnosis and treatment are vital. SB 3 will allow families more options to access early, intensive treatment and will improve the future of hundreds of Wisconsin's children.



February 9, 2009

SB 3?

Good morning. My name is Peggy Helm-Quest and I am the mother of two children and serve on the Autism Society of Wisconsin (ASW) Board. My oldest child Nate is 14 and was diagnosed with Asperger's Syndrome/Autism at the age of 4. As a state employee (I work for the Division of Public Health as a consultant), I have had to change insurance providers 4 times due to continual denials regarding Nate's health care after his diagnosis of Asperger's was put on his health record - only to default to the insurance provider I currently maintain, because there are no other insurance provider choices left to choose from.

When Nate was 3, we began our quest to seek a psychological assessment to determine why Nate was exhibiting violent tantrums lasting hours on end. Asperger's syndrome is not a more milder form of Autism, it's presentation is just different and requires a different skill-set to address, manage, and cope with the tantrums, rages, meltdowns, and anxiety when the person with Asperger's is unable to communicate their frustrations and sensory overload.

Getting an insurance authorization to see a Psychologist was denied, so we paid out-of-pocket for an initial evaluation and follow-up consultation. We left her office with an apology and a diagnosis. Being in the health field, I sought a second opinion to see a Developmental Pediatrician. That was also denied by my insurance. We continued to appeal for over a 1 year period, meanwhile his diagnosis questioned any insurance support for even basic health services, so we changed insurance providers.

Our Pediatrician helped secure 1 (one) Developmental Pediatrician visit which confirmed the diagnosis at age 4. The Developmental Pediatrician referred Nate to a Neuro-Psychologist to help further define his disorder. After being put on over a 1 (one) year waiting list, the insurance company blocked the appointment on the day of the appointment, citing coverage denied. At this point, Nate was able to read and had a vocabulary of a 5th grader - however he was not toilet trained, could not play with other children, and experienced huge behavior challenges. We applied to Medicaid, but was denied because Nate did not meet "level of care".

Because of the lack of health insurance coverage for Nate's autism related health needs, his quality of life has been severely impacted. As an example, Nate has been in 9 (nine) different school placements in 10 (ten) years, suffers from post traumatic stress disorder (PTSD), and his anxiety and depression prevents him from age appropriate social interactions.

Fast forward to today - Nate is a freshman in high school, he has been denied necessary health care since the age of 4 at an intensity, frequency, and duration to address his PTSD, anxiety, depression, and sensory defensiveness issues - including group therapy, OT, PT, and dental specialty care. Because of his diagnosis, Nate has been discriminated against in accessing psychological cognitive behavioral therapy as anxiety and depression are co-morbidities of autism and autism is not a covered diagnosis - even though others with anxiety and depression without an autism diagnosis would be afforded psychological therapy to address their needs.

The continual lifelong healthcare needs of children like Nate are unknown, however if children are to become productive citizens such as Nate is capable of doing (he would

like to be a pilot) accessing appropriate services immediately upon diagnosis is imperative, that also includes lifetime health benefits with a lifespan approach to healthcare.

Thank you for your time and supportive action to address healthcare coverage, healthcare access, and the healthcare needs of people with autism.

Peggy Helm-Quest
167 Church St
Merrimac, WI 53561
608-493-4131

Nate Helm-Quest
Age 14





INSURANCE TESTIMONY
Monday, February 9, 2009

SB 3?

Glen Sallows and Tamlynn Graupner

About 5 years ago, Wisconsin, along with most other states, experienced budget deficits when the Federal Government reduced block grants to the states. At that time, there were about 1,000 Wisconsin children receiving treatment to reverse the devastating effects of autism. In the midst of this financial difficulty, our Governor and legislature pulled together to create a plan to ensure that these children would continue to receive treatment. All Wisconsinites should be grateful for this decision because by treating children with autism when they are young, almost half can make dramatic improvement. I have had the opportunity to see these children become adolescents, do well in school, enjoy their friends, develop their own interests and become concerned about other children with autism who have not had access to treatment. As we showed in our study, these children were able to achieve average IQ's, language, and social skills thereby saving state money in special education services and long term care expenses. For every dollar spent, Wisconsin saves \$19 dollars down the road.

The waiver went into effect in 2004 and provided continuing funding for treatment at an affordable cost by limiting the number of children who could be treated. Initially this was not a problem, but the incidence of autism is increasing and according to the CDC, has now reached 1 in 150 children, with higher rates for boys. The result for Wisconsin children, was a waiting list to receive services that eventually approached 2 years. This created several problems. Treatment is most

effective when begun prior to age 4 or 5, but with a 2 year wait, more and more children began treatment older than these ages, which some studies have shown is too late to reap the full benefits of treatment. This is thought to be due to decreased brain plasticity as children age beyond the preschool years. The waiting list also resulted in many children being close to mandatory school age when they could finally start treatment, making it impossible for them to receive the number of hours necessary to produce optimal benefit.

Insurance coverage promises to solve many of these problems by providing additional monies. Even though insurance coverage may be available for only a part of those afflicted with autism, this will reduce the waiting list for those without insurance. Children will have access to necessary treatment earlier, allowing more children to achieve optimal outcome, thereby reducing expenses for special education and long term care. Families of these children will be delivered from a lifetime of stress. Finally, it will actually reduce costs for insurance companies because young children who have benefitted from treatment, have fewer injuries, fewer hospitalizations and other health related problems.

Passing this legislation is the right thing to do. It will help thousands of young Wisconsin children and their families. It will reduce school district and state expenses. The increase in premiums is a few dollars a month, and if you or your constituents had a child with autism, passing this legislation will make all of you feel that you are able to do the best possible thing for your child. Your constituents will thank you for looking out for them in their hour of need.

And that is why we all do what we do. We want to help our fellow man because it makes us all feel that the world is a better place.





KIM HIXSON

STATE REPRESENTATIVE • WISCONSIN LEGISLATURE • 43RD ASSEMBLY DISTRICT
Serving Rock, Walworth, Jefferson and Dane Counties

REPRESENTATIVE HIXSON TESTIMONY ON SENATE BILL 3

Date?

Good Morning. Chairman Carpenter, members of the committee, thank you for the opportunity to appear before your committee this morning in support of Senate Bill 3, which would extend insurance coverage to families who have children with autism.

Before I speak about the merits of this legislation, I would also like to recognize all of the families here today, who have worked so hard to bring this important legislation to this point today. These families have shown what good hard-working people, who love their children and want the best for them, can accomplish. These families like so many other families across the State of Wisconsin and our nation, face joys and challenges in caring for an autistic child *every* day, the likes of which we can only imagine. And thanks to their hard work we have a very strong bill, which with your help can finally be signed into law.

Even though Autism is a disease almost like any other, many insurance companies refuse to provide coverage. In order to get treatment for their child, many families must *pay right out of their pocket* – sometimes sacrificing their home, their hopes and their dreams. As Sen. Robson mentioned, as many as a half-million Americans under the age of 21 have autism. That's about 1 in every 150 children who are affected by this disease. Maybe you know one of those affected.

We need to make sure that the struggles of families touched by autism do not include financial worries as well. This legislation would provide relief to not only those families with autism, but to all of society. By diagnosing and treating autism early, these children and families will be able to succeed with no limitations. It will also help us keep costs down to taxpayers in the long-term by these children having less need for support services later in life.

This legislation differs from the version introduced last session in three key ways:

- It includes minimum coverage levels for intensive and post-intensive treatment at \$60,000 and \$30,000, respectively of 30-35 hours per week for at least four years;
- It includes speech, language and occupational therapy coverage;
- And, it provides for the reduction of coverage – only when it is determined that less coverage is medically appropriate.

Insurance companies spend a lot of money on advertising and marketing to assure us that we are “in good hands” or that they are just “like a good neighbor” and will be there when we need help. But when parents struggle to find help for a child with autism, many insurance companies are nowhere to be found. At least 18 other states now require insurance companies to do what is right and cover autism spectrum disorders. Wisconsin should join them. Thank you for the opportunity to come and speak with you about this important legislation. I urge you to support SB-3. These families need our support.





KEVIN PETERSEN

STATE REPRESENTATIVE

Date?

Thank-you Chairman Carpenter and other members of the Senate committee on Public Health, Senior Issues, Long-Term Care, and Job Creation for hearing my testimony today on **Senate Bill 3 – The Autism Insurance Mandate**.

The Lord has blessed my wife and myself with two beautiful daughters sitting with me today – Nicole age 11 and Kaylee age 9. Both daughters diagnosed autistic pervasive developmental disorder not otherwise specified (PDD – NOS).

Our lives are just like the lives of all the other families at this hearing and throughout the state of Wisconsin with autistic children. It is a daily roller coaster of challenges and emotions.

As a legislator with autistic children I am able to both relate with the autism challenges and emotions as well as the legislative bureaucracy involved with this bill. What has to be remembered is when we vote on the floor, we don't vote on emotions, press releases, or news media hype, we vote on the words as they are stated in the bill. For it is the words printed in the actual bill that become law.

It is for that reason I find Senate Bill 3 – the Autism Insurance Mandate - has three major flaws when addressing the needs of autistic children and their families.

First, read the analysis by the Legislative Reference Bureau for the Autism Insurance Mandate bill, Sentence one: "This bill requires health insurance policies and self-insured governmental and school district health plans to cover the cost of treatment for an insured for autism ..."

Noticeably exempt from those words are "self insured private business." Nearly 50% of all Wisconsin residents get their insurance through their employers who self-fund their health insurance plans. These plans are regulated by federal law (Employee Retirement Income Security Act [ERISA]) and are exempt from all state mandates.

Approximately 20% of Wisconsin residents are in government programs, like Medicare, which are also exempt from state mandates. Furthermore, the bill can

only apply to Wisconsin employers, so if you live in Hudson, Prairie du Chien, or Hurley and cross the border to work at a job in Minnesota, Iowa, or Michigan, your autistic child would not be covered by the mandate either.

In a memo to my office dated January 13, 2009, from the non-partisan Legislative Fiscal Bureau, these numbers are confirmed. The memo states: "The Wisconsin Office of the Commissioner of Insurance (OCI) estimates that approximately 29% of Wisconsin's population has health insurance coverage to which the state insurance coverage mandates directly apply."

Even Governor Doyle's press release dated February 3, 2009 confirms this fact. The last sentence in the second to last paragraph states: "By passing this bill, the current waiting list for autism treatment can be cut by one-third, providing more kids access to the services they deserve sooner."

In other words, less than one in three autistic children in Wisconsin would get their intensive in home therapy paid for by insurance under the Senate's autism insurance mandate.

Secondly, per the non-partisan Legislative Fiscal Bureau's estimate attached to this bill: "This bill requires all health insurance plans offered by the Group Insurance Board (GIB) under Chapter 40 of the Wisconsin State Statutes to provide coverage for Autism Syndrome Disorder (ASD) which includes Autism, Asperger's syndrome and Pervasive Development Disorder not otherwise specified."

According to the Government Insurance Board's consulting actuary, the estimated cost of insurance premiums for this bill would range from \$7.4 million to \$8.7 million dollars annually for state employees. Additionally, the annual cost for plans offered to local government employees would range from \$1.4 million to \$1.6 million.

I want you and everyone in this room and in the State of Wisconsin to realize that if legislators vote "yes" for the Autism Insurance Mandate, they are voting to spend over \$10 million dollars per year of taxpayer money to ensure kids of government employee's including themselves are 100% covered for autism services while leaving 2/3 of the state's population uncovered by such mandate.

Rather than spending an additional \$10 million tax dollars on state employee and local government healthcare premiums to cover only 1/3 of the state's autistic children, we can spend less than \$6 million dollars fully funding the autism waiver program to eliminate the waiting list completely. Many of you are aware that last session, Representative Newcomer (another parent of an autistic child) and I brought just such a proposal forward. We will be bringing this proposal forward again this session.

Thirdly, there is no funding mechanism guarantee in Senate Bill 3 - the Autism Insurance Mandate - that would ensure the 2/3's of the children not covered would have access to state assistance.

Under 2007 Wisconsin Act 20 (the 2007-09 biennial budget act) approximately \$83 million dollars is budgeted to support autism treatment services. Of that \$83 million, \$34 million is Wisconsin General Purpose Revenue and \$49 million is Federal matching funds.

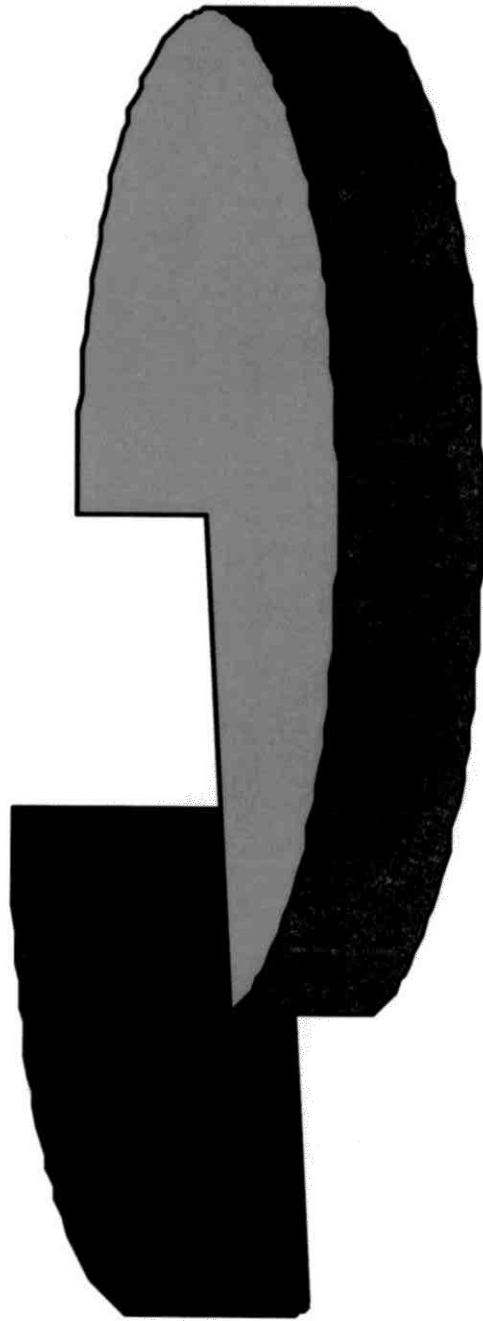
We can not forget that in 2003, Governor Doyle's first budget proposed to eliminate state funds for intensive in-home care for autism. There are no safe guards in this bill which would keep him or other legislators from raiding or eliminating the state's current financial commitment to autism in the next biennial budget. Because of the Autism Insurance Mandate's exclusion of 2/3 of Wisconsin's autistic children, a decrease in funding could effectively increase the state's waiting list for the autism waiver program.

I find it unfathomable that legislators under the Capitol dome in Madison - both the Senate and the Assembly - would prey on the emotions of families like mine throughout the state with autism, and give them false hope that an insurance mandate only covering 29% of the autistic kids in this state is satisfactory.

There's a big difference between a political answer and a real solution. The last thing autistic children and their families need are 1/3 measures. The parents of autistic children have told us what their children need. Now, let's work together to ensure that 100% of autistic children receive the service they so vitally require.

Coverage Under a Mandate

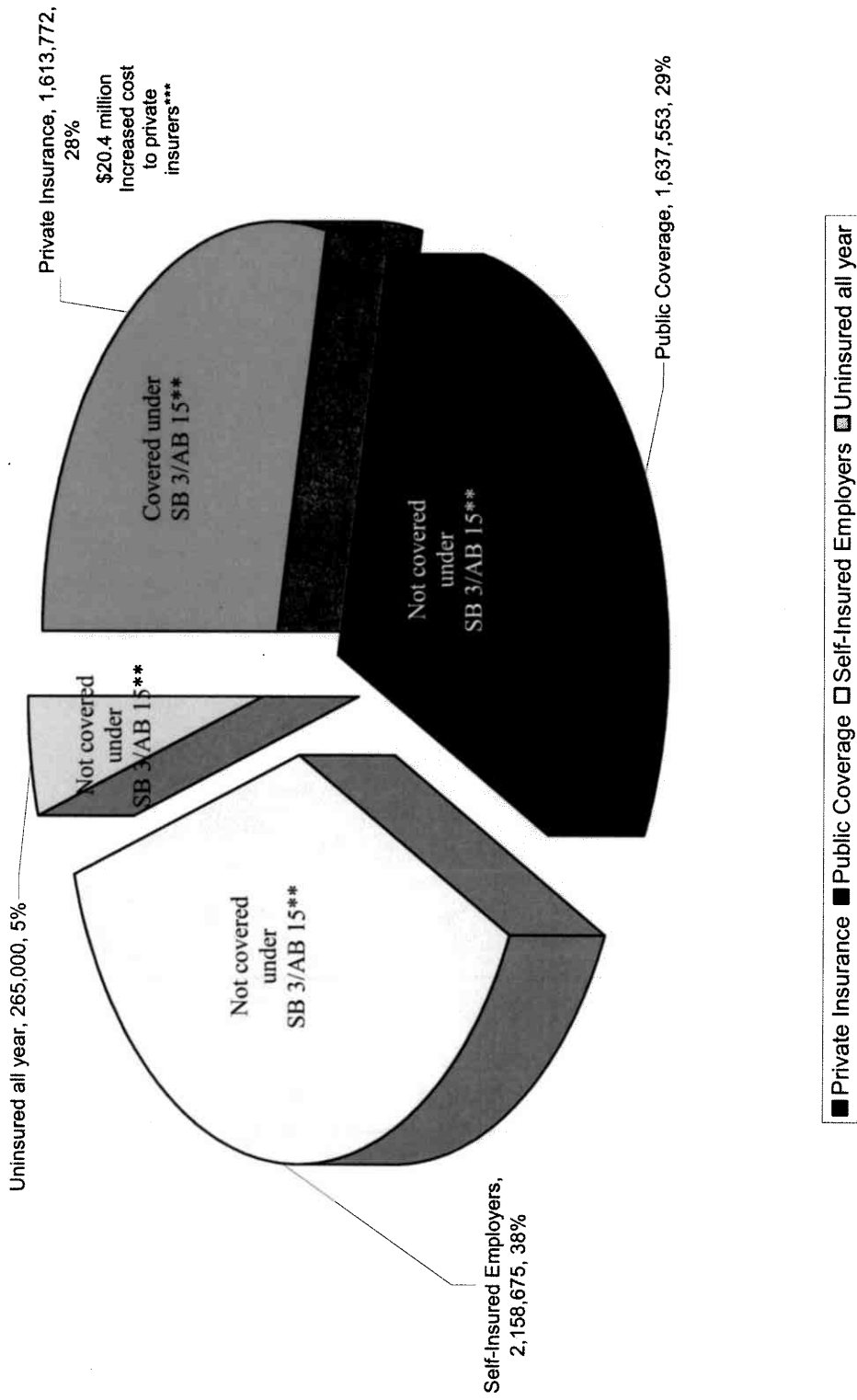
1,613,772*
28%
Covered**



4,061,228*
72%
Not Covered**

* Office of the Commissioner of Insurance memo, June 6, 2008 and 2007 graph
** Legislative Fiscal Bureau memo, January 13, 2009 SB3/AB 15 coverage distribution

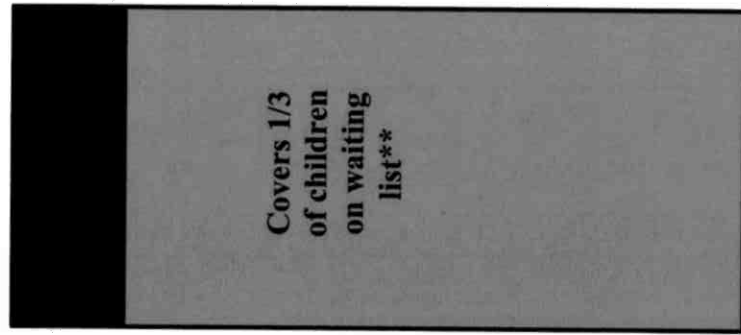
Wisconsin Health Coverage 2007



* Office of the Commissioner of Insurance, Graph
 ** Legislative Fiscal Bureau memo, January 13, 2009, SB3/AB 15 coverage distribution
 *** Office of the Commissioner of Insurance memo, June 6, 2008

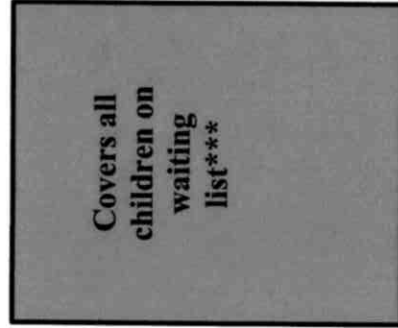
Annual Cost to State/Local Taxpayers (GPR)

\$10,310,000



Local Employees*

\$5,475,189



State Employees*

**SB 3/
AB 15**

**Newcomer/
Petersen Bill**

* Senate Bill 3, Legislative Fiscal Bureau memo, January 27, 2009
 ** Office of Commissioner of Insurance memo, June 6, 2008
 *** February 27, 2008 Legislative Fiscal Bureau memo
 **** January 13, 2009 Legislative Fiscal Bureau memo to Kevin Petersen
 Incorporate federal matching funds under autism waiver program for Newcomer/Petersen Bill





WISCONSIN LEGISLATIVE COUNCIL

*Terry C. Anderson, Director
Laura D. Rose, Deputy Director*

TO: SENATOR JUDY ROBSON
FROM: Jessica L. Karls, Staff Attorney
RE: 2009 Senate Bill 3 and Senate Substitute Amendment __ (LRBs0006/1)
DATE: February 6, 2009

This memorandum describes 2009 Senate Bill 3, relating to health insurance coverage of treatment for autism spectrum disorders, and Senate Substitute Amendment __ (LRBs0006/1) to the bill.

2009 SENATE BILL 3

Senate Bill 3 generally requires that health insurance policies, and self-insured governmental health plans (but not private sector self-insured health plans), provide coverage for an insured of treatment for an autism spectrum disorder if the treatment is provided by: (1) a psychiatrist; (2) a person who practices psychology; (3) a social worker who is licensed or certified to practice psychotherapy; (4) a paraprofessional working under the supervision of a social worker who is licensed or certified to practice psychotherapy, a person who practices psychology, or a psychiatrist; or (5) a professional working under the supervision of an outpatient mental health clinic.

“Autism spectrum disorder” is defined as an autism disorder, Asperger’s syndrome, or pervasive developmental disorder not otherwise specified.

The coverage required under the bill may be subject to any exclusions, limitations, and cost-sharing provisions that apply generally under the policy or plan. The bill does not apply to a health insurance policy that covers only certain specified diseases; a health care plan offered by a limited service health organization or a preferred provider plan that is not a defined network plan; a long-term care insurance policy; or a Medicare replacement policy or Medicare supplement policy.

The bill generally first applies to health insurance policies that are issued or renewed, and self-insured governmental health plans that are established, extended, renewed or modified, on the effective date of the bill, which is the first day of the seventh month beginning after publication.

SENATE SUBSTITUTE AMENDMENT — (LRBs0006/1)

Senate Substitute Amendment __ (LRBs0006/1) generally requires that health insurance policies, and self-insured governmental health plans (but not private sector self-insured health plans), provide coverage for an insured of treatment for the mental health condition of autism spectrum disorder if the treatment is ***prescribed by a physician*** and provided by any of the following who are ***qualified to provide intensive-level services or post-intensive-level services***: (1) a psychiatrist; (2) a person who practices psychology; (3) a social worker who is licensed or certified to practice psychotherapy; (4) a paraprofessional working under the supervision of a social worker who is licensed or certified to practice psychotherapy, a person who practices psychology, or a psychiatrist; (5) a professional working under the supervision of an outpatient mental health clinic; (6) ***a speech-language pathologist; or (7) an occupational therapist.***

The substitute amendment defines additional terms, including “intensive-level services” and “post-intensive-level services.” “Intensive-level services” is defined as evidence-based behavioral therapy designed to help an individual with autism spectrum disorder overcome the social, behavioral, and cognitive deficits associated with the disorder. “Post-intensive-level services” is defined as therapy that occurs after completing treatment with intensive-level services and that is designed to maximize and sustain gains made during treatment with intensive-level services or, for an individual who has not and will not receive intensive-level services, therapy that will improve the individual’s condition. The Commissioner of Insurance is required, by rule, to further define “intensive-level services,” “post-intensive-level services,” “paraprofessional,” and “qualified.” In addition, the Commissioner may promulgate rules governing the interpretation or administration of the requirements in the substitute amendment.

The substitute amendment requires that the coverage provide at least ***\$60,000 for intensive-level services per insured per year, with a minimum of 30 to 35 hours of care per week for a minimum of four years, and at least \$30,000 for post-intensive-level services per insured per year.*** If a supervising professional, in consultation with the insured’s physician, determines that less treatment is medically appropriate, the minimum monetary amounts or duration need not be met. Beginning in 2011, the monetary amounts must be adjusted annually, based on changes in the consumer price index, and the Commissioner of Insurance must publish the new amounts each year in the Wisconsin Administrative Register.

Under the substitute amendment, the coverage may be subject to deductibles, copayments, or coinsurance that generally apply to other conditions covered under the policy or plan, but the coverage may ***not*** be subject to exclusions or limitations, including limitations on the number of treatment visits. The substitute amendment does not apply to: (1) a health insurance policy that covers only certain specified diseases; (2) a health care plan offered by a limited service health organization or a preferred provider plan that is not a defined network plan; (3) a long-term care insurance policy; or (4) a Medicare replacement policy or Medicare supplement policy.

The substitute amendment generally first applies to health insurance policies that are issued or renewed, and self-insured governmental health plans that are established, extended, renewed, or modified, on the first day of the fifth month beginning after publication.

If you have any questions, please feel free to contact me directly at the Legislative Council staff offices.

JK:wu:ksm





State of Wisconsin / OFFICE OF THE COMMISSIONER OF INSURANCE

Jim Doyle, Governor
Sean Doherty, Commissioner

Wisconsin.gov

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Found in SB 3 folder.

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 Senate Bill 178, 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.

Senate Bill 178

Senate Bill 178 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.

Senate Bill 178 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).¹

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

The Diagnostic and Statistical Manual of Mental Disorders, 4th 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.³ Educational and behavioral interventions use highly structured and intensive skill oriented training sessions to help children develop social and language skills.⁴ Medication may be prescribed to manage symptoms of anxiety, depression and to treat severe behavioral problems.⁵

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.^{6 7} After a few years of treatment, 47% of the experimental group (9 of 19 children) were reported to have achieved "normal functioning."⁸

¹ 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>

² Ibid.

³ 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

⁴ Ibid.

⁵ Ibid.

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

⁷ 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.*

⁸ 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.⁹

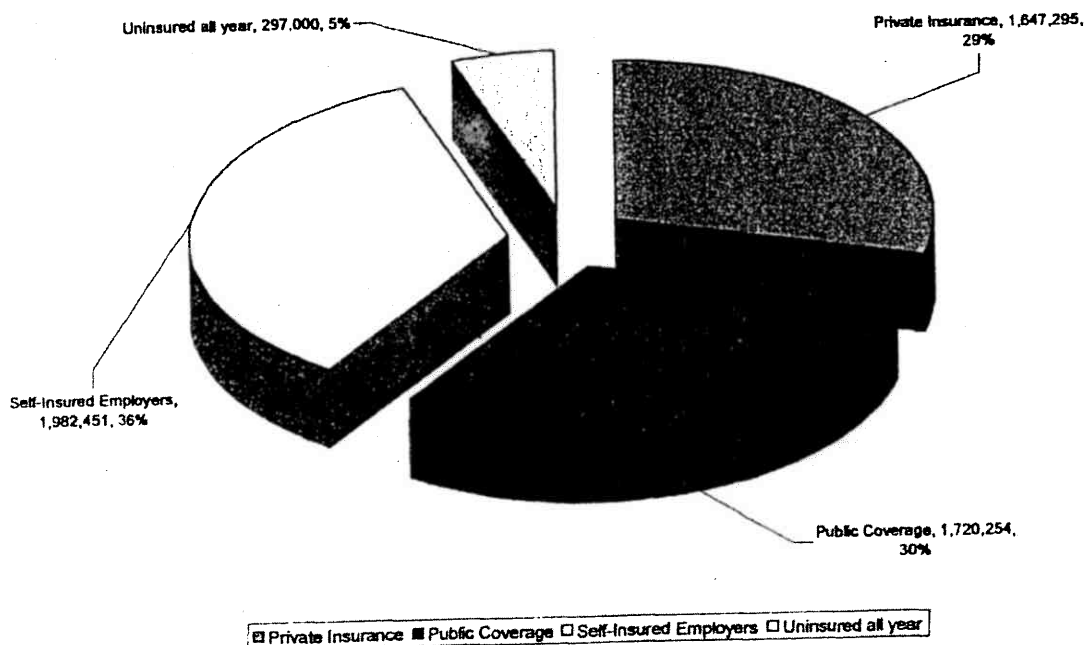
Social Impact Factors

Private insurance

Fully insured health insurance products cover approximately 1.65 million state residents,¹⁰ 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 SB 178. It is unknown whether there would be any indirect impact with unregulated self-funded plans if SB 178 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



⁹ Ibid.

¹⁰ 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%.¹¹ 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 2002.¹² 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.¹³ 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.¹⁴ 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.¹⁵ As a result, the study concluded special education trends should not be used to support claims of an autism epidemic.¹⁶

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,

¹¹ 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.

¹² 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.

¹³ 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

¹⁴ Ibid.

¹⁵ Ibid.

¹⁶ Ibid.

behavioral therapists, occupational therapists, physical therapists, psychologists and social workers.¹⁷

It is uncertain whether some of the treatment services provided by the professionals listed in SB 178, including intensive behavioral treatment services, might fall under a health insurance policy's exclusions for educational services. SB 178 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

¹⁷ 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.¹⁸

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 SB 178. 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, SB 178 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. SB 178 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.

SB 178 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

¹⁸ 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, SB 178 may result in positive treatment results that would not have otherwise been realized.

SB 178 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

SB 178 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 SB 178. 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 SB 178; but at a lower intensity than younger children.

Increased Utilization of Services

SB 178 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 SB 178 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 2006¹⁹. Insurers and business groups argue that mandated coverage of specific benefits can lead to expensive health

¹⁹ 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.²⁰

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.²¹ Intensive behavioral treatment costs can reach or exceed \$50,000 a year.²² Some estimates place the cost closer to \$32,000 each year from age 3 to age 7.²³ 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 SB 178 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.

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

²¹ 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.

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

²³ 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.

Mental Health	Specific Law
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 SB 178 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 SB 178, 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.²⁴

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"

²⁴ 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.²⁵ SB 178 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, SB 178 will provide access to treatment when none would have been available at all. Assuming improved outcomes resulting from early, unlimited access to treatment, SB 178 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.²⁶
- Total lifetime special education costs for a person with ASD is estimated to be \$150,483.²⁷
- 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).²⁸
- Lifetime physician and dental costs for a person with ASD are estimated to be \$42,259.²⁹

Long Term Care Support

- Total lifetime costs for adult care are estimated to be \$662,192.³⁰
 - Ranging from \$25,000 at ages 23-27 years to around \$7,000 at ages 63 to 66 years.³¹

²⁵ 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.

²⁶ 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.

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

²⁸ 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*

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

³⁰ Ibid.

³¹ Ibid.

Lost Productivity

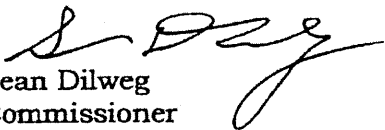
- Lifetime productivity losses for those with autism are estimated to be \$971,072 and for the parents of autistic individuals losses are estimated to be \$904,595.³²

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

³² Ibid.

Autism FAQ - Definition of Autism

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

**INTENSIVE IN-HOME TREATMENT FOR CHILDREN WITH
AUTISM, ASPERGER'S OR PERSISTENT 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 Persistent 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:

I. 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.