2009 SENATE HUMAN SERVICES

SB 2174

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2174

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-21-09

Recorder Job Number: 7441

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened the hearing on SB 2174 to provide for the creation of an autism spectrum disorder task force; relating to residential care for children with autism spectrum disorder; and to provide an appropriation.

Senator Heckaman introduced SB 2174 and explained that it came about after several meetings by stakeholders who spent a lot of time and effort developing a state autism plan. One of the roadblocks was difficulty in finding a sponsoring agency. To alleviate the problem they decided to have the Governor appoint a task force to develop and approve the plan. The bill doesn't have anything to do with changing in residential care. It only has to do with the parallelism of the word autism spectrum disorder in the whole sections of the bill.

The fiscal note would be to provide mileage and travel expenses for the family members who would be involved on this working group. She provided a packet of e-mail testimony from people who couldn't appear in person. Attachment #1.

Cathy Harstad, FamNet, testified in support of SB 2174. Attachment #2. She also provided the committee with testimony from a parent describing a situation they encountered for their child when untrained individuals attempted to respond. Attachment #3.

Donene Feist, Family Voices of ND, testified in support of SB 2174. Attachment #4.

Vicki Peterson, Bismarck, testified in support of SB 2174. Attachment #5.

Carlotta McCleary, NDFFCMH, testified in support of SB 2174. Attachment #6.

Senator Dever stated that sometimes we have services for different programs but we fail to pull them together. He asked (1) if that's the case with autism and (2) if, with autism, there is such a broad range of what it consists of that the approach to dealing with it is also a broad range.

Ms. McCleary answered that services are provided to children and youth by the division of mental health and substance abuse. Some are also being served in the partnership program, the school systems, special education, and some qualify for the developmental disability waiver. Some kids are truly needy in areas of gaps where they are having a difficult time becoming eligible for special education services. It is really important to build on what we already have and do the best job we can in coordinating it.

Senator Dever observed that people who come and testify on bills such as this are people who put themselves forward to access those services. They seek out what services are available. There are a lot of people out there who don't do that. He wasn't sure this bill would address how to make known to people what services are available.

There was discussion on getting this information out to the public.

Dan Ulmer, BC/BS of ND, spoke in support of SB 2174. He offered some background history on mental illness issues. It was discouraging to him that the autistic kids today fall off the DD qualification – the waiver they are talking about. A problem of this bill is that it won't take care of the problem today. Some of the problems they are seeing are that they are adding 30-60 with this diagnosis a year. They don't know why. A significant number of kids are covered under BC – the vast majority of the money is for psychiatric care, psychotropic, and that type.

Bob Rutten, ND DPI, expressed his support to SB 2174. Attachment #7

Sandy Smith, Parent, spoke in support of SB 2174 and told her story about her son, Tyler. See attachment #8.

Elaine Grasl spoke in favor of SB 2174. Attachment #9

Bruce Murry, ND Protection and Advocacy Project, offered support for SB 2174. Attachment #10.

There was no opposing testimony.

JoAnne Hoesel, Dept. of Human Services, offered information on services provided and planned in the area of Autism Spectrum Disorders. See attachment #11. She also offered an amendment for consideration by the committee. Under the task force where it talks about the chairperson of the task force, they would like to change it to the director of the Dept. of Human Services or designee.

Senator J. Lee asked Dan Ulmer about the insurance coverage for autism disorders in ND.

Mr. Ulmer said they don't cover for behavioral therapy.

Tammy Gallup-Millmer, ND Department of Health, said they concur with the proposed change that the leadership role be taken by the Dept. of Human Services.

There was a short discussion on the fiscal note and sending this to appropriations.

The hearing on SB 2174 was closed.

Additional testimony – Attachment #13

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2174

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-26-09

Recorder Job Number: 7774

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened SB 2174 for committee work. She asked Dan Howell from the Ann Carlson Center to help give the committee some insight.

Dan Howell, Ann Carlson Center for Children, talked about the school and the children they serve there. He talked about in home support programs and the belief that all autistic children do not need to live in a residential environment. It has to be the most least restrictive environment. They have changed their focus and mission. They are not a residential treatment center anymore. They are an organization that wants to take care of children and adults in their home communities.

The genesis of this bill was created by four people who all had some aspect of helping families with autism. This bill will be able to leverage some federal funding for autism. A state plan for autism is needed to get those funds. There needs to be a broad constituency base to that task force to try to address under one single focus autism in ND.

They support this and think the state should have a large focus in this bill.

He provided the committee members with a Statement of Need, Attachment #14.

There was some discussion on proposed amendments. Mr. Howell said he would get back to **Senator J. Lee** after he talked to the people who work with autism on a daily basis to see what language or tweaks they might suggest.

Some discussion also took place on if it would be appropriate to expand this. It was recommended to not do that.

Cal Rolfson, Representing the Ann Carlson Center, offered to work with others to make this workable.

Senator J. Lee adjourned the committee work.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2174

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 1-27-09

Recorder Job Number: 7916 (Meter 08:15), 7918

Committee Clerk Signature	Mary K Monson

Minutes:

Senator J. Lee opened discussion on SB 2174.

There was a short discussion on possible amendments.

Senator J. Lee provided the committee with information she received from Dan Howell, Director of the Ann Carlson School, in response to her request. Attachment #12.

Discussion was closed.

Job #7918

Senator J. Lee opened SB 2174 for additional committee work.

There was discussion on whether the word residential could or should be taken out, the funding, moving from state health officer to director of Dept. of Human Services, and the definition of the task force. Discussion also centered on using the phrase autism spectrum disorder. Wording for an amendment was discussed.

Senator Heckaman moved to adopt the amendments.

Seconded by **Senator Marcellais**.

Roll call vote 6-0-0. Amendment adopted.

Senator Heckaman moved a **Do Pass on SB2174 as amended**.

Seconded by **Senator Dever**.

Roll call vote 6-0-0. Motion carried.

Carrier is **Senator Heckaman**.

90411.0201
Title.0300

Adopted by the Human Services Committee
January 27, 2009

1-28-09

PROPOSED AMENDMENTS TO SENATE BILL NO. 2174

Page 1, line 12, after the underscored semicolon insert "and"

Page 2, line 6, replace "state health officer, or the officer's" with "director of the department of human services, or the director's"

Page 4, line 30, replace "$5,000" with "$3,000"

Page 4, line 31, remove "state" and replace "health" with "human services"

Renumber accordingly

Date: 1-27-09

Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2174

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number Amendments

Action Taken ☐ Do Pass ☐ Do Not Pass ☐ Amended ☐ Rerefer to Appropriations

☒ Adopt Amendment ☐ Reconsider

Motion Made By Sen. Heckaman Seconded By Sen. Marcellais

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair	✓		Senator Richard Marcellais	✓	
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment

If the vote is on an amendment, briefly indicate intent:

Date: 1-27-09

Roll Call Vote #: 2

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2174

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 90411.0201 Title.0300

Action Taken ☒ Do Pass ☐ Do Not Pass ☒ Amended ☐ Rerefer to Appropriations

☐ Adopt Amendment ☐ Reconsider

Motion Made By Sen. Heckaman Seconded By Sen. Dever

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair	✓		Senator Richard Marcellais	✓	
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment Senator Heckaman

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2174: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2174 was placed on the Sixth order on the calendar.

Page 1, line 12, after the underscored semicolon insert "and"

Page 2, line 6, replace "state health officer, or the officer's" with "director of the department of human services, or the director's"

Page 4, line 30, replace "$5,000" with "$3,000"

Page 4, line 31, remove "state" and replace "health" with "human services"

Renumber accordingly

2009 HOUSE HUMAN SERVICES

SB 2174

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2174

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 3, 2009

Recorder Job Number: 10041

Committee Clerk Signature	Vicky Crabtree

Minutes:

Chairman Weisz opened the hearing on SB 2174.

Sen. Heckaman sponsored and introduced the bill: Testified in support of bill.

Chairman Weisz: You mentioned leveraging the federal funds. Are those 100%?

Sen. Heckaman: (Inaudible).

Bruce Murray, lawyer with ND Protection and Advocacy Project: Testified in support. **See Testimony #1.**

Donene Feist, State Director for Family Voices of ND: Testified in support. **See Testimony #2.**

Rep. Potter: With birth to past 18, this bill is really for children.

Donene Feist: This is a state plan from birth to adulthood.

Rep. Potter: Confused because title talks about children.

Donene Fiest: (Inaudible).

Chairman Weisz: Nothing defines to age 18. Not limited in the bill. How many in the state currently have been diagnosed with autism.

Donene Feist: If you take 1 in 150 out of 20,000, you are going to get pretty close.

Chairman Weisz: Not the whole population, just the youth.

Rep. Conrad: (Inaudible).

Donene Feist: I'm comfortable with the definition, but more (inaudible).

Charlotta McCleary, Executive Director of ND Federation of Families for Children's Mental Health: Testified in support. **See Testimony #3.**

Bob Rutten, Director of Special Education in ND Dept. of Public Instruction: Testified in support. **See Testimony #4.**

Rep. Conrad: I think (inaudible).

Bob Rutten: It's actually a change in the reporting (inaudible) now reported in a separate category (inaudible). We have seen a decline in certain disability categories and increase in some other categories.

Doug Johnson, Executive Director ND Council of Educational Leaders: Testified in support. **See Testimony # 5.**

JoAnne Hoesel, Director of Division and Developmental Disabilities: Testified in support. **See Testimony #6**

Rep. Hofstad: Are there facilities that are making application for children specifically with autism?

JoAnne Hoesel: The bill before you and the autism residential, there has not been funding for children in that facility for over twenty years. That is why children having autism seek services in group homes and foster care and residential child care facilities that are not specific to their disorder.

Rep. Hofstad: Our goal would be to move these children for those facilities we have now into the facilities that are specific for them?

JoAnne Hoesel: I wouldn't necessary say that. I think it is unknown what the plan will be.

Rep. Frantsvog: The proposed legislation in front of us talks about residential care for children with autism, but in your testimony, you talked about work being done at Minot State University in putting together a state autism plan. Aren't both of these projects going to be the same thing?

JoAnne Hoesel: We had a meeting last week and the group headed by Minot State and the people attending, did agree we would have one group in the state. Having two groups wouldn't be a good thing to do.

Rep. Frantsvog: It's seems to me it is two groups working towards the same objective. Couldn't you combine your resources and be one group?

JoAnne Hoesel: That's exactly what's going to happen.

Rep. Conrad: Should we be identifying (inaudible).

Chairman Weisz: Number 3.

Rep. Conrad: I'm sorry.

Bruce Murry: The question of residential services came up in the final drafting of the bill. It was somewhat of a language cleanup which touched on a number of different sections that mentioned residential services. So the fact it sounds so related to residential services is a little bit of an accident in the process.

James Moench, Director of ND Disability Advocacy Consortium: Testified in support. With the autism spectrum, all trying to get something going. What's missing is the coordination at bring it all together. That is the goal of this bill.

NO OPPOSITION.

Chairman Weisz closed the hearing.

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2174

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 4, 2009

Recorder Job Number: 10205

Committee Clerk Signature	Vicky Crabtree

Minutes:

Chairman Weisz: Let's take up SB 2174.

Rep. Porter: Motion a DO PASS.

Rep. Conklin: Second.

Roll Call Vote: 11 yes, 0 no, 2 absent, Rep. Conrad and Uglem.

MOTION CARRIED DO PASS.

BILL CARRIER: Rep. Hofstad.

Date: 3-4-09

Roll Call Vote #:

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2174

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Rep. PORTER Seconded By Rep. Conklin

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN ROBIN WEISZ	✓		REP. TOM CONKLIN	✓	
VICE-CHAIR VONNIE PIETSCH	✓		REP. KARI L CONRAD	A	
REP. CHUCK DAMSCHEN	✓		REP. RICHARD HOLMAN	✓	
REP. ROBERT FRANTSVOG	✓		REP. ROBERT KILICHOWSKI	✓	
REP. CURT HOFSTAD	✓		REP. LOUISE POTTER	✓	
REP. MICHAEL R. NATHE	✓				
REP. TODD PORTER	✓				
REP. GERRY UGLEM	A				

Total (Yes) 11 No 0

Absent 2

Bill Carrier Rep. HOFSTAD

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2174, as engrossed: Human Services Committee (Rep. Weisz, Chairman) recommends **DO PASS** (11 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2174 was placed on the Fourteenth order on the calendar.

2009 TESTIMONY

SB 2174

#1

Heckaman, Joan M.

From: Mary Niehaus [mary.niehaus@ndsu.edu]
Sent: Tuesday, January 20, 2009 12:09 PM
To: Lee, Judy E.; Erbele, Robert S.; Dever, Dick D.; Heckaman, Joan M.; Marcellais, Richard; Pomeroy, Jim R.
Cc: Bill Niehaus
Subject: SB 2174

Dear members of the Legislative Committee:

I am a parent of a 11 year old son who was diagnosed with Asperger Syndrome at the age of 5. Because I was in tune to my child's behaviors, largely due to skills learned through the past "Parents as Teachers" program in Fargo, I was able to see there was something "different" about my child around the age of 4. My son's behaviors were evaluated both at home and at a private Kindergarten which resulted in a Asperger's syndrome diagnosis. I did all that I could as a parent to learn about Asperger's and was well versed when my son transferred to a public school for 1st grade and I knew exactly what he needed. I was fortunate to have my son attend a school that took iniative to learn about Asperger's learning styles. Though my son does well academically, he needed help with socialization and organizational skills, two things that don't come naturally as with neurotypical people, and are not included in the general educational curriculum. From networking with others, I know that I have been more fortunate than some families with Aspergers children in elementary school.

I am confident my son's success is due to early intervention and elementary teachers who were able to identify his needs and know what types of skills that are needed. A large part of his extra help was in Elementary school where he was part of "friendship circles" every year. Because of this successful elementary school experience, he currently isn't requiring any special services in middle school except for a good counselor willing to listen and search [illegible]r answers, and parents who are on top of it, making sure he is on task and learning social [illegible]ills appropriately.

Unfortunately, the Parents as Teachers program has been dissolved. In my opinion, early intervention is key and teaching parents how to identify possible SOCIAL behaviors is very important. There are tests to identify academic and physical needs, but social tests are more difficult to administer. Home based services and other community education opportunities to train parents would be a huge benefit - especially for those who are not self-researcher like I am.

Because every transition in life is especially difficult for ASD individuals, I can foresee needs for support groups at colleges and maybe some special classes to introduce the students at a more specific level than what occurs for the general student body.

I strongly encourage the passage of a bill that would estabilsh a task force to address development of a state plan addressing community based services for individuals on the autism spectrum in North Dakota. Please include Individuals with ASD, family member and professionals involved with these individuals.

--
Mary Niehaus

2438 Lilac Lane
Fargo, ND 58102

[illegible]ne: (701) 293-9625

Heckaman, Joan M.

From: Sharlynn Torkelson [tork3hawk@I29.net]
Sent: Tuesday, January 20, 2009 1:00 PM
To: Lee, Judy E.; Erbele, Robert S.; Dever, Dick D.; Heckaman, Joan M.; Marcellais, Richard; Pomeroy, Jim R.
Subject: SB2174
Attachments: 26b1.gif; imstp_animation_butterflies_en_020908.gif

Dear committee,

I am writing to request that a task force be established to address the issues of people with autism spectrum disorders.

I am a mom with a 15 year old who has been diagnosed two years ago with High functioning Autism and language based disability. He also has OCD, anxiety disorder and Disruptive Behavioral Disorder. I have been searching for a diagnosis for Matthew since he was four years old. Because there are not enough professionals that deal with autism it took us many years and many different diagnoses before Matthew was properly diagnosed. I think about all the time that has been lost in helping Matthew. If he would have been diagnosed sooner, have more programs to help him, things could be so different.
We just now got the diagnosis of Matthew having the language base disability. He has trouble learning and retaining that information. He has memory blips. We had to wait four months to get in to talk to a professional about Matthew's learning problems. Now we are told we have to wait another three to four months before Matthew can get into see a psychologist that deals with Matthew's needs We worry about getting Matthew the help he needs to function in this world. We are not a wealthy family. We worry about being able to afford the treatment that Matthew needs. I am disabled, not able to work myself.
Matthew's anxiety levels are so high that we are home schooling. He is very seclusive. We would like to get Matthew to the point where he doesn't have to be fearful and can participate in other programs with other kids who have the same diagnosis.
I worry about Matthew's future and what will become of him. Who will be there to help Matthew with a job, or will he be able to work since he is afraid and hates crowds of people. Going into a store sends his anxiety levels so high he has melt downs.
Help is desperately needed for these kids. Help is needed for parents who are raising a child on the autism spectrum. Help is needed for professionals to be able to diagnose sooner and get these kids on a right path sooner. The process takes way too long. North Dakota needs more professionals that deal with autistic individuals.
I strongly encourage the passage of a bill that would establish a task force to address development of a state plan addressing community based services for individuals on the autism spectrum in North Dakota. Please include individuals with ASD, family members and professionals involved with these individuals.
I would suggest that the following be addressed by such an autism task force:

Community and home based services

Proper identification of autism spectrum disorders

Training opportunities for professionals

Participation in research opportunities and review of current research

Development of proper interventions utilizing a coordinated team approach

Consistency of assessments and service provision

Coordinated services between all professionals involved with the individual and their family- Case Management
Family support

Comprehensive services across the developmental life span

I thank you for your time and consideration of passing SB2174.

Sharlynn Torkelson

<>

Heckaman, Joan M.

From: bkstan56@loretel.net
Sent: Tuesday, January 20, 2009 9:55 AM
To: Heckaman, Joan M.
Cc: Judy Lee jlee@nd.gov; Robert Erbele rerbele@nd.gov; Dick Dever ddever@nd.gov; Joan Heckaman jheckaman@nd.gov; Richard Marcellais rmarcellais@nd.gov; Jim Pomeroy jpomeroy@nd.gov
Subject: SB 2174

January 19, 2009

Regarding SB 2174

Honorable Senator Heckaman and members of the committee,

I would like to provide testimony on SB 2174 as a professional service provider, volunteer, advocate, and concerned citizen.

Over the past 8 years I have worked with over 350 children, adolescents and adults on the autism spectrum, specifically those with Asperger’s Syndrome, High Functioning Autism, Pervasive Developmental Disorder Not Otherwise Specified and Non-verbal Learning Disabilities from across North Dakota.
I have done primary assessments, given second opinions, provided individual, couples, family and group therapy, as well as give training to a variety of professionals (mental health, medical, law enforcement, schools…) and community organizations (churches, youth programs…).
I facilitate weekly parent support groups and am a founder of the Red River Valley Asperger Network, on whose board of directors I currently serve.

tism Spectrum Disorders are a neurological difference which present primarily as difficulties in language/communication and social interactions. It is a complex difference that impacts every aspect of a person’s life, and lasts throughout their lifetime. While some individuals are able to flourish without intervention, most need supports in order to be successful in school, employment, and in the community.

Nearly every family and individual that I know, who are dealing with autism, have a horror story to tell about their past or current experience in obtaining appropriate services.

One of the primary barriers in receiving necessary interventions for individuals with autism spectrum disorders is the complexity of the disorder. There is little understanding of the characteristics of people with High Functioning Autism, Pervasive Developmental Disorder NOS (PDD-NOS), or Asperger’s syndrome. Because of the difficulties and inadequacies in the current diagnostic criteria many children and adults are misdiagnosed. There is also Non-verbal Learning Disability that is not currently a medical diagnosis but NVLD is very similar to Asperger’s syndrome with distinct differences that are important in developing an appropriate intervention. There is a flood of research currently being conducted, but many professionals find it difficult to keep up with recent developments.
Advanced training and education are not always encouraged or available.

While many other states have established plans to address the needs of individuals on the autism spectrum, North Dakota is not one of them. There is currently no standard protocol for identifying Autism Spectrum Disorders or to develop appropriate interventions.

In order for a child to receive services in school for autism they must meet the criteria for ucational autism”. Even if a child has received a medical diagnosis of an autism spectrum disorder if they do not meet the state criteria set forth by the Department of Public Instruction they will not receive special services for autism.

Sometimes an IEP or 504 plan will be developed with appropriate interventions without the classification.

Unfortunately some children will not receive services at all. There is no consistency in the school evaluation or which services will be provided. Unfortunately there are no standardized measures that are considered adequate (Attwood, 2006). Also most school staff, teachers, and alleged school "autism experts" do not have adequate knowledge or experience to properly identify the needs of children who have Asperger's Syndrome, High Functioning Autism, PDD NOS or Non-verbal Learning Disabilities. Therefore, children with spectrum disorders are often label as being "oppositional, manipulative, lazy, apathetic…." and will not receive services that meet their needs.

The same is true within the mental health and medical fields in that there is not a standard protocol for diagnosis or intervention. They receive improper interventions and medications. Too often these children are placed in programs for individuals with psychiatric, behavioral or emotional disturbances which, according to Dr. Ami Klin at Yale (2003) is the "worst possible mismatch".

The term 'evidenced based practices' is common in most professions. The research for all aspects of autism spectrum disorders is happening at a rapid pace. A broad range of topics continue to be researched as there is currently no consensus regarding cause, identification/assessment techniques, or interventions.

There are few scientific studies measuring the effectiveness of specific interventions for Asperger's Syndrome, High Functioning Autism or PDD-NOS. However, lack of evidence is not the same as a lack of benefit. Asperger's Syndrome has only been a valid diagnosis since 1994 so there has not been enough time to establish evidence based parameters.

There are effective interventions but few professionals have a good understanding of them.

It is also important to note that people with autism, especially Asperger's Syndrome, are at a high risk for other mental health issues such as depression and anxiety especially when they do not receive supportive services.

Interventions for these issues must be specific to this unique population and conducted by qualified clinicians who have both an understanding of autism and other mental disorders.

Services to address transition issues of education, employment, and independent living are critical to long term success, but they are significantly lacking within North Dakota.

I am talking about amazing individuals who can contribute greatly to the betterment of our state and world, if they are given the opportunity. Providing community based comprehensive services over duration of their lives will ultimately improve the quality of life for these individuals and decrease costs to the health care industry and the community.

I strongly encourage the passage of a bill that would create a task force to address the development of a state plan establishing comprehensive community based services for individuals on the autism spectrum in North Dakota.

I would suggest that the following be addressed by such an autism task force:

- Community and home based services
- Proper identification of autism spectrum disorders
- Training opportunities and incentives for professionals
- Participation in research opportunities and review of current research
- Development of proper interventions utilizing a coordinated team approach
- Consistency of assessments and service provision

- Coordinated services between all professionals involved with the individual and their family
- Family support
- Comprehensive services across the developmental lifespan

It would be my hope that this task force would include individuals on the autism spectrum and their families. They are the only true experts on this topic.

Thank you for allowing me the opportunity to address this critical issue.

Sincerely,

Barbara Stanton, PhD, LPCC

#2

Testimony on Senate Bill 2174
2009 Legislative Session
January 21, 2009
By Cathy Haarstad, MS
Director of FamNet
To: Senator Judy Lee, HS Committee Chairperson

Dear Madam Chairperson and Committee Members,

Thank you for the opportunity to testify on behalf of Senate Bill 2174 in support of a state plan on autism.

My husband and I are the parents of an 18 year old daughter with intellectual disability and PDD-NOS (pervasive developmental disability-not otherwise specified) which is one form of autism spectrum disorder. Our daughter is doing relatively well thanks to a good family life, special education, respite services for our family, effective medication and extensive behavior intervention that, unfortunately we ourselves have often needed to provide.

That journey has taken its toll on our family and marriage but like many other frontier families we endure. We would rather work with our neighbors to find positive solutions to the challenges in life. We do the best we can and after almost 30 years we are still together. Many other ND families whose children have Autism in our state are not so fortunate. Nationally, the divorce rate among families of children with Autism is almost 90%. And it may surprise you to learn that many of these children are not eligible for DD services and some students with autism spectrum disorders are not eligible for special education under the current criteria set by our state.

I work at the ND Center for Persons with Disabilities as a research associate. Through NDCPD's affiliation with the Association of University Centers on Disability and a network of similar medical schools, we have access to the best research findings on Autism Spectrum Disorders in the country. I am not testifying on behalf of the center but like most North Dakotans I try to be a good neighbor. I read the research that comes across my desk and cannot help but see what it means for my daughter and ND families like my own.

I am also the director of FamNet – a newly formed network of ND family support agencies that specialize in serving children with special healthcare needs or disabilities. We have been asked to share information resources with several ND advocacy groups. Together we have connected with several state agency representatives and providers that are also interested in development of a state plan on autism. We believe Senate Bill 2174 positions ND to make a timely and systemic response to the rising incidence of autism spectrum disorders in ND.

Some people claim that ASD is a developmental disorder and is best addressed through education. Others stress that this is a neurological disorder and is best addressed through behavioral therapy and other health treatments. There are many reasons for the differences in these two labels and much confusion and even disagreement among families, educators and health practitioners. This makes it difficult for us to move forward with a unified response.

The truth is that we don't know what causes ASD. We do know that it has both genetic and environmental roots with medical, educational and environment implications. We know that Autism is a complex spectrum disorder that requires an in-depth look at data collection, services, service coordination, equity, and workforce development.

Our planning group has gathered preliminary data and while not complete, the emerging evidence indicates that the rate of ASD is increasing significantly in ND as it is in the rest of the country. National studies (CDC, 200&) indicate that one in every 150 boys is now being diagnosed with an autism spectrum disorder. We do not yet have a complete picture of the rate increases for ND. Data presented last spring at a statewide symposium on ASD indicated that 1 out of every 288 school children in ND has ASD. Differences in how agencies collect data and how they define autism spectrum disorders make it difficult to compare groups and engage in effective decision-making. We believe this is another reasons for developing a state plan.

We believe that unless ND agencies work together with families to develop an effective plan and to make data-driven decisions, children, youth and adults with ASD along with families, schools and service agencies will be hard pressed to respond effectively and that the long term cost to our state may be significant. Because of the complexity of the disorder, multiple systems are involved in serving children and families. Individual departmental or agency responses will not serve us well. We have been working as families and within state agencies to do what we can. We are also supporting as a first response an autism waiver that has been included in Governor Hoevan's budget. However, without a plan, a road map, adequate resources and a public/private partnership to coordinate services and decide what the needed infrastructure and next steps should be, these attempts are likely to fall short. We believe that the proposed legislation is a first step in making a reasonable, cost-effective response to this issue for ND.

Congress has already realized that states are facing a significant rise in the number of children and adults with autism and has responded by making critical funds available to all states. Another important reason for introducing this legislation today is the opportunity to secure funds available to ND through the Maternal and Child Health Combating Autism Act. Without a state plan, ND will be ineligible to access the additional funding intended to support state efforts to respond to this emerging health and educational challenge.

You may hear today that ND parents of children with autism spectrum disorders are dissatisfied with the lack of appropriate services in both urban and rural settings in our state, with the limited numbers of trained professionals that are prepared to serve children with ASD and the cost of providing appropriate services to a child with ASD. We are!

However, we realize that even if the ND Legislature appropriated significant dollars to pay for recommended services our state would still be faced with significant challenges. Applied behavioral analysis, individualized for the unique needs of the child, along with other evidence-based approaches, provided through intensive, early intervention models that include in-home behavior intervention are being recommended to us by the American Academy of Pediatricians, the National Institute of Health, the Centers for Disease Control, the National Academy of Science and our family doctors. Our children need these services and they are not available. There is currently only one board-certified specialist in applied behavioral analysis in ND and the infrastructure to train and pay more such specialists may not exist. Insurance does not currently cover this service and schools were never designed to provide direct training in the home.

Yet our children need these services and we cannot overcome these circumstances alone. We have reached out to state agencies and providers for solutions and have come here together today to ask for your support for legislation to create a planned response. We recommend that families be at the table when decisions are made because our children, spouses, neighbors, relatives and communities bear the impact and are the ultimate stakeholders.

We are a cautious group but we believe that it is time to more forward. This proposed legislation will create the necessary public/private partnership with the authority to recommend to the legislature what ND needs to make a systemic response to autism; to assess its impact on our state and to suggest who has the resources and responsibility to respond and what that response should be; and finally to recommend mobilization of resources and strategies to meet the need. We believe there are real costs associated with conducting such an important undertaking and ask you to approve SB 2174 as a signal to the people of ND that our legislature has taken a serious and considered step to meeting this challenge. We would like to thank Senator Heckaman, and the members of this committee for their support.

#3

State Plan on Autism
Testimony by Pam Treibold – Parent
January 21, 2009
ptriebold@wennsoft.com

Dear Senator Judy Lee and members of the Human Services Committee,

Another reason for creating a ND State Plan on Autism has to do with the need to look at disparities in service and consider how to address personnel development needs:

You may be aware that Federal Special Education law only references the term autism and not autism spectrum disorders. For that reason, the ND state guidelines adopted in 2005 do not include an educational diagnosis for children with other forms of autism such as Asperger's syndrome or PDD-NOS. While it is true that the language in the Federal legislation is limited, that is not the whole story.

When children do not receive individualized education services, teachers and administrators may react to a child's unusual behaviors in ways that can be counterproductive and unpleasant. The impact on children and families can be traumatic.

> *These events occurred last year. Although their son was diagnosed with Asperger's syndrome (another form of autism spectrum disorders) by two independent physician's and a psychologist, the school would not concur that he had an educational disability under current state guidelines which recognize only autism and not any of the forms of autism included in the Diagnostic and Statistics Manual (IV-TR). As a result, the child received none of the environmental and educational services that would have been guaranteed to him if he qualified for services under IDEA or under the 504 Rehabilitation Act which provides for students with a broader range of disabilities. Instead, he was viewed as a "naughty child" who needed to "learn to behave" and was eventually placed at age 7 in a time-out room (illegal) for over 70 minutes. His grandmother was visiting the school and happened to discover him there in a fetal position – the door was being held shut by the teacher because he had screamed and kicked. He is now afraid*

> *to go to school, sleeps with a night light, has started to wet the bed for the first time, is resisting physical exams from his doctor and has lost all self-esteem and interest in activities he used to enjoy.*

While we has been referred to appropriate support agencies, and will receive information on how to exercise our legal right to have our child receive a free and appropriate public education, the underlying need for a state plan that addresses the full range of issues related to services for children with autism spectrum disorder is urgent.

Thank you for your attention.

#4

Same given to House.

Testimony on Senate Bill 2174
2009 Legislative Session
January 21, 2009
Senator Judy Lee, HS Committee Chairperson

Dear Madam Chairperson and Committee Members,

My name is Donene Feist and the state director for Family Voices of North Dakota. Through Family Voices have had the opportunity to interact with many families across the state.

Thank you for the opportunity to testify on behalf of Senate Bill 2174 in support of a state plan on autism.

Earlier this spring a stakeholders group gathered to discuss service options for children within the Autism spectrum should a waiver be developed for children with autism.

As part of the process, Family Voices of North Dakota assisted in obtaining information from families conducted through a Survey Monkey tool, on the types of services families needed for their child with autism or would like to see happen. This was done so as a waiver was developed, family input being a crucial piece, in the development of services for these children. The questions in the survey were asked from the ages of birth-22, of families with a child or youth with autism.

For ages birth-5 years of age the top 3 services families requested were: Family Training, accurate evaluations, and intensive home and community based supports.

For children ages 6-13 years of age the top 3 services families requested were: ongoing consultation, family training and program development. Program development as families did not feel that current programs met their child's needs.

For youth ages 14-22 years of age the top 3 services families requested were: employment support, program development and community inclusion.

I share this information with you as like all of our children with special health care needs, each comes with a unique set of abilities. What works for one child, may not work for another child. With that said, autism is complex. With all of the information, and varying opinions a plan that collectively brings all to the table is vital.

The incidence of autism, one might say are at epidemic proportions. This is a difficult diagnosis. The variables are enormous. Many of these families fall in gap areas of service provision. Many are not eligible for DD services.

Additionally, I am assisting 2 students from Edgeley High School on an awareness project of children with special health care needs. Of the families who have completed the survey, preliminary findings are nearly 23% of the families had medical costs of $5000 or more annually, many of the families in this category stating they had a child within the autism spectrum disorder. Nearly aggregate of 57% of families had from 4-20 service providers working with their child.

Given the information from the 2 surveys which we will be happy to share with you, I am always shocked with the constant maze that families have to navigate. We hear frequently from families their exhaustion in trying to navigate this maze. We hear their fears, sense of isolation and uncertainties for the future. Our challenges together are many.

While there are just as many opinions of best practices, service provisions and treatments there are as many definitions of autism. The definition I have personally decided that seems the most logical as a parent advocate is: Autism spectrum disorders (ASDs) are a group of neuro-developmental disabilities defined by significant impairments in social interaction and communication with the presence of unusual and repetitive behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations, resistance to change in daily routines or environmental changes.

Because of the varying definitions, services, families' choice, data collection and best practices, we believe these are only but a few of the reasons why it is vital to develop a state plan. We cannot take a silo approach to services provided for children within the autism spectrum. It will take a collective effort for all of us.

Congress recognized in the Deficit Reduction Act the plight of many families through the Family Opportunity Act. It has again realized the plight of families, through the Combating Autism Act. North Dakota heeded that call in the development of our Children's with Disabilities Program. We can heed that call again. However, we need a plan to not only meet the needs of these children, family and individuals across the lifespan, but also to do what is in the best interest for the state.

Family Voices has always maintained that if you develop a service system that will assist the families who utilize the services the most, for our most complex children, you create a system that will benefit all individuals. A paradigm shift in thinking if you will. A state plan would certainly be a first step to bringing everyone to the table.

Thank you for your consideration.

Donene Feist
Family Voices of North Dakota
PO Box 163
Edgeley, ND 58433

OUR FAMILY'S STORY

Joe and Janice Kern, Grafton North Dakota

Parents to Kenny, Charlie, Tommy and Jack

We have four children. They are all boys. Our second-born son, Charlie was suspected to have autism at age 23 months by a team of people from Infant Development. They informed us of their suspicion and we were taken by complete surprise. While we did have concerns about his development, we hadn't considered autism.

We followed up on their suspicion and met with a pediatric psychiatrist for a possible diagnosis. This was not easily accomplished as she is located 130 miles away. We learned from other families that some doctors won't diagnose a child so young.

The pediatric psychiatrist diagnosed our son as having "Autistic Disorder" and gave us a list of suggested books.

We continued with the program of Infant Development which was a once-per-week visit to our home. They helped with very early and very basic intervention strategies such as 'Communication Temptation' and 'PECS' which were very helpful to our family.

We wanted to find a doctor to oversee Charlie's care, help us with treatments. We were referred to a doctor who was not a specialist with autism but did see a lot of children with autism. He was the first person to suggest ABA. We learned that our insurance could possibly cover the cost of a consult for ABA programming but not the therapy itself. We decided to pursue and learn more anyway.

While waiting for the initial consult with the ABA therapist we saw another doctor. She too recommended ABA therapy. However, this doctor knew much more about it and recommended it as our only treatment option. Unfortunately, she was not a therapy provider either.

During our initial consult with the ABA therapist, we soon learned that in order to provide this therapy for our son, we would have to be trained ourselves. By this time, ABA had been recommended by two different doctors so we were willing to try it.

This was very exhausting for our family. While we were able to maintain employment, we also had to oversee 4-5 therapists coming in and out of our home, pay them, train them, review the programs, etc.... while working, raising a child with autism and three other children.

This didn't last long and I could no longer work outside of our home. Autism presents a difficulty with finding childcare among many other issues.

Thankfully ABA had a tremendous impact on our son and we fully credit this therapy for teaching him to speak. First in words, next in sentences.

Donene Feist

From: Brenda CLIFTON [jbbcac@msn.com]
Sent: Tuesday, January 20, 2009 10:42 PM
To: fvnd@drtel.net
Subject: Family story about ASD impact

My wife and I have four children, three boys and one girl. The boys are 24, 12, and 11. Every one of them has some aspect of ASD. Our daughter, age 22, moved out of the house two years ago and is currently going to college.

Our oldest son, age 24, has Asperger's and learning disabilities. He did get through college with the help of disability services and a father, who tutored him in almost all of his classes. He has a full – time job but only earns $9 an hour. Because of his student loan payments he does not earn enough money to live on his own so he is still at home. He is tries hard but he is frequently very self-centered and does not understand the additional stress he brings to our household because of his unrealistic persistence in having things his own way.

Our second son, age 12, also has Asperger's. He does not have learning disabilities but he is also very self-centered. His form of Asperger's frequently takes the form of irritability and rage. It is not unusual for him to rage at his mother after school as he unleashes all his pent up stress and frustration from school. He has hit both of his parents and struck his older brother in the face. We are currently trying to get him enrolled in the PATH program. The PATH program is an alternative to hospitalization. It allows us to have him taken out of the home to a safe environment without having him arrested or hospitalized. So far, we have had to call the police to our home once. Our second son sees a therapist twice a month and a psychiatrist once a month.

Our third son, age 11, is autistic and mentally handicapped. He sees a therapist one to two times a month. He is a kind wonderful boy but he will always need help. We keep him very active, but these activities bring expenses not covered by any insurance. We have also had to install a security system in our home to ensure that he will not leave the house unsupervised and get lost.

Our medical bills this year will total over $15,000. This is our out-of-pocket cost after the insurance coverage. I am very worried about what will happen as I get older because we have not been able to save for retirement.

The stress of constantly having to care for our children, to constantly struggle to pay the medical bills, has been very damaging to us. We have no time to ourselves.

Sincerely,

James & Brenda Clifton

SB 2174

I feel this bill is a start in a good direction. In our experience we had poor early intervention diagnostics, by primary physician and school staff. We were denied age appropriate (FAPE) by our school system for kindergarten. We were told he was too immature to start in public school. In the private pre- school our son attended his behaviors were noticed and we were advised to seek counsel with doctors. We had several wrong diagnoses. It wasn't until after the 2nd hospitalization at a private psych hospital, that he was diagnosed with Aspergers Syndrome – Autism Spectrum Disorder in 5th grade. However even when we had the correct diagnosis the hospital did not know how to coordinate medical and physiological treatment for our son and give advice to the school. This lack of coordinated medical treatment and school training lead to two more hospitalizations and two months in juvenile detention. We lost the custody of our son due to medical depravation and he was placed in a residential treatment center. This center let us assist and help train the staffs, so we did finally get help. Having autism spectrum specific training and programs would have helped us immensely. This would limit the exposure to conduct disorders that these kids pick up on, as they are easy targets. He was a vulnerable child and will be also as an adult. We would like to see some transition programs to assist these individuals when time comes to get on their own. Our concern for the future is that our Son can live independently with support, not homeless or in prison eventually to being a productive member of society.

I could provide all medical records, IEPs, and related time lines to support these statements. We have carried these with us to the U of Min. and the treatment centers seeking help with our son. We adopted our son to give him a chance at life, not to give up on him the way some of the systems have. I can bring these to Bismarck if further documented testimony is needed.

Murray Nelsen

714 10th Ave E

West Fargo, ND

#5

Testimony on SB 2174
Human Services
01/21/2009

Madam Chair Lee and members of the Human Service Committee, I am here to state testimony in favor of SB 2174. My name is Vicki Peterson and I live in Bismarck. I am a single parent of a six-year-old son with autism. Autism Spectrum Disorders are a group of neurobiological developmental disabilities, affecting in varying degrees, impairments in verbal and non-verbal communication, social interactions, and unusual repetitive behaviors including, learning styles, paying attention, and reacting to sensations and resisting change in routines and environments. Autism Spectrum Disorders impact the life span of an individual.

Aaron, my son, early in life suffered from several chronic health issues that include feeding and tactile sensory issues, severe gastrointestinal attacks, continuous upper respiratory infections and a rare and unusual sleep pattern. At ten months of age, my son, started regressing in areas of development, and in a short time loss many of his fine motor skills, had increased sensory issues, and in one week loss all verbal communication. After many changes in physicians, I followed the advice of a pediatrician and arranged for Aaron to have diagnostic testing done at an Autism Center in Minnesota. Aaron was officially diagnosed with Autism and Sensory Processing Disorder at fifteen months. I asked the specialists before returning to North Dakota," What is my next step?" The reply was to go home and hope for the best. Instantly my family was faced with a world full of isolation, nonacceptance, and a system that seemed impossible to understand. Financial stress became a way of life. For my family a new and different world began. With the help of trusted friends and family, we moved forward. We began with proper education settings, interventions that would work specifically for Aaron, and continued to search for expertise in healthcare providers. Guidance from family centered organizations, helped with the maze of systems my son would be a part of. I became the best possible advocate for my son with the tremendous help and mentoring from other parents whom have children with special healthcare needs.

As my family moves forward, we have gained knowledge, created a new way of life and thinking, and are becoming part of the community again. We continue to search for interventions, therapists, nutritional experts, and financial help in private and public programs. We develop learning opportunities and strive to give Aaron the best possible education alongside his peers. Aaron has made remarkable progress in communication and I can proudly say has regained some verbal communication skills and continues to improve in this area. I feel very fortunate to have a great team that continues to work with Aaron and my family.

My hope would be for all families to have access to health insurance coverage to cover all the needs of their loved one with an autism spectrum disorder. To be able to access best practices in intervention, wrap-around services, and care co-ordination. To receive services in programs and providers who are knowledgeable in ASD. I worry about the future for my son. Will he become independent, will their be appropriate transition services available for him as he enters the adult world, will he be able to continue his education and become a meaningful partner in our community, what will the quality of life be for him. These are questions that are constantly on my mind. I also worry about rural North Dakota, where I grew up, will those families have access to services. I worry if I will be able to afford to send my other son to the college he chooses with the financial stress we encounter. Will Aaron be ridiculed and bullied due to lack of awareness? I trust that positive changes can happen, as Aaron has taught that well to my family.

In support of SB 2174 which will:

- Create a North Dakota Autism Spectrum Disorder Task Force that will enable us to identify gaps in services and programs for people with Autism Spectrum Disorders.
- Address the issue that ASD, spreads across the lifespan of an individual. (ASD= Autism Spectrum Disorders including: Autism,

Asperger's, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Developmental Disorder- None Otherwise Specified.}

- Design and implement statewide best practices guidelines for people with ASD. To include training for providers and families.
- Provide solutions to the state of North Dakota for accessing services and attracting providers to reside and to work in ND specializing in ASD.
- To work in collaboration with all agencies and families to raise awareness.
- To include under-served, self- advocates, and families as partners in decision and policymaking.

I thank you for your time and consideration for SB2174.

Vicki L Peterson
319 Aspen Avenue
Bismarck, ND 58503
vicki_asdc@msn.com

#6

Same given to House.

Testimony
Senate Bill 2174
Senate Human Services Committee
Senator Judy Lee, Chairman
January 21, 2009

Chairman Lee and members of the Committee: my name is Carlotta McCleary. I am the Executive Director of ND Federation of Families for Children's Mental Health (NDFFCMH). NDFFCMH is a parent run advocacy organization that focuses on the needs of children and youth with emotional, behavioral and mental disorders and their families, from birth through transition to adulthood.

NDFFCMH works with many families whose children have an Autism Spectrum Disorder. The NDFFCMH provides families parent-to-parent support and advocacy services.

I am also the parent of a young man who is transitioning to adulthood. My son Garrett has Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). PDD-NOS is an Autism Spectrum Disorder.

NDFFCMH believes North Dakota should develop a state plan on autism spectrum disorders. Many of our children and youth with autism spectrum disorders are having difficulty with eligibility into the very programs that would be most beneficial to meet their needs.

We support the Department of Human Services (DHS) budget that includes an autism waiver for children birth through five. Many of our children and adults do not currently meet the eligibility that ND DHS has set in its Developmental Disability Waiver.

We know that the needs go far beyond the current Autism Waiver proposal. Children and youth with autism spectrum disorder continue to have needs across their life span. Their needs do not stop at the age of five. Many of the transitioning age youth lack the adaptive skills necessary to become independent adults. There is a need for ongoing support for employment as well as supportive living arrangements.

We need a plan that will address the needs of children, youth and adults with Autism Spectrum Disorders and a plan that will coordinate services among the different agencies that have responsibility in meeting the needs. A public and private partnership needs to be developed that will truly address the complex needs for this population.

Thank you for your time.

Carlotta McCleary, Executive Director
ND Federation of Families for Children's Mental Health
PO Box 3061
Bismarck, ND 58502

Phone/fax: (701) 222-3310
Email: carlottamccleary@bis.midco.net

#7

Same given to House.

TESTIMONY ON SB 2174
SENATE HUMAN SERVICES COMMITTEE
January 21, 2009
By Robert Rutten, Director of Special Education
Department of Public Instruction
701-328-2277

Madam Chairman and members of the committee:

My name is Bob Rutten and I serve as the director of special education in the ND Department of Public Instruction. I am here to express support for the proposed autism spectrum disorder task force as outlined in SB 2174.

The office of special education within the ND Department of Public Instruction is responsible for the general supervision of the Individuals with Disabilities Education Act (IDEA), the nation's federal special education law. In the 1990's autism was added to the list of defined disabilities within the implementing regulations of the IDEA. It became a distinct disability category within the special education law as a result of that change.

The following table presents longitudinal data regarding the number of children and youth who have disabilities and who receive special education and related services in the schools of North Dakota. As you can see there has been a significant increase in the number of children with autism identified and served in special education since 1999. That year there were 112 children for whom autism was identified as the primary disability. In 2007 the schools of our state were serving 444 children with this primary disability. Additionally, North Dakota permits use of a category of disability known as Non Categorical Delay for children up through age nine who are experiencing developmental delays. In that disability category there are 1,122 children receiving special education services. It is probable that a sizable number of these children may, in fact, have autism. However, there has been a well-documented decline in North Dakota's overall K-12 student enrollment for many years. It is especially compelling that we are serving almost the same number of students in special education as we were in 1999 despite an approximate decrease of 18% in the overall student population.

Comparison by Disability for Dec. 1999 through Dec. 2007

Disability	Dec 1999	Dec 2000	Dec 2001	Dec 2002	Dec 2003	Dec 2004	Dec 2005	Dec 2006	Dec 2007
Autism	112	135	160	197	240	278	320	375	444
Deaf	43	38	38	35	0	2	0	0	0
Deaf/Blind	3	4	4	4	1	2	2	12	8
Emotional Disturbance	973	1,037	1,096	1,123	1,193	1,278	1,127	1,087	1,054
Hearing Impairment	111	106	102	102	147	137	139	126	109
Mental Retardation	1,241	1,246	1,200	1,169	1,142	1,092	970	975	906
Non-Categorical Delay 3-5	216	271	305	325	397	423	451	504	567
Non-Categorical Delay 6-9		49	132	223	260	361	433	517	555
Other Health Impaiment	542	640	781	960	1,086	1,236	1,296	1,388	1,417
Orthopedic Impaiment	177	158	159	158	137	182	148	132	124
Speech Impairment	4,416	4,251	4,204	4,262	4,301	4,619	4,307	4,245	4,032
Specific Learning Disability	5,686	5,620	5,353	5,247	5,043	4,973	4,594	4,387	4,307
Traumatic Brain Injury	31	35	33	35	41	46	51	32	37
Visual Impairment	61	60	63	61	56	52	45	45	46
TOTAL	13,612	13,650	13,630	13,901	14,044	14,681	13,883	13,825	13,606

In 2003 the Department of Public Instruction partnered with the Department of Human Services to create the document *Guidelines: Identifying, Serving, and Education Children and Youth with Autism.* Statewide training was provided related to the content of this guidance material for educators, parents, and related services providers.

The level of national interest in autism continues to remain at exceptionally high levels. Parents and schools across America are working together to increase awareness and proficiency in serving children and youth who have this life-long, nonprogressive developmental disability. The Department of Public Instruction supports this proposal to create a task force for the purpose of developing a state autism spectrum disorder plan. Through preliminary meetings with members of the state autism plan workgroup, it has become apparent that a state plan would sharpen the focus of our state's efforts to provide appropriate services for North Dakotans with autism. It has the potential to articulate areas of need in the current system of care, across services, and across the lifespan. The Department of Public Instruction reviewed the content of the proposed legislation and urges your support.

#8

Autism - The Smith Family Story

Sandy Smith
165 23rd Ave E.,West Fargo, ND
701-367-9855
sandysmith@ndautismcenter.org

My son, Tyler was diagnosed in December 2003 with Pervasive Developmental Disorder which is on the Autism Spectrum. He was 19 months old. Although, we sensed something was wrong, it was still devastating to hear the news. However, what was even more devastating was to find out how inadequate the services and funding for children diagnosed with autism are in North Dakota. The lack of funding at a state level and the fact that ND insurance companies do not cover the therapy needed has resulted in very few if any autism professionals moving into or staying in our state.

Everyone told us how lucky we were that we got a diagnosis so early and that early intervention was paramount in helping children with autism. We were referred to the Infant Development Program at South East Human Services when our son was about 17 months old. The people we worked with from the Infant Development Program were outstanding. However, my son needed much more than the one visit per week from a therapist that was available from Infant Development. I was also informed that the West Fargo School District had an Early Childhood Special Education Preschool but they would not accept him until he was three! He needed intensive Applied Behavioral Analysis (ABA) therapy immediately and every day that went by without it lessened his chances of having a good prognosis and caused great stress for our family.

Fortunately, I work at Microsoft and they have an autism therapy benefit as part of their National Premera Blue Cross and Blue Shield insurance program. They would pay 80% of the costs for 40 hours of ABA therapy per week. However, I found out very quickly that there was no one in the state of North Dakota that was certified by Microsoft's Premera Blue Cross and Blue Shield to provide this service for my son. Again, I was devastated! I had insurance that would pay but no providers.

I went on a personal crusade to find someone that could help. After much work I finally got the name of the Fargo Public Schools autism consultant and a paraprofessional who had some training in ABA. Unfortunately, the autism consultant didn't have the qualifications needed to become certified for my insurance. However, since the days were ticking by, I privately paid this consultant and the paraprofessional to start an in home ABA therapy program in June of 2004. Six months precious months had passed since my son was diagnosed!

I eventually did find an autism consultant in Grand Forks, ND that met the strict requirements of my insurance and she was certified in December of 2004. I had been privately paying for therapy for 7 months because of the lack of autism professionals in this area. We were also dealt another blow in August of 2006 when this consultant moved to the Boston, MA area to get specialized training to get her doctorate degree. There was no place in ND that she could get this experience. At first she flew back once per month to supervise my son's program. However, after about a year the visits we far fewer and my son's behaviors required more frequent consultation.

At this point, I knew we had to take matters into our own hands. With help of my daughter, my son's senior ABA therapist and her mother, we started a 501c3 non-profit organization called the North Dakota Autism Center, Inc. After more than two years of work and fundraising we opened the NDAC in Fargo on November 17, 2008. We were lucky enough to find a North Dakota native in Omaha, NE who is a Board Certified Behavior Analyst that wanted to move back to North Dakota to be our Program Director. We now have 9 children with autism receiving services and are typically adding about 2 clients per month. Although we do charge a fee for children to be enrolled it is by no means enough to meet all of our financial needs. We depend heavily on fundraising events put on by volunteers, private donations and grants from area foundations.

It shouldn't be this difficult to get services for our children with autism. As I said in the beginning of our story, the lack of funding at a state level and the fact that ND insurance companies do not cover the therapy needed result in very few if any autism professionals moving into or staying in our state. Children with autism spectrum disorders can have a good long term prognosis with the right intervention. However, ND children are at a definite disadvantage unless more funding is available to pay the autism professionals. Fund it and the professionals will come.

#9

Senate Bill 2174 A Bill For An Act To Provide For The Creation Of An
Autism Spectrum Disorder Task Force

January 21, 2009

Human Services Committee
Senator Judy Lee, Chair

Madame Chair Lee and Members of the Human Services Committee:

My name is Elaine Grasl; I am a member of District 47. I am here in support of Senate Bill 2174; a bill for an act to provide for the creation of an Autism Spectrum Disorder Task Force.

Autism Spectrum Disorder has become much better known in the past few years with organizations like Autism Speaks and others keeping it in the forefront. Technology used to study the brain continues to advance which holds the promise of revealing new secrets. New treatments are being developed and remain to be developed.

What we know is that within a small hard case is cradled an organ of wonderful intricacies. It long ago occurred to me that along with the differences the so-called various brain-involved disorders may have, there are certain commonalities. We need to work together towards a common purpose. ...So it is needed that this task force be pulled together to develop this state plan.

Autism Spectrum Disorder better and more completely describes the wide range of disability, but I hope the excluded "autistic-like" excludes no individuals. I also thought, per the advice of a researcher, that a neurologist or a psychoneurologist be included in the task force, but I imagine that would be difficult to achieve. Perhaps, if nothing else, one or the other could be consulted.

Please support the task force especially with family involvement.

Elaine Grasl
7314 Sunshine Lane
Bismarck, ND 58503-9134
701-223-8149

#10

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

BILL 2174 (2009) SENATE HUMAN SERVICES COMMITTEE

Honorable Judy Lee, Chairman

January 21, 2009

Chairman Lee, and members of the Senate Human Services Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A). P&A supports and commits to cooperate with the partners named in SB 2174, with or without the amendments proposed to date.

People with Autism Spectrum Disorders (ASD) do not fit neatly into our state's service delivery system. Therefore, even people who functional, adaptive behavior is similar to that of a person with intellectual disabilities (i.e., Intelligence Quotient <70). Services are brought to bear from a variety of programs, funding sources, and philosophical perspectives. Fragmentation and confusion is a side effect.

Please consider this bill favorably and direct all state agencies with a stake in serving North Dakotans with ASD to develop a coherent and effective plan for services. If possible, please consider funding to reimburse individuals with ASD and their families to be effective participants.

Thank you very much for your consideration.

#11

Testimony
Senate Bill 2174 –Department of Human Services
Senate Human Services Committee
Senator Judy Lee, Chairman
January 21, 2009

Chairman Lee, and members of the Senate Human Service Committee, I am JoAnne Hoesel, Director of the Division of Mental Health & Substance Abuse Division and Developmental Disabilities Division for the Department of Human Services. I am here to today to provide information on services provided and planned in the area of Autism Spectrum Disorders (ASD) by or through the Department of Human Services (DHS).

The Department, through its developmental disabilities (DD) and mental health areas, has been involved in ASD issues since the mid 90s. This area is rapidly changing, highly emotional, and ripe with differences of opinion.

In the area of mental health, over 186 children with pervasive developmental disabilities, a type of disorder on the autism spectrum, were served at the regional human service centers in state fiscal year 2008. The state's wraparound process for children and adolescents with emotional disturbances and in need of intensive care coordination began in 1994. A significant number with ASD are served by this program. DHS licenses group homes, residential child care facilities, psychiatric residential treatment facilities, child and adult foster homes, waiver services including DD group homes and individuals with ASD are served throughout this array.

In the area of developmental disabilities, both North Dakota's Individuals with Disabilities Education Act (IDEA) Advisory Committee and Interagency Coordinating Committee participated on an autism task force that was appointed in March 2001. The outcome of this effort was autism guidelines for both DPI and DHS' early intervention programs. The guidelines were published in March of 2003.

Currently, the Family Support Services area of developmental disabilities provides family in-home supports through structured interventions and respite. Individuals with ASD also receive services through the array of DD Medicaid waiver services. In the area of early intervention, family subsidy, Right Track, newborn screening, and Infant Development, evaluations, support families of children with ASD.

The Department works with Minot State University to coordinate services with their recently obtained federal grant that targets school-aged children with ASD. We are currently involved in the group that is writing a state autism plan.

The Department holds monthly state review team meetings that include mental health, substance abuse, developmental disabilities, Medicaid, education, and juvenile justice. These meetings bring a collaborative perspective to difficult situations despite valiant local and regional efforts. Many times, the team reviews individuals who have disorders on the autism spectrum and both mental health, developmental disabilities, and education systems find it difficult to provide adequate services.

The Department provides training to both developmental disabilities and mental health professionals. An autism spectrum expert trained individuals, multi-day training for early intervention staff was held; three training sessions were offered last year with a follow-up planned for the summer of 2009; an autism track is planned for the mental health conference this spring; and the Department sponsored the attendance of several people at the Network of Autism Training & Technical Assistance Projects conference in the fall of 2008.

In preparation for this legislative session, the Department held several stakeholder meetings focused on this area to gain feedback and recommendations for focus within the Department's budgeting process. The Autism Waiver, which is funded in the Governor's budget, is a result of that feedback. This autism waiver is planned for children ages zero to five. This waiver will provide refined and targeted services for diagnosis and intensive evidence-based interventions. Early intervention plays a critical role in early diagnosis and treatment, and this waiver plans to develop a team of professionals with specialized training to diagnos and design specialized programs.

Chairman Lee and members of the committee, as more information is learned and experience gained in the area of ASD, DHS will continue its commitment, efforts, and collaboration to support children and families in North Dakota.

I will answer any questions you may have at this time.

#12

Lee, Judy E.

From: Dan Howell [Dan.Howell@annecenter.org]
Sent: Tuesday, January 27, 2009 12:30 PM
o: crolfson@comcast.net; Lee, Judy E.
c: Murry, Bruce D.; Heckaman, Joan M.
ubject: Re: Autism request of Dan Howell

Senator Lee- Thank you so much for the opportunity to testify in support of SB 2174. I hope that I answered your questions.

It was my understanding that you had questions with regards to some of the amendments that were being contemplated . These amendments to the bill had to do with the definition of autism spectrum disorder.

Bruce Murray and I spoke afterwards and it would appear to us that the definition for ASD would be a better discussion for the Task Force that this bill is looking to create.

The Task force could then bring back a definition to the governor and legislative council outlined in the bill by July 1 2010.

I also think the word "residential" in line three of the bill could be omitted.

Senator Lee, I would suggest that the Appropriation be removed from the bill as I feel expenses for the meetings can be borne by members of the task force or their agencies. If parents need reimbursement, I believe that reimbursement can be paid by organizations outside of stat government. This would avoid having the bill go to appropriations.

Thank you again for the opportunity to assist, if there is anything else I can do please el free to contact me.

Dan Howell

>>> <crolfson@comcast.net> 1/25/2009 3:30:18 PM >>>

Dan Howell will have something to you early next week, as promised, regarding SB 2174.* He and the Anne Carlsen Center are great state leaders in this area.* I think you said you wanted it by Wed. and I just want to confirm that is an adequate time frame for you.* Thanks, as always, for your leadership.* Cal Rolfson

----- Original Message -----
From: "Judy E. Lee" <jlee@nd.gov>
To: crolfson@comcast.net
Sent: Sunday, January 25, 2009 2:37:01 PM GMT -06:00 US/Canada Central

Subject: RE: Autism request of Dan Howell

SB 2174's title is to provide for the creation of an autism spectrum disorder task force and relating to residential care for children with autism spectrum disorder.
Since ACS is an expert in this area, I'd appreciate any insight and recommendations that Dan might have.

ator Judy Lee
2 Brentwood Court

#13

NDLA, Intern 02

From: Murry, Bruce D.
Sent: Monday, January 26, 2009 3:32 PM
To: NDLA, Intern 02
Subject: FW: An amendment to SB2174 ?

Bruce Murry
Public Policy Advocate
ND Protection & Advocacy
(sent from a remote location)

From: Cathy Haarstad [cathy.haarstad@minotstateu.edu]
Sent: Monday, January 26, 2009 8:34 AM
To: Roxane; VICKI PETERSON; Murry, Bruce D.; carlottamccleary; Donene Feist1; Elaine Grassle; janice_kern@tacanow.org; jocelyn@autismnd.org; BobH@blackgoldpotato.com; mark.sloan@AutismND.org
Cc: Heckaman, Joan M.
Subject: RE: An amendment to SB2174 ?

Senator Heckaman has asked us to reach consensus on a definition for the bill so she can take care of that in her committee work which may begin as soon as today. The last definition submitted for consideration is:

Autism Spectrum Disorder (ASD), also referred to as autism, is a neuro-developmental disorder which results in developmental delay or disability. Autism affects the way the brain functions, resulting in difficulties with communication and social interaction, and unusual or repetitive patterns of behavior, activities and interests.

The term "spectrum" refers to a continuum of severity or developmental impairment. Children and adults with ASDs have behaviors that cover a wide spectrum, with individual differences in: 1) Number and kinds of symptoms; 2) Severity: mild to severe; 3) Age of onset; 4) Levels of functioning; and 5) Challenges with social interactions

The committee will consider not only the needs of individuals who have been formally diagnosed with ASD but also individuals who may have the disorder but have been served under other diagnostic categories; including and not limited to non-categorical delays; or who may have behaviors on the spectrum but were not formally diagnosed in childhood.

Can you live with this, does it get at the concerns expressed earlier or if not, what would you suggest? I would prefer that we avoid the term "autistic-like" if possible.

Cathy Haarstad

North Dakota Center for Persons with Disabilities 500 University Avenue W.
Minot, ND 58707
1-800-233-1737
701-858-3230
cathy.haarstad@minotstateu.edu
http://www.ndcpd.org
Fax: 701-858-3483

Bring together what may not be done alone to enhance the well being of families with children that have special health care needs or disabilities.

-----Original Message-----
From: Roxane [mailto:romanick@bis.midco.net]
[illegible]ent: Sunday, January 25, 2009 11:23 PM
[illegible]: Cathy Haarstad
Cc: VICKI PETERSON; bruce murray; carlottamccleary; Donene Feist1; Elaine Grassle; jane heckamen
Subject: Re: An amendment to SB2174 ?

One more thought...I think Vicki's language that she found from Iowa nails it.

Roxane

Lee, Judy E.

From: Cathy Haarstad [cathy.haarstad@minotstateu.edu]
Sent: Tuesday, January 27, 2009 10:16 AM
To: Murry, Bruce D.; Heckaman, Joan M.; dan.howell@annecenter.org; Lee, Judy E.
[illegible]ubject: RE: An amendment to SB2174 ?

I can certainly live with the decision not to include a formal definition and defer that job to the planning committee once formed.

Two things are of the utmost importance to the families that have walked this road. 1) That this bill passes and we do whatever it takes to secure that; 2) that the term "people with autism spectrum disorders" not be removed from the bill.

Any definition of that term can wait for the planning committee to be established by the legislation.

Cathy Haarstad

North Dakota Center for Persons with Disabilities 500 University Avenue W.
Minot, ND 58707
1-800-233-1737
701-858-3230
cathy.haarstad@minotstateu.edu
http://www.ndcpd.org
Fax: 701-858-3483

Doing together what may not be done alone to enhance the well being of families with children that have special health care needs or disabilities.

-----Original Message-----
From: Murry, Bruce D. [mailto:bmurry@nd.gov]
Sent: Monday, January 26, 2009 4:47 PM
To: Elaine Grasl; Cathy Haarstad; Roxane; vicki_asdc@msn.com; c mccleary; Donene Feist; janice_kern@tacanow.org; jocelyn@autismnd.org; bobh@blackgoldpotato.com; mark.sloan@autismnd.org
Cc: Heckaman, Joan M.
Subject: RE: An amendment to SB2174 ?

Absent strong objections from those who know more than I -- all of you -- I plan to recommend Senator Heckamen ask to amend out the definitions from this bill. I personally think we should update the definitions AFTER we complete the study process. Advocates simply dont agree on the definition questions. I need to check with my boss and will check for feedback from you all. Please forgive me if I transition beyond assertive in this process. If so please speak up.
Bruce Murry
Public Policy Advocate
ND Protection & Advocacy
(sent from a remote location)

From: Elaine Grasl [goldenmomentsonsunshine@hotmail.com]
Sent: Monday, January 26, 2009 3:10 PM
To: cathy.haarstad@minotstateu.edu; Roxane; vicki_asdc@msn.com; Murry, Bruce D.; c mccleary; [illegible]ene Feist; janice_kern@tacanow.org; jocelyn@autismnd.org; bobh@blackgoldpotato.com; [illegible]k.sloan@autismnd.org

Cc: Heckaman, Joan M.
Subject: RE: An amendment to SB2174 ?

I was following the conversation last evening but I was unable to reply, except to Cathy, which I did a little earlier. I agree that there may have been gaps with the original; this more specific definition seems to take care of a lot of the problem. I sure would not like to see anyone disregarded due to lack of a diagnosis or whatever might occur to cause them to be left out.
eg

> From: cathy.haarstad@minotstateu.edu
> To: romanick@bis.midco.net; vicki_asdc@msn.com; bmurry@nd.gov;
> carlottamccleary@bis.midco.net; fvnd@drtel.net;
> goldenmomentsonsunshine@hotmail.com; janice_kern@tacanow.org;
> jocelyn@autismnd.org; BobH@blackgoldpotato.com;
> mark.sloan@AutismND.org
> CC: jheckaman@nd.gov
> Date: Mon, 26 Jan 2009 08:34:03 -0600
> Subject: RE: An amendment to SB2174 ?
>
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> Doing together what may not be done alone to enhance the well being of families with children that have special health care needs or disabilities.

>
>
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> From: Roxane [mailto:romanick@bis.midco.net]
Sent: Sunday, January 25, 2009 11:23 PM
To: Cathy Haarstad
> Cc: VICKI PETERSON; bruce murray; carlottamccleary; Donene Feist1;
> Elaine Grassle; jane heckamen
> Subject: Re: An amendment to SB2174 ?
>
> One more thought...I think Vicki's language that she found from Iowa
> nails it.
>
> Roxane

Windows LiveT: E-mail. Chat. Share. Get more ways to connect. Check it out.<http://windowslive.com/explore?ocid=TXT_TAGLM_WL_t2_allup_explore_012009>

1-27-09

PROPOSED AMENDMENTS FOR SB 2174

Page 2, line 6, replace "state health officer, or the officers" with "director of the department of human services, or the directors"

Page 4, line 31, replace "health" with "human services"

Renumber accordingly

2174

To Sen. Judy Lee
From Dan Howell

Alaska study

Autism Issues and Needs

The Governor's Council on Disabilities & Special Education

Preliminary Report of the Ad Hoc Committee on Autism: Findings and Recommendations

Governor's Council on Disabilities and Special Education

2006

Kathleen Fitzgerald, Chair
Millie Ryan, Executive Director

State of Alaska
Department of Health & Social Services
Governor's Council on Disabilities & Special Education
P.O. Box 240249 • Anchorage, Alaska 99524-0249
Telephone: (907) 269-8990 • FAX: (907) 269-8995
Toll Free in Alaska: 1 (888) 269-8990
http://www.hss.state.ak.us/gcdse/

Austism Ad Hoc Committee Members

Brita Bishop: Division of Behavioral Health
Dr. Teresa Bunsen: University of Alaska Anchorage
Kathy Fitzgerald: Governor's Council on Disabilities and Special Education Council Member
Jerry Fuller: Department of Health & Social Services, Office of the Commissioner
Rebecca Hanson: Division of Senior and Disability Services
Kris Johnston: Governor's Council on Disabilities and Special Education Council Member
Erin Kinavey: Office of Children's Services
Margaret Lowe: Alaska Mental Health Trust Authority
Terry Manning: Department of Education and Early Development
Nancy Nagarkar: Special Education Service Agency
Cindy Olson: Parent
Patrick Pillai: Special Education Service Agency
Susan Ryan: University of Alaska Anchorage
Chris Saddler: Parent
Don Shackelford: Parent
Scott Sidell: Governor's Council on Disabilities and Special Education Council Member
Jayson Smart: Stone Soup Group
Donna Swihart: Governor's Council on Disabilities and Special Education Council Member

Austism Ad Hoc Committee Staff

Kathy Allely: Governor's Council on Disabilities and Special Education
John Hischer: Governor's Council on Disabilities and Special Education MSW Student Intern.

Table of Contents

Executive Summary

Although incremental changes have occurred on behalf of children and adults with Autistic Spectrum Disorders (ASD) in Alaska, the pace and amount of change has been inadequate to meet needs. Alaska does not have a system to capture the prevalence of ASD, but as in other states, the educational and service delivery systems have experienced an increased demand for ASD-specific intervention in recent years.

[illegible]rts agree that early identification and diagnosis of ASD is important.

Experts agree that early identification and diagnosis of ASD is important. Screening identifies those in need of a comprehensive evaluation and assessment, and a diagnosis leads to appropriate interventions. Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997). ASD specific interventions may speed the child's development, ameliorate inappropriate behaviors, and improve functioning over their lifetime. While not all children with ASD experience dramatic improvement with intervention, many do.

The overall cost of caring for a person with autism over his or her lifetime is estimated to be $3.2 million (Ganz, 2006). Applying national prevalence rates of 1/166 to Alaska's 10,000 births annually results in about 60 babies born each year who will likely develop ASD. The lifetime cost for the 60 Alaskan babies born this year would total $192 million, as well as for the 60 babies born every subsequent year.

When children do not receive early intervention, the cost of caring for them over their lifetime exerts a substantial economic burden on society. Behavioral therapies represent only 6.5% of the total cost of caring for an individual with ASD. By contrast, adult care represents 21% and lost productivity is nearly 31% of the total annual expense involved in caring for an individual with ASD.

The Governor's Council on Disabilities and Special Education, with the concurrence of the Alaska Mental Health Trust Authority, convened an Ad Hoc Committee on Autism to develop recommendations to present to the Alaska Legislature and Administration. The group organized their 21 recommendations around identification, diagnosis, and treatment. Recommendations were prioritized by the Committee, and submitted to the Council's Executive Committee for final approval.

The following four recommendations were ranked as the Committee's highest priorities. Although each is a separate recommendation, their interdependent nature requires they be considered as a package. One recommendation is to increase screening of children for ASD. Screening is a quick process used to differentiate children who may experience ASD, and identifies those who need a complete developmental and medical assessment. Without enhancing the capacity for comprehensive assessment and diagnosis, screening would be a disservice, leaving families concerned but experiencing a very lengthy wait before confirming or ruling out a diagnosis of ASD. Similarly, because the value of early diagnosis is in the potential for amelioration; diagnosing more children with ASD will make the existing shortage of services even more critical. To provide an adequate level of services, training for families, teachers, and direct service providers is essential to increase the size and quality of the workforce. Finally, the need for family support will intensify as more children are identified with ASDs.

Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

1. **Greatly expand autism resources and referral services** so that the program is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.

   Several activities are envisioned to expand the functions of an autism resource center. These include:

   - An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person.
   - The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;

- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems and political advocacy, guardianship, medical services, and other topics as needed.

2. **Establish universal screening for autism spectrum disorders**, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for comprehensive assessment for children with risk factors for ASD.

   Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

   Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

Early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children.

3. **Increase the capacity for comprehensive, timely assessments and diagnosis** of Autism Spectrum Disorders using a multidisciplinary team that is embedded with a system for referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).

   Screening for ASD will identify those children who require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, opthamology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

Assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family.

Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

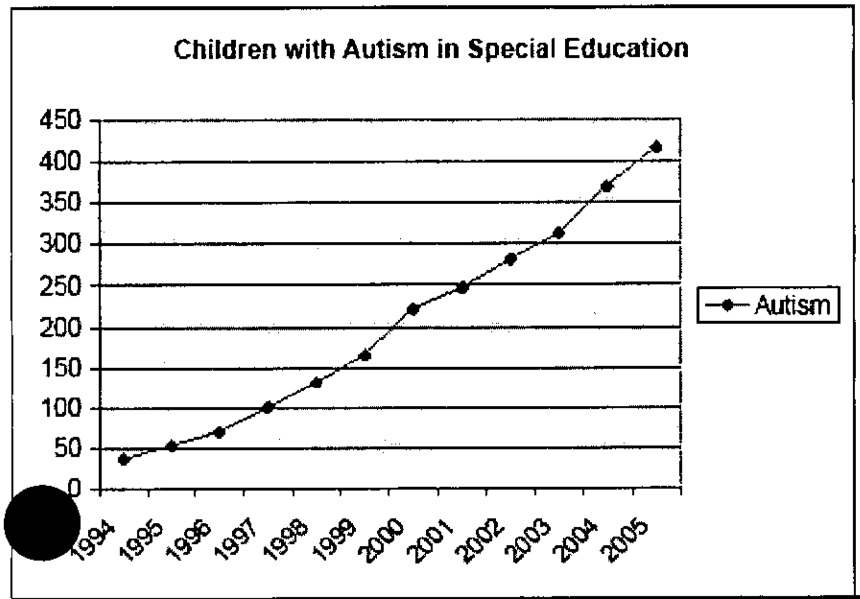
The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

4. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that the Medicaid State Plan be modified to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.

Introduction
Autism Spectrum Disorder

Autism is a complex developmental disability that is the result of a neurological disorder affecting the functioning of the brain (Autism Society of America). Autism Spectrum Disorders (ASD) includes Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, and Childhood Disintegrative Disorder. Studies have produced varying prevalence rates, in part due to method of diagnosis and size of the sample; however, 1 in 166 children are thought to have an Autism Spectrum Disorder (Centers for Disease Control and Prevention, n.d.),. Each year about 10,000 babies are born in Alaska, suggesting that 60 of those babies will be identified in their early childhood as having an ASD. Another indicator that Autism is climbing in Alaska comes from the public school system. The number of children with autism in the Alaskan School system has risen each year for the past 13 years. These trends are similar in other states.



Growth of the Number of Cases of Autism in Alaskan Schools

ASD covers a wide range of symptoms, from very mild to severe. ASD affects social skills, communication, and cognitive development. ASD affects the individuals' ability to convey or interpret others emotions. Children may engage in restricted and/or repetitive play and have

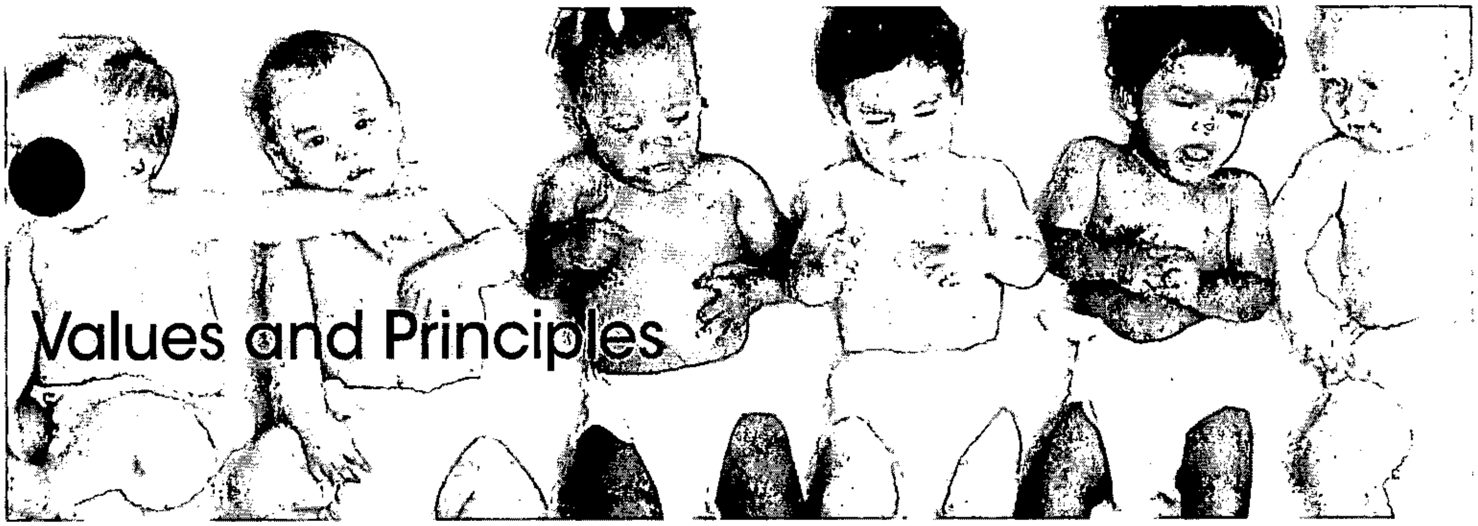
Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking.

unusual attachments to objects. People with ASD might not seem interested in other people and prefer to be alone. Some children with ASD do not like to be held or cuddled, and many do not make eye contact with others. Individuals with ASD also show varied degrees of impairment in their verbal and nonverbal communication. Some individuals with ASD may be nonverbal, while others may not have any difficulty speaking. Some repeat something previously heard or use stock phrases or learned scripts to communicate. Cognitively, individuals with ASD develop differently from others. Many people with ASD have difficulty processing sensory stimuli and verbal input, and this affects their understanding of the world around them.

Ad hoc Committee on Autism

On December 6th 2005, the Governor's Council on Disabilities and Special Education's convened an Ad Hoc Committee on Autism. The purpose of this group was to examine the current status of services needed by people with ASD and their families and make recommendations to the Legislature and state policymakers. The 17 member committee consists of parents of children with ASD, Governor's Council members, and representatives from the Department of Health & Social Services, Division of Senior and Disability Services, Division of Behavioral Health, Department of Education & Early Intervention, Office of Children Services, and the University of Alaska Anchorage. The Committee met monthly over the course of five months. This report contains the recommendations of the Governor's Council and the Ad hoc Committee on Autism.

The report is organized around the following three major areas: Values and Principles, Identification/Screening/Diagnosis, and Services. Topics are prefaced with a summary of the Committee's evaluation of Alaska's current status and followed by recommendations.



Values and Principles

The following statements articulate the values that guided the Committee's work and recommendations.

> **Early intervention works, is cost-effective and fiscally responsible.**

People with Autistic Spectrum Disorders:

- Have great promise, gifts and potential;
- Deserve the opportunity to engage actively in the community, with friends and family and in work and volunteer positions;
- Contribute to their families, communities, and Alaska;
- Represent ethnic, socioeconomic, racial, and religious groups, speak many languages and live in urban, rural and remote areas of the state; and
- Are people first – ASD is only a part of who they are.

Early intervention works, is cost-effective and fiscally responsible.

Services for people with ASD need to be:

- Individualized, based on family choice and need;
- Family directed, and based on principles of self-determination;
- Evidence-based;
- Provided as soon as possible after identification and diagnosis;
- Culturally appropriate and relevant, available in urban and rural areas;
- Coordinated, comprehensive and collaborative across all disciplines and state service systems;
- Available across the lifespan, and the full spectrum of autistic disorders;
- Delivered in a manner that maximizes independence by providing the supports and services needed; and
- Built on and honoring of individual strengths.

Identification and Diagnosis

The importance of early [illegible]ntification and diagnosis [illegible]dividuals with autism cannot be overstated.

The importance of early identification and diagnosis of individuals with autism cannot be overstated. Early identification and diagnosis of autism leads to early intervention. Children with autism identified early and enrolled in early intervention programs show significant improvements in their language, cognitive, social, and motor skills, as well as in their future educational placement (National Research Council, 2001). There is also empirical evidence that shows children who enter early intervention at younger ages show greater results than children who enter intervention programs at an older age (Harris & Handleman, 2000; Sheinkopf & Siegal, 1998). There is also a financial incentive for the early identification, diagnosis, and intervention for children with autism. Ninety percent of children with autism who do not receive effective early intervention will require special or custodial care throughout their lives, and this is estimated to cost the United States $35 billion dollars a year (Ganz, 2006).

Where we are now

For the past 14 years, the Children's Hospital at Providence has supported the Center for Children with Special Needs, staffed with a neurodevelopmental pediatrician skilled in the diagnosis of children with ASD and other developmental disabilities. In addition, the State of Alaska sponsors neurodevelopmental screening clinics in locations around the state. However, despite Child Find efforts on the part of early intervention and school districts, not all children with significant developmental delays are referred for a neurodevelopmental evaluation prior to entering school. Children residing in more remote, rural locations may be identified later than children in communities in more urban settings. Accurate identification of the child's pattern of development/learning style and behavior (i.e. autism diagnosis) leads to an appropriate school certification and program as well as an approach to solving behavior problems. Families living outside of Anchorage with children who are suspected of having autism frequently must wait for an appointment and then travel to Anchorage for a medical work-up and diagnosis.

The current definition used by Alaska's Department of Education & Early Development to determine eligibility is also an obstacle for the provision of special education services for students with ASD. This definition includes Autism, but not the other disorders in the spectrum. This committee proposes a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

Currently there is not an accurate count of persons with ASD in the state. This adds to the difficulty of planning and securing resources for statewide autism services. This affects people with autism, their families, state and local governments, school districts, and federal agencies. Having hard data on autism in the state will provide a comprehensive information resource that can direct state policies and service decisions that will improve the lives of people with ASD and their families. Autism registries have already been shown to be effective for planning and providing services in the states of Missouri, Virginia, West Virginia, Florida, and Delaware. An autism registry will also facilitate early detection and diagnosis of people with autism.

Identification and Diagnosis

Recommendations

1. **Establish universal screening for autism spectrum disorders, using a tool such as the parent-completed Modified Checklist for Autism in Toddlers (M-CHAT), and provide systematic referral for a comprehensive assessment for children with positive screens.**

   Screening is a quick, simple and inexpensive process to identify children who have symptoms that could indicate a disorder. Like hearing or vision problems, early identification and diagnosis of ASD can lead to a better response to treatment and lifelong outcome for children. Universal screening of children at well-child exams is recommended to ensure that children with ASD are identified as early as possible in life. The M-CHAT is a 23-question, parent-completed survey that can be used at well-child check-ups and is valid for children between the ages of 16 and 36 months.

Screening does not take the place of a comprehensive assessment; rather it identifies those children who would benefit from a complete evaluation. The next step for children who show possible signs of an ASD is to refer them to early intervention or the school district where the process of a developmental assessment can begin. A protocol for children with risk factors for ASD should be developed to ensure they are referred for further testing and a comprehensive developmental assessment.

> Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains.

2. **Increase the diagnostic capacity throughout the state by developing a system to provide timely, comprehensive diagnosis of Autism Spectrum Disorders using a multidisciplinary team and systematic referral to appropriate services (i.e. Early Intervention/Infant Learning Program, school districts, medical and other clinical providers).**

Children who appear at risk of having an ASD require a comprehensive assessment across developmental and physical domains. Professionals from multiple disciplines are needed to conduct a complete assessment (i.e. neurodevelopmental pediatrics, psychology, speech, occupational and physical therapy, opthamology, audiology). For young children it is especially critical to perform a differential diagnosis to rule out any other possible genetic or medical disorders.

Currently few clinicians and specialists are skilled and trained in performing ASD assessments. Investing in training and developing specialists in ASD will reduce the time between screening and a comprehensive assessment, as all testing needs to occur before a definitive diagnosis can be made.

The comprehensive assessment leads not only to diagnosis, but to a plan of intervention and services for the child and family. Families need information and active referral to link up with needed health, educational, financial and family support resources.

3. **Expand the educational definition of autism to include all disorders in the Autism Spectrum Disorder. See Appendix A for recommended definition language.**

The current definition of autism used by the Alaska Department of Education &

Recommendations Cont...

Early Development to determine the eligibility is restrictive, including Autism Disorder, but not other disorders in the spectrum. The Committee recommends a definition that includes Pervasive Development Disorder, Asperger's Syndrome, and Childhood Disintegrative Disorder.

It is important to define ASD broadly so that students receive an appropriate education. Some children with ASDs are incorrectly categorized as emotionally disturbed resulting in educational programs that disregard the neurological basis for the disorder, and instead treat the child as though they had a behavioral condition. Children receiving proper services are more likely to achieve better outcomes and exit the special education system earlier. A broad definition benefits the State by reducing costs, and providing more accurate data.

Children receiving proper services are more likely to achieve better outcomes.

4. **Establish and maintain a statewide autism registry or surveillance program.**

   Alaska does not have a reliable way of assessing the number of individuals in the state with ASD. Having valid statistics on the prevalence of ASD in Alaska is critical to understanding trends, planning and developing programs to meet the educational and lifelong needs of individuals with ASD, future budgeting, and ensuring adequate numbers of people trained to provide specialized services. By understanding the prevalence of autism in Alaska, we will be better prepared to garner financial support from many sources to help Alaskan children and adults with ASD. The data collected will also allow our state legislature and school districts to better plan for growing needs for Alaskan's with autism.

5. **Develop capacity to diagnose Asperger Syndrome in older children and adults.**

   Unlike other ASDs, Asperger Syndrome is typically not diagnosed in early childhood, but rather when the child is in school or even as an adult. A multidisciplinary team familiar with the features of Asperger Syndrome is needed to do an adequate assessment. Components of this assessment include taking a physical and developmental history, and conducting communication and psychological evaluations. Results of the evaluation need to be translated into a coherent picture and communicated to the child's family or the adult.

Service

There is a critical shortage of services for people with ASD in the state.

There is a critical shortage of services for people with ASD in the state. Reasons for this include an inadequate workforce, lack of evidence-based intervention programs within the state, especially for young children, and a need for more training for all those who work or come into regular contact with individuals with ASD. The lack of services influences the quality of the medical, dental, educational, and treatments offered to people with autism. Without these services, especially in the early childhood years when intervention can dramatically affect long-term outcomes, individuals with ASD and their families will fail to reach their potential, be less self-sufficient and more reliant on state-funded services, and unable to fully contribute as a citizen.

Where we are now

Providing medical and dental care for individuals with autism can be complicated. The most common medical problems linked with autism are seizures, accidents and injuries, infections, dental problems, and nutritional issues (Volkmar, 2000). Pediatricians are located only in urban areas of the state or on an itinerant basis to hub communities. Smaller communities may be served by family practice physicians, nurse practitioners, or physician assistants while remote areas of the state are most commonly served by community health aides and practitioners. While pediatricians in particular are familiar with autism, many families are unable to access a medical provider who can advise them about the treatment options families may learn about. As many of these treatment options are controversial, having a medical provider knowledgeable about the current status of autism treatment, would guide families in making informed decisions.

There are a number of evidence-based educational interventions used throughout the country. In Alaska, educational services are provided by the Early Intervention/Early Intervention/Infant Learning Program (EI/ILP) for children birth to three, and by school districts for children from 3 to 18 or 22, depending on the student's Individual Education Plan. The EI/ILP delivers services in the family's home. An early interventionist, early childhood special education teacher, speech therapist, physical therapist, occupational therapist and/or paraprofessional supervised by an early interventionist work with families to teach them ways to enhance their child's development. School districts serve children and youth with ASD through their Individual Education Plan, which outlines the goals and services to be delivered. A statewide assessment of school districts' educational programs for students with ASD has not been conducted. However, nationally-recognized intensive intervention programs designed specifically for individuals with ASD, such as applied behavioral analysis, floor time, and TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children) are largely unavailable to families unless they are able to pay for the services of a consultant outside the state. The Anchorage School District does provide some specialized classrooms for children with ASD.

Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important.

This is a critical aspect of autism services because the major treatment for autism is early and ongoing educational intervention. Presently, there are some limited and inconsistent services provided by school districts, private and home programs. Most school districts do not have the capacity to provide intensive interventions for students with autism. Part of the problem is that in both the rural and urban parts of the state, there is difficulty in the recruitment and retention of staff experienced with autism. The intensive, one-on-one nature of many interventions is prohibitively expensive for many school districts. There is also currently a limited amount of time provided for extended school year services. These services may be provided by the school district to some children with developmental disabilities who regress when not in school and are offered during regular school breaks. When extended school year services provided by school districts, some children with autism behaviorally and cognitively regress.

Providing effective autism treatments is found to be deficient in Alaska. Since individuals with ASD have different needs and abilities, providing a range of evidence-based treatments is extremely important. Many parents are forced to go out of state and spend a lot of money to get the services their children need. There are currently pockets of well-trained professionals providing autism related services in Alaska, but they are mostly clustered in the major urban centers. In Alaska, Medicaid does not reimburse for intensive behavioral treatment as a medical service. Intensive behavioral treatment is an important component of autism treatment.

A contributing factor to the lack of treatment and services for individuals with Autism Spectrum Disorders, is an inadequate level of training, resources and support for professionals and parents. More in-state training is needed, especially due to the high turnover rate in the direct service field and in school districts throughout Alaska.

More in-state training is needed.

Service Recommendations

Medical Services

1. **Expand specialty clinics at hospitals for individuals with autism.**

   Medical services are critical because children with ASD are more likely to develop certain medical conditions such as seizures, accidents and injuries, infections, and dental and nutritional problems. This committee recommends that medical services be expanded to include consultation with the child's or adolescent's primary care provider and other service providers. Families and providers often need advice on such issues as medication, toileting, sleep disturbances, behavior and aggression, self-injurious behaviors, motor tics, social skills, and others.

2. **Amend Medicaid regulations to ensure reimbursement for evidence-based medical interventions and psychological assessments and interventions. Currently only psychologists working in mental health clinics or under the supervision of a psychiatrist are allowed to bill Medicaid.**

   School districts perform psychological evaluations every three years. Because children develop rapidly in the early years, a new evaluation is typically needed to complete an assessment. Child psychologists are uniquely qualified to perform cognitive and adaptive behavior skills, and this is an important element of the diagnostic process. Adding psychology services for Medicaid recipients would alleviate this problem.

3. **Develop the capacity of medical providers to work successfully with individuals with ASD.**

   Increasing the capacity of medical providers to work with individuals with ASD is essential to providing quality health and dental care for the ASD population. Communication and behavior problems as well as unusual and unpredictable response to stimuli complicate medical and dental care. Specialized training and skills will help medical and dental professionals provide quality care for those with ASD in Alaska.

   The Committee recommends that training on ASD be provided at medical conferences in Alaska.

There is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis.

Educational Services

1. **Adopt best practice guidelines and set measures of effectiveness of educational services for children with ASD.**

   The National Autism Center is developing national standards for the treatment of ASD. Using evidence-rating criteria the Center will produce a set of national research-based standards for education and behavioral intervention for children with autism. The Committee recommends that Alaska adopt best practice standards, based on national standards, for interventions and educational services provided to individuals with ASD in Alaska.

2. **Provide adequate funding to establish intensive early intervention services for children with autism through the Early Intervention/Early Intervention/Infant Learning Program, Head Start and school district preschool programs.**

   Intensive early intervention has been documented to be an effective intervention for children with ASD (Dawson & Osterling, 1997; Green, 1996). Although the specific intervention models are a source of controversy, there is strong evidence supporting the validity of intensive early intervention beginning as early as possible after diagnosis (Sheinkopf & Siegel, 1998).

   Children under three with developmental delays are served by the Early Intervention/Infant Learning Program. Some children receive a diagnosis of ASD before their third birthday and will begin receiving services through this program. Families receive periodic home visits from an early intervention specialist, based on the child and family needs. Eligible three to five year old children attend public preschool or Head Start programs.

3. **Adequately fund and provide appropriate intensive interventions based on best practices to children with ASD in the educational system.**

   Currently, schools provide either limited or no ASD-specific intervention programs for children qualified to receive special education. Rather than endorsing a specific model, the Committee recommends that evidence-based models for ASD intervention become available in the educational system. Families need to be provided a choice of models and an opportunity to decide which approach will best meet their child and family's needs. Interventions require a time and lifestyle commitment from the families.

Research has documented the efficacy of early, intensive intervention (Sheinkopf and Siegel, 1998, Dawson and Osterling, 1997).

4. **Enlist Alaska's universities' support and collaboration in developing certification and degree programs for students interested in specializing in autism interventions.**

   The University of Alaska system and the small number of private colleges in the state are a resource that can be used to help develop the workforce needed to provide effective services for individual with ASD. Education, Special Education, Social Work, and Psychology degree programs, with a certification in autism interventions can help alleviate the current shortage of qualified personnel. The University of Alaska Anchorage also has the Washington, Wyoming, Alaska, Montano, and Idaho (WWAMI) Biomedical program affiliated with the University of Washington School of Medicine. This program can be used to increase the number of medical doctors in state who specialize in diagnosing and treating children with ASD.

5. **Build capacity for all early intervention and childcare programs, and school districts, to adopt evidence-based, non-aversive behavioral interventions, such as positive behavioral support and best practice interventions with proven outcomes.**

   Challenging behaviors often accompany ASD. When individuals are limited in their communication skills, they may use behaviors as a way to let others know what they want and need. Positive behavior support helps adults decipher the communication intent of behavior, and teaches alternative ways individuals can express themselves. Programs that serve children with ASD need training and tools for helping the adults better support the communication

Service Recommendations Cont...

and behavioral needs of students with ASD.

Children with ASD present unique and difficult needs that require specific skills from teachers and education professionals. Currently, no specific certification in ASD interventions for teachers and educational professionals exists in the state.

6. **Investigate amending Medicaid regulations to allow reimbursements to districts for school-based intensive autism interventions to Medicaid eligible students.**

   About half of Alaska's children are Medicaid eligible. Adding intensive intervention for ASD as a Medicaid service would permit the state to collect federal funds to help cover the expense. Shifting some of the cost of intervention would permit school districts to use their funding to reach non-Medicaid students as well.

Children with ASD present unique and difficult needs that require specific skills from teachers and educational professionals.

Home and Community-Based Services

1. **Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services.**

   The Deficit Reduction Act permits flexibility within state Medicaid plans. It is recommended that Alaska modify their Medicaid Plan to include time-limited autism intervention services. If modifying the Alaska Medicaid Plan is not feasible, the Committee recommends that the state develop an Autism waiver modeled after Minnesota or Wisconsin. A third alternative would be to change eligibility within the Home and Community Based Waiver to ensure children with ASD receive time-limited intensive services.

2. **Provide supplemental grant funding for providers to offer treatment services for individuals with autism who are not eligible for Medicaid or meet level of care.**

   Not all individuals with ASD meet level of care requirements for a Medicaid Home and Community-based waiver or TEFRA, but would benefit from intervention. The DD grant program supports individuals with developmental disabilities who are not eligible for a waiver. Additional funding in the DD grant program would help meet the needs of children and adults with ASD.

Service Recommendations Cont...

3. **Bring training on diagnosis and interventions to Alaska.**

   Alaska faces a shortage of clinically trained personnel experienced in performing diagnostic assessments and follow-up treatment. The Committee recommends improvement in the availability and expertise of these specialists to assess and treat ASD. Very few psychologists in Alaska are experienced in administering assessment tools for autism and evaluating the results, especially for young children.

   Several University-based Autism centers provide training that, if brought to Alaska, would expand statewide capacity for timely and accurate diagnosis and appropriate intervention.

Bring training on diagnosis and interventions to Alaska.

4. **Change Medicaid regulations to provide reimbursement for autism treatments as a medical service.**

   Although research has shown promising results stemming from autism interventions for some individuals with ASD, there are significant differences in the costs, degree of family involvement required, availability, and content and structure of these programs. The Committee believes a continuum of intervention options should be available and billable through Medicaid. Such interventions may significantly reduce the lifetime cost of care for individuals with ASD.

5. **Remove licensing barriers that prevent out-of-state autism specialists from practicing in Alaska.**

   Out-of-state autism specialists would help provide quality treatment for those with ASD in Alaska. Current state licensure and billing regulations that prohibit out-of-state health providers from practicing in the state need to be reviewed and revised so they may provide services for individuals with ASD in Alaska.

Parent Training

1. **Greatly expand services offered through an autism resource center, so that it is well funded, independent, and highly visible with a long-range plan for satellite programs throughout the state.**

Service Recommendations Cont...

Several activities are envisioned to expand the functions of an autism resource center. These include:

- An annual comprehensive fair/institute for families to provide up-to-date medical information, guidance in navigating the system, and other topics. Disseminate the institute through a CD or a webcast for people who cannot attend in person;
- The establishment of local resource centers across Alaska that are independent in nature, but collaborative with other providers, and state/local/national experts;
- Training for parents in systems advocacy/political advocacy;
- Regional, technical assistance traveling teams with professional oversight; and
- Comprehensive parent training in education, systems advocacy, guardianship, medical services, and other topics as needed.

Service Provider Development

1. **Fund and deliver training to develop qualified staff who will provide evidence-based autism treatment services in home, child care and community-based settings.**

   There is a critical shortage of staff to work directly with individuals with developmental disabilities. The failure to provide evidence-based services to children and adults with Autism Spectrum Disorders impedes their development and limits their potential over their entire lifetime. Training is inadequate for those who provide care to individuals with Autism Spectrum Disorders.

There is a critical shortage of staff to work directly with individuals with developmental disabilities.

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APPENDIX A

PROPOSED DEFINITION OF AUTISM
FOR THE DEPARTMENT OF EDUCATION AND EARLY DEVELOPMENT

1. **Autism Spectrum Disorders (ASD)**

   To be eligible for special education and related services as a child with ASD, a child must:

   a. exhibit a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age three, that adversely affects educational performance; and

   b. require special facilities, equipment, or methods to make the child's educational program effective; and

   c. be diagnosed as having an autism spectrum disorder by a psychiatrist, physician, or psychologist; and

   d. be certified by a group consisting of qualified professionals and a parent of the child as qualifying for and needing special education services.

   Characteristics of ASD include:

   - Irregularities and impairments in communication
   - Engagement in repetitive activities and stereotyped movements
   - Resistance to environmental change or change in daily routines
   - Unusual responses to sensory experiences

A child who manifests the above characteristics after age 3 may also be diagnosed as having autism spectrum disorder.

A child who is diagnosed as having Asperger's Syndrome or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS) and who manifests the above characteristics may be found eligible for special education under the category of ASD.

#1

TESTIMONY – PROTECTION AND ADVOCACY PROJECT
SENATE BILL 2174 (2009)
HOUSE HUMAN SERVICES COMMITTEE
Honorable Robin Weisz, Chairman
March 3, 2009

Chairman Weisz, and members of the House Human Services Committee, I am Bruce Murry, a lawyer with the North Dakota Protection and Advocacy Project (P&A). P&A is a state agency advocating for North Dakotans with disabilities. P&A supports SB 2174.

This bill asks state government to take a comprehensive look at how North Dakotans with Autism Spectrum Disorders (ASD) fare in our current economy and society, with or without outside services. The ASD Taskforce will certainly focus upon students with ASD. The Taskforce needs to look at adults as well.

The taskforce will need to consider that the intelligence of people with ASD varies from genius level having substantial limitations. Some North Dakotans with ASD would have been referred to institutional living in the 1960s. Others might have seemed, literally, to be absent minded professors. Many do not qualify for our Medicaid Waivers for people with developmental disabilities. All of these North Dakotans can be more productive and happy if they learn skills and techniques to approach those around them and other of life's puzzles.

The bill also changes some definitions of autism and ASD. These changes may be premature. There is not a clear consensus what these terms mean. The Committee may wish to amend the bill to remove the definitional changes and allow the Taskforce to report back in 2011. Conversely, the Taskforce could recommend changes to the proposed language in 2011 if necessary.

Thank you for your consideration.

#5

Testimony on SB2174

By

Dr. M. Douglas Johnson, Executive Director—NDCEL

Chairman Weisz and members of the House Human Services Committee, for the record my name is Doug Johnson and I am the executive director of the ND Council of Educational Leaders which represents North Dakota's school leaders. I am here to testify in support **SB 2174.** However, I do believe that there should be some consideration for possible unintended consequences which this bill could have if it is adopted as currently drafted.

First, I am concerned with the ND Century Code defining a disability category. It is clear in this bill that the definition proposed for Autism Spectrum Disorders is specific for Residential Care Facilities. However, I am concerned that this could have broader implications as it establishes a state definition of Autism Spectrum Disorders in ND Century Code. In the past we as a state have defined special education following the definition categories that are defined in The Individuals with Disabilities Education Act (IDEA). The definition and categorical term that is used in Section 300.8 of IDEA regulations which are followed by the state are from Section 300.8 are as follows:

> (c) Definitions of disability terms. The terms used in this definition of a child with a disability are defined as follows:
>
> (1) (i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
>
> (ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

(iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

The issue is that **SB2174** could be expanding the categorical area of Autism to include Autism Spectrum Disorders. The North Dakota Autism guidelines (http://www.dpi.state.nd.us/speced/guide/autism.pdf) follow the categorical area of Autism identified in IDEA not Autism Spectrum Disorders as defined in **SB2174**. If this bill is limited to only defining this disability category for Residential Care Facilities, I am not concerned. However, if this bill passes and establishes a definition of Autism Specturm Disoders in ND Century Code that is to be used in our K-12 education system then I would have concerns about the definition and categorical label that is being proposed as it would significantly increase the number of students our schools would serve under IDEA. I ask that the committee makes sure that **SB2174** only for a definition Autism Spectrum Disorders is specific for Residential Care Facilities.

Second, **SB2174** deals with the membership of the appointed task force. It does not appear that there is any representation from education administration on this task force. I believe that any state task force that has some potential implications on our education system should include some type of representation from education administration. I am not too concerned about who this would be possibly be a representative from the NDCEL and could be a designee from a the ND director's study council, a special education director, a principal, or a superintendent a some of the items this task force is charged with developing seem to have potential implications on education.

Chairman Weisz and Committee members this concludes my testimony on **SB2174**. I would be glad to answer any questions that you have at this time.

#1

Testimony
Senate Bill 2174 –Department of Human Services
House Human Services Committee
Representative R. Weisz, Chairman
March 3, 2009

Chairman Weisz, and members of the House Human Services Committee, I am JoAnne Hoesel, Director of the Division of Mental Health & Substance Abuse Division and Developmental Disabilities Division for the Department of Human Services. I am here today to provide information on services provided and planned in the area of Autism Spectrum Disorders (ASD) by or through the Department of Human Services (DHS).

The Department, through its developmental disabilities (DD) and mental health areas, has been involved in ASD issues since the mid 90s. This area is rapidly changing, highly emotional, and ripe with differences of opinion.

In the area of mental health, over 186 children with pervasive developmental disabilities, a type of disorder on the autism spectrum, were served at the regional human service centers in state fiscal year 2008. The state's wraparound process for children and adolescents with emotional disturbances and in need of intensive care coordination began in 1994. A significant number with ASD are served by this program. DHS licenses group homes, residential child care facilities, psychiatric residential treatment facilities, child and adult foster homes, waiver services including DD group homes and individuals with ASD are served throughout this array.

In the area of developmental disabilities, both North Dakota's Individuals with Disabilities Education Act (IDEA) Advisory Committee and Interagency Coordinating Committee participated on an autism task force that was appointed in March 2001. The outcome of this effort was autism guidelines for both DPI and DHS' early intervention programs. The guidelines were published in March of 2003.

Currently, the Family Support Services area of developmental disabilities provides family in-home supports through structured interventions and respite. Individuals with ASD also receive services through the array of DD Medicaid waiver services. In the area of early intervention, family subsidy, Right Track, newborn screening, and Infant Development, evaluations, support families of children with ASD.

The Department works with Minot State University to coordinate services with their recently obtained federal grant that targets school-aged children with ASD. We are currently involved in the group that is writing a state autism plan.

The Department holds monthly state review team meetings that include mental health, substance abuse, developmental disabilities, Medicaid, education, and juvenile justice. These meetings bring a collaborative perspective to difficult situations despite valiant local and regional efforts. Many times, the team reviews individuals who have disorders on the autism spectrum and both mental health, developmental disabilities, and education systems find it difficult to provide adequate services.

The Department provides training to both developmental disabilities and mental health professionals. An autism spectrum expert trained individuals; multi-day training for early intervention staff was held; three training sessions were offered last year with a follow-up planned for the summer of 2009; autism presentations are planned for the mental health conference this spring; and the Department sponsored the attendance of several people at the Network of Autism Training & Technical Assistance Projects conference in the fall of 2008.

In preparation for this legislative session, the Department held several stakeholder meetings focused on this area to gain feedback and recommendations for focus within the Department's budgeting process. The Autism Waiver, which is funded in the Governor's budget, is a result of that feedback. This autism waiver is planned for children ages zero to five. This waiver will provide refined and targeted services for diagnosis and intensive evidence-based interventions. Early intervention plays a critical role in early diagnosis and treatment, and this waiver plans to develop a team of professionals with specialized training to diagnose and design specialized programs.

Chairman Weisz and members of the committee, as more information is learned and experience gained in the area of ASD, DHS will continue its commitment, efforts, and collaboration to support children and families in North Dakota.

I will answer any questions you may have at this time.