

**2013 SENATE HUMAN SERVICES**

**SB 2193**

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

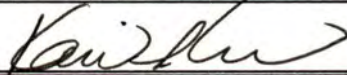
SB 2193

1/22/13

Recording Job Number: 17514

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

**Chairman Lee** opens hearing on SB 2193.

**Senator Heckaman** from New Rockford representing the constituents in District 23 introduces bill to the committee. See attached testimony #1.

**(0:3:28) Senator Dever** states that he was approached earlier in the session by a mother of a child with autism with concern over having information that might be individually identifiable in a database.

**Senator Heckaman** explains that she visited with the Health Department on this issue and they feel that the development of this database will contain numbers that are identifiable to the Health Department but not the names of the individuals. No personal information will be released. The database was their last priority in this because until you can diagnose you can't fill a database up and can't put people in regions. Their first recommendation is the coordinator.

**Senator Dever** recalls her concern being on a House bill and **Senator Heckaman** explains that there are some bills in the House on autism but she can't speak on them because she's not sure what they are.

**Chairman Lee** is under the impression that this bill is the task force's recommendations and the House bill is the recommendations that came out of the Human Services interim committee.

**Senator Heckamen** states that she thinks this is correct and explains the task force's role in this.

No further questions from the committee for Senator Heckamen.

**Senator Mathern**, presents testimony on behalf of **Dr. Barbara Stanton**, an outpatient therapist specializing in autism spectrum disorder at Prairie at St. Johns. See attached testimony #2.

**(0:10:43) Senator Anderson** asks Senator Mathern to elaborate on the voucher system and how it is supposed to improve the care of the autism patient.

**Senator Mathern** explains that the 3 bills that are in House that came from the interim committee are promoting continued study of the subject as well as promoting the concept of a registry and more assistance to education. There is also a voucher program, which is not in the bill, that provides families the ability to pay for services for their children's needs and getting those services in the market.

No further questions from the committee for Mr. Mathern.

**Vicki Peterson**, a single mother of two boys, one whom has autism, speaks in support of the bill. See attached testimony #3.

**(0:19:26) Senator Axness** asks if the autism waiver is throughout the lifespan of someone with ASD.

**Ms. Peterson** explains that at the present time the autism waiver is not. It is from birth up to the 5<sup>th</sup> birthday. Refocusing the waiver to include the lifespan would greatly help the people of ND and fill those gaps.

**(0:20:09) Senator Dever** doesn't see the Medicaid waiver addressed in any of the appropriations and wonders if there should be a fiscal note. Committee discussion continues and **JoAnne Hoesel** steps up to the podium with information on the waiver in regards to cost (see attachment #4). Senator Dever asks if there should be a fiscal note generated just from the information she provided and Chairman Lee adds that it would be helpful if she is able to work on one for the committee.

**(0:25:13) Ms. Peterson** steps back up to read testimony on behalf of **Toby Cherney**, a parent with an autistic child. See attached testimony #5.

No questions from committee for Ms. Peterson.

**Cathy Haarstad**, Director of the Pathfinder Parent Center and parent of a child with special needs who has ASD, testifies in support of the bill. See attached testimony #6.

**(0:37:54) Senator Anderson** asks Ms. Haarstad to explain the difference between her center that serves people through age 26 where the waiver states through the end of life.

**Ms. Haarstad** explains that her center ends services in terms of family support at age 26 because that is aligned with the federal funding that they receive. They are funded by the office of special education programs.

**Chairman Lee** asks if the age of 26 is a stable level of capability or are there still changes as that individual continues to age.

**Ms. Haarstad** explains that it depends on whether they had early intervention and how many coping behaviors they have already learned to navigate their way through adult life. The most critical issue is getting and keeping employment during adulthood.

**Mindy Iverson**, a married, stay-at-home mother of son with autism and degree holder in Elementary Education as well as Child Development, speaks in support of SB 2193. See attached testimony #7.

**Carlotta McCleary**, Executive Director of ND Federation of Families for Children's Mental Health (NDFFCMH), speaks in support of the bill. See attached testimony #8.

**Donene Feist**, Director for Family Voices of North Dakota, speaks in support of the bill. See attached testimony #9.

**Christine Hogan**, with Protection and Advocacy, speaks on behalf of Teresa Larson, in support of the bill. She did not provide written testimony but briefly expresses P & A's strong support for the autism waiver.

**Tamara Gallup-Millner**, Director of the Division of Children's Special Health Services for the North Dakota Department of Health, testifies in neutral. See attached testimony #10.

Per the request of Chairman Lee, **Eric Monson**, CEO of the Anne Carlson Center, shares with the committee information about what his center does and provides different examples of its services.

There are no further questions or testimony.

The hearing is closed.



# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

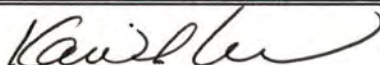
SB 2193

1/23/13

Recording Job Number: 17570

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Brief update for SB 2193 from **Levy Andrist** from Vogel Law Firm representing the Anne Carlson Center and the ND Occupational Therapy Association:

There was a meeting last week on 3 bills that were forwarded through the interim process regarding the ASD and how the state should address it. This was left open for subcommittee of interested parties and subcommittee members to discuss various proposals. No subcommittee has been appointed yet but they hope it will occur this week.

**Chairman Lee** asks if there was any discussion about the waiver in any of the bills that were presented in the House.

**Mr. Andrist** states that there was although only in the context that the bill that is presented here more so reflects the suggestions and recommendations of the autism task force. On the House side, the focus is on a voucher system not on a waiver so there are two different approaches. There is some overlap with an autism registry and some moneys for training on both the House and Senate side.

**Senator Larsen** asks if there was also funding for diagnosing and **Senator Anderson** clarifies that there is funding in this bill for diagnosis teams.

**Senator Dever** brings up that they are still waiting on a fiscal note that they requested and **Chairman Lee** asks the law intern to talk to Legislative Council about it. The committee recognizes the challenge in coming up with a number but there has to be a ballpark figure.

Discussion is recessed until further information is received.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

SB 2193

1/28/13

Recording Job Number: 17939

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Committee discussion continued on SB 2193:

**Dr. Kenneth Fischer**, Medical Director, Behavioral Health, for BCBSND, reviews his submitted testimony and explains to the committee that he stands in neutral and is here as a resource to the committee. He also discloses that he is a child and adolescent psychiatrist who has treated autistic children and sits on the autism task force as a voting member. See attachment #11.

**Chairman Lee** shares with the committee that Dr. Ted Kleiman and his wife, who both are recently retired pediatricians, will be doctors of the day next Monday and will provide additional professional input as well.

Dr. Fischer's testimony ends at meter 0:49:25.

Chairman Lee expresses her appreciation to Dr. Fischer for putting all of this information together.

**(0:50:07) Senator Dever** asks if applied behavioral analysis (what Dr. Fischer refers to) and behavioral analysis (what the bill refers to) are the same thing.

**Dr. Fischer** states that the bill is a little less precise than it probably should be because it's probably talking about both and proceeds to explain the confusion behind it.

**(0:54:33)** The committee begins to go through the bill section by section with Dr. Fischer in order to clear up any questions they have. Chairman Lee recognizes that Senator Anderson is not present but that they will go over the information with him.

**(0:57:28) Tammy Gallup-Millner**, with the Children's Special Health Services Division in the ND Department of Health, steps up to the podium to help answer questions about the database. Chairman Lee asks Ms. Gallup-Millner to help come up with some information

for the committee so that they can consider it and see where it fits. Ms. Gallup-Millner states that someone from her department is working on a fiscal note with the Department of Human Services for section 2 of the bill and further goes over what has been discussed in the Health Department.

**(1:02:04 - 1:08:25)** Discussion on mandatory/voluntary reporting: Dr. Fischer provides an example from a former patient in regards to diagnosing and the database. Senator Dever wonders if there is a database provision in any of the other bills associated with autism and Ms. Gallup-Miller states that it is House Bill 1038. The term registry vs. database is different and the appropriation amount is less. Dr. Fischer follows with observations about the terms registry vs. database and Ms. Gallup-Millner makes a database observation.

Committee continues to go through the sections with Dr. Fischer.

**(1:18:37)** **Chairman Lee** expresses that she wants to continue a committee discussion on whether sections 4 & 5 are needed in the bill. Dr. Fischer proceeds to share observations and answer committee questions.

Committee agrees that it's best not to rush this and discussion was closed.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol


SB 2193

1/30/13

Recording Job Number: 18034

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Chairman Lee opens continued committee discussion on SB 2193:

**Dr. Barbara Stanton**, outpatient therapist specializing in autism spectrum disorders at Prairie St. John's, presents further information to the committee and explains her experience and expertise. She did not provide written testimony.

Autism spectrum is a very complicated issue because there hasn't been enough research yet to have a really clear understanding either of causes, effective diagnostic techniques, and effective care. She states that she attended most of the meetings for the autism spectrum disorder task force and explains to the committee the three bills relating to this on the House side. HB 1037 is to continue the study of autism spectrum disorders, HB 1038 has a two part component: one is for registry similar to the database in SB 2193 and the second is to provide education for educators/education staff and personnel, and HB 1039 takes a look at providing a voucher system in order to cover services that are not otherwise paid for by insurance or other reimbursement sources. Chairman Lee suggests that it might be best to see how the House acts on these bills before they move forward because ultimately they need to reconcile these.

**(0:06:21) Chairman Lee** asks Ms. Stanton to explain the difference between a voucher and a waiver. Ms. Stanton states that her experience with the Medicaid waiver system has not been positive and explains to the committee the current autism waiver system by providing case examples. There is agreement between the two bills on the registry/database. Ms. Stanton also states that she doesn't feel there is enough detail about the autism coordinator or those functions/job duties or the training effort and further goes on to express her concerns.

**(0:12:22) Senator Anderson** references Dr. Fischer and when he expressed that he felt like the approach we were taking was too disconnected and that we needed to put the autism spectrum disorder under the authority of the Health Department, Medicaid, etc. as a core function and asks Dr. Stanton her take on this.

**Dr. Stanton** states that it depends on who it's under and explains that providing care for individuals with an autism spectrum disorder is not a core service of the regional human service centers so it's hard to imagine the Department of Human Services managing this. It is critical when you talk about having someone monitor this that you come at with a multidisciplinary approach. Further discussion continues on where the core function should be placed.

**(0:24:05) Senator Dever** asks Dr. Stanton about the involvement of the public schools and if the purpose is to provide treatment for autism or is it to support the primary goal of providing an education.

**Dr. Stanton** states that the department of education federally talks about education in a very broad term. It's not just providing the academics but also teaching children to be responsible citizens. In regards to children with autism spectrum, they are taking about the needs to teach them those social skills and the ability to be able to interact appropriately with other individuals. Public schools are overwhelmed by needing to meet these needs. Conducting proactive training allows things to be much better for everyone involved and ultimately saves time and money.

**(0:26:22 - 0:33:55)** Discussion about the teams Dr. Stanton referred to, proper diagnosis, early interventions, and support systems.

**(0:33:59 - 0:37:32)** Discussion on the voucher system and why Dr. Stanton disagrees with Dr. Fischer on this program.

**(0:40:27)** Dr. Stanton clarifies the meaning of "quasi-experimental design" for the committee.

Discussion is closed.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

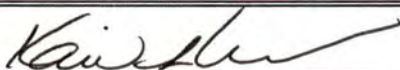
SB 2193

2/4/13

Recording Job Number: 18217

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

**Chairman Lee** opens continued discussion on SB 2193 and introduces Dr.'s Ted and Linda Kleiman, recently retired pediatricians and doctors of the day for the legislature. There are here per Chairman Lee's request to make any additional comments and to answer committee questions.

**Dr. Ted Kleiman** presents information concerning the DSM (psychiatric manual) and how it's changing, the amount of literature and articles talking about the treatment and methodologies, Applied Behavioral Analysis (ABA), and the lack of data and good information.

**(0:07:42 - 0:10:20) Senator Anderson** states that it was discussed that the database should be based on the DSM 5 criteria and asks Dr. Kleiman if he agrees with that. Dr. Kleiman states that this is where all the action is going to be so you have to use this, but you also have to have people who really know what they are doing. Senator Anderson follows by asking who can make that diagnosis right now and Dr. Kleiman goes through those medical professionals. Discussion between Senator Anderson and Dr. Kleiman continues about the importance of capturing in the database the medical professional who makes the diagnosis as well as discussion on the voucher programs.

**(0:10:20 - 0:17:55)** Discussion about proper training and intense intervention. Dr. Kleiman discusses the possible other developmental disabilities or behavioral problems that might have an impact on the outcomes and the concern about being discriminatory only focusing on one condition.

Senator Dever wonders if Dr. Kleiman has had similar conversations with the House side on the similar bills. Dr. Kleiman explains that he hasn't read those bills and is here only because of his involvement from knowing Chairman Lee.

No further questions from the committee for Dr. Kleiman.



**(0:20:30) Dr. Kenneth Fischer** steps up to the podium to inform the committee that he and Dr. Stanton will be in the House tomorrow for those bills and they have also shared information with the Chairman and the Rep from the interim committee.

**Dr. Barbara Stanton** also steps up to share an update with the committee that the advocates for autism issues came together on Friday with the consensus council in Bismarck to discuss which elements of the bills they felt that they could all support.

These elements include:

- support of all three House bills
- In regards to SB 2193: the registry, the importance of education and who needs to be educated, and the Medicaid waiver.

In regards to the Medicaid waiver, Dr. Stanton shares what she has heard from the advocacy organizations (which she lists) and explains that they had a very different idea of how the waiver would be administered and the types of services that apparently did not happen at that time (she provides an example). The hope is that if there is something that moves forward with the waiver that the input from stakeholders who experience the waiver issues is included with the input from the experts.

**(0:24:00 - 0:29:15)** Discussion on how the voucher program and waiver are different. Chairman Lee asks Dr. Stanton to provide the committee with the information that was discussed between the advocates and the consensus council (see attachment #12 from Teresa Larsen's testimony on 2/6 that provides this information). Dr. Stanton also states that she agrees with Dr. Kleiman on the importance to record in the database the medical professional that makes the diagnosis and their title and further explains her conversations with the House side on these issues.

**(0:29:46)** Chairman Lee asks Dr. Kleiman what he thinks about autism spectrum being made a part of the core services that are overseen by the behavioral health division of the Department of Human Services but with the data belonging in the Health Department. Dr. Kleiman explains that the database has to be consistent with a systematic approach. The long-term follow-up is a critical part that has to be assessed. Senator Anderson and Dr. Fischer both reinforce how important long-term follow-up is.

Discussion is closed.

Side note: Chairman Lee briefly references an article on autism from the Wall Street Journal (see after attachment #11).

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol


SB 2193

2/6/13

Recording Job Number: 18382

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Chairman Lee opens the continued discussion on SB 2193 and states that JoAnne Hoesel will also be back after the session to share information from the Department of Human Services.

**Teresa Larsen**, director at the Protection and Advocacy Project, a state agency that advocates for the rights of people with disabilities, presents information to the committee. She did not provide written testimony during the hearing but later sent her notes to the committee, per the request of Chairman Lee. See attachment #12.

**(0:10:11) Vicki Peterson**, parent of a child with autism and who works as a family consultant for Family Voices of North Dakota (presented testimony during initial hearing), steps up to offer additional input. Chairman Lee expresses that they are not re-opening the hearing and asks for her to only add concrete information out of fairness to the others that have testified. Ms. Peterson states that she is going to provide information about the voucher and waiver systems.

**(0:12:33 - 0:17:50)** Discussion between Chairman Lee and Ms. Peterson on the relevance of dental and vision services as it relates to autism, and services provided in the educational system.

**Carlotta McLeary** steps up to podium to provide additional information about the educational system. Chairman Lee stresses the importance of educating everyone in the system that has involvement with the children (lunch lady, bus drivers, custodians, etc.). Ms. McLeary expresses that the issue lies with who is going to provide the funding for this.

Discussion is closed until after the session.



# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

SB 2193

2/6/13

Recording Job Number: 18448

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Continued committee discussion on SB 2193:

**JoAnne Hoesel**, from the Department of Human Services, is back to speak and present additional information to the committee on the appropriation detail and the comparison of the proposed bills related to Autism Spectrum Disorder. See attachments #13.

**(0:12:10 - 0:16:50)** In regards to her discussion on SB 2193, Senator Dever questions the amounts and Ms. Hoesel states that this is based on information they received from the Health Department. The Medicaid waiver did not have a cost in the bill so the fiscal note was provide per the committee's request. This would be a combination of the waiver, the case managers, and the fiscal agent. In regards the fiscal agent, there is a discussion on whether or not a 1099 can be issued and the findings based on what other states are doing. Senator Anderson asks if there is an estimate of how many diagnoses you might expect in ND. Ms. Hoesel states that they don't have specific numbers for ND but the national is 1 out of 88 right now so is would be about 13,000. Senator Anderson explains his reasoning behind the question.

They move on to discuss HB's 1037 and 1038. **(0:18:12) Tammy Gallup-Millner** from the Department of Health steps up to the podium to address Senator Axness' question about the database being more expensive.

Discussion continues on HB 1039.

**(0:22:08) Ms. Hoesel** then distributes and explains the Fiscal Note Summary to the committee. See attachment #14.

Discussion is closed.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

SB 2193

2/11/13

Recording Job Number: 18741

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Continued discussion on SB 2193:

**Chairman Lee** states that she visited briefly with Rep. Weisz and Rep. Hofstad from the House and they suggested to work off one bill. Senator Axness states that the voucher was moved Do Not Pass in the House this morning.

**Chairman Lee** handed out a rough draft amendment and reviews it with the committee. See attachment #15. She explains that this is a narrower, modified version of the voucher bill for coverage of the following value added autism services that traditionally don't fall under the definition of medical necessity.

**(0:2:18) Senator Anderson** asks the Health Department if they need to put language in that says that the title/degree of the person making the diagnosis will be recorded. Tammy Gallup-Millner from the Health Department responds by referencing the department's initial testimony on their recommendations. Chairman Lee follows by referencing line 1 on the attachment she just handed out (#15) and that Alan Knutson is working on the details of what professionals will be on that list. Discussion continues on the specifics of recording in the database.

**(0:06:20) Senator Anderson** clarifies with Chairman Lee about adding a section on the voucher program and states that they also need to add the panel of experts/providers who decide what is appropriate for spending the voucher on. Chairman Lee agrees. Senator Anderson also suggests adding mandatory reporting to avoid any resistance.

**(0:08:56 - 0:14:34)** Committee continues to review attachment #15. Dr. Fischer's testimony was also referenced regarding the Medicaid waiver system. Senator Axness asks, in regards to the modified voucher system, if eligibility is going to be addressed. Chairman Lee explains that it was discussed to focus more on providing those services through education and that the goal is to make sure these children don't fall off the services through finding a different way for these services to be provided in an appropriate fashion.

**(0:14:50 - 0:18:00)** Committee discusses the attachment from Dr. Fischer (see attachment #16) as well as further information from Maggie Anderson regarding making ASD a core service under the Department of Human Services.

**Chairman Lee** continues to review attachment #15 (sec 4 - 7) and suggests that the committee members review this information on their own before they get the amendments from Legislative Council in the morning.

**(0:21:37) Senator Anderson** asks Ms. Hoesel for the department's thoughts on not expanding the waiver but rather going to a voucher system. Ms. Hoesel states that there are two major differences between those two approaches: 1) eligibility with the Medicaid waiver, and 2) they need an institutional level of care and management of it. She further explains these differences to the committee.

**(0:25:13) Chairman Lee** asks if this would allow us to accommodate those children who do need the ASD services but do not have intellectual disabilities. Ms. Hoesel explains the current ASD waiver to clarify. Chairman Lee follows by asking her recommendation on how to make sure these children aren't falling off the services at the age of 5. Ms. Hoesel explains how important the training is and that the school is a huge factor. If you want to avoid children falling off/no longer being eligible for services and yet needing those services then you would want to look at an evaluation piece to verify that there is a need for ongoing services as opposed to putting an age to it.

**(0:31:28) Senator Larsen** asks if the fiscal note is with the waiver or the voucher. Ms. Hoesel explains that the fiscal note was based on how SB 2193 reads right now so it would be on the waiver. The \$10 million was inclusive of all the sections of the bill.

**Senator Dever** states that "community access" was added to the list and Chairman Lee proceeds to list examples of community access.

Committee briefly reviews the 3 House bills that correspond.

**Chairman Lee** reiterates that she would like the committee to review this information so it's fresh in their minds for when they receive the amendments from Legislative Council. She stresses that this bill is going to be far from finished when it leaves the committee, but they need to focus it a bit and work closely with the House in getting it to something that will work.

Discussion is recessed until tomorrow.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

SB 2193

2/12/13

Recording Job Number: 18789

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Continued discussion on SB 2193:

Committee reviews the rough amendments prepared by the Legislative Council (13.0192.03001) that were briefly introduced to the committee yesterday by Chairman Lee. See attachment #17. Chairman Lee states that this is a long way from perfect but they need a starting point.

**(0:09:04) Senator Dever** wonders about the reasoning behind the Do Not Pass on House bill. Chairman Lee states that they are not opposed of the voucher but thought they would be better off to work on one bill. Senator Dever follows by asking if there is going to be funding for the vouchers. Chairman Lee states that, yes, this needs to be included.

**(0:11:19) JoAnne Hoesel**, from the Department of Human Services, steps up to the podium per the request of Chairman Lee and provides testimony that was delivered in the House Interim Committee (see attached testimony #18), and the House Human Services Committee for HB 1039 (see attached testimony #19). Ms. Hoesel also recommends that there be a clarification on the non-developmental disability ASD because ASD is a developmental disability. They are attempting to clarify that this voucher system would serve individuals that weren't served in the DD system. Section 3 would read, "...a feasible service delivery system for individuals not served in the developmental disability system who have autism spectrum disorder."

**(0:18:36 - 0:26:16)** Not relating to the bill - June Herman, Regional Vice President of Advocacy for the American Heart Association, interrupts the committee briefly to discuss American Heart Association Day at the Capitol.

Testimony from Ms. Hoesel continues.

**(0:32:28)** - Chairman Lee distributes the new amendments prepared by Legislative Council (13.0192.03002) and reviews it with the committee (see attachment #20). Ms. Hoesel

continues to answer committee questions as they discuss the amendment. Committee offers thoughts on how they should move forward.

**(0:43:56)** - Ms. Hoesel throws out the idea of piloting the voucher and discusses with the committee options of how and who this program could work for. There is more flexibility with the voucher system. Per the request of the committee, Ms. Hoesel will find out if there are screening/assessment tools that help identify service support needs.

**(1:00:30)** - Chairman Lee reviews her notes on what has been discussed:

- If there is a dollar limit and who gets it
  - Functioning scale tied to the voucher
  - First come first serve
  - How do the dollars hook up to education so that services can be provided after school and weekends?
  - Potential of a pilot voucher covering children falling off the waiver
- Committee discusses these points.

**Ms. Hoesel** informs the committee that she and Carlotta McLeary created a spreadsheet for House Human Services including what was in their service plans and identified what the school, the insurance, and a voucher might pay for. This will be provided for the committee.

**Chairman Lee** suggests breaking so that the members in the room can do some thinking, as well as give Legislative Council time to amend the amendments.

**Senator Anderson** suggests including in the requirements for the recording in the database the discussion about the credentials and the person making the diagnosis. Chairman Lee agrees that this is a good idea.

The committee wraps up the discussion by looking at the original bill and clarifying where the amendments will go to see if they missed anything.

Discussion is recessed until after the session this afternoon.



# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

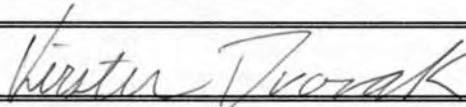
SB 2193

2/12/13

Recording Job Number: 18832

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Chairman Lee re-opens the discussion on SB 2193:

**JoAnne Hoesel** is back up to the podium and explains that she put together the documents (3 in total) that Chairman Lee requested during the discussion this morning:

1) HB 1039 ASD Voucher Services and Supports (attachment #21)

**(0:04:30) Senator Axness** references section 2 of the amendment for the voucher program and notices that it says "under age 18" and wonders if it would be up for consideration to have the same language of "to 21" to continue the assistance and services that the schools are not providing. Chairman Lee states that she forgot to mention that the department actually brought this up and thanks him for reminding her because it's something they need to discuss.

2) ASD Medicaid Waiver/ASD Voucher - General Fund (attachment #22)

**(0:09:10 - 0:12:02)** Discussion between the committee and Ms. Hoesel on the waiver vs. voucher in regards to federal funding, setting the dollar amount, and the appeal rights of individuals.

3) Chart that outlines the flow of how to walk through the eligibility and functioning down to how services are delivered (attachment #23)

**(0:18:27) Senator Axness** references attachment #23 and wants to make sure it's simplified so it's easy for the family/coordinator to understand the eligibility and what other services are available. Ms. Hoesel explains that this is similar to their Transition to Independence Program and describes the concept.

**(0:21:53 0:27:05)** Ms. Hoesel shares the cost with the committee: \$2 million in the 2013-15 budget for the ASD waiver for birth up to age 5. Discussion between Chairman Lee and Ms.

Hoesel continues on the eligibility of the DD waiver and ASD waiver and the differences as the child ages. Senator Axness also offers his thoughts.

**(0:27:27)** Committee discusses appealable benefits.

**(0:30:12 - 0:32:45)** Ms. Hoesel offers information/numbers on the youth aging out of the ASD waiver each year:

- Waiver period 11/1/11 - 10/31/12: 29 children enrolled and 6 of them turned five during this period and were no longer eligible for the waiver
- Waiver period 11/1/12 - 10/31/13: 29 children enrolled and 3 of which have already aged out with 10 more that will age out by the end of the waiver year

**(0:34:30)** Discussion on Case Managers

**(0:36:36)** Julie Leer, Attorney with the Department of Human Services addresses the question about setting up a new appeals process for the voucher.

**(0:39:40 - 0:53:40)** Committee reviews the new amendment from Legislative Council (13.0192.03003) and offers additional changes. See attachment #24. Ms. Clark and Ms. Leer address adding an appeals process. Ms. Hoesel also offers considerations on expanding the age through 21.

Ms. Clark from Legislative Council suggests hog housing the bill. The committee agrees this will be cleaner. Discussion is recessed until tomorrow.

# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Human Services Committee Red River Room, State Capitol

SB 2193

2/13/13

Recording Job Number: 18881

☐ Conference Committee

Committee Clerk Signature:



### Explanation or reason for introduction of bill/resolution:

To provide for the establishment of an autism spectrum disorder database.

### Minutes:

You may make reference to "attached testimony."

Continued discussion on SB 2193:

**Chairman Lee** opens committee work and roll is taken. Senator Larsen and Senator Dever are not in the room yet. Chairman Lee announces a brief recess until the amendments are received from Legislative Council.

(Recording continues on same job number)

**(0:00:33 - 0:04:30)** Committee work reconvenes and all members of the committee are present. Chairman Lee notes the draft amendment 13.0192.03004 (see attachment #25) that was emailed to the committee last night. Legislative Council is still not finished with the new amendment but the committee reviews Senator Axness' draft amendment 13.0192.03005 (see attachment #25) in the meantime. The only difference between the two is that Senator Axness added the last sentence on page 2, section 2, subsection 1. Senator Dever suggests adding "...and potential for improvement" at the end of this new sentence. Committee is in agreement with this addition and the law intern messages Ms. Clark in Legislative Council to add this.

**Chairman Lee** announces a recess until approximately 10:00am to allow Legislative Council to finish the amendment.

(Recording continues on same job number)

**(0:05:36 - 0:15:05)** **Chairman Lee calls committee back to order.** Jennifer Clark from Legislative Council presents and reviews the new amendment 13.0192.03006 with the committee (see attachment #27) and answers committee questions. Maggie Anderson from DHS contributes to the conversation on the fiscal note.

**Chairman Lee** suggests moving it forward in its current form in order to give everyone more time to figure out what exactly these parameters have to be. There will be additional



information available once it gets to Appropriations and they will most definitely be talking with House Human Services about it. Ultimately it comes back to this committee in the Conference Committee.

**(0:19:06) Chairman Lee** clarifies the core services discussion for the committee.

**(0:20:55 - 0:29:45)** Senator Anness asks for clarity on the language that Senator Dever added earlier. Senator Dever explains his reasoning and Ms. Hoesel steps up to offer further insight. Discussion continues on whether this language should be left in or taken out. Senator Anness moves to strike it out. Committee is in agreement.

**(0:29:50 - 0:34:50)** - Discussion on the exclusions in subsection 2. Attachment #16 from Dr. Fischer was referenced as to where these exclusions came from.

**Senator Dever** moves to adopt the amendment 13.0192.03006, with the exclusion of the words "and potential for improvement" in section 2, subsection 1.

**Senator Anderson** seconds.

Senator Dever supports his motion with the understanding that there might perhaps in the future be potential for improvement in the consideration of the items now being excluded. Chairman Lee states that she agrees.

**Roll call vote:** 4-0, motion carries (vote is left open for Senator Larsen who briefly stepped out of the room)

**Senator Anderson** moves Do Pass as Amended and Rerefer to Appropriations.

**Senator Anness** seconds.

Senator Dever expresses his concern with the fact the parameters aren't in here and, with the way it stands right now, the sky is the limit. He will support the motion with the understanding that there will be further improvement in the process to the bill.

**Roll call vote:** 4-0, motion carries (vote is left open for Senator Larsen)

**Senator Lee** is the carrier.

Senator Larsen's vote was documented off the record by the clerk. He voted YES on both motions.

Attachment #28 - Additional information received on the Autism Voucher Program not referenced in discussion.

**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/22/2013**

Bill/Resolution No.: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$1,292,118		\$1,770,069
Expenditures			\$2,960,130	\$1,292,118	\$3,415,845	\$1,770,069
Appropriations			\$1,475,171	\$1,292,118	\$3,415,845	\$1,770,069

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, expands the autism Medicaid waiver and provides appropriations for the autism database, a state autism coordinator, statewide training efforts, behavioral analyst certification and diagnostic teams.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Sections 1 and 2 of SB2193, establishes the autism spectrum disorder database that will be administered by the department of health. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to establish and maintain the database the department of health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTEs. Therefore the additional appropriation needed for the database and FTEs would be \$190,816, all of which would be general fund. Section 3 of the bill expands the autism spectrum disorder Medicaid waiver. An appropriation is needed to expand from 30 individuals per month to 80 is \$2,042,925 of which \$1,017,581 is general fund and \$1,025,344 is federal funds. Due to the increase in individuals an appropriation is needed for 8 half time FTEs, one for each of the regions, this is to maintain a 1:60 ratio of clients to case managers and not knowing where the additional 50 individuals may be we are estimating .5 FTE for each region, or 4 total FTEs; \$508,152 of which \$254,076 is general fund. An appropriation would also be needed to expand the fiscal agent contract for the additional 50 individuals which would be \$25,396 of which \$12,698 would be general fund. Sections 4, 5, 6, and 7 of SB2193 include appropriations of \$494,135, for the state autism coordinator and staff, \$158,032 for the statewide autism spectrum disorder training effort, \$198,864 to provide funding support for individuals to complete a board-certified behavioral analyst program, and \$433,280 to provide autism spectrum disorder evaluation, diagnostic, and service planning teams, all of which are general fund.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

The other fund revenue is additional Medicaid funding the department will be able to access.

**B. Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the department of health for the 2013-2015 biennium is comprised of: 2 FTEs for the establishment and administration of the autism spectrum disorder database \$291,464, of which all is general fund; cost for establishing and maintaining the database including operating expenses to support the 2 FTEs \$100,000, of which all is general fund. The fiscal impact for the department of human services for the 2013-2015 biennium is comprised of: 6 FTEs for state autism coordination and case managers \$883,043, of which \$628,967 is general fund, operating costs including training and conference dollars to support autism coordination FTEs \$119,244, of which all is general fund, costs to support the statewide autism spectrum disorder training efforts \$158,032, of which all is general fund, costs to provide funding support for individuals to complete a board-certified behavioral analyst program \$198,864, of which all is general fund, costs to provide autism spectrum disorder evaluation, diagnostic, and service planning teams \$433,280, of which all is general fund, costs to expand the fiscal agent contract for additional 50 individuals \$25,396 of which \$12,698 is general fund, costs to expand the autism spectrum disorder Medicaid waiver \$2,042,925, of which \$1,017,581 is general fund and \$1,025,344 is federal funds. The fiscal impact for the department of health for the 2015-2017 biennium is \$361,464, of which all is general fund. This would include on-going supports costs for the autism spectrum disorder database and the costs to retain the 2 FTEs. The fiscal impact for the department of human services for the 2015-2017 biennium is \$4,824,450 of which \$3,054,381 is general fund. This would include costs to retain the 2 FTEs for state coordination, 8 half time FTEs for case management, costs to continue the training efforts, behavioral analyst certification, diagnostic teams, fiscal agent contract, and the costs to continue the autism spectrum disorder Medicaid waiver.

**C. Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The department of health will need an appropriation increase from what is included in the bill, of \$190,816, of which all is general fund. For the 2015-2017 biennium the department of health will need an appropriation increase of \$361,464, of which all is general fund. The department of human services will need an appropriation increase from what is included in the bill of \$2,576,473 with \$1,284,355 being general fund, to expand the autism spectrum disorder Medicaid waiver, add 8 half time FTEs for case management and expand the fiscal agent contract. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$4,824,450, of which \$3,054,381 is general fund.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/05/2013

JB  
2-13-13  
10f3

PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a department of human services study and report to the legislative management; and to provide an appropriation.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

**SECTION 1.**

**Autism spectrum disorder database - Rulemaking - Confidentiality.**

1. The state department of health shall establish and administer an autism spectrum disorder database. The database must include a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable research and analysis of the autism spectrum disorder, and provide services to individuals with an autism spectrum disorder.
2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the



2 of 3

receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

## **SECTION 2.**

### **Autism spectrum disorder voucher program - Appeal.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age twenty-two who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills. In determining the amount of a voucher for which an applicant may be determined eligible under this section, the department shall consider the applicant's level of functioning.
2. The department shall adopt rules addressing management of this voucher program and establishing the eligibility requirements and exclusions for this voucher program. The program may not provide a voucher for early intensive behavioral intervention, including applied behavioral analysis, intensive early interventional behavioral therapy, intensive behavioral intervention, the Lovaas method, the Denver model, LEAP (learning experiences - an alternative program for preschoolers and parents), TEACCH (treatment and education of autistic and related communication handicapped children), pivotal response training, or discrete trial training.
3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.

**SECTION 4. APPROPRIATION - STATE DEPARTMENT OF HEALTH - AUTISM SPECTRUM DISORDER DATABASE.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the sum as may be necessary, to the state department of health for the purpose of establishing and administering an autism spectrum disorder database, for the biennium beginning July 1, 2013, and ending June 30, 2015. The state department of health is authorized one full-time equivalent position for this purpose.

**SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$400,000, or so much of the sum as may be necessary, to the department of human services for the purpose of hiring a state autism coordinator who would be responsible for implementing a resource and service center to provide information and services for individuals with autism spectrum disorder, developing a statewide outreach plan, conducting regional meetings and an annual conference, and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and ending June 30, 2015. The department of human services is authorized one full-time equivalent position for this purpose.

**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$500,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015."

Renumber accordingly

Date: 2/13/13  
Roll Call Vote #: 1

2013 SENATE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 13.0192.03007

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ Amended ☒ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Sen. Dever Seconded By Sen. Anderson

Senators	Yes	No	Senator	Yes	No
Chairman Judy Lee	✓		Senator Tyler Axness	✓	
Vice Chairman Oley Larsen	✓				
Senator Dick Dever	✓				
Senator Howard Anderson, Jr.	✓				

Total (Yes) 5 No 0

Absent 0

Floor Assignment \_\_\_\_\_

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

Date: 2/13/13  
Roll Call Vote #: 2

2013 SENATE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 13.0192.03007

Action Taken: ☒ Do Pass ☐ Do Not Pass ☒ Amended ☐ Adopt Amendment  
☒ Rerefer to Appropriations ☐ Reconsider

Motion Made By Sen. Anderson Seconded By Sen. Axness

Senators	Yes	No	Senator	Yes	No
Chairman Judy Lee	<input checked="" type="checkbox"/>		Senator Tyler Axness	<input checked="" type="checkbox"/>	
Vice Chairman Oley Larsen	<input checked="" type="checkbox"/>				
Senator Dick Dever	<input checked="" type="checkbox"/>				
Senator Howard Anderson, Jr.	<input checked="" type="checkbox"/>				

Total (Yes) 5 No 0

Absent 0

Floor Assignment Sen. Lee

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



**REPORT OF STANDING COMMITTEE**

**SB 2193: Human Services Committee (Sen. J. Lee, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2193 was placed on the Sixth order on the calendar.

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a department of human services study and report to the legislative management; and to provide an appropriation.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

**SECTION 1.**

**Autism spectrum disorder database - Rulemaking - Confidentiality.**

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2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

**SECTION 2.**

**Autism spectrum disorder voucher program - Appeal.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age twenty-two who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills. In determining the amount of a voucher for which an applicant may be determined eligible under this section, the department shall consider the applicant's level of functioning.
2. The department shall adopt rules addressing management of this voucher program and establishing the eligibility requirements and exclusions for this voucher program. The program may not provide a voucher for early intensive behavioral intervention, including applied behavioral analysis, intensive early interventional behavioral therapy, intensive behavioral intervention, the Lovaas method, the Denver model, LEAP (learning experiences - an alternative program for preschoolers and parents), TEACCH (treatment and education of autistic and related communication handicapped children), pivotal response training, or discrete trial training.
3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.

**SECTION 4. APPROPRIATION - STATE DEPARTMENT OF HEALTH - AUTISM SPECTRUM DISORDER DATABASE.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the sum as may be necessary, to the state department of health for the purpose of establishing and administering an autism spectrum disorder database, for the biennium beginning July 1, 2013, and ending June 30, 2015. The state department of health is authorized one full-time equivalent position for this purpose.

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**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$500,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015."

Renumber accordingly

**2013 SENATE APPROPRIATIONS**

**SB 2193**

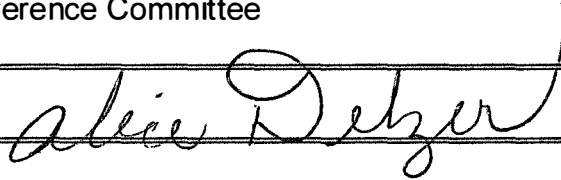
# 2013 SENATE STANDING COMMITTEE MINUTES

## Senate Appropriations Committee Harvest Room, State Capitol

SB 2193  
02-19-2013  
Job # 19151

☐ Conference Committee

Committee Clerk Signature



### Explanation or reason for introduction of bill/resolution:

A BILL Re: Autism spectrum disorder database and program department and a Human Services Study (DO PASS)

### Minutes:

Testimony Attached

**Chairman Holmberg** called the committee to order on Tuesday, February 19, 2013 at 9:00 am in regards to SB 2193. All committee members were present.

**Senator Joan Heckaman, District 23** introduced bill and provided Testimony attached # 1.

**Senator Judy Lee, District 13** - This is a work in progress. Just briefly going through it you will see there will be a database that is going to be put in to place that is going to record all cases of autism spectrum disorder which I'm going to call ASD. It also establishes criteria for the diagnosis and that will be under the diagnostic and statistical manual of mental disorders. It talks about physical evaluation and adopting rules and those kinds of things. The Health Department will be responsible for this database and appropriate confidential measures will be taken. The voucher program is where you would probably have some interest as far as the cost is concerned; we are looking at trying to make sure that we are going to support programs that have medically proven to be effective. The kinds of treatments that would be included in this would be those kinds of interventions that have proven to be effective and as time goes by as there's more scientific data on some other kinds of interventions certainly those would be considered but at this point it talks about in section 2 subsection 1 some of those things that would be included. We also would be talking about what wouldn't be, there are exclusions that are specifically excluded because they do not have a proven effectiveness. We would also be looking in section 3 on having a report, and section 4 talks about an appropriation again for establishment of this database and there is also in section 5 the original bill called for 2 people in the coordinators a position right now it has been reduced to 1 coordinator. Then the training which is a really significant things here. We need to make sure we have additional training available not only for teachers because I'm sure you are aware children are covered for special needs services in their 3<sup>rd</sup> birthday up to their 22<sup>nd</sup> birthday and that is provided through the schools. It's based on what is appropriate for a public education and there are certainly things needed beyond the educational component during a regular school day but also nights and weekends. (7:42)

**Chairman Holmberg** - The work in progress has a long way to go and the budgets of course, the bill has a couple small appropriations in it but the financial impact really is within the budget of Human Services and the Health Department it's certainly too late to reopen the scab on the Health Department at this stage but if the committee wants to pass the bill knowing full well that we will have to look at Human Services when it comes over here and also the Health Department over in the House and then clearly on a conference committee.

**Senator Judy Lee** - I respectfully request you not throw out any of these components.

**Senator Mathern** handed out testimony from Dr. Barbara Stanton, Testimony attached #2 in favor of SB 2193.

**Christine Hogan, P&A Project** - In support of SB 2193 and provided Testimony attached # 3.

**Carlotta McCleary, ND Federation of Families for Children's Mental Health (NDFFCMH)** testified in favor of SB 2193 and provided Testimony attached # 4.

**Senator Warner** - Do you have a national organization which publishes a list of best practices?

**Carlotta McCleary** - I haven't specifically researched what all the best practices are listed within ASD but I do know that a lot of organizations do a list, particular best practice approaches.

**Maggie Anderson, Department of Health**, went through how the fiscal note was created. (21:20)

**Senator Mathern** - We had an interim study that came up with a bill and then we had the study of the governor's task force that came up with a bill. I was a little bit concerned that one group of people was going this way and one group of people was going that way and they really weren't working together until more in the last month or so. I think we could have even accomplished more if everybody was working together than we have thus far. I'm wondering, in this study how do you see that going forward? Do you see it as an executive branch study, the legislature being involved, is there some way we could all work together on this?

**Maggie Anderson** - My understanding of the study, and this is based on conversations we had with the committee and Senator Lee was that at one point there was a version of an amendment that would have indicated that the Department of Human Services should add ASD as a core service. We shared just by placing it on a list has implications to staffing. We don't currently have ASD services at the Human Service Center. There are some times that a child who has a developmental disability or a mental illness also has a diagnosis of ASD but the universe would be much greater. So that would be either a reduction in services that we are able to provide for mental health and substance abuse or an increase in staff. So it was, lets study where the appropriate location of who becomes the expert to set criteria for ASD. That is really what the study is entailing, is to that one piece.

**Senator Mathern** - Is it an executive branch study?

**Maggie Anderson** - The way the amendment read was that the Department of Human Services in consultation with experts who have experience in the diagnosis, treatment, and the assessment of ASD.

**Senator Wanzek** - The \$2 million for vouchers where is that money coming from?

**Chairman Holmberg** - It would have to be added in the department budget. It is just a vehicle and it needs a lot of tune up.

**Vickie Peterson, a Family Voices Consultant** - I am up here to answer a question from the committee about establishing interventions and practices. There is an agency out there, it's called the National Autism Standards Report, and they look at the interventions and strategies for Autism Spectrum Disorders. They look at it as being established treatments, emergency treatments and un-established interventions for Autism Spectrum Disorders. That is the national one and they work closely with the Autism Research Institute.

**Senator Erbele** - I served on the interim committee. As you said this is a vehicle and I think we need to put a wheel on it and move it down the road. They need this service.

**Senator Erbele moved a do pass. Seconded by Senator Wanzek.**

**A Roll Call vote was taken. Yea: 13; Nay: 0. Absent: 0.**

**Senator Judy Lee will carry the bill.**

The hearing was closed on SB 2193.



**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/14/2013**

Amendment to: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			\$3,511,318	\$0	\$9,741,758	\$0
Appropriations			\$2,219,854	\$0	\$9,741,758	\$0

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, creates an Autism Spectrum Disorder (ASD) voucher program and an ASD study and report and provides appropriations for the autism database, a state autism coordinator and statewide ASD training efforts.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The Fiscal Effect in 1A above, assumes that once the estimated cost of vouchers have been exhausted no additional voucher payments will be made. Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*



- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts. The fiscal impact for the Department of Health for the 2015-2017 biennium is \$391,464, all of which is general fund. This is the cost of the 2 FTES and the on-going costs to support the autism spectrum disorder duties. The fiscal impact for the Department of Human Services for the 2015-2017 biennium is \$9,741,758, all of which is general fund. This would include costs to retain the FTE for state coordination, costs to continue the training efforts, and the voucher costs.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

For the 2013-2015 biennium the Department of Health would need an additional appropriation authority from what is included in the bill of \$190,816 all of which is general fund. For the 2015-2017 biennium the Department of Health will need a general fund appropriation of \$391,464, of which all is general fund, to maintain the 2 FTES for the administration of the autism spectrum disorder database and other duties. For the 2013-2015 biennium the Department of Human Services will need an appropriation increase from what is included in the bill of \$2,219,854, all of which is general fund, to issue vouchers and to complete the study and report for legislative management. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$9,741,758 of which all is general fund, for the voucher program and to maintain the 1 FTE for autism coordination and training efforts.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/19/2013

**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/22/2013**

Bill/Resolution No.: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$1,292,118		\$1,770,069
Expenditures			\$2,960,130	\$1,292,118	\$3,415,845	\$1,770,069
Appropriations			\$1,475,171	\$1,292,118	\$3,415,845	\$1,770,069

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, expands the autism Medicaid waiver and provides appropriations for the autism database, a state autism coordinator, statewide training efforts, behavioral analyst certification and diagnostic teams.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Sections 1 and 2 of SB2193, establishes the autism spectrum disorder database that will be administered by the department of health. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to establish and maintain the database the department of health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTEs. Therefore the additional appropriation needed for the database and FTEs would be \$190,816, all of which would be general fund. Section 3 of the bill expands the autism spectrum disorder Medicaid waiver. An appropriation is needed to expand from 30 individuals per month to 80 is \$2,042,925 of which \$1,017,581 is general fund and \$1,025,344 is federal funds. Due to the increase in individuals an appropriation is needed for 8 half time FTEs, one for each of the regions, this is to maintain a 1:60 ratio of clients to case managers and not knowing where the additional 50 individuals may be we are estimating .5 FTE for each region, or 4 total FTEs; \$508,152 of which \$254,076 is general fund. An appropriation would also be needed to expand the fiscal agent contract for the additional 50 individuals which would be \$25,396 of which \$12,698 would be general fund. Sections 4, 5, 6, and 7 of SB2193 include appropriations of \$494,135, for the state autism coordinator and staff, \$158,032 for the statewide autism spectrum disorder training effort, \$198,864 to provide funding support for individuals to complete a board-certified behavioral analyst program, and \$433,280 to provide autism spectrum disorder evaluation, diagnostic, and service planning teams, all of which are general fund.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

The other fund revenue is additional Medicaid funding the department will be able to access.

**B. Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the department of health for the 2013-2015 biennium is comprised of: 2 FTEs for the establishment and administration of the autism spectrum disorder database \$291,464, of which all is general fund; cost for establishing and maintaining the database including operating expenses to support the 2 FTEs \$100,000, of which all is general fund. The fiscal impact for the department of human services for the 2013-2015 biennium is comprised of: 6 FTEs for state autism coordination and case managers \$883,043, of which \$628,967 is general fund, operating costs including training and conference dollars to support autism coordination FTEs \$119,244, of which all is general fund, costs to support the statewide autism spectrum disorder training efforts \$158,032, of which all is general fund, costs to provide funding support for individuals to complete a board-certified behavioral analyst program \$198,864, of which all is general fund, costs to provide autism spectrum disorder evaluation, diagnostic, and service planning teams \$433,280, of which all is general fund, costs to expand the fiscal agent contract for additional 50 individuals \$25,396 of which \$12,698 is general fund, costs to expand the autism spectrum disorder Medicaid waiver \$2,042,925, of which \$1,017,581 is general fund and \$1,025,344 is federal funds. The fiscal impact for the department of health for the 2015-2017 biennium is \$361,464, of which all is general fund. This would include on-going supports costs for the autism spectrum disorder database and the costs to retain the 2 FTEs. The fiscal impact for the department of human services for the 2015-2017 biennium is \$4,824,450 of which \$3,054,381 is general fund. This would include costs to retain the 2 FTEs for state coordination, 8 half time FTEs for case management, costs to continue the training efforts, behavioral analyst certification, diagnostic teams, fiscal agent contract, and the costs to continue the autism spectrum disorder Medicaid waiver.

**C. Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The department of health will need an appropriation increase from what is included in the bill, of \$190,816, of which all is general fund. For the 2015-2017 biennium the department of health will need an appropriation increase of \$361,464, of which all is general fund. The department of human services will need an appropriation increase from what is included in the bill of \$2,576,473 with \$1,284,355 being general fund, to expand the autism spectrum disorder Medicaid waiver, add 8 half time FTEs for case management and expand the fiscal agent contract. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$4,824,450, of which \$3,054,381 is general fund.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/05/2013

Date: 2-19-13Roll Call Vote # 1

**2013 SENATE STANDING COMMITTEE  
ROLL CALL VOTES**

BILL/RESOLUTION NO. 2193Senate Appropriations Committee☐ Check here for Conference Committee

Legislative Council Amendment Number \_\_\_\_\_

Action Taken Do PassMotion Made By KK Seconded By TW

Senators	Yes	No	Senator	Yes	No
Chairman Ray Holmberg	✓		Senator Tim Mathern	✓	
Co-Vice Chairman Bill Bowman	✓		Senator David O'Connell	✓	
Co-Vice Chair Tony Grindberg	✓		Senator Larry Robinson	✓	
Senator Ralph Kilzer	✓		Senator John Warner	✓	
Senator Karen Krebsbach	✓				
Senator Robert Erbele	✓				
Senator Terry Wanzek	✓				
Senator Ron Carlisle	✓				
Senator Gary Lee	✓				

Total (Yes) 13 No \_\_\_\_\_

Absent \_\_\_\_\_

Floor Assignment H.S. J. Lee

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

**REPORT OF STANDING COMMITTEE**

**SB 2193, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman)**  
recommends **DO PASS** (13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING).  
Engrossed SB 2193 was placed on the Eleventh order on the calendar.

**2013 HOUSE HUMAN SERVICES**

**SB 2193**



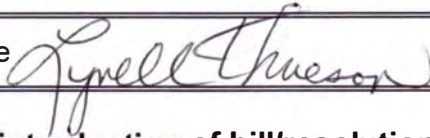
# 2013 HOUSE STANDING COMMITTEE MINUTES

## House Human Services Committee Fort Union Room, State Capitol

SB 2193  
March 12, 2013  
Job #19804

☐ Conference Committee

Committee Clerk Signature



### Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for the Department of Human Services study and report to the legislative management and to provide an appropriation to establish an autism spectrum disorder database.

### Minutes:

Testimony 1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12; 13, 14, **15**  
**16** Handout #3

**Chairman Weisz** opened the hearing on SB 2193.

**00:26 Senator Joan Heckaman:** from **District 23, New Rockford** introduced and supported the bill. (See Testimony #1) Three years of work by the Governor's autism task force. Meets quarterly to determine current services available in ND, surveyed needs in the state, and developed a plan for services for individuals with autism. Section 3 of the bill asks for a study. What is the relevance for the study? We as a task force are doing that already and they are open meetings that anyone can attend.

**4:05 Senator Judy Lee:** from **District 13, West Fargo** testified in support of the bill. Changes were made in the Senate Human Services committee. The goal is to provide appropriate services that demonstrate the effectiveness of beginning a program to serve children who are now currently served under the waiver. The waiver covers children up to age 5 and has to be eligible for institutionalized care. What is the scope of this need in the state? What kinds of services are most appropriately provided? This needs to be at a doctor professional level. Section 2 is a voucher system. This wraps around the waiver because it's for children younger than 3, older than 5, and meet services beyond those which would be provided that are education related. It is not income based. Section 3 is a report from the Department of Human Services. Departments would evaluate the progress of this voucher program. We want to make sure we are focusing the best possible way on the children who most need it. In order for us to use state dollars wisely and establish a program that will be successful, we felt it was best to begin with a core group of services that we know work, that can provide benefits to the children, begin the process of diagnosis, identification, and education/training.

**12:40 Representative Fehr:** On page 1, line 22, the first DSM5 has not been published yet?

**Senator Judy Lee:** No.

**12:54 Representative Fehr:** I'm wondering if there was testimony in terms of this, since we don't know what DSM5 will see, will it in fact be a good tool to use?

**Senator Judy Lee:** We didn't get anyone who suggested that there would be any serious issue with using the DSM5.

**15:05 Teresa Larsen: Director of the Protection and Advocacy Project and member of the Autism Spectrum Disorder Task Force:** testified in support of the bill. (See Testimony #2) There are a number of concerns regarding the ASD legislation. A diversified group has met to work towards achieving consensus on language for SB 2193. This group has come to an agreement on the language. Passed out a handout. (See Handout #3)

**21:26 Representative Porter:** In Section 2 did you have a cost figure that went with that language?

**Teresa Larsen:** I believe we would be using the same cost figure.

**21:56 Representative Porter:** What is the total number of individuals using that figure end up being?

**Teresa Larsen:** 42 new individuals.

**23:25 Colin Vieweg:** A 13 year old boy with autism testified in support of the bill. (See Testimony #4) We need more help in services. The voucher system will help us get services that our families have trouble affording.

**26:59 JoAnne Vieweg:** Grandmother to Colin Vieweg testified in support of the bill. (See Testimony #5) JoAnne handed out testimony for Chris McEwen. (See Testimony #6) Colin feels he needs to advocate for those who can't speak up for themselves. Our organization is in contact with 98 families and individuals who are involved in the autism spectrum. We supply support groups, community education, and help with advocacy. She is interested in the training component and voucher system. Teachers need good training and ongoing professional development. The voucher system would help fund services that these types of children need.

**34:25 Donene Feist: Director of Family Voices of ND,** testified in support of the bill. (See Testimony #7) Donene handed out a testimony in support of the bill by Toby Cherney, a parent of an autism child. (See Testimony #8) We provide emotional and informational support to families across the state that have a child with autism spectrum disorder. Our staff provides assistance to those families through a service that provides emotional support and educational assistance to assist them with various needs. There is a need for the voucher and the expanded waiver.

**44:22 Vicki Peterson:** A mother of a child with autism and family consultant for **Family Voices of ND** testified in support of the bill. (See Testimony #9) Section 1, concerning the database and language, many parents have contacted her regarding the research and

analysis as well as the department may provide these records to other state agencies. Protecting this database is essential. There are also concerns about the language of a complete physical evaluation. Made reference to Section 2. A voucher system is needed.

**50:59 Craig DeGree:** A licensed child psychologist. (See Testimony #10) He is not in favor or exclusion of early intensive behavioral interventions as identified in Section 2. More needs to be done at an earlier age.

**53:20 Wade Nagel:** A dad of a 3 year old son with autism. Testified in support of the bill. Son was normal until 16-18 months and noticed a change. Wouldn't respond to name had his hearing tested. Took him to pediatrician and they said wait it out for several months. When we went back he was diagnosed with autism. The medical community wrote our son Watson off at age 2. No one we talked to said this is curable. My wife and I started getting information from the internet and started our own therapy on our son. Early intervention is essential with children with autism. We hooked up with the Anne Carlson Center and they did a card therapy which is evidence based. He now speaks in full sentences and goes to day care. If he continues with this growth he will go to regular kindergarten. Early and intensive intervention is the way to go.

**1:05:31 Missy Brademeyer:** Is in support of this bill. Has a son 13 years old. Feels it's important that we introduce early intensive behavior programs. We feel we lost our son at the age of 2 to autism. We began using the internet through ABA because resources were not available. We are with the Anne Carlson Center and the card therapy. Teaching concepts to our children and if we could have had that knowledge we would have been a lot farther along than we are now. (Told how she taught her autism son the concepts of on top, underneath, over and under.) This is how an effective program works. These children are so smart and can be productive members of society.

**1:12:24 Carlotta McCleary: Executive Director of ND Federation of Families for Children's Mental Health:** testified in support of the bill. (See Testimony #11) This is a parent-run advocacy organization that focuses on the needs of children and uses emotional behavior and mental disorders and their families from birth to transition to adulthood. It works with children and youth and their families. We support the establishment of the autism spectrum disorder database, the autism spectrum disorder pilot voucher program, and a study for the Department of Human Services comprehensive training effort. This voucher program allows serving children who are graduating from the current autism waiver. It should be expanded to include others. The Department of Human Services should establish a process to determine the evidence based practices and promising practices.

**1:15:28 Eric Monson: From Anne Carlson Center.** (See Testimony #12) An outline was put together showing some positions relative to ABA therapy and the waiver program. We support this bill. Think about the delivery of health care or social services in rural areas and how the exclusions would affect that.

**1:19:27 Representative Porter:** Getting children early treatment and intervention, there is a big skimming of this money that's going to FTE's that have nothing to do with the treatment of the children. Did you look at that?

**1:20:22 Eric Monson:** I'm convinced we need some structure on what services should be excluded. The education is needed in the schools where they can identify autism.

**1:22:33 Representative Porter:** There are 22 different FTE's that are inside this bill. Am I seeing something wrong?

**Eric Monson:** I haven't counted the FTE's. In terms of the database a positive impact we received is much better cancer treatment.

**1:24:16 Representative Porter:** Get the treatment to the children; don't spend it all on overhead.

**Eric Monson:** I can't disagree with that. We should have a database registry.

**1:26:05 Representative Porter:** Would you expand the scope of the Anne Carlson Center? So we are paying less overhead and more for the treatment?

**Eric Monson:** We are prepared to enter the same kind of partnership that we offered in the last session.

**1:27:01 Representative Mooney:** Could you explain what card stands for? It's paramount that parents receive training as well, correct?

**Eric Monson:** Center for Autism and Related Disorders. Yes, we have developed our programming with that as a central focus.

**1:28:04 Representative Silbernagel:** Could you summarize how you might expand what you have proposed?

**Eric Monson:** Last session there was a bill introduced to require an insurance mandate. This would provide certain services for children and adults on the autism spectrum. We offered to match dollar for dollar what the state might put into the program. (a cap put in place) We would get some program going; begin the research, and understanding the numbers.

**1:29:57 Representative Mooney:** Would you have any way of being able to come up with numbers to give a comparison between what it costs to treat a child who is 15-17 years old or later in life as compared to when they are younger?

**Eric Monson:** We have seen studies that demonstrate that. In terms of our own work, it's probably too short a time to receive data.

**1:31:16 Dr. Barbara Stanton:** from **Prairie St. John's** testified in support of the bill. (See Testimony # 13) There is need for a study to be done. There is need for a tracking system in the state to plan future services, access funding, and give us the opportunity for data sharing. It will benefit families across the state. Taking a look at the diagnostic guidelines is also important. This bill will point us in the right direction.



**1:44:09 Representative Oversen:** Could you speak on the list of excluded services on early behavioral intervention in general? Why would we exclude that or is it the fact that it's not a specific form?

**1:44:28 Dr. Stanton:** Part of the problem is broad based and vague. We need to continue to develop a better understanding. They are not ineffective. We want to identify services that we know can be effective, have a positive outcome, and to come back with more data, research, and more understanding.

**1:49:40 JoAnn Hoesel:** from **DHS**. The voucher system is divided into five areas. There are three priority groups. The waiver has reached its max which is 30 children.

**1:57:00 Tamara Gallup-Milner: Director of the Division of Children's Special Health Services of ND for the Department of Health:** (See Testimony #14) If this bill is adopted, the Department of Health requires clarification and a number of items listed in her testimony. The bill requires a complete evaluation of the individual.

**2:03:28 Gerry Teevens: Special Education Director for the Dept. of Public Instruction:** provided information on the bill. (See Testimony #15) Support of this bill is to reinstate the appropriation for the Department of Public Instruction to provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and supports to individuals with autism.

Hearing closed.

HANDED IN TESTIMONY IN SUPPORT

Amanda Lausch: (See Testimony #16)

# 2013 HOUSE STANDING COMMITTEE MINUTES

## House Human Services Committee Fort Union Room, State Capitol

SB 2193  
April 1, 2013  
Job #20737

☐ Conference Committee

Committee Clerk Signature

*Vicky Crabtree*

### Explanation or reason for introduction of bill/resolution:

Relating to autism spectrum disorder database.

### Minutes:

See Attachment #1

Chairman Weisz: Let's look at SB 2193. Rep. Fehr has some amendments.

Rep. Fehr: (See Attachment #1) (Rep. Fehr went through the amendment.)

10:17

Rep. Fehr: I move the amendment.

Vice-Chair Hofstad: Second.

Chairman Weisz: You are keeping the funding intact that is in the coordinator and the training, correct?

Rep. Fehr: That's correct.

Chairman Weisz: I assume the 35 will add about \$2.5 million fiscal effect?

Rep. Fehr: It will come out to a little more than \$2.5 million.

Chairman Weisz: JoAnn can you come up please. About \$1.8 million right?

12:38

JoAnn Hoesel: The existing bill is based on a voucher. The voucher was based on the waiver, but the current voucher is based on 42. We would have to go and adjust it to that number if you want us to do that.

Chairman Weisz: Would the expenses be somewhat similar per child or less?

Hoesel: We would base it on the same methodology.



Rep. Oversen: The current bill is up to 22, but the amendment is only through age 5.

Chairman Weisz: The bill is assuming 42 through age 22.

Hoesel: Your cost is per child. The service mix will be different based on age; it won't affect the amount of dollars. We did a fiscal note for HB 1012 for 42 slots and that would be the one you would want to look at.

Chairman Weisz: Is the total is?

Hoesel: \$2,342,000 and that is at 50/50 FMAP.

Rep. Mooney: How does the rest of the population get taken care of?

Chairman Weisz: They won't be. The intent of the amendment was that you could either cover virtually all of the 0-5 range or you can cover a small portion of them from 0-22. My question is to qualify for the waiver you have to qualify for institutional care?

Hoesel: It is based on the child's income.

Rep. Fehr: In terms of numbers of slots and looking at what you currently been doing and requests you have for the waiver, what will the additional 35 do?

Hoesel: The waiver is fairly new and I don't think the earlier time is representative of the demand or need. We have 35 slots currently. We filled 30 in February. We have three individuals on the waiting list at this time. Our early intervention program has 850. That has developmental delays not specific to ASD, but could be inclusive of that. You are looking at 35 and the existing 30. There would certainly be that many children in the state that meet that criteria.

Rep. Fehr: Since you just filled the 30 in February and if this is passed you will have additional slots and probably in the next two years you will exceed the 35.

Hoesel: That is a possibility.

Rep. Fehr: One of the things of going with a Medicaid waiver as opposed to a voucher is that you have federal money for about half of it. We are targeting the neediest individuals. Looking at up to age 5 is to do an early intervention.

Rep. Silbernagel: We currently have 42 slots and adding 35?

Chairman Weisz: Currently it is 30 slots in the waiver.

Rep. Silbernagel: Total slots would be 65?

Chairman Weisz: Yes. The additional cost would be \$1.9 million.

Rep. Silbernagel: We are currently doing now is?

Chairman Weisz: Roughly, \$1.5 million give or take.

Rep. Silbernagel: Ball park \$5 million.

Chairman Weisz: I'd say under 4. (Asking JoAnn Hoesel.) What would the total be?

Hoesel: We have to write this waiver, but the current budget for the 30 slots for a biennium is about \$2.1 million and add this and you have the full biennium. The \$3.2 million is for 18 months.

Chairman Weisz: You are looking at about \$4-4.5 million.

Rep. Mooney: Didn't we not get testimony that after the 3-5 year olds the greater problems lie? There is not methodology that follows through with these kids?

Chairman Weisz: There is money available to the education system and there is the \$500,000 that helps with that training.

Rep. Mooney: We haven't had any subcommittee work or public or study group input on this. This is a dramatic change from what was brought forward in the bill.

Chairman Weisz: There will be a lot of discussion in conference committee if we pass this out.

Rep. Muscha: You said this way we could help 80%, but they would have to qualify for Medicaid and be institutionalized.

Chairman Weisz: The 80% I used as an example. Those that qualify for the institutional care and the child's income meets the Medicaid; adding these slots will probably cover the majority of those that fit into that criteria. You will do 1/6 the kids by going to age 22.

Rep. Fehr: I put together an amendment a week and half ago and was struggling how to tweak the voucher system. I came to the conclusion that going with the Medicaid waiver is preferable. We already have a Medicaid system and it makes sense to stay with a system already in existence. You do give up some flexibility with not having the voucher system.

Rep. Oversen: We are missing the intention behind the voucher system. Average age of diagnosing Asperger's is age 6 and they would miss all services that are offered. I'm unnerved by the waiver idea and I think we should work with the voucher. I'm resistant to this amendment.

ROLL CALL VOTE ON AMENDMENT: 9 y 4 n 0 absent

MOTION CARRIED

Rep. Fehr: I move a Do Pass as Amended and re-referred to Appropriations.

House Human Services Committee  
SB 2193  
April 1, 2013  
Page 4

Vice-Chair Hofstad: Second.

ROLL CALL VOTE: 12 y 1 n 0 absent

Bill Carrier: Rep. Fehr

**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/14/2013**

Amendment to: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			\$3,511,318	\$0	\$9,741,758	\$0
Appropriations			\$2,219,854	\$0	\$9,741,758	\$0

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, creates an Autism Spectrum Disorder (ASD) voucher program and an ASD study and report and provides appropriations for the autism database, a state autism coordinator and statewide ASD training efforts.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The Fiscal Effect in 1A above, assumes that once the estimated cost of vouchers have been exhausted no additional voucher payments will be made. Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts. The fiscal impact for the Department of Health for the 2015-2017 biennium is \$391,464, all of which is general fund. This is the cost of the 2 FTEs and the on-going costs to support the autism spectrum disorder duties. The fiscal impact for the Department of Human Services for the 2015-2017 biennium is \$9,741,758, all of which is general fund. This would include costs to retain the FTE for state coordination, costs to continue the training efforts, and the voucher costs.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

For the 2013-2015 biennium the Department of Health would need an additional appropriation authority from what is included in the bill of \$190,816 all of which is general fund. For the 2015-2017 biennium the Department of Health will need a general fund appropriation of \$391,464, of which all is general fund, to maintain the 2 FTEs for the administration of the autism spectrum disorder database and other duties. For the 2013-2015 biennium the Department of Human Services will need an appropriation increase from what is included in the bill of \$2,219,854, all of which is general fund, to issue vouchers and to complete the study and report for legislative management. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$9,741,758 of which all is general fund, for the voucher program and to maintain the 1 FTE for autism coordination and training efforts.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/19/2013

**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/22/2013**

Bill/Resolution No.: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$1,292,118		\$1,770,069
Expenditures			\$2,960,130	\$1,292,118	\$3,415,845	\$1,770,069
Appropriations			\$1,475,171	\$1,292,118	\$3,415,845	\$1,770,069

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, expands the autism Medicaid waiver and provides appropriations for the autism database, a state autism coordinator, statewide training efforts, behavioral analyst certification and diagnostic teams.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Sections 1 and 2 of SB2193, establishes the autism spectrum disorder database that will be administered by the department of health. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to establish and maintain the database the department of health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTEs. Therefore the additional appropriation needed for the database and FTEs would be \$190,816, all of which would be general fund. Section 3 of the bill expands the autism spectrum disorder Medicaid waiver. An appropriation is needed to expand from 30 individuals per month to 80 is \$2,042,925 of which \$1,017,581 is general fund and \$1,025,344 is federal funds. Due to the increase in individuals an appropriation is needed for 8 half time FTEs, one for each of the regions, this is to maintain a 1:60 ratio of clients to case managers and not knowing where the additional 50 individuals may be we are estimating .5 FTE for each region, or 4 total FTEs; \$508,152 of which \$254,076 is general fund. An appropriation would also be needed to expand the fiscal agent contract for the additional 50 individuals which would be \$25,396 of which \$12,698 would be general fund. Sections 4, 5, 6, and 7 of SB2193 include appropriations of \$494,135, for the state autism coordinator and staff, \$158,032 for the statewide autism spectrum disorder training effort, \$198,864 to provide funding support for individuals to complete a board-certified behavioral analyst program, and \$433,280 to provide autism spectrum disorder evaluation, diagnostic, and service planning teams, all of which are general fund.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

The other fund revenue is additional Medicaid funding the department will be able to access.



**B. Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the department of health for the 2013-2015 biennium is comprised of: 2 FTEs for the establishment and administration of the autism spectrum disorder database \$291,464, of which all is general fund; cost for establishing and maintaining the database including operating expenses to support the 2 FTEs \$100,000, of which all is general fund. The fiscal impact for the department of human services for the 2013-2015 biennium is comprised of: 6 FTEs for state autism coordination and case managers \$883,043, of which \$628,967 is general fund, operating costs including training and conference dollars to support autism coordination FTEs \$119,244, of which all is general fund, costs to support the statewide autism spectrum disorder training efforts \$158,032, of which all is general fund, costs to provide funding support for individuals to complete a board-certified behavioral analyst program \$198,864, of which all is general fund, costs to provide autism spectrum disorder evaluation, diagnostic, and service planning teams \$433,280, of which all is general fund, costs to expand the fiscal agent contract for additional 50 individuals \$25,396 of which \$12,698 is general fund, costs to expand the autism spectrum disorder Medicaid waiver \$2,042,925, of which \$1,017,581 is general fund and \$1,025,344 is federal funds. The fiscal impact for the department of health for the 2015-2017 biennium is \$361,464, of which all is general fund. This would include on-going supports costs for the autism spectrum disorder database and the costs to retain the 2 FTEs. The fiscal impact for the department of human services for the 2015-2017 biennium is \$4,824,450 of which \$3,054,381 is general fund. This would include costs to retain the 2 FTEs for state coordination, 8 half time FTEs for case management, costs to continue the training efforts, behavioral analyst certification, diagnostic teams, fiscal agent contract, and the costs to continue the autism spectrum disorder Medicaid waiver.

**C. Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The department of health will need an appropriation increase from what is included in the bill, of \$190,816, of which all is general fund. For the 2015-2017 biennium the department of health will need an appropriation increase of \$361,464, of which all is general fund. The department of human services will need an appropriation increase from what is included in the bill of \$2,576,473 with \$1,284,355 being general fund, to expand the autism spectrum disorder Medicaid waiver, add 8 half time FTEs for case management and expand the fiscal agent contract. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$4,824,450, of which \$3,054,381 is general fund.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/05/2013

April 1, 2013

YIC  
4/1/13

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2193

Page 1, line 1, remove "the establishment of an autism spectrum disorder database and"

Page 1, remove line 2

Page 1, line 3, replace "study and report to the legislative management" with "expansion of the autism spectrum disorder medicaid waiver"

Page 1, remove lines 5 through 23

Page 2, remove lines 1 through 31

Page 3, replace lines 1 through 20 with:

**"SECTION 1. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER MEDICAID WAIVER.** The department of human services, during the biennium beginning July 1, 2013, and ending June 30, 2015, shall seek approval from the federal centers for medicare and medicaid services to expand the department's autism spectrum disorder medicaid waiver to cover thirty-five additional individuals from birth through age five. The expansion to the waiver must become effective on or after January 1, 2014, and must include appropriate behavior intervention and treatment services that may include evidence-based and promising practices, case management services, technology and technology-based support, in-home support, equipment and supplies, home monitoring, respite care, residential supports and services, and behavioral consultation."

Page 4, line 6, replace the first comma with a semicolon

Page 4, line 6, replace the second comma with a semicolon

Page 4, line 6, replace ", and parent training," with "; training to support behavior analyst certification; training to improve independent living skills, preemployment opportunities, and executive and social skills; training and educational materials for parents; and parenting education"

Renumber accordingly

Date: 4-1-13  
Roll Call Vote #: 1

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

House Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number \_\_\_\_\_

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ Amended ☒ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Fehr Seconded By Rep. Hofstad

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ	✓		REP. MOONEY		✓
VICE-CHAIRMAN HOFSTAD	✓		REP. MUSCHA		✓
REP. ANDERSON	✓		REP. OVERSEN		✓
REP. DAMSCHEN	✓				
REP. FEHR	✓				
REP. KIEFERT	✓				
REP. LANING		✓			
REP. LOOYSEN	✓				
REP. PORTER	✓				
REP. SILBERNAGEL	✓				

Total (Yes) 9 No 4

Absent \_\_\_\_\_

Floor Assignment \_\_\_\_\_

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

See Attachment #1

Date: 4-1-13  
Roll Call Vote #: 2

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

House Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number \_\_\_\_\_

Action Taken: ☒ Do Pass ☐ Do Not Pass ☒ Amended ☐ Adopt Amendment  
☒ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Fehr Seconded By Rep. Hofstad

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ	<input checked="" type="checkbox"/>		REP. MOONEY	<input checked="" type="checkbox"/>	
VICE-CHAIRMAN HOFSTAD	<input checked="" type="checkbox"/>		REP. MUSCHA	<input checked="" type="checkbox"/>	
REP. ANDERSON	<input checked="" type="checkbox"/>		REP. OVERSEN	<input checked="" type="checkbox"/>	
REP. DAMSCHEN	<input checked="" type="checkbox"/>				
REP. FEHR	<input checked="" type="checkbox"/>				
REP. KIEFERT	<input checked="" type="checkbox"/>				
REP. LANING		<input checked="" type="checkbox"/>			
REP. LOOYSEN	<input checked="" type="checkbox"/>				
REP. PORTER	<input checked="" type="checkbox"/>				
REP. SILBERNAGEL	<input checked="" type="checkbox"/>				

Total (Yes) 12 No 1

Absent 0

Floor Assignment Rep. Fehr

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

**REPORT OF STANDING COMMITTEE**

**SB 2193, as engrossed: Human Services Committee (Rep. Weisz, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (12 YEAS, 1 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2193 was placed on the Sixth order on the calendar.

Page 1, line 1, remove "the establishment of an autism spectrum disorder database and"

Page 1, remove line 2

Page 1, line 3, replace "study and report to the legislative management" with "expansion of the autism spectrum disorder medicaid waiver"

Page 1, remove lines 5 through 23

Page 2, remove lines 1 through 31

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Page 4, line 6, replace the first comma with a semicolon

Page 4, line 6, replace the second comma with a semicolon

Page 4, line 6, replace ", and parent training," with "; training to support behavior analyst certification; training to improve independent living skills, preemployment opportunities, and executive and social skills; training and educational materials for parents; and parenting education"

Renumber accordingly

**2013 HOUSE APPROPRIATIONS**

**SB 2193**



# 2013 HOUSE STANDING COMMITTEE MINUTES

## House Appropriations Committee Roughrider Room, State Capitol

SB 2193  
4/4/13  
Job #20905

☐ Conference Committee

Committee Clerk Signature

*Vicky Crabtree*

### Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for expansion of the autism spectrum disorder Medicaid waiver; and to provide an appropriation.

### Minutes:

Rep. Robin Weisz, District 14: Introduced the bill.

Min 3:00 talked about 1038/1039 with Chairman Delzer

Weisz: That had nothing to do with services, it was strictly a registry. The money was put into the DPI budget. I know the Senate has made a few small changes in 1038 so it now looks much like 2193.

Continued going over the bill min 4:45.

06:40

Chairman Delzer: What will make them come in for training?

Weisz: Nothing, other than the fact that 1 in 50 children are autistic.

Chairman Delzer: Do you have budgets for this \$500,000? Did you ask for budgets on either of them?

Weisz: No we don't have budgets. We did not ask for budgets on either one of those.

Rep. Skarphol: The \$400,000 in Section 2, what portion is salary and operating?

Lori Laschkewitsch, OMB: I don't have that, but I can try to get it for you.

Rep. Wieland: It's been my opinion and the interim committee that it is premature to have a coordinator at this time. We have the registry set up, and the coordinator would maybe be appropriate two years from now. I don't think we should be looking at a coordinator at this particular time. \$400,000 would be far in excess of the cost of a coordinator. I hope we can remove section 2 before we are done with this bill. I would also like to see how section 3

will be done. The proposal of \$198,000 for teacher training was to hire someone to go out to the schools and work with them there. I feel \$500,000 is far in excess of what we need.

Rep. Pollert: If I'm correct, the Senate bill was what came from the Autism task force, whereas HB 1038 came from the interim committee going in a different direction. I don't know if the Senate has currently switched 1038 to 2193 so they look similar. The DHS is already working on the autism spectrum and there has to be some positions in there working.

Weisz: min 11:28 1037, 1038, 1039 all came from the interim committee. HB 1039 was the interim voucher bill. You are correct 2193 did not come from the interim committee; it was from the task force. The language that you see in sections 2 and 3 was not in 1039.

Rep. Kempenich: When this bill came over, it was \$3M for this biennium and \$9M for next biennium?

Weisz: Correct.

Rep. Wieland: The majority of those recommendations were in that bill. 1039 did have the vouchers in it. We separated that because we wanted the registry, and we wanted the education. We did not want the vouchers to cloud those issues. I know the senate had made changes in 1038; they are using the voucher system, they are not using the waiver.

Chairman Delzer: We'll have to get a current FN for this and take it up again.

Weisz: The current Medicaid waiver is around \$2.4M and is in the governor's budget. The waiver portion we have would expand that and increase it by the \$1.26 M and these sections are completely over and above that.

14:20

Chairman Delzer: Currently they're covered from 0-4. That is based on 30 slots, and you are adding 35 slots.

Weisz: That includes all the FTEs and administrative costs. We were given the indication that if we expand the waiver, a 100% of that could go for the programs costs and not additional administration costs.

Rep. Nelson: In the FN, it does talk about additional FTEs for DOH and DHS. Do your amendments to the bill change any of that? What is the total FTE requirement?

Weisz: That's a good question. Some will go away because they were involved in the voucher. The FTE for the coordinator and trainer doesn't change. The expansion of the waiver does not require additional FTEs.

Rep. Nelson: There is one FTE currently in the health department. That stays the same, there is someone working with autism registry?

Weisz: There isn't an autism registry or data base now. There is not anybody now. If there is FTE involved in the health department autism it isn't for the data base.

Chairman Delzer: The FN we have is based on the Senate's bill.

Weisz: Correct.

Laschkewitsch, OMB: Regarding salaries, there is \$212,000 for salaries, fringes and the remainder is for statewide outreach, regional meetings, and the annual conference. This information is from DHS.

Chairman Delzer: Do you the dollar figures for each one of those?

Laschkewitsch: No I do not.

Chairman Delzer: Can you get that for us?

Laschkewitsch: Yes I can.

Chairman Delzer: We will set this one aside.

# 2013 HOUSE STANDING COMMITTEE MINUTES

## House Appropriations Committee Roughrider Room, State Capitol

SB 2193  
4/9/13  
21036

☐ Conference Committee

Committee Clerk Signature



### Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for expansion of the autism spectrum disorder Medicaid waiver; and to provide an appropriation.

### Minutes:

You may make reference to "attached testimony."

Chairman Delzer called the committee back to order. We'll start with 2193. There is a new Fiscal Note. This bill deals with autism spectrum, which came out of policy with the waiver; expanding the waiver from age 0-4 to age through 5 and I think it is an additional 35 in the bill, the way it is to us, autism coordinator for \$400,000, and the Dept. of Human Services and does \$500,000 or so much for the training effort. We have a new amendment from Rep. Wieland, .04005.

03:00

Rep. Wieland: Correct. We worked through some things with the Chairman of the Human Services because some of the things that are very important were not in 2193. We wanted to make sure that even though 1038, which is the original bill that the Interim Committee worked on, is over in the Senate. We had the opportunity to at least try to get the things that were important and that the House passed. There are five parts in these that we want to make sure we cover. No. 1, we were talking about using the waiver. This would give the increase in labor to cover 20 additional individuals, from birth through age 5, but we would like to change that to 13, it does not change the fiscal note in any way, because of the number of slots that are involved, I'd like to get that change to be included, "up to age 13". That would be part 1. This would be the waiver. No. 2 is the training for DPI and there is \$198,000 but that's in the DPI budget. There is a coordinator in here that would be in the department. The coordinator was shown to be a cost of \$400,000 in working with the department; we reduced that down to \$265,136.00. A disorder database is a part of this. It would be run through the Dept. of Health and it is \$200,648 but we had gotten a quote from the Dept. of Health during the interim committee and that would reduce that down to \$148,132. The fifth item is the training for professionals. It came over with \$500,000 and the amendment would change that to \$250,000. That would be some training for doctors and workers that work with autistic kids. Those are the five points that are included in this amendment and I move the amendment.

Chairman Delzer: I have a motion to amend 2193 with .04005. Is there a second.

Rep. Kreidt: Second the motion.

Ch. Delzer: Rep. Wieland, both the bill as it came out of policy and the amendments are all subject to FMAP. They are all eligible for federal match.

Rep. Wieland: Yes, that's one of the reasons that the waiver may be better for us to use because it does include FMAP.

Ch. Delzer: Vouchers would be strictly general funded.

Rep. Wieland: Vouchers would be all general fund. That is what's in the bill; I believe the vouchers are what coming over in 1038 from the Senate.

Rep. Bellew: What is an autism spectrum disorder Medicaid waiver?

Chairman Delzer: That's the waiver we currently have in place that we are serving 25 children with, I believe.

Rep. Bellew: What does it do?

Ch. Delzer: It gives them services.

Rep. Wieland: It provides services to a few of the children in the state.

Chairman Delzer: They have to be eligible for institutional care.

Rep. Wieland: Correct.

Ch. Delzer: They don't have to be in institutional care, but they have to be eligible for it. It gives them training and services.

Rep. Nelson: You mentioned that you would like to see the age of those 20 additional individuals would go from 5 to 12. What is the reason for that and are you going to move that.

Rep. Wieland: The reason for that is that it covers an area that has not been covered before in the waiver. In talking with the people that are knowledgeable about how the waiver would work, they wanted ages 21 and 22, age 13 will still provide additional services to and include some kids that they cannot serve currently.

Rep. Nelson: I would move to amend to change that age limit from 5 to 13.

Ch. Delzer: We haven't taken care of the first amendment. Let's do that. Then we can further amend. Further discussion on .04005.

Rep. Guggisberg: In the amendment, the waiver is to cover 20 additional individuals. Is that beyond the additional 35 individuals covered in the current bill?

Chairman Delzer: No, it is changing the 35 to 20.

Rep. Guggisberg: So we're covering less, but we may raise the age.

Chairman Delzer: Yes. Further discussion. Voice vote, motion carried.

Chairman Delzer: Were they going to fill the 20 spots with kids up to 5 years old when we go to 13, does that put a lot more competition on there. Or does that just allow for the right ones to get covered?

Rep. Wieland: I can't totally answer that question. In the original waiver, we had difficulty filling it, though it is filled now. The waiver we had previously, it took a long time and the cost in there was \$2 million and at the end of the first year of the biennium, there was something like \$148,000 that was spent. This would open the door and increase the opportunity for more children.

Rep. Nelson moved further amend, on section 2 of the amendment to increase the age limit from age 5 to age 13.

Rep. Wieland: Second the motion.

Chairman Delzer: Rep. Wieland, did you have a chance to visit with the policy committee on this.

Rep. Wieland: I did and presented them with a copy of the amendments and they had no objection to them.

Rep. Delzer: You asked about age 5 to 13.

Rep. Wieland: I just informed them I was going to do that, but I did not get a confirmation from them.

Chairman Delzer: We have the motion before us. Any discussion? Voice vote, motion carried. We have the amended bill before us, what are the committee's wishes.

Rep. Wieland: I move a Do Pass as amended.

Rep. Nelson: Second the motion.

Ch. Delzer: Clerk will call the roll for a DP as amended.

17 YES 3 NO 2 ABSENT

DO PASS AS AMENDED

CARRIER: Rep. Wieland



**FISCAL NOTE**  
**Requested by Legislative Council**  
**04/11/2013**

Amendment to: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$804,915		
Expenditures			\$1,444,379	\$804,915		
Appropriations			\$781,111	\$804,915		

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB 2193 provides for: the addition of 20 individuals to the Autism Spectrum Disorder (ASD) medicaid waiver; the establishment of an ASD database; a study; appropriations for an ASD database, state autism coordinator and statewide ASD training.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Section 1 - requires the Dept. of Health (DoH) to establish and administer an autism spectrum disorder database. The database must include information deemed relevant and appropriate by the DoH in order to complete epidemiological surveys and enable research and analysis of the autism spectrum disorder. Section 2 expands the ASD waiver by 20 individuals from birth through age 13. This would require an appropriation of \$1,005,600 of which \$502,800 would be general fund and \$502,800 would be federal funds. In addition the Department of Human Services (DHS) needs additional operating funding of \$89,094, of which \$44,547 is general fund for the costs of a fiscal agent (\$6,734), waiver assessments (\$64,800), and waiver appeals (\$17,560). Section 3 - requires the Dept. of Public Instruction (DPI) to provide training and support to general education classroom teachers and other school related staff. This would require an appropriation of \$198,000, of which all would be general fund, for DPI to contract with a national expert and conduct the training. Section 4 requires the DHS to conduct an ASD study and report the outcomes and recommendations to legislative management. This would require an appropriation of \$50,000, of which all would be general fund. Section 5 includes a general fund appropriation to the DoH for \$148,132, including an FTE to establish and administer the database. The DoH will need an additional appropriation of \$243,332, of which all is general fund, for a second FTE and operating costs for the autism spectrum disorder database. Sections 6 and 7 include general fund appropriations for the DHS of \$265,136, for the state autism coordinator and \$250,000 for statewide autism spectrum disorder training efforts. These expenditures are eligible for Medicaid funding at 50%, the excess general funds appropriated in these sections would be used to help offset the costs of the waiver expansion. Because the bill has an expiration date of June 30, 2015, there are no costs reflected for the 2015-2017 biennium.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

Additional revenues are related to additional federal funds the state would be able to access.

- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Section 1 - requires the Dept. of Health (DoH) to establish and administer an autism spectrum disorder database. The database must include information deemed relevant and appropriate by the DoH in order to complete epidemiological surveys and enable research and analysis of the autism spectrum disorder. Section 2 expands the ASD waiver by 20 individuals from birth through age 13. This would require an appropriation of \$1,005,600 of which \$502,800 would be general fund and \$502,800 would be federal funds. In addition the Department of Human Services (DHS) needs additional operating funding of \$89,094, of which \$44,547 is general fund for the costs of a fiscal agent (\$6,734), waiver assessments (\$64,800), and waiver appeals (\$17,560). Section 3 - requires the Dept. of Public Instruction (DPI) to provide training and support to general education classroom teachers and other school related staff. This would require an appropriation of \$198,000, of which all would be general fund, for DPI to contract with a national expert and conduct the training. Section 4 requires the DHS to conduct an ASD study and report the outcomes and recommendations to legislative management. This would require an appropriation of \$50,000, of which all would be general fund. Section 5 includes a general fund appropriation to the DoH for \$148,132, including an FTE to establish and administer the database. The DoH will need an additional appropriation of \$243,332, of which all is general fund, for a second FTE and operating costs for the autism spectrum disorder database. Sections 6 and 7 include general fund appropriations for the DHS of \$265,136, for the state autism coordinator and \$250,000 for statewide autism spectrum disorder training efforts. These expenditures are eligible for Medicaid funding at 50%, the excess general funds appropriated in these sections would be used to help offset the costs of the waiver expansion. Because the bill has an expiration date of June 30, 2015, there are no costs reflected for the 2015-2017 biennium.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

For the 2013-2015 biennium the DoH will need an appropriation increase from what is included in the bill of \$243,332, of which all is general fund, and 1 FTE. For the 2013-2015 biennium the DHS will need an appropriation increase from what is included in the bill of \$1,144,694 of which \$339,779 is general fund and \$804,915 is federal funds, to increase the waiver by 20 individuals and meet the requirements of sections 2, 4, 6, and 7 of this bill. For the 2013-2015 biennium the DPI will need an appropriation increase of \$198,000, of which all is general fund. There is no impact for the 2015-2017 biennium since the bill contains an expiration date of June 30, 2015.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 04/12/2013

**FISCAL NOTE**  
**Requested by Legislative Council**  
**04/02/2013**

Amendment to: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$1,407,364		\$1,761,744
Expenditures			\$1,407,364	\$1,407,364	\$1,761,745	\$1,761,744
Appropriations			\$507,364	\$1,407,364	\$1,761,745	\$1,761,744

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the addition of 35 individuals to the Autism Spectrum Disorder (ASD) medicaid waiver and provides appropriations for a state autism coordinator and statewide ASD training efforts.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Section 1 requires the Department of Human Services to expand the autism spectrum disorder medicaid waiver by 35 individuals. An appropriation is needed to expand from 30 individuals per month to 65. This amount is \$1,759,800 of which \$879,900 is general fund and \$879,900 is federal funds. In order to expand the waiver an additional appropriation would also be needed for assessments, fiscal agent and appeals which would be \$154,928 of which \$77,464 would be general fund and \$77,464 would be federal funds. Sections 2 and 3 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts. These appropriations are all general fund, however, the expenditures would be able eligible for Medicaid funding at 50%, therefore the general funds appropriated in these sections would be used to offset the above costs of the waiver. The net effect is that the general fund appropriation needed in 2013-2015 would be less due to the general funds appropriated in the bill.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

Additional revenues are related to additional federal funds the state would be able to access.

- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Section 1 requires the Department of Human Services to expand the autism spectrum disorder medicaid waiver by 35 individuals. An appropriation is needed to expand from 30 individuals per month to 65. This amount is \$1,759,800

of which \$879,900 is general fund and \$879,900 is federal funds. In order to expand the waiver an additional appropriation would also be needed for assessments, fiscal agent and appeals which would be \$154,928 of which \$77,464 would be general fund and \$77,464 would be federal funds. Sections 2 and 3 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts. These appropriations are all general fund, however, the expenditures would be eligible for Medicaid funding at 50%, therefore the general funds appropriated in these sections would be used to offset the above costs of the waiver. The net effect is that the general fund appropriation needed in 2013-2015 would be less due to the general already appropriated in the bill. The fiscal impact for the Department of Human Services for the 2015-2017 biennium is \$3,523,489, of which \$1,761,745 is general fund and \$1,761,744 is federal funds. This would include costs to retain the FTE for state coordination, costs to continue the training efforts, and the additional waiver costs.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

For the 2013-2015 biennium the Department of Human Services will need an appropriation increase from what is included in the bill of \$1,914,728, of which \$507,364 is general fund and \$1,407,364 is federal funds, to increase the waiver by 35 individuals. For the 2015-2017 biennium the Department of Human Services will need an appropriation increase of \$3,523,489 of which \$1,761,745 is general fund and \$1,761,744 is federal funds, for the additional waiver costs and to maintain the 1 FTE for autism coordination and training efforts.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 04/04/2013

**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/14/2013**

Amendment to: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			\$3,511,318	\$0	\$9,741,758	\$0
Appropriations			\$2,219,854	\$0	\$9,741,758	\$0

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, creates an Autism Spectrum Disorder (ASD) voucher program and an ASD study and report and provides appropriations for the autism database, a state autism coordinator and statewide ASD training efforts.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

The Fiscal Effect in 1A above, assumes that once the estimated cost of vouchers have been exhausted no additional voucher payments will be made. Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

Section 1 and 4 requires the Department of Health to establish an autism spectrum disorder database and to complete epidemiologic surveys. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to maintain the database and complete the surveys the Department of Health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTES, all of which are general fund. Section 2 requires the Department of Human Services to establish an autism spectrum disorder voucher program. It is estimated the Department would issue \$2,134,734 of vouchers, and incur \$35,120 in legal costs for appeals, all of which are general fund. Section 3 of the bill requires the Department of Human Services to study autism spectrum disorder services and report the outcomes and recommendations to legislative management during the 2013-2014 interim. The cost of this study is estimated to be \$50,000, all of which are general fund. Sections 5, and 6 include a general fund appropriations for the Department of Human Services of \$400,000, for the state autism coordinator and \$500,000 for statewide autism spectrum disorder training efforts. The fiscal impact for the Department of Health for the 2015-2017 biennium is \$391,464, all of which is general fund. This is the cost of the 2 FTES and the on-going costs to support the autism spectrum disorder duties. The fiscal impact for the Department of Human Services for the 2015-2017 biennium is \$9,741,758, all of which is general fund. This would include costs to retain the FTE for state coordination, costs to continue the training efforts, and the voucher costs.

- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

For the 2013-2015 biennium the Department of Health would need an additional appropriation authority from what is included in the bill of \$190,816 all of which is general fund. For the 2015-2017 biennium the Department of Health will need a general fund appropriation of \$391,464, of which all is general fund, to maintain the 2 FTES for the administration of the autism spectrum disorder database and other duties. For the 2013-2015 biennium the Department of Human Services will need an appropriation increase from what is included in the bill of \$2,219,854, all of which is general fund, to issue vouchers and to complete the study and report for legislative management. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$9,741,758 of which all is general fund, for the voucher program and to maintain the 1 FTE for autism coordination and training efforts.

**Name:** Paul R. Kramer

**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/19/2013



**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/22/2013**

Bill/Resolution No.: SB 2193

- 1 A. **State fiscal effect:** *Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.*

	2011-2013 Biennium		2013-2015 Biennium		2015-2017 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues				\$1,292,118		\$1,770,069
Expenditures			\$2,960,130	\$1,292,118	\$3,415,845	\$1,770,069
Appropriations			\$1,475,171	\$1,292,118	\$3,415,845	\$1,770,069

- 1 B. **County, city, school district and township fiscal effect:** *Identify the fiscal effect on the appropriate political subdivision.*

	2011-2013 Biennium	2013-2015 Biennium	2015-2017 Biennium
Counties			
Cities			
School Districts			
Townships			

- 2 A. **Bill and fiscal impact summary:** *Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).*

SB2193 provides for the establishment of an autism spectrum disorder database, expands the autism Medicaid waiver and provides appropriations for the autism database, a state autism coordinator, statewide training efforts, behavioral analyst certification and diagnostic teams.

- B. **Fiscal impact sections:** *Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.*

Sections 1 and 2 of SB2193, establishes the autism spectrum disorder database that will be administered by the department of health. The bill contains an appropriation of \$200,648 to establish the database and authorizes the hiring of 1 FTE. In order to establish and maintain the database the department of health will need \$391,464, with \$100,000 being operating costs and \$291,464 for 2 FTEs. Therefore the additional appropriation needed for the database and FTEs would be \$190,816, all of which would be general fund. Section 3 of the bill expands the autism spectrum disorder Medicaid waiver. An appropriation is needed to expand from 30 individuals per month to 80 is \$2,042,925 of which \$1,017,581 is general fund and \$1,025,344 is federal funds. Due to the increase in individuals an appropriation is needed for 8 half time FTEs, one for each of the regions, this is to maintain a 1:60 ratio of clients to case managers and not knowing where the additional 50 individuals may be we are estimating .5 FTE for each region, or 4 total FTEs; \$508,152 of which \$254,076 is general fund. An appropriation would also be needed to expand the fiscal agent contract for the additional 50 individuals which would be \$25,396 of which \$12,698 would be general fund. Sections 4, 5, 6, and 7 of SB2193 include appropriations of \$494,135, for the state autism coordinator and staff, \$158,032 for the statewide autism spectrum disorder training effort, \$198,864 to provide funding support for individuals to complete a board-certified behavioral analyst program, and \$433,280 to provide autism spectrum disorder evaluation, diagnostic, and service planning teams, all of which are general fund.

3. **State fiscal effect detail:** *For information shown under state fiscal effect in 1A, please:*

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*

The other fund revenue is additional Medicaid funding the department will be able to access.

**B. Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*

The fiscal impact for the department of health for the 2013-2015 biennium is comprised of: 2 FTEs for the establishment and administration of the autism spectrum disorder database \$291,464, of which all is general fund; cost for establishing and maintaining the database including operating expenses to support the 2 FTEs \$100,000, of which all is general fund. The fiscal impact for the department of human services for the 2013-2015 biennium is comprised of: 6 FTEs for state autism coordination and case managers \$883,043, of which \$628,967 is general fund, operating costs including training and conference dollars to support autism coordination FTEs \$119,244, of which all is general fund, costs to support the statewide autism spectrum disorder training efforts \$158,032, of which all is general fund, costs to provide funding support for individuals to complete a board-certified behavioral analyst program \$198,864, of which all is general fund, costs to provide autism spectrum disorder evaluation, diagnostic, and service planning teams \$433,280, of which all is general fund, costs to expand the fiscal agent contract for additional 50 individuals \$25,396 of which \$12,698 is general fund, costs to expand the autism spectrum disorder Medicaid waiver \$2,042,925, of which \$1,017,581 is general fund and \$1,025,344 is federal funds. The fiscal impact for the department of health for the 2015-2017 biennium is \$361,464, of which all is general fund. This would include on-going supports costs for the autism spectrum disorder database and the costs to retain the 2 FTEs. The fiscal impact for the department of human services for the 2015-2017 biennium is \$4,824,450 of which \$3,054,381 is general fund. This would include costs to retain the 2 FTEs for state coordination, 8 half time FTEs for case management, costs to continue the training efforts, behavioral analyst certification, diagnostic teams, fiscal agent contract, and the costs to continue the autism spectrum disorder Medicaid waiver.

**C. Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.*

The department of health will need an appropriation increase from what is included in the bill, of \$190,816, of which all is general fund. For the 2015-2017 biennium the department of health will need an appropriation increase of \$361,464, of which all is general fund. The department of human services will need an appropriation increase from what is included in the bill of \$2,576,473 with \$1,284,355 being general fund, to expand the autism spectrum disorder Medicaid waiver, add 8 half time FTEs for case management and expand the fiscal agent contract. For the 2015-2017 biennium the department of human services will need an appropriation increase of \$4,824,450, of which \$3,054,381 is general fund.

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**Agency:** Department of Human Services

**Telephone:** 701-328-4608

**Date Prepared:** 02/05/2013

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2193

In lieu of the amendments adopted by the House as printed on pages 1175 and 1176 of the House Journal, Engrossed Senate Bill No. 2193 is amended as follows:

Page 1, line 1, remove "and"

Page 1, line 2, remove "an autism spectrum disorder voucher program"

Page 1, line 3, remove the second "and"

Page 1, line 3, after "appropriation" insert "; and to provide an expiration date"

Page 2, remove lines 13 through 31

Page 3, replace lines 1 through 5 with:

**"SECTION 2. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER MEDICAID WAIVER.** The department of human services, by January 1, 2014, shall seek approval from the federal centers for medicare and medicaid services to expand the department's autism spectrum disorder medicaid waiver to cover twenty additional individuals from birth through age thirteen and to provide appropriate behavior intervention and treatment services that may include evidence-based and promising practices, case management services, technology and technology-based support, in-home support, equipment and supplies, home monitoring, respite care, residential supports and services, and behavioral consultation.

**SECTION 3. DEPARTMENT OF PUBLIC INSTRUCTION - AUTISM SPECTRUM DISORDER EDUCATIONAL TRAINING AND SUPPORT.** The department of public instruction shall provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism spectrum disorder."

Page 3, line 16, replace "\$200,648" with "\$148,132"

Page 3, line 23, replace "\$400,000" with "\$265,136"

Page 4, line 4, replace "\$500,000" with "\$250,000"

Page 4, after line 7, insert:

**"SECTION 8. EXPIRATION DATE.** This Act is effective through June 30, 2015, and after that date is ineffective."

Renumber accordingly

**STATEMENT OF PURPOSE OF AMENDMENT:**

**Senate Bill No. 2193 - Summary of House Action**

	Executive Budget	Senate Version	House Changes	House Version
State Department of Health				
Total all funds	\$0	\$200,648	(\$52,516)	\$148,132
Less estimated income	0	0	0	0
General fund	\$0	\$200,648	(\$52,516)	\$148,132

Department of Human Services				
Total all funds	\$0	\$900,000	(\$384,864)	\$515,136
Less estimated income	0	0	0	0
General fund	\$0	\$900,000	(\$384,864)	\$515,136
Bill total				
Total all funds	\$0	\$1,100,648	(\$437,380)	\$663,268
Less estimated income	0	0	0	0
General fund	\$0	\$1,100,648	(\$437,380)	\$663,268

### Senate Bill No. 2193 - State Department of Health - House Action

	Executive Budget	Senate Version	House Changes	House Version
Autism spectrum database		\$200,648	(\$52,516)	\$148,132
Total all funds	\$0	\$200,648	(\$52,516)	\$148,132
Less estimated income	0	0	0	0
General fund	\$0	\$200,648	(\$52,516)	\$148,132
FTE	0.00	1.00	0.00	1.00

### Department No. 301 - State Department of Health - Detail of House Changes

	Reduces Funding for Autism Spectrum Disorder Database <sup>1</sup>	Total House Changes
Autism spectrum database	(\$52,516)	(\$52,516)
Total all funds	(\$52,516)	(\$52,516)
Less estimated income	0	0
General fund	(\$52,516)	(\$52,516)
FTE	0.00	0.00

<sup>1</sup> Funding is reduced for the autism spectrum disorder database.

### Senate Bill No. 2193 - Department of Human Services - House Action

	Executive Budget	Senate Version	House Changes	House Version
State autism coordinator		\$400,000	(\$134,864)	\$265,136
Autism spectrum training		500,000	(250,000)	250,000
Total all funds	\$0	\$900,000	(\$384,864)	\$515,136
Less estimated income	0	0	0	0
General fund	\$0	\$900,000	(\$384,864)	\$515,136
FTE	0.00	1.00	0.00	1.00

### Department No. 325 - Department of Human Services - Detail of House Changes

	Reduces Funding for State Autism Coordinator <sup>1</sup>	Reduces Funding for Autism Spectrum Disorder Training <sup>2</sup>	Total House Changes
State autism coordinator	(\$134,864)		(\$134,864)
Autism spectrum training		(250,000)	(250,000)
Total all funds	(\$134,864)	(\$250,000)	(\$384,864)
Less estimated income	0	0	0

General fund	(\$134,864)	(\$250,000)	(\$384,864)
FTE	0.00	0.00	0.00

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<sup>1</sup> Funding is reduced for the state autism coordinator.

<sup>2</sup> Funding is reduced for statewide autism spectrum disorder training to be implemented by the Department of Human Services.

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A section is added regarding an autism spectrum disorder Medicaid waiver.

A section is added regarding training provided by the Department of Public Instruction for classroom teachers and other school staff.

A section is added providing that the bill is effective for the 2013-15 biennium only.

Date: 4/9/13  
Roll Call Vote #: 1

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

House Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number .04005

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ Amended ☒ Adopt Amendment  
☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Wieland Seconded By Rep. Kreidt

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer			Rep. Streyle		
Vice Chairman Kempenich			Rep. Thoreson		
Rep. Bellew			Rep. Wieland		
Rep. Brandenburg					
Rep. Dosch					
Rep. Grande			Rep. Boe		
Rep. Hawken			Rep. Glassheim		
Rep. Kreidt			Rep. Guggisberg		
Rep. Martinson			Rep. Holman		
Rep. Monson			Rep. Williams		
Rep. Nelson					
Rep. Pollert					
Rep. Sanford					
Rep. Skarphol					

Total Yes \_\_\_\_\_ No \_\_\_\_\_

Absent \_\_\_\_\_

Floor Assignment \_\_\_\_\_

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

*voice vote carries*



Date: 4/9/13  
Roll Call Vote #: 2

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

House Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number \_\_\_\_\_

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ Amended ☒ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Nelson Seconded By Rep. Wieland

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer			Rep. Streyle		
Vice Chairman Kempenich			Rep. Thoreson		
Rep. Bellew			Rep. Wieland		
Rep. Brandenburg					
Rep. Dosch					
Rep. Grande			Rep. Boe		
Rep. Hawken			Rep. Glassheim		
Rep. Kreidt			Rep. Guggisberg		
Rep. Martinson			Rep. Holman		
Rep. Monson			Rep. Williams		
Rep. Nelson					
Rep. Pollert					
Rep. Sanford					
Rep. Skarphol					

Total Yes \_\_\_\_\_ No \_\_\_\_\_

Absent \_\_\_\_\_

Floor Assignment \_\_\_\_\_

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

in action 2 of amendment .04005  
increase age limit from 5 to 13

Voice vote carries

Date: 4/9/13  
Roll Call Vote #: 3

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2193

House Appropriations Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 13.0192.04006

Action Taken: ☒ Do Pass ☐ Do Not Pass ☒ Amended ☐ Adopt Amendment  
☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Wieland Seconded By Rep. Nelson

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer		X	Rep. Streyle		X
Vice Chairman Kempenich	X		Rep. Thoreson	X	
Rep. Bellew	X		Rep. Wieland	X	
Rep. Brandenburg	X				
Rep. Dosch		X			
Rep. Grande	X		Rep. Boe		
Rep. Hawken	X		Rep. Glassheim	X	
Rep. Kreidt	X		Rep. Guggisberg	X	
Rep. Martinson	X		Rep. Holman	X	
Rep. Monson	X		Rep. Williams	X	
Rep. Nelson	X				
Rep. Pollert					
Rep. Sanford	X				
Rep. Skarphol	X				

Total Yes 17 No 3

Absent 2

Floor Assignment Rep. Wieland

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

**REPORT OF STANDING COMMITTEE**

**SB 2193, as engrossed and amended: Appropriations Committee (Rep. Delzer, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS (17 YEAS, 3 NAYS, 2 ABSENT AND NOT VOTING).** Engrossed SB 2193, as amended, was placed on the Sixth order on the calendar.

In lieu of the amendments adopted by the House as printed on pages 1175 and 1176 of the House Journal, Engrossed Senate Bill No. 2193 is amended as follows:

Page 1, line 1, remove "and"

Page 1, line 2, remove "an autism spectrum disorder voucher program"

Page 1, line 3, remove the second "and"

Page 1, line 3, after "appropriation" insert "; and to provide an expiration date"

Page 2, remove lines 13 through 31

Page 3, replace lines 1 through 5 with:

**"SECTION 2. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER MEDICAID WAIVER.** The department of human services, by January 1, 2014, shall seek approval from the federal centers for medicare and medicaid services to expand the department's autism spectrum disorder medicaid waiver to cover twenty additional individuals from birth through age thirteen and to provide appropriate behavior intervention and treatment services that may include evidence-based and promising practices, case management services, technology and technology-based support, in-home support, equipment and supplies, home monitoring, respite care, residential supports and services, and behavioral consultation.

**SECTION 3. DEPARTMENT OF PUBLIC INSTRUCTION - AUTISM SPECTRUM DISORDER EDUCATIONAL TRAINING AND SUPPORT.** The department of public instruction shall provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism spectrum disorder."

Page 3, line 16, replace "\$200,648" with "\$148,132"

Page 3, line 23, replace "\$400,000" with "\$265,136"

Page 4, line 4, replace "\$500,000" with "\$250,000"

Page 4, after line 7, insert:

**"SECTION 8. EXPIRATION DATE.** This Act is effective through June 30, 2015, and after that date is ineffective."

Renumber accordingly

**STATEMENT OF PURPOSE OF AMENDMENT:**

**Senate Bill No. 2193 - Summary of House Action**

	Executive Budget	Senate Version	House Changes	House Version
State Department of Health				
Total all funds	\$0	\$200,648	(\$52,516)	\$148,132
Less estimated income	0	0	0	0
General fund	\$0	\$200,648	(\$52,516)	\$148,132

Department of Human Services				
Total all funds	\$0	\$900,000	(\$384,864)	\$515,136
Less estimated income	0	0	0	0
General fund	\$0	\$900,000	(\$384,864)	\$515,136
Bill total				
Total all funds	\$0	\$1,100,648	(\$437,380)	\$663,268
Less estimated income	0	0	0	0
General fund	\$0	\$1,100,648	(\$437,380)	\$663,268

**Senate Bill No. 2193 - State Department of Health - House Action**

	Executive Budget	Senate Version	House Changes	House Version
Autism spectrum database		\$200,648	(\$52,516)	\$148,132
Total all funds	\$0	\$200,648	(\$52,516)	\$148,132
Less estimated income	0	0	0	0
General fund	\$0	\$200,648	(\$52,516)	\$148,132
FTE	0.00	1.00	0.00	1.00

**Department No. 301 - State Department of Health - Detail of House Changes**

	Reduces Funding for Autism Spectrum Disorder Database <sup>1</sup>	Total House Changes
Autism spectrum database	(\$52,516)	(\$52,516)
Total all funds	(\$52,516)	(\$52,516)
Less estimated income	0	0
General fund	(\$52,516)	(\$52,516)
FTE	0.00	0.00

<sup>1</sup> Funding is reduced for the autism spectrum disorder database.

**Senate Bill No. 2193 - Department of Human Services - House Action**

	Executive Budget	Senate Version	House Changes	House Version
State autism coordinator		\$400,000	(\$134,864)	\$265,136
Autism spectrum training		500,000	(250,000)	250,000
Total all funds	\$0	\$900,000	(\$384,864)	\$515,136
Less estimated income	0	0	0	0
General fund	\$0	\$900,000	(\$384,864)	\$515,136
FTE	0.00	1.00	0.00	1.00

**Department No. 325 - Department of Human Services - Detail of House Changes**

	Reduces Funding for State Autism Coordinator <sup>1</sup>	Reduces Funding for Autism Spectrum Disorder Training <sup>2</sup>	Total House Changes
State autism coordinator	(\$134,864)		(\$134,864)
Autism spectrum training		(250,000)	(250,000)
Total all funds	(\$134,864)	(\$250,000)	(\$384,864)
Less estimated income	0	0	0
General fund	(\$134,864)	(\$250,000)	(\$384,864)
FTE	0.00	0.00	0.00

<sup>1</sup> Funding is reduced for the state autism coordinator.

<sup>2</sup> Funding is reduced for statewide autism spectrum disorder training to be implemented by the Department of Human Services.

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A section is added regarding an autism spectrum disorder Medicaid waiver.

A section is added regarding training provided by the Department of Public Instruction for classroom teachers and other school staff.

A section is added providing that the bill is effective for the 2013-15 biennium only.

**2013 TESTIMONY**

**SB 2193**

SB 2193

Madam Chairman and members of the Senate Human Services Committee. I am Senator Joan Heckaman from New Rockford and I represent the constituents in District 23.

I am here today to introduce you the SB 2193. This bill is the culmination of 3 ½ years of work by the Governor's Autism Task Force established by SB 2174 during the 2009 Legislative Assembly.

Since its organization, the Task Force has met quarterly to determine the current services available in North Dakota, survey the needs in the state, and develop a comprehensive plan.

The Task Force is comprised of members representing the following stakeholders: The medical community, a psychologist, a representative of the Department of Public Instruction, a parent, a behavioral analyst, a representative of the Department of Health, a representative from the largest health insurer in the state, a legislator, the Anne Carlsen Center, faculty representing the autism training program at UND, a special education director, protection and advocacy, the developmental community, Pathfinders, and the chairman of the Task Force from the Department of Human Services. I represent the North Dakota State Legislature.

The work of the Task Force resulted in North Dakota's first State Plan. This plan was presented to Governor Hoeven in the summer of 2010. Following the development of that initial state plan, the Task Force continued to meet and develop recommendations that were presented during the 2011-12 Interim.



This bill before you today is not in chronological order of the Task Force's recommendations as you will hear about later. Legislative Council said there is a need to have the Data Base listed first.

In Section 1 is the Data Base, section 2 is the appropriation to the Department of Health to fund the establishment of that database. Section 3 is the expansion of the Autism Spectrum Disorder Medicaid Waiver. Section 4 is the Task Force's 1<sup>st</sup> priority, the hiring of a state coordinator for the program. Other sections contain the establishment and funding of a training program, support for increasing the number of behavioral analysts in the state, and funding for evaluation, diagnostic, and service planning teams.

Intervention at any stage is important for this disorder. But early evaluation and intervention prove significantly more successful.

The Task Force supports these recommendations. I will defer to them as they are the experts in this disorder.

Thank you for your attention to the work of the Task Force and its important recommendations before you today.

Senator Joan Heckaman

Chairman Lee and Members of the Senate Human Services Committee:

I am Dr. Barbara Stanton. I am employed at Prairie at St. John's as an outpatient therapist specializing in autism spectrum disorders. I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I also conduct trainings and workshops about autism for educators, law enforcement, early childhood educators, daycare providers, medical and mental health professionals, religious organizations, and the community at large.

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families. I average 14 intakes per week from individuals looking for a diagnostic assessment, therapy services or clarification of prior diagnoses.

I would like to speak in support of services for individuals with autism as noted in **Senate Bill 2193**.

Autism is a complicated neurological disorder that impacts communication skills, social interactions, and behavior. It is a lifelong disorder.

Every week new research studies are published. It is important to continually monitor this research and advances in evidence based assessments and interventions.

The Center for Disease Control reported in May of 2012 that 1 in 88 children meet the criteria for an autism spectrum disorder; 1 in 54 boys. Of those, 30 – 40% are considered to have high functioning autism. Autism is more prevalent than childhood cancers, multiple sclerosis and cystic fibrosis combined.

There is a genetic basis to autism.

Autism is a spectrum disorder in which there is great variation in individual differences.

While there have been advances in research there are gaps in our understanding of autism such as

causation, public concerns of health and safety including issues of obesity and mental health, efficacy of interventions, transitions to independence, employment and building public private partnerships; just to name a few.

Every day I hear the stories from families who are desperate to find services for their children with autism. Many of them drive for hours from both urban and rural areas of North Dakota to see me. And as difficult as it is to get services for children, for adults the situation is even more dire. These are not services to make life easier or more convenient. These are services that can determine success or failure; life or death.

Thank you for listening to my testimony today regarding this important issue. I urge this legislature to pass legislation to expand services to individuals and families who deal with the impact of an autism spectrum disorder. I would also ask you to consider HB 1039 which establishes a voucher program for services that would open opportunities for people, wherever they live, wherever they are on the spectrum and whatever their needs are, to receive services.

In 2011 The Autism Society of America stated in a memo to congress:

"Moving to a voucher-based system will significantly improve the quality of services and care, eliminate fraud and abuse, and improve access to the ever-shrinking pool of healthcare providers willing to accept Medicaid reimbursement rates. A voucher-based system would allow people to receive care on the private market, decreasing the financial burden on federal and state governments."

I would be happy to answer any questions that you may have.

**Testimony**

**In favor of Senate Bill 2193**

**Chairman Senator Judy Lee**

**Senate Human Services Committee**

Chairman Lee and Members of the Senate Human Service Committee:

I am Vicki Peterson, a single mother of two boys, Aaron whom has autism. I am here today to speak in favor of Senate Bill 2193, and the issues of autism spectrum disorders. Autism Spectrum Disorders (may refer to them as ASD.) are a set of neurobiological disorders that are lifelong and have deficits in core areas of social skills, communication, stereotyped or repetitive behaviors and interests and in some cases cognitive delays. Autism Spectrum Disorders, as its name states, is a spectrum and in the new DSM-V (*Diagnostic and Statistical Manual of Mental Disorders*) due out in May 2013, will range from mild to severe and are across the lifespan.

Senate Bill 2193 addresses ASD in our state as a comprehensive plan that follows closely to the recommendations of the State Autism Task Force.

- **The need and priority to have a State Autism Coordinator is essential.**

As a parent of a child with autism and a person whom works with families across the state whom have children and youth with special healthcare needs, we need someone to coordinate the efforts in our state around training and education and act as a point person currently serving this population in our state. I would encourage this person have "hands-on" experience with ASD and the ability to listen to stakeholders. Families, providers and advocates would always want services to be top priority, in this particular instance, I believe to achieve success with services; the infrastructure has to increase adequate resources to support the needs of persons with Autism Spectrum Disorders.

- **The development of an autism database would be the tool that will be able to collect accurate data on persons in the state with ASD.** A database could obtain counts of this population, to improve knowledge and understanding of ASD and to plan for services for both children and adults in our state with Autism Spectrum Disorders. The incidence of ASD is increasing, with the database this will improve the policies that as a state we implement.
- **Expanding and Refocusing the existing Autism Waiver.** The eligibility range of the existing autism waiver is birth to the child's 5<sup>th</sup> birthday. Across the state of ND, there is an infant development program that is designed to help children and their families whom have children identified with delays age birth to 3<sup>rd</sup> birthday and not according to diagnosis, key to success is early intervention. The American Academy of Pediatrics recognizes this at age 18 mos. (*AAP Developmental Screening Tools D-PIP 11/2007*). The need to change the age requirement for the autism waiver to age 18 mos., or the asked for age of 3yrs., through the lifespan will provide for the comprehensive services for persons with ASD and fill the gap. I would ask you to consider having a process of re-determination dates (an example of age 9, 14, 22) as services may change as a child continues to grow, transition, and become an adult. Needs change but the Autism Spectrum Disorder remains. Holding stakeholder meetings with the collaboration efforts of professionals, parents of children and adults on the Autism Spectrum, to define services that would benefit those being served. Behavioral issues are a major concern for parents and professionals, as of now that type of intervention is not available in the autism waiver. Social Skills therapy is not included as well, even though social and communication are core deficits of autism. Adults with ASD, needs services to help with independent living skills, job coaching and peer to peer relationships. Re-focusing on autism will be an improvement for the autism waiver and a program that could work for the benefit of all people with Autism Spectrum Disorders.
- **Addition of Behavioral Analysts in the state of ND.** Behavioral issues are a growing concern for both parents and professionals. The experts in this field at present are located in eastern ND and one area of central ND. This is not fulfilling

the need and most certainly not in western and most of central ND where the population is increasing the most. There needs to be better access to behavioral analysts and increase the numbers of that profession in our state. I believe this bill would provide a start for that to happen. The opportunity to have 2 or more behavior analysts in each of the 8 regions of ND will fill the gaps currently existing.

- **Diagnostic Teams.** Best practice for diagnosing ASD is a multidisciplinary team of professionals (*AAP Developmental Surveillance and Screening of Infants and young Children; Pediatrics 2001*). Currently we have limited number of diagnostic teams in the state. The need to expand these types of teams into all the regions of ND is critical to accessing service availability and will decrease the burden on families and persons whom are seeking diagnostics. Navigating systems that families and persons with special healthcare needs including ASD, is a daunting effort and needs to be a point of high concern. Whether a diagnosis of an ASD or not, persons are searching for help. Parent organizations in the state need help to continue to accomplish this task. Parents, professionals and self-advocates turn to these organizations for guidance, information and support.

I urge this committee to take action on this bill for persons with autism. All of us deserve to have access to quality of life, to become independent community members and productive citizens.

My son, Aaron, has taught me much in his journey of life so far, I know he will teach me and many others more. Many learn and live in distinct ways, with help and support; Aaron's life can be spectacular, along with all persons with special needs and disabilities.

Thank you for your time and consideration of SB2193.

Vicki L Peterson  
[vickiasdc@bis.midco.net](mailto:vickiasdc@bis.midco.net)  
701-258-21237

**SB 2193 Appropriation Detail**

JoAnne Haisel

Attachment #4

<u>Section</u>	<u>Cost</u>	<u>Detail</u>
<b><u>Section 2.</u></b>	\$200,648	
Database		Costs based on information received from Minot State University who manages the database for those with hearing loss. Personnel and operating costs.
<b>Section 3.</b>		
Medicaid Waiver	\$27,239 X #	Using DD traditional waiver which is budgeted on each person cost \$27,239 per year for waiver services. Depending on the number intended to serve total costs would include this Number times number served.
<b>Section 4.</b>	\$494,135	
Coordinator & Assistant		Coordinator salary & fringe= \$212,478; assistant salary & fringe= \$103,125; operating to include stipends for attendance at regional meetings, annual conference expenses, website management, costs to facilitate meetings to develop standards = \$178,532
<b>Section 5.</b>	\$158,032	
Statewide Training		2 day Regional trainings including time of 2 trainers for a total of 48 days of training= \$98,832 Parent Training = \$6,400 Physician Training= on-line training includes continuing education units= 4,800.00 Statewide training fund for completing college coursework= \$48,000
<b>Section 6.</b>	\$198,864	
Behavioral Analyst Capacity		Provide funding support (2 in each region). To complete the St. Paul on-line BCBA program including supervision up through the test. \$11,704 X 16 = \$187,264. Costs will be dependent on whether studies are taken full or part time.
<b>Section 7.</b>	\$433,280	
ASD Diagnostic Teams		8 Regions/ 8 children each clinic- Diagnostic clinics range from \$1,725 to \$5,045 per child. This includes paying for the time of experienced parent, physician, occupational therapist, physical therapist, family support specialist. 5 - 15 children evaluated per region per year.





### Testimony

### Senate Bill 2193

### Senate Human Service Committee

Chairman Senator Judy Lee and Members of the Senate Human Service Committee:

My name is Toby Cherney and I am the parent of a wonderful little boy named Alexander. Alexander has autism. Alexander will be five years old January 26<sup>th</sup>, 2013. He will no longer be eligible for the Autism waiver that exists in the state of ND right now as of January 25<sup>th</sup>, 2013.

Alexander was the first child on the Autism Waiver and even with its glitches it was still better than what we are going to have after Friday of this month. Alexander's therapies, in-home supports, opportunities for equipment and supplies he may need to be independent, and certain environmental changes will no longer be available.

Ever since my son was diagnosed when he was 2 ½ it has been a constant battle to get help. We have fought and kicked and screamed and sent emails to get help for our son. The only way we found out about what services were available was from Family Voices and other parents. Once we found some help, it was quickly gone in a very short period of time as our son turns 5. This is too short of time to gain progress, to access therapies for speech and occupational therapy, to allow in-home supports to help Alexander and help our family thrive as community members. Alexander receives speech and physical therapy and in-home supports through the Anne Carlson Center. It is so important for him to continue these services while he is still young to help him as he gets older. Early intervention is the key.

I have a \$2000 deductible on my health insurance so continuing therapies after he is discharged from the waiver will not work.

We had his 4 year 9 month DD eligibility meeting last month and I was told at the meeting that "its not our responsibility to take care of your son after he turns 5 its yours and the schools!" I know it is not your responsibility but we as parents are looking to you for guidance.. we are looking to you for understanding and compassion. Parents are looking for ways to help our children. We are not asking for handouts we are looking for assistance, so our children can become independent and productive community members. To do that our family needs to be whole and we need the help of others to achieve this. We need the waiver expanded, the age group that it covers is wrong for ND, we have an early

intervention program that can help our youngest of children from birth to 3, now help our children from 3 to life. Remember autism is a life-long disability.... We need Behavioral Consultations and therapies and we as a state need to increase the access to the professional staff in the area of behavioral issues and concerns... We need ways to help us be better parents and training for us as parents so that we do not have to rely on a system to help us. We have had a constant struggle to get help for our son.. and it shouldn't have to be that way. We need our insurance companies to start paying for more services so that it doesn't fall all on the state to help. We as parents shouldn't have to fight to get help. This bill is a good bill.. it needs to be swiftly as autism is growing in our state... .. Because there are families out there that a year without services will make a huge difference in the progress made by our children. We just can't end services and expect that there won't be any regression and as parents we will have to start the process all over again from step one. I would like to see an Autism Coordinator in the state that has knowledge of autism and not someone just put in that role, someone with hands on experience for persons with autism.. To hold stakeholder meetings with parents and professionals at the table, the professionals need to hear us as parents as we live autism 24-7 everyday... To totally understand what we as parents are going thru.. no one will ever understand or have compassion or be able to make the program work without the personal experience. They need to walk in our shoes.

I am asking this committee as a parent, as a mother, as a community member please address autism in our state, and please pass a comprehensive autism bill that will work for families, a new and improved autism waiver for families.

Please help my son as I am trying to help him..

Thank you for your time:

Toby Cherney,

Mother to Alexander Cherney

Email address: [chernfamily5@centurylink.net](mailto:chernfamily5@centurylink.net)

Phone number 701-320-3104



## Legislative Testimony

SB 2193

Human Services Committee

Tuesday, January 22<sup>nd</sup>, 2012

Chairman Lee and Members of the Committee,

My name is Cathy Haarstad. I am the director of the Pathfinder Parent Center. I am also the parent of a child with special needs who has ASD. Pathfinder is federally funded to provide statewide information and education to families of children with special needs aged birth to 26 including ASD. We serve approximately 1500 families per year on an individual basis which is about 1/10<sup>th</sup> of the families receiving special education services in ND. We reach about 60,000 parents and professionals with information on:

- Understanding **IDEA**, procedural safeguards, Section 504, ADA or other pertinent laws
- Helping to prepare for their child's **IEP meeting** and achieve their educational, developmental, and transitional goals
- How to **resolve disputes** using alternative methods
- Understanding their child's **diagnosis or condition** and identifying related strategies for effective parenting or **parent involvement**

I am testifying in support of SB 2193 to address the need for a comprehensive approach to meeting the needs of children and adults with ASD and their families.

ASD is a multi-system condition. The families that we support are engaged not only with the local school system, health clinics, and area mental health professionals but with the Departments of Health, Human Services, and Education as well as with research being conducted by higher education and with the insurance industry. Effective services require coordination of multiple services at many levels.

In the interest of time, I am sharing specific information about the section of the bill that calls for provision of regional clinics charged with offering diagnosis and intervention services.

**The single greatest challenge for ND families in parenting a child with ASD and participating in their education is to understand how to intervene with that child at home in ways that are aligned with the strategies being recommended by professionals.**

**Parenting involves nurturing.** How do you nurture a child that won't look at you and demands that you leave them alone or repeats what you say but cannot make their own sentences? **Parenting involves teaching.** How do you teach a child to take a bath or shower when they scream at the sight of the tub or shower, not just at age 2 but at age 12 or 14?

How do you set limits for a child, teen or adult who responds to a request to try a new food or play with a toy or go into the next room by biting themselves or engaging in repetitive behaviors in response to the verbal input or social interaction?

Families must know not only how to access and navigate the various systems but to explain the disability to siblings and members of the extended family, establish routines for a child with tactile or auditory sensitivities, help that child learn to follow directions, take care of themselves, understand relationships, take part in holiday rituals, behave appropriately in the community, cooperate with teachers and child care providers and cope with the numerous transitions and changes that are part of family life.

A divorce rate of 80 to 90% for families of children with ASD happens when attempting to meet the needs of a child with ASD takes place by trial and error and therefore consumes the life of one of the partners to the exclusion of all else. ASD does not only impact education and health, it impacts the well-being of parents. Support for families on how to effectively parent a child with ASD is essential and not readily available. Our center and other family support centers in ND have attempted to offer family support to some extent but we simply do not have the resources to provide a concentrated level of service beyond the general information and parent advising that we provide.

When asked what it would take to bring this type support to families of children with ASD we realized that a family support component should be offered as part of all regional clinics so that at least one person on the team would have not only the special information that parents need but the resources to support the family in their unique role as parents of a person with ASD. While a few specialty or research programs have offered this type of service, all too often, services end at the door of the school or diagnostic clinic because the professionals are not willing to work after hours or programs lack the resources to provide in-home support services.

The proposed budget for this section was intended to be divided among the 3 family support organizations in ND. Each of these programs realizes some federal funding under different programs which provides a mechanism for making sure these services meet state and federal requirements. Current federal funding is simply not sufficient to even provide full time staff needed for a statewide initiative. Each organization has a slightly different focus (Pathfinder = education and parenting) (Family Voices = Health and Health Care) Federation of Families for Children's Mental Health (Mental Health). A break-down of the estimate we used to arrive at the proposed budget is included. Since our services must be FREE to families to meet federal requirements we have no way to accept voucher funding.

I would be pleased to answer any questions that you may have.



## Funding For Family Support – ASD Task Force Recommendations

Action	Purpose	Outcome	COST
<b>STATEWIDE TASK FORCE OR ADVISORY COMMITTEE PARTICIPATION</b>			
Participation in task force or advisory panel	Many parents including those employed by various family support organizations are not able to participate without support due to the cost of travel and the difficulty of planning for support for a child with ASD while attending a meeting.	<ul style="list-style-type: none"> <li>Assure that progress is aligned with the needs of families statewide</li> <li>Assure families are directly engaged in participatory decision-making</li> <li>Assure that family perspective is honored during planning</li> <li>Assist in obtaining feedback from families over time</li> </ul>	Cost for 2/4 meetings per year with another 2/4 held via IVN Mileage 350 miles (average) @ \$.51 per mile Hotel \$77 x 2 nights Per Diem \$25 x 2 meetings Stipend \$75 per day x 4 mtg Child Care \$25 per day x 4  Total \$782.50
<b>CONDUCT PARENT TRAINING STATEWIDE</b>			
Participation in regional trainings for parents using a curricula developed by the Anne Carlsen Center and the Pathfinder Parent Center	Provider agencies are willing to include parents in training and typically do not develop training to meet the unique needs of families. Parenting classes offered through the NDSU Parent Center Network do not duplicate the type of training.	<ul style="list-style-type: none"> <li>Offer regional trainings on parenting a child with ASD at the novice and advanced levels</li> <li>Assure training addresses the needs of families in an in-home situation and is not merely a clinical representation of research without regard to the practical challenges of parenting.</li> <li>Reduce stress associated with a lack of realistic parenting solutions that can be implemented at home</li> </ul>	Cost for a six week training parent experience that can be attended face-to-face or via webinar twice per year in each region.  \$16.64 per hour x 4 hours per week x 6 weeks x 2 sessions annually x 8 regions.  Total \$6389.76
<b>PROVIDE FAMILY SUPPORT STATEWIDE</b>			
Provision of regional family support using a dedicated experienced parent model serving on regional diagnostic and support teams	Provider agencies have large caseloads (75 to 90) and are unable to provide the informational and emotional support needed. Only about 60% of families whose children have ASD have an intellectual disability. Schools have repeatedly stated they are unable to provide the level of support needed. Family support providers are currently receiving numerous calls from families (as many as 50 in one day) with each call taking 45 minutes to an hour. There are many families besides those needing support for ASD who also benefit from parent-centered family support.	<ul style="list-style-type: none"> <li>Reduce stress associated with limitations in available support</li> <li>Families learn how to structure support for children with ASD in the home and balance demands for 1-1 behavioral support with family life.</li> <li>Assist parents in navigating the service system and obtaining regional support as it is developed</li> </ul>	Cost = salary and fringe for 1 FTE Experienced Parent assigned to the regional ASD Diagnostic and Support Team. Salary \$34,620.00 Fringe @ 24% = \$8308.80 Total 42,928.80

#4

*Testimony  
In Favor of SB2193  
Chairman Senator Judy Lee  
Senate Human Service Committee  
January 22, 2013*

Chairman Senator Lee and Members of the Senate Human Service Committee:

My name is Mindy Iverson. I am a married, stay-at-home mother of two and have a degree in Elementary Education as well as Child Development. My son Jack is 5 ½ years old and was diagnosed with Autism in May of 2011. Here is our story.

On August 20, 2007, a 6 pound 5 ounce healthy baby boy was born. Jack was an easy baby. He slept through the night at 5 ½ weeks only waking up once a night the first five weeks, would eat and go right back to sleep. He was happy, alert and hit all the developmental milestones on time. At 18 months, we noticed a change in our little boy. He started throwing tantrums. We joked that he was so advanced he entered terrible two's early. His tantrums started with head banging. If you told him no or he thought you were going to tell him "no" he would throw his head into whatever was closest. The doctors assured me he wouldn't hurt himself and told me to ignore the behavior. This was hard to ignore when your child tries to hit his head onto a concrete driveway. We would later find out that with sensory integration issues Jack's body does not register feeling as it is happening. He doesn't get dizzy by spinning in a circle until he is ready to throw up, nor does his head immediately hurt if he hits it. Yet, doctors are still convinced he would not do it if it was hurting him. His tantrums also consisted of hitting me in the face. This occurred mostly during transitions. I noted it when we tried to take a parent/child gymnastics class and a parent/child music class. It is very hard as a parent to have everyone in the room look at you like you are bad parent because your child runs around screaming and when you try to calm him down he starts hitting you. I went through a period of time where I felt like a bad parent, because it seemed that was how everyone was looking at me. Shopping was a nightmare, my husband and I would go to a store and hope to get through it without a meltdown. We referred to it as being like a ticking time bomb; you never knew when it would go off.

In June 2010 I took Jack to a free speech screening. I had been concerned about his speech for a while and despite everyone telling me I had too high of expectations for my son I wanted to get a screening for peace of mind. During the screening, Jack threw one of his "typical" meltdowns. The person screening him asked if he does this often. I replied, "yes, terrible two's" with a smile. She then wanted to know if I had time to take him to an Occupational Therapist Screening. After the screening, we needed to have our doctor refer us to have him screened by their Occupational Therapy Department. Jack was diagnosed with Sensory Dysfunction and began Occupational Therapy. My husband and I went to the Internet and found out everything we could about Sensory Dysfunction and how we could better help our son.

Still unhappy about his speech, I kept pushing for Jack to begin Speech Therapy. At first he loved it. But as time went on we saw less and less progress. If he said 5 words in a 30 minute session, we were lucky. At OT I did not go in the room. I had frustration here too, when we asked about potty training it was not their position they said to help. Sensitivity to food was also an issue, we received no help. My understanding was that OT was to help them with life skills. Then the phone call came, Jack's OT and Speech Therapists were both on the line. They had finally ran into each other and visited about Jack's progress at therapy or lack thereof. I find it important to mention they share a receptionist and their rooms are on the same floor, in the same wing, very near each other. I did not want to hear what they had to say. My worst fear was that my son has Autism and they called to tell me they thought Jack needed to be seen by a Psychologist. They felt it was more than Sensory Dysfunction and the Psychologist could make that diagnosis.

We saw a psychologist three times. She confirmed my fear. My son has Autism. My new job was to be his advocate. I knew I needed to find a new place for Jack to receive therapy. My wish is that there would be a place he could play with other kids and get therapy. Jack loves playing with children. At that time he would ask daily to play with kids. I tried to put him in part-time daycare so he could play with other children but our area has limited daycare opportunities. In my searching, I found Red Door Pediatric Therapy and BECEP. With BECEP, we met with a team consisting of a Speech Therapist, Occupational Therapist, Special Education Teacher, and Psychologist.

I then found out about the Autism Waiver. So I began the application process, which I was warned could take a while. It was May 2011. Awhile, was ok with me. I figured in two months I would have him qualified and I could get intervention in the home to help me help my son. Months passed and we still had not heard anything. Jack turned 4 on August 20<sup>th</sup>. One can only be on the waiver until age 5. I made it through the summer without the support I was hoping for. I started to question if I should continue with the waiver. In October the team assigned to us finally came out to observe our son. They observed Jack, asked him questions, and thought we were doing great things for him. Three weeks passed and we still were not approved for the waiver. As Thanksgiving approached, I called our case manager's supervisor, our team's supervisor and still got no where. Everyone reassured me they felt bad for me and were still waiting on the OT's report from the Team that came to observe. I then called Family Voices, I had there brochure and just needed to know what I could do to light a fire under these people. When I explained everything to them, they gave me a name of one more person at Minot State University I could call, and luckily that person is someone I personally know. One more phone call and then the report finally was in the Monday morning after Thanksgiving. We officially were on the waiver Dec. 2011. Keep in mind this is 7 months after I turned in my paperwork. This is unacceptable. In ND we do not have many resources and the ones we have take entirely too long.

The Autism Waiver provided Jack with some new equipment in our home to go with the equipment I had previously purchased. All of them help him in different ways. We had intervention in the home to give us new ideas on certain issues. They helped me find programs for Jack to keep a routine schedule for the summer. We also had OT in the home once a week for the summer which taught me how to keep a Sensory Diet in place through the summer. I



also had Respite Care for Jack on the Autism Waiver. This was helpful if I had appointments or wanted to attend Educational Programs on topics to help Jack.

Early intervention is the key to helping children with Autism. I have now lost 1 year of intervention on the therapy we got at St. A's, and another 7 months waiting for intervention from the Autism Waiver. We need more resources, as well as doctors that can guide parents. Ideally, you should be able to go to a doctor and then be provided resources for medical treatment, homeopathic treatment, therapy services, and resources to use in the home and day-to-day life. It should not take two years for a person to find services for their child. I am thankful that I do live in Bismarck because I can't imagine those who live in small, rural communities in ND. The financial commitment is not something our family planned for. Having a child with Autism adds many expenses out of pocket for special diet, therapies and other added medical expenses. All the resources in the world do not do us a lot of good if we do not know about them or how to access them. This is how the State Coordinator will help families.

As an individual with an education background I feel it is important to add, teachers need more training when it comes to Autism. With the statistics that are out there, teachers are going to have children with autism in their classroom. They need to be provided with tools on the best ways help these children succeed. I have always advocated that every child learns differently.

Programs in our community also need to be trained on how to work with children with Autism. I enrolled Jack in a community dance program and by the second day he was released from the program because the teacher was not comfortable with my son in her class, even though I had given them tools to help Jack in a group community setting. I offered to go with Jack in the dance room. They had a closed-door policy so that was not allowed. Jack was sad. I was devastated. Cross-training between professionals and parents and community partners is needed across the state. I believe with the passing of this bill, it will be a start.

If I could add one more thing I would want you to consider the siblings. We have to consider how Autism affects the sibling. I mentioned I am a mother of two. My daughter is 2, however most people wouldn't guess that. She is two and already missed out on parts of childhood. If Jack has a meltdown she is expected to walk beside me to the vehicle so I can safely carry Jack. She does not get to be in gymnastics, dance, or other programs because if I do not have someone to watch Jack I cannot take her. I know he will not just sit on the side and watch like other siblings. Her whole life has been taking a backseat to her brother because he has Autism. Families need adequate resources and respite to keep families whole.

Jack is a cute little boy, he has a smile that charms you and eyes that sparkle. He loves to joke with people and get a laugh. My ultimate goal for Jack is to be happy, accepted in the community and to become an independent community member. Jack is no longer receiving services on the Autism Waiver. From the time the waviered services started for Jack until they ended was not a sufficient amount of time to have. Our allotted OT sessions covered by insurance continue to be cut. The cost to continue Jack's Occupational Therapy is above our means and could very soon be terminated. If a wavier were in place for Jack right now that service could be achieved which is critical for Jack to become an independent and vital part of our community as he grows. My husband and I will continue to find the resources we can to

provide the best opportunities for our son. It is hard to navigate without a go to person that knows the services that are available.

In conclusion, we need the support of bill 2193 to continue to help Jack, He deserves the opportunity for quality of life.

Thank you for listening to our story. We look forward to seeing and using the improvements implemented. I would be happy to answer any questions.

*Mindy M. Iverson*

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**Testimony  
Senate Bill 2193  
Senate Human Services Committee  
Senator Judy Lee, Chairman  
January 22, 2013**

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 children and youth with an Autism Spectrum Disorder and their families. I am also the parent to a young man with Pervasive Developmental Disorder (NOS) which is an Autism Spectrum Disorder. Therefore I have personal knowledge of the lifelong needs of individuals ASD and their families.

Senate Bill 2193 is well thought out. The autism spectrum disorder database will enable the state to better understand and provide services to individuals with an ASD. Expanding the department's autism spectrum disorder waiver to cover individuals from three to end of life will allow individuals with ASD access to services that are desperately needed. Coordination is a key component to having a system that meets the needs for individuals with an ASD.

Authorizing the Department of Human Services to hire a state coordinator and an assistant to provide this coordination and outreach will make it much easier for families to understand and navigate the system. Having a comprehensive training effort in our state will be very helpful.

Individuals have many missed opportunities due to the lack of training and understanding.

Families need to understand autism and how it impacts their family member. As well as

providers that individuals come in contact with. Behavior analysts are needed in North Dakota. Lastly, establishing ASD diagnostic teams will allow individuals with timely evaluations and diagnostics as well as treatment planning.

To truly help individuals with ASD all people involved in their lives must understand the uniqueness of ASD in order to meet their needs. The way we always do it simply will not work for individuals with an ASD.

Thank you for your time.

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Testimony on SB2193  
2013 Legislative Session  
January 22, 2013

Senator Judy Lee, HS Committee Chairperson

Madame Chairwoman and Members of the Senate Committee on Human Services

My name is Donene Feist and I am the Director for Family Voices of North Dakota. I rise today in support of SB 2193.

Family Voices of North Dakota provides emotional and informational support to many families across North Dakota who has a child with an autism spectrum disorder. Many times, staff of Family Voices has provided assistance to these families through assisting them access services, providing emotional support and educational information to assist them with their various needs.

Family Voices of North Dakota is a partner with the ND State Autism Task Force, and fully supports the recommendations of the Task Force work that is provided within this bill.

#### **SECTION 1. Autism spectrum disorder database**

Family Voices of North Dakota feels a database is a necessary step. While data indicates that there are as many as 1 in 88 children in North Dakota with autism, it is necessary, not just for the 2013-2015 legislative years, but also beyond this time frame to house a database which will assist in capturing the number of children and youth, but additionally services needed for this population. Family Voices of North Dakota has been in contact with many states that are in the process or have developed a database. This will be important to further understand the complexities of ASD and develop ongoing policy in the days moving forward. We fully support an ongoing database.

#### **SECTION 3. DEPARTMENT OF HUMAN SERVICES' AUTISM SPECTRUM DISORDER MEDICAID WAIVER.**

FVND fully supports an expansion in the age of the ASD Medicaid Waiver. While the current ASD waiver ends for children at age 5, unfortunately ASD does not end at age 5. It is vital that children continue to access services currently available to them under the current waiver.

While initially implementation of the autism waiver had its challenges. The number of slots committed for the waiver are nearly full, with one remaining opening. The infrastructure needed for the waiver has improved greatly, and the problems identified in the waiver corrected. Many funds have been dedicated to the implementation of the waiver, and while it initially took some time. There is no need to throw the baby out with the bath water so to speak. An expansion is vital for families. Additionally, Family Voices of ND provided many referrals of families to the Department for families to access the waiver.

You have heard the many statistics on costs associated for families of children with ASD. To often these children don't fit into any one criterion. The autism waiver expansion beyond the age of 5 would assist many families who fall in the gaps of obtaining services and children advancing to the best of there ability.

Much feedback and dialogue has been obtained from families through the work of the task force. Many surveys were completed with assistance from Family Voices. It will be vital to continue to receive feedback from those who utilize the services. While the needs of children with ASD change, just as quickly, are the changes in treatments, support and ongoing needs as children get older.

Therapies not addressed in the current autism waiver are therapies for behavioral and social issues that children, youth and adults with ASD many face. Another issue not addressed in the current waiver is the need for family support. Family support and education is a vital component in services for families with a child with ASD.

Across the country, ASD waivers exist. Many states like North Dakota have struggled to adequately address this population. The rise in occurrence for ASD has left states with little choice but to address the needs.

FVND suggests expanding the waiver to meet the ongoing needs of these children, youth adults and families.

#### **SECTION 4. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE AUTISM COORDINATOR**

The need for an ongoing coordinator for ASD cannot be understated, and is an essential component in the infrastructure in services for ASD. The needs are great for families. A coordinated effort will assure consistency across the state, as well as a partnership with persons who require the ongoing services. Additionally, this person will coordinate ongoing efforts, dialogue, discussions, feedback etc. This will also ensure service delivery and enhance infrastructure, not only for the Department in administering ASD services but also that there always be a go-to person, who is familiar with the needs and services. Again, the needs are great. Priority to increase the infrastructure and support for the Department is a critical component.

#### **SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT**

The State Autism Task Force also recognizes the need for ongoing training. Training is necessary for providers and families. It is also vital to have training regionally for access to ongoing needs and supports. Training is vital component in all the work that is being done with ASD. The training component will compliment the other work that is being done.

#### **SECTION 6. DEPARTMENT OF HUMAN SERVICES – BEHAVIORAL ANALYSTS.**

An increase in the number of behavior analysts is crucial. Many families are traveling long distances to see a service provider. Behavioral issues are a concern for both families and providers. Currently there are few Behavioral Analysts in the western portion of the state, and limited in the central portion of North

Dakota. With the increase in numbers, FVND believes this will begin to address the shortage needs in the state. Families should be able to access services within their home communities and not have to go across the state to access services. The needs are rising, they are not decreasing. The State Task Force recognizes this need. FVND fully supports the needs to increase providers across the state.

## **SECTION 7. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - AUTISM SPECTRUM DISORDER DIAGNOSTIC TEAMS**

While there are a few diagnostic teams in North Dakota, again the need is great, and quite honestly the needs are greater than current availability of diagnostic teams and services. Teams should be available in each region of the state.

Family Voices provides ongoing navigation of services and emotional support to all families including families with an ASD diagnosis. From the vantage point of our agency, keeping up with the needs of families is great. We also need an increase in staff to provide the support that is needed to families. Last May, we increased the number of staff whom assists ASD families as the needs have greatly increased.

We still do not have the number of staff necessary to meet the needs. We continue to do provide the support, information and education, but our infrastructure is also strained. We currently do not have enough funds to increase staff hours to meet the need. Additionally, many of our services are grant driven. We will continue to provide support to all families, just know that we too are struggling to meet the needs.

In closing, we fully support the State ASD Task Force and their recommendations. Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights. This bill will embrace the needs of families and move us forward in the right direction.

We thank you for your consideration.

We are happy to answer any questions that you may have.

Donene Feist  
FVND Director  
701-493-2634



**Testimony**  
**Senate Bill 2193**  
**Senate Human Services Committee**  
**Tuesday, January 22, 2013**  
**North Dakota Department of Health**

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Tamara Gallup-Millner and I am Director of the Division of Children's Special Health Services for the North Dakota Department of Health. I am here to provide information regarding SB 2193.

Section 1 of the bill instructs the North Dakota Department of Health to establish and administer an autism spectrum disorder (ASD) database that includes a record of all reported cases of ASD in the state and any other information deemed relevant and appropriate by the department in order to complete epidemiologic surveys of the ASD, enable analysis of the ASD and provide services to individuals with an ASD. Section 2 provides an appropriation of \$200,648 in general funds to the Department of Health for the purpose of establishing and administering the ASD database and authorizes one full-time equivalent position for this purpose.

If SB 2193 is adopted, the Department of Health requests clarification on a number of items bulleted below in order to ensure we establish and administer a successful database or registry.

- Is reporting into the database to be voluntary or mandatory? Based on past experience with other voluntary reportable conditions, it is the department's recommendation that reporting be mandatory to assure the database will provide a complete and accurate record of all ASD cases in North Dakota. As with other registries maintained in the Department of Health (e.g., HIV), confidentiality would be maintained and the data kept in a secure system.
- Who determines an individual has an ASD and from whom should the department accept a valid report for the database? Who actually reports the ASD may affect the validity of the data. Self-reporting is different than data obtained from individuals qualified to make medical diagnoses based on established criteria. ASD is not a simple diagnosis. The Division of Children's Special Health Services currently provides contract funding for

five ASD diagnostic clinics per biennium, using a team approach for the diagnostic process.

- Who is expected to complete the epidemiologic surveys, analysis and provide services to individuals with ASD? Is it the Department of Health, the Department of Human Services, or some other entity? Language in lines 11 through 13 of the bill differs from what was communicated when the Department of Health was initially contacted for information regarding the database or registry. At that point, it was communicated that an accurate number of individuals with ASD was needed. To carry out the responsibilities as currently written in the bill, individuals would need to understand the intricacies of ASD and have a background in public health informatics. Ongoing FTE would be needed to carry out this level of responsibility.
- Upon request of advocates, the Department of Health provided an initial cost estimate for a simple autism registry. With that option, ASD was to be added to an existing system, the ND Electronic Disease Surveillance System, also known as Maven. This system will need to be customized in order to use it for an ASD database. By the time staff is hired, the autism database is operational, and reporting initiated, it's realistic to anticipate a two-year time frame before the system is fully functional. In addition, costs are likely more than originally expected. Items that were not initially included in the department's estimate include such things as maintenance costs from the system vendor, staff travel, and educational resources to create awareness for registry reporting.

There is a bill in the House (House Bill 1038) that contains similar instruction to the Department of Health. In that bill, the term "registry" is used rather than "database" and the appropriation is \$148,132 rather than \$200,648.

This concludes my testimony. I would be happy to answer any questions you may have.

**Senate Bill 2193****Senate Human Services Committee****Senator Judy Lee, Chairwoman****January 29, 2013**

Chairwoman Lee and members of the Senate Human Service Committee, for the record I am Dr. Kenneth Fischer, Medical Director, Behavioral Health, for Blue Cross Blue Shield of North Dakota (BCBSND). I am a board certified Adult, Child and Adolescent Psychiatrist. I thank you for the opportunity to present these comments to your committee today. BCBSND is neutral on this bill, but recognize the public policy implications and want to raise the following issues:

**I. Epidemiology, Diagnosis and treatment of Autism Spectrum Disorders (ASD)****What is an Autism Spectrum Disorder?**

Autism Spectrum Disorder (ASD) is a lifelong neurobiological brain based medical condition that is without a known cure, is frequently associated with modest improvements over time that are hard fought, expensive, and at times frustrating for all involved. Autism affects every aspect of the individual affected, from how they think (many are intellectually disabled), act (see the world differently than "neurotypicals"), to how they communicate (many autistics have a vocabulary of a preschooler in the body of a teen or an adult; 40% of autistic children have no speech at all). Many require some form of lifelong comprehensive care. Their care places an extraordinary emotional, physical, social and financial burden on the family.

**What causes ASD?**

The best available evidence indicates that despite the specific cause being unknown, Autism Spectrum Disorders are highly heritable (passed on through one's genes). Advanced paternal age and maternal age are already known to be associated with an increased risk of autism in one's offspring. Other factors remain under scientific investigation. After birth (non genetic) environmental causes of Autism have been proposed, in particular the measles-mumps-rubella (MMR) vaccine and mercury containing vaccines.

In 2001, the *Institute of Medicine* reviewed epidemiological population-based studies and concluded that there was no evidence of a causal association between the MMR vaccine and autism. Studies conducted since the publication of that review have supported this conclusion. But there is no evidence to date that children with neurodevelopmental disabilities, including Autism, in the United States have increased mercury concentrations in their blood or significant levels of environmental exposure to mercury. Using data sets from the U.S., Sweden, and Denmark, to date, no consistent association has been found between thimersol-containing vaccines and autism.

**How common is ASD?**

Using national 2009 data, the incidence of ASD in general population on average is 9/1000. The range was from 4.2/1000 in Florida to 12.1 in Arizona and Missouri (2006). Given the variability, it is difficult to extrapolate a national incidence and apply it to a specific State, because of variability of access to proper diagnoses and other factors.

Average increase in prevalence at study sites was 57% from 2002-2006. ASDs are 4-5 times more likely in males. If one sib has ASD, the risk for another is 2-8%. If one identical twin has ASD, the other has 70-90 % chance for developing an ASD. In non-identical twins the risk decreases to around 10%. It is estimated that only about 10% of children with an ASD have an identifiable genetic, neurological or metabolic disorder, such as Fragile X or Down Syndrome.

### **ASD, language functioning, and IQ**

About 40% of ASD kids do not have speech. Another 25%-30% have some words by 12-18 months then lose them. Others may speak, but not until later in childhood.

Prevalence of Global Developmental Delay/Intellectual Disability with ASD is currently just under 50%. Recent reports from England peg a rate as low as 26%. A report published by Centers for Disease Control in 2009, shows that 30-51% (41% on average) of kids with an ASD also have an Intellectual Disability (intelligence quotient < 70).

### **What is the first step to diagnosis?**

Screening in doctor's office via surveillance at well baby PCP visits. More intensive screening if family history positive for ASD. Clinicians need education on tools for screening, tools for diagnosis to increase likelihood of correct diagnosis versus vague impression or adopting "wait and see..."

Screening tools can be divided into two groups: non-specific that focuses on abnormal development, and specific screeners for ASD. Average age for correct diagnosis is 4+, but last decade was age 8.

Prompt screening is a must if infant or toddler shows no babbling or gesturing by 12 months, no single words by 16 months, lack of 2 word spontaneous phrases by 24 months, and any loss of any language or social skills at any age.

### **What are best practice standards for diagnosis?**

Most children in North Dakota are served by a primary care clinician for developmental screening and health needs. "The Affordable Care Act (ACA)" recognizes that prevention, early intervention and when necessary, treatment of all medical conditions including ASDs are an integral part of improving and maintaining overall health. Coordination, communication, and linkage with primary care can no longer be optional for safe, effective and affordable care.

Immediate referral, usually by the primary care physician in the medical home, in the first few months to years of life at the moment an ASD is simply suspected, to a school based early intervention program, is critical because ASD children often have language delays and the inability to "learn how to learn" by the condition's very nature. Note: for a diagnostic assessment of ASD to be considered medically necessary by insurance, the assessment must be multidisciplinary in nature and include:

1. A *diagnostic assessment* by an appropriately trained and licensed professional (preferably physicians in Child and Adolescent Psychiatry, Child Neurology, or Developmental Pediatrics; if evaluation is done by general primary care physician or pediatrician, consultation with child psychiatry, child neurology developmental pediatrician along with child psychology is highly recommended). A broad and deep differential diagnosis complicates the evaluation of because

many behavioral health diagnoses can cause ASD like symptoms, and many medical diagnoses are accompanied by ASD symptoms. Blood work (lead level, metabolic testing, CBC, thyroid, genetic karyotyping), measure of head circumference, imaging (MRI of brain), EEG, may be involved.

2. A current list of DSM 5 diagnoses.
3. A *complete physical evaluation* by a licensed physician (with particular attention to family history for an Autism Spectrum Disorder, mental retardation, fragile X Syndrome, tuberous sclerosis; seizures, brain injuries).
4. *Testing* supervised and interpreted by a licensed PhD psychologist or Psychiatrist, including Intellectual testing, Adaptive testing, Communication testing (Expressive and Receptive Language), Autism measures (ADOS, CARS, ADI-R, etc) , hearing testing by an Audiologist, etc.

While the definitive diagnosis is being established, work can begin in the school setting with multidisciplinary teams, because integrated teams are necessary to facilitate development and learning, promote socialization in a natural peer environment, reduce maladaptive behaviors (usually by methods that are eclectic, incorporating some principles of operant learning theory, and other behavioral theories as appropriate), and educate and support both the family and the school system.

The Federal Individuals with Disabilities in Education Act (IDEA) guarantees a “free and appropriate public education.” One part of IDEA requires school districts to conduct outreach to pre-school children ages 0-3 who may be disabled and need special services, called early intervention services. Autistic children would be identified through this process, and the district would be expected to supply services to those children. IDEA also requires school districts to set up an “individual education program” for disabled children aged 3-21, and to provide special services to such children. States are required to comply with IDEA and to submit compliance reports to the US Dept. of Education.

### **What Works for ASD children in school**

The primary goals of education are to minimize autism’s core features (social, communication and narrow interests) and associated deficits, maximize independence and quality of life, and minister to affected families who are often in distress. Therefore, multidisciplinary Early Educational Interventions, behavioral therapies (in the child’s natural school environment) and habilitative therapies (SL, PT, OT in the child’s natural school environment) remain the cornerstone of treatment.

Although elementary, middle and high school programs to educate and habilitate autistic children may differ in philosophy and relative emphasis placed on particular strategies, they share common goals. There is an emerging consensus that important principles and components of effective early childhood intervention for children with ASDs.

These principles include entry into early intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made; active engagement of the child in systematically planned, developmentally appropriate educational activities designed to address identified objectives; low student-to-teacher ratio to allow sufficient 1 on 1 time and small group instruction to meet specific individualized goals; inclusion of a family component (including parent training as needed).

Additional principles include promotion in the school setting and beyond for interaction with typically developing peers to the extent that these opportunities are helpful in addressing specified educational



goals; ongoing measurements and documentation of the individual child's progress toward educational objectives, resulting in adjustments in programming when indicated; incorporation of a high degree of structure through elements such as predictable routine, visual activity schedules, and clear physical boundaries to minimize distractions; implementation of strategies to apply learned skills to new environments and situations (generalization) and to maintain functional use of these skills.

Finally, principles include the use of assessment based curricula that address functional spontaneous communication; social skills and self management preferably in the child's natural peer/school environment; functional adaptive skills that prepare the child for increased responsibility and independence; reduction of disruptive and maladaptive behavior by using empirically supported, evidence based and outcomes driven strategies; cognitive skills, such as symbolic play and perspective taking preferably in the child's natural peer/school environment; finally, traditional readiness skills and academic skills as developmentally appropriate.

## **II. Public and Private Insurance Coverage**

Children with a diagnosis of ASD have the same comprehensive medical coverage under public (Medicaid) and private (BCBSND) insurance that would be available to any other member. This typically includes coverage for routine medical care, childhood immunizations, surgery, hospitalizations, and pharmaceuticals.

Medicaid and BCBSND also pay for mental health and related services including Diagnostic Evaluations, Speech Therapy, Occupational Therapy, Physical Therapy, Inpatient Hospital/Partial Hospital/Residential Treatment and addiction services, PATH family support services, along with Outpatient Psychotherapies for children and their families, in some form consistent with the specifics of the member's benefit language.

Health insurance exists as a means to pay for safe, effective, patient centered, timely, efficient, and affordable health care services ("The right care, for the right person, at the right time, in the right place, for the right reason"). This is in addition to educational interventions appropriately delivered in the school under federal and state programs. ND Medicaid and BCBSND recognize the critical need to effectively coordinate our responsibilities with the relevant federal, state, and local agencies.

## **III. Standard Insurance requirements for evidence-based, outcomes driven care**

Medicaid, BCBSND, Medicare, and other private insurers, provide coverage for their members with any established diagnosis, including ASDs, when such treatment is provided by appropriately trained, licensed and credentialed clinicians. BCBSND, for example, seeks to ensure the highest quality of care that is evidence--based; evidence is information that suggests a clearly identified outcome will result from a clearly identified practice or intervention. BCBSND, for example, uses the national Technology Evaluation Center (TEC Criteria) as a primary resource for the development of medical policy. In 2002, TEC was re-awarded a 5-year contract from the Agency for Healthcare Research and Quality (AHRQ) as one of 13 Evidence-based Practice Centers (EPC) in the United States.

It is important that any health care professional wishing to work with an ASD child understand how to evaluate the evidence used to support all treatments, including Complementary and Alternative medicine, psychopharmacologic, individual/family/group psychotherapeutic/OT/PT/SL and other commonly used interventions. The evidence supporting or refuting a treatment should include peer

reviewed studies with appropriately diagnosed, well defined homogeneous study populations; a randomized, double blind placebo-controlled design; an adequate sample size to support statistical analysis presented; control for confounding factors; and use of appropriate, validated outcome measures. Only appropriately controlled studies are helpful in proving that an effect is attributable to the intervention being studied.

For any service to be medically necessary and payable, clinicians are required by all public and private payers to provide: objective, baseline measurements of behaviors/ symptoms to be targeted in terms of frequency, intensity and duration; descriptions of specific treatment interventions including the number of service hours required; objective measures of progress for each intervention; strategies for generalization of learned skills; strategies for coordinating treatment with school-based special education programs; plans for transition and measurable discharge criteria and a discharge plan once goals are met.

In the case of treatments for ASD in general, research into what treatments actually work and can fulfill the above expectations, is in its infancy. Randomized controlled trials, larger sample sizes (number of kids enrolled), uniform outcome measures (to see if what we're doing is making a difference), and greater consistency (by providers trained to the highest available standards) are needed. The professional consensus is that much additional research is needed to identify the minimum characteristics required for any treatment to demonstrate efficacy (content, technique, how often, when to start and when to stop).

All payers attempt to shape but not dictate care delivery, and necessarily rely on providers in the office, to help members form realistic expectations about the likelihood of a good outcome of a particular service. Payers try, to the extent policy and payment methods allow, to shape provider-member discussions around the right care under varying circumstances. Providers frequently dislike that part of a payer's role. Most will continue to struggle to make fair, prudent *and* cost conscious decisions in an effort to balance quality and sustainability in our fee for service environment

### **What about Applied Behavioral Analysis?**

There have been hundreds of published studies on ABA with most not meeting research clinical trial criteria. ABA is in reality, not a specific "therapy" but a term referring to a range of interventions that must be uniquely applied for each separate individual autistic child. There is no set formula, agreed upon procedure, practice or curriculum that defines ABA in a way consistent with the payer regulatory requirements of evidence based outcomes driven care noted above and now enshrined into the intent of the Accountable Care Act.

Intervention intensity (i.e. what "dose" of the treatment) remains, according to the latest standards of care, an elusive concept. Elusive because the quality of the intervention (type of therapy being offered, training of the therapist), the degree to which the child's attention and engagement are secured and maintained during the treatment, number and nature of response opportunities and other related factors, are all likely to contribute to the intensity or "dosage", if you will, of the intervention, and its effectiveness.

In general only a minority of children show significant improvements with ABA related services (less than half receive any benefit, with a small percentage receiving "significant" but limited improvement; and no objective way to know when to stop what is an extremely intensive, costly form of treatment).

Variability in outcome can be predicted by pre-treatment IQ, level of communication skills and having milder symptoms at outset. Most gains are achieved in the first year of treatment with lesser gains in subsequent years. Maximal benefit is usually by age 8. This bill proposes lifelong services broadly and imprecisely defined. In those states where similarly mandated benefits went beyond age 8 or so, the costs remain astronomical and lawsuits are under way by those states left with “unfunded mandates.”

Finally, the bill allows for the provision of services like (ABA) anywhere the family chooses to go, with the net result of moving the care out of the setting where best practice guidelines and an emerging expert consensus believe they should stay: the school.

See also [Summary of the Interim Legislative Human Services Committee held on Tuesday, July 31, 2012.](#)

Drs. Ted and Linda Kleiman, pediatricians in Fargo with an extensive autism practice, stressed to the committee that “treatment has been all over the map...evidence based medicine was lacking and needed...proper diagnosis was highly inconsistent...and that there is simply no evidence based research to support some of the treatments, like Applied Behavioral Analysis (ABA) which is currently being suggested and pushed...” Rod St Aubyn of BCBSND supported Dr. Kleimans’ findings on July 31, 2012 by providing the committee with a TEC Special Report on Applied Behavioral Analysis/EIBI.

### **What about Complementary and Alternative Medicine Treatments?**

Any clinician working with ASD children should strongly encourage families to seek additional information when they encounter the following claims or situations: treatments that are based on overly simplified scientific theories; therapies that are claimed to be effective for multiple different, unrelated conditions or symptoms; claims that children will respond dramatically and some will be cured or approach “normal” behaviors; use of case reports or anecdotal data rather than carefully designed studies to support claims for treatment; lack of peer reviewed references or denial of the need for controlled studies; or treatments that are said to have no potential or reported adverse effects.

For most of the following Complementary and Alternative Medicine interventions, there is not enough scientific evidence yet to support or refute their use for ASDs: Auditory Integration training, behavioral optometry, cranio-sacral manipulation, dolphin assisted therapy, music therapy, and facilitated communication, immunoregulatory interventions (e.g. Dietary restriction of food allergens or administration of immunoglobulin or antiviral agents), detoxification/chelation therapy, gastrointestinal treatments (e.g. Digestive enzymes, antifungal agents, probiotics, “yeast free diet”, gluten/casein free diet, and vancomycin), dietary supplement regimens purported to act by modulating neurotransmission or through immune factors or epigenetic mechanisms (eg vitamin A,C, B6, magnesium, folic acid, folinic acid, B12, dimethylglycine and trimethylglycine, carnosine, omega 3 FAs, inositol, various minerals and others.

This is not to suggest some of the above vitamins, probiotics, omega 3 FAs, other interventions are not helpful for an autistic child’s general health ...just not the brain based condition itself. Parents of ASD kids will understandably pursue interventions that they believe may represent some hope of help, particularly if the therapies are viewed as “free of side effects or benign.” Unfortunately, families are routinely exposed to unsubstantiated, pseudoscientific theories and related clinical practices that are at best ineffective and compete with known and validated treatments or at worst, lead to physical, emotional or financial harm (to the family or the paying entity). Nothing in the bills prevents dollars being spent for any of these things.

### **Do Not Forget Families**



The child's treatment team (preferably coordinated with/by the child's medical home) should focus on the family as well. Parents and siblings of children with ASDs experience more stress and depression than those of children who are typically developing. Physicians, therapists, teachers and other health care professionals can support parents by providing anticipatory guidance; training in involving them as co-therapists; assisting them in obtaining access to resources; providing emotional support to parents and siblings of affected children, including referral to counseling when necessary.

One of the chief strategies for helping families is by guiding them to available ongoing supports and services during critical periods or crises. Natural supports include spouses, extended family, neighbors, religious institutions, and friends, social networks of other families with ASD kids and community agencies (such as PATH and Partnerships) that provide training, respite, social events, and case management. Finally, formal supports when available can include publicly funded, state administered programs such as early intervention, special education, vocational and residential/living services, respite services, in home services, etc.

No matter what economic, budgetary and educational models the state considers, it really comes down to family and community. There is a lot that funding and teaching can do. Families and communities who are meaningfully mentored by appropriately trained professionals with regard to their understanding of autism—learn to walk alongside the affected one, no matter the life-long implications.

When both families and local communities learn this way, the burden of weighing “benefit/cost” of any intervention becomes less significant, because the bar has been raised; family and community have engaged one another so that their joint comprehension and ability to truly engage the autism afflicted child is enhanced

Reflecting on the current limitations in the field of autism in our knowledge of what works and doesn't work, we need to be cognizant that our public schools need to be equipped with resources to do their job. To be successful, parents and teachers need to be partners not adversaries. Our own ND Autism Task Force reached similar conclusions.

#### **IV. Complex Regulatory and Benefit Administration concerns raised by SB 2193**

##### **Medicaid and Private Insurance**

Medicaid is the key funding resource for public children's mental health with eligibility for services determined by economic status, expanded eligibility (e.g. disability). Private health insurance is based on a consumer's ability to pay directly for services (self pay or fee for service), employer and employee funded insurance, or self purchased insurance consistent with the Accountable Care Act. Private health insurance accounts for roughly 50% of mental health and addictions services provided in the U.S.

Like the private health insurance sector, Medicaid is governed by processes that attempt to steward limited resources while seeking to provide high quality, evidence based, outcomes driven, cost effective care. In the case of ASDs, several factors need to be considered: the impact of ASD on multiple life areas, the chronic nature of the illness, multisystem involvement, and the existence of a complicated patch-work mental health system in North Dakota. Much like the rest of the nation, there is not a simple, integrated “system” of mental health care in most towns and cities, but rather multiple overlapping systems, where variability in the quality of diagnosis and treatment and complexity of accessing services is common.

Interacting with these financial, administrative, and medical policy based structures, and creating the need for individualized education and treatment of each ASD child and their family, are the specific family systems issues, strengths and weaknesses, the local health care infrastructure and culture, etc.

### **Medicaid “Waiver”**

One cannot advocate for an improved mental health system in North Dakota for those with ASDs without understanding the nature of the system as it currently exists, including its strengths, limitations, and progression over time in areas including institutional, professional, wraparound, and school based mental health and related educational services. Relevant questions that might then arise include: what are the regulatory opportunities and barriers to school based mental health and related educational services for ASD children? (There is a bill to study the current state of mental health care delivery to children and adults before the 2013 ND legislature).

A Medicaid Waiver is a mechanism to provide services that would otherwise not be permissible, or to provide them in a way that would otherwise not be permissible given pre-existing federal rules, frameworks around medical necessity and appropriateness, etc. Many states seek waivers as a way to allow states to access federal money for specified, approved uses that are presumably more flexible, innovative and non-traditional in nature.

Waivers, unlike block grants, do not involve the transfer of funds from the feds to the states. They still need to be considered part of an overall state funding strategy, because once a waiver is approved by the federal government, involved services become subject to partial federal reimbursement. The federal government provides funds for medically necessary services to enrolled individuals through Medicaid, among other large insurance programs.

Even though the concept of cost effective care is financially and administratively based, the achievement of cost effective care has clear clinical correlates. When best practices and evidence based, outcomes driven guidelines are followed, cost effective care is actually high quality care (see the Accountable Care Act which enshrined these research findings and principles into law).

There are a multiplicity of rules and regulations regarding eligibility for mental health care that emanate from the policy and administrative entities that manage these different programs. These rules and regulations exist to provide quality assurance and quality improvement on behalf of Medicaid beneficiaries. Examples include prior authorization, concurrent treatment reviews, intensive care management of service utilization, along with data analytics that see patterns and trends that impact outcomes and risk. These are just a few tools used by Medicaid, Medicare, and private health insurers to steward resources while optimizing use of evidence based practices consistent with an individual's severity of illness and risk.

Yet, SB 2193 contains no defined accountability for benefit design, benefit administration, benefit regulation. Consequently, its passage could undermine Medicaid's main tools to ensure quality and control costs.

As written, the bill would define eligible services very broadly. There would need to be precisely defined uniform standards, content and criteria included in the definitions of the proposed ASD related services that meet (1) the legal standards established through state, federal and case law, and (2) identify “best practice” and ethical standards of any willing provider type wishing to treat the ASD affected individual under the parameters of the waiver.

The Waiver related services presumably include assessments, medical care, mental health services, occupational therapy and equipment, speech and language services, assistive technology, case management, transportation, educational supports, respite care, executive and social skills training programs, and development and implementation of behavioral intervention plans.

The waiver proposes essentially a mini benefit plan administrators program for the comprehensive care of autism that goes far beyond traditionally (non-medically necessary) defined “supports” (transportation, housing, independent living, educational supports and employment services, respite care). The waiver seeks unusually (from a payer regulatory perspective) broad and deep coverage for “services” that are imprecisely defined but have enormous fiscal implications.

The oversight of such a waiver would exceed the simple management of accumulators for dollars spent. It would require alternative Medicaid oriented case review and appeals processes, provider credentialing, and medical necessity policies and procedures, than currently exist within a public or private insurance plan.

The bill does not specify criteria that need to be met for evaluation and the fulfillment of basic principles of care management. Such criteria are important because, in the case of autism spectrum disorders, there are many irrelevant and sometimes harmful approaches to treatment. Treatment for ASD, by its nature, must be highly individualized. As stated, these individuals vary greatly with respect to their ability to benefit from any given treatment.

The bill as written would appear to require Medicaid to recognize and reimburse providers without any reference to Medicaid’s ability to enforce its own quality control or credentialing processes. The bill appears to create an entirely unique and separate system for autism services that bears no resemblance to the way Medicaid currently provides coverage for all other medical services and will undermine their efforts to balance the interests of members and ratepayers.

How could Medicaid manage services that by definition (as proposed) are medically unnecessary but necessary from a social services perspective? How do you price “respite-care, transportation” when there are no frames of reference as Medicaid currently doesn’t cover or review for such services?

### **Unintended Regulatory and Benefit Administration consequences**

If these services were ever to be administered by a private company (Medicaid contracts out some of their current benefit administration), the contract would have to be competitively bid and the bid document would need to lay out the parameters and duties required by the contractor, all of which are not addressed in the bill.

Taking these elements into consideration, what controlling authority would define the “eligible” services themselves? Who determines reimbursement rates (state? Contractor? School? Provider?) If a Medicaid contractor were to determine the eligibility (or “medical necessity and appropriateness”) for these alternative services, what process would be used as contractors are not legally allowed to do administrative rules?

If funding is limited to the appropriated amounts, are awards basically “first come first serve”? Transportation services are included; what rate is reimbursed and to what facility? Closest? Family choice? Technology is included; there may be several options for assistive technology that vary significantly in cost and quality; who decides which piece is allowed and how much reimbursement?

What about Issues with providers not sure how to bill, contracting with providers, different state licensure requirements and medical record documentation, privacy issues, network issues, required supervision and quality control, determination of codes submitted for reimbursement, etc.

### **Unintended Regulatory and Political Consequences**

This legislation in itself may be interpreted as discriminatory, with enormous long term fiscal implications depending on how such questions would be resolved. There are numerous developmental/cognitive/intellectual disabilities (e.g. Down syndrome, cerebral palsy, mental retardation) that require, in many cases, lifelong support for those living with the disability and present families with significant hardships. The discussion around assisting individuals with autism spectrum disorders should be shifted to a conversation about meeting the needs of all individuals with developmental disorders. Legislation mandating that Medicaid provide broad, poorly defined, and extremely expensive benefit coverage of one particular developmental disorder places other such disabilities on an unequal footing.

### **V. Regulatory Consequences if an ABA Benefit were included in the Waiver**

The waiver in no way precludes the use of dollars for ABA services.

The waiver would represent a significant shift in the types of services covered by public health insurance. The outcomes expected of Applied Behavioral Analysis (ABA) more closely mirror educational programs than the medical coverage policies of public or private insurers. ND Medicaid, BCBSND, Medicare and Sanford, like most carriers, do not cover this type of therapy.

By passing this Medicaid waiver bill, ABA and other non evidence based treatments risk becoming an entitlement set against the need for any existing framework of medical necessity. Alternatively, If the Medicaid waiver was somehow designed to allow Medicaid to suspend their current medical necessity framework, would Medicaid want to be in the position of having to approve services when requested for ND's Medicaid "waiver" population, all the while presumably maintaining their current official medical policy position (similar to BCBSND) that some of these services remain medically unnecessary and unduly cost inefficient for the "non-waiver" population?

### **Current Costs for ASD**

In 2011, the BCBSND Global Costs for Behavioral Health treatment (does not include medical or surgical costs in figure) for 826 members with Autism was approximately 7 million dollars. Services included were institutional (Inpatient, Partial Hospital, Residential Treatment), professional (Outpatient Individual, family, and group psychotherapies, testing, evaluations) and medication related costs. These are only for non ABA mental health services meeting the standards of medical necessity.

### **BCBSND Projected Cost Estimates of an ABA benefit**

According to the actuarial estimates provided by BCBSND to the Senate Government and Veterans Affairs Committee, Senator Dever, Chairman, at the committee's request, around February 3, 2011 when Senate Bill 2268 ("Autism Mandate") was under discussion:

Used 2010 claims data; assumes treatment providers in state, billing at 2010 rates.

Total Annual Cost Estimate, if 25% of 557 eligible ASD children were to receive ABA services, was 25 million dollars.



Total Annual Cost Estimate, if 50% of 557 eligible ASD children were to receive ABA services, was 50 million dollars.

Updated estimates from 2012 place the number of eligible children at a much higher 826, not the 557 identified in 2010. Therefore the projected costs would increase proportionately.

### **Industry Projected Cost Estimates of an ABA benefit**

A current (2012) general estimate based on common industry practices for standard outpatient treatment, using existing CPT coding available for ABA services:

Less intensive treatment defined as 19 hours or less/wk for a year would cost \$25,000 annually per child; this translates to 20.4 million dollars annually if 800 eligible children used the benefit.

Intensive treatment defined as 20-40 hours/wk for a year would cost \$53,000 annually per child; this translates to 43 million dollars annually if 800 eligible children used the benefit.

According to different (2009) Actuarial estimate for the Missouri waiver/mandate for ABA, the projected hourly use was 30hr/week at \$45/hour. 30 times 52 weeks equals 1560 hours/year. 1560 hours and \$45/hr equals \$72,200 per year/child. For 400 identified ASD kids, this would be 28 million/yr. For 600 identified ASD kids, this would be 42 million/yr. For 800 identified ASD kids, this would be 56 million/yr.

### **Existing State Mandate and Medicaid Waiver costs for an ABA benefit**

For one unnamed public/ private insurance carrier, 15% of ASD members used 81% of their state's waiver on ABA/intensive therapies alone; 315 children accounted for 9.7million ABA spend as part of that year's 12 million total claims Medicaid Waiver cost.

Another state has a broad coverage mandate for ABA therapy in terms of dose, frequency, duration and age limits allowed; consequently, this local private carrier spent 18 million in 2011 for 422 members for ABA alone (this does not include all this plan's other institutional, professional, and medication related Behavioral Health spend).

South Carolina has a Medicaid Waiver for ABA treatment. Treatment duration is limited to 3 years to age 10, with a 50K max/year/child. A 3 million budget for 2007 treated 120 kids that year. By 2008, the South Carolina budget grew to 7.5 million for 320 children (These figures are not adjusted for inflation in 2013 dollars). This has been considered a "reasonable and best case scenario" from cost perspective.

### **Projected Cost Estimates of the non ABA related services in proposed Waiver**

Estimates of cost for care for services anticipated by the waiver are difficult to develop because SB 2193 would require Medicaid to pay for such a broad and deep array of services that are currently beyond the utilization management scope of any insurer, public or private because they "waive" the scope of "medical necessity" by design.

## **VI. Conclusions**

Medicaid, like Medicare, BCBSND and other private payers, believes that all treatments for ASD children, including behavioral and educational interventions, should be based on sound science. Federal law requires payers to review and update their medical necessity policy regularly.

All payers' policy and payment methods work to promote a continuum of services that support recovery and resilience, prevention and early intervention, all the while emphasizing cost effective, evidence based and outcomes driven approaches, with special consideration for our rural population.

No one has offered the Senate Human Services Committee to date, data that indicates precisely how a waiver will impact the cost of the treatment that is delivered. The current cost for just one treatment modality —ABA therapy—can cost as much as \$30,000-\$50,000 per year. These figures are just for ABA type services alone, not including the rest of the proposed service list. And the bill would extend the benefit to lifetime age ranges, in the context of what many payers public and private in multiple states with mandates already know to be a limited ability to regulate the spend or the benefit once enacted.

As previously noted, additional estimates of cost for care are difficult to develop because SB 2193 would require Medicaid to pay for such a broad and deep array of services that are currently beyond the utilization management scope of any insurer, public or private because they "waive" the scope of "medical necessity" by design

And would such a waiver be discriminatory and therefore eventually need to be applied to all disabilities for which there are hundreds of diagnoses beyond ASD.

What would the hierarchy be for payment for other services the families wanted or needed once the 30 K is spent? At the end of a benefit, how do you measure outcome and what if need more? Particularly for those services not falling under medical necessity definition and therefore not covered by Medicaid or private insurance?

It is worth noting that the \$30,000 annual cap—adjusted yearly for inflation—may be misleading. If an individual exhausts his or her annual benefit prematurely, it is unlikely that state regulators would permit ND Medicaid, or any Medicaid based insurer, to simply cease reimbursing for benefits, arguing that such disruption in care could be harmful to the individual. The emotionally charged nature of what is proposed in SB2193 should not overshadow the reality that this benefit mandate would increase the cost of Medicaid sponsored health insurance premiums and ultimately negatively affect access to care for services already known to be medically necessary, safe and effective.

Medicaid (and BCBSND) already provides broad coverage for autism spectrum disorders. North Dakota already has an autism specific Medicaid waiver to allow for greater flexibility and creativity in providing services to this population; they now require a recalibration for blending and braiding the funding between the education system and Medicaid to ensure coordinated, collaborative care across systems.

The Waiver represents a subtle cost shift and member /provider expectation shift more broadly--from a public program predominantly educational in nature (state and federal cost sharing as mandated under IDEA, partnering with the schools and certain providers) to a worrisome Medicaid expansion.

The bill fails to outline the actuarially projected cost (via delineated strategies sufficiently flexible to promote efficiency, control costs, and pay for performance in ways consistent with the ACA and the way healthcare is inexorably moving), clinical and administrative implications of benefit design, administrative oversight, and basic accountabilities under state and federal law (e.g. common service definitions, utilization management measurements/criteria, quality requirements, system performance expectations, and consumer/family/youth outcomes).

Nor does the bill resolve the critical but unanswered questions regarding what the affected state agencies' collective and individual roles need to be to ensure the waiver's success given the extremely large potential costs involved (Autism is not currently a core service of DHS). The bill understandably appears to want imprecisely defined solutions to complex problems, incompletely framed.



# Who Can Outgrow or Recover From Autism

A New Study Sparks Debate About Early Diagnosis and Calls for Further Research Into Why Some Improve

By SHIRLEY S. WANG

Evidence is growing for a notion long observed by doctors and parents: Some children with autism appear to grow out of their symptoms and recover fully.

The reasons aren't entirely clear, but a recent study adds to the body of scientific work suggesting some autistic people get better. Led by a team from the **University of Connecticut**, researchers last week reported that they had identified 34 people who had all been diagnosed with autism by age 5 but years later were indistinguishable from peers on language, socialization and communication skills.

The individuals, ranging from 8 to 21 years old, had originally been diagnosed by autism specialists or other trained doctors.

The work "provides convincing evidence there is a group of people who certainly have all of the symptoms of an autism-spectrum disorder when they're young, who look like they have no symptoms later," said Thomas Insel, head of the National Institute of Mental Health, which funded the work. Dr. Insel wasn't involved in the study.

For years, clinicians and parents have described patients and loved ones whose autism symptoms seem to disappear completely. But these individuals haven't been closely studied, making it hard to determine whether they had autism in the first place or were misdiagnosed. The possibility of recovery is spurring interest in figuring out who might get better and why.

Deborah Fein, a professor of psychology and pediatrics at the University of Connecticut, and her colleagues decided several years ago to examine how children with autism fare over time, with particular interest in those who achieved what they called an "optimal outcome." In their first study on the topic, published in 2007, they



Jake Exkorn, playing soccer at camp in Maine, was diagnosed with autism at age 2, but by 4, he no longer had it, his mother says.

screened children at age 2 and again at 4. Of the 73 toddlers who were initially diagnosed with an autism-spectrum disorder, 13 of them, or 18%, no longer qualified for the diagnosis at age 4.

Autism diagnoses have climbed sharply for years, with 1 in 88 U.S. children now thought to have an autism-related disorder, according to the Centers for Disease Control and Prevention.

Though experts encourage diagnosing children as early as possible, with some saying that 1-year-olds can be identified as being at high risk for autism-related conditions, they caution

that early diagnosis is challenging and some children may be mislabeled.

In the latest work, published Jan. 15 in the *Journal of Child Psychology and Psychiatry*, Dr. Fein said the researchers sought to exclude children in whom the original diagnosis was questionable. But they didn't examine in this study why they seemed to get better.

"It's now apparent that some have a very good prognosis," said the NIMH's Dr. Insel. "The problem is we don't know how to identify that group."

Experts speculate that a combination of early, high-quality therapy and bio-

logical and genetic factors are likely responsible.

Karen Siff Exkorn said her son Jake, who was diagnosed with a "classic case" of autism at 2 years old, made slow but steady progress with a combination of 40 hours a week of behavioral treatment, as well as speech and occupational therapy. When he was 4, the specialist told her Jake no longer had autism.

"That news was as shocking to me as when he was diagnosed," said Ms. Exkorn, a management consultant in Sparkill, N.Y. "We didn't even know that

recovery was a possibility."

Now 16, Jake attends a regular high school, has many friends, plays on the school football team and was voted team captain at sports camp last summer, she said.

Dr. Fein and her colleagues are now analyzing data to see if there is a link between a certain type of therapy and an optimal outcome, and will be examining brain scans of children initially diagnosed with autism to see if they became structurally the same as typically developing children.

Based on previous studies, Dr. Fein

**Diagnosing autism early can be difficult, experts warn. Some children may be mislabeled but catch up later.**

estimates 10% to 20% of children who were diagnosed with autism may achieve optimal outcomes.

Some experts caution that even people who no longer meet diagnostic criteria for autism may have subtle, residual idiosyncrasies.

Fred Volkmar, director of the Child Study Center at the Yale University School of Medicine, who wasn't involved in the recent study, described one former patient who has a master's degree, goes to work and lives on his own, but every night he eats the same meal, canned fish, reads on the computer about software and then goes to bed.

In many ways he could be considered as having an optimal outcome, said Dr. Volkmar. At the same time, the man wants to have a girlfriend but doesn't know how to talk about subjects outside of his one narrow interest, and he serves canned fish to anyone he has over.



**NDLA, S HMS - Herrick, Kari**

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**From:** Larsen, Teresa A.  
**Sent:** Wednesday, February 06, 2013 2:31 PM  
**To:** Lee, Judy E.; Anderson, Jr., Howard C.; Axness, Tyler; Dever, Dick D.; Larsen, Oley L.  
**Subject:** SB 2193 - autism

**Importance:** High

Dear Chairman Lee and Committee Members:

Thank you for giving me the opportunity to speak with you this morning regarding autism legislation. As requested, here are my notes.

This is something many of us feel very passionate about as we see and hear about the unmet needs for individuals with a diagnosis on the autism spectrum as well as their families. There is also a vast need for training for school personnel who, we believe, want to do the 'right thing' but are not equipped with the needed information and resources. While the goal is for them to be equipped to support students during the school day, there is also the important need to assist individuals and families with services and supports while the children are not in school.

During the Interim, and early into the Legislative Session, there has been a big disagreement about how to implement autism services. While all agree that the current waiver is not providing the needed services, and is narrow in scope of eligibility (particularly by age), stakeholders have basically disagreed on how to make needed changes. This is inherent in the House Bills (particularly 1039) which call for a new 'voucher system' and SB 2139 which would 'expand and refocus' the Autism waiver to broaden eligibility (ages 3 – lifelong) and includes services, such as behavior therapy, which are absent in the current waiver.

A meeting was convened on February 1, 2013, and facilitated by the Consensus Council. In attendance were Cathy Haarstad (Pathfinder Parent Center); Dr. Barb Stanton (Prairie St. John); Donene Feist (Family Voices of ND); JoAnne Viewig (grandmother from Fargo); Eric Monson (Anne Carlsen Center); Vicki Peterson (parent from Bismarck); Carlotta McCleary (Federation of Families for Children's Mental Health); Kris Wallman (Autism Society – Fargo); and myself. Senator Heckaman was invited but could not attend because of her schedule with the Legislature. Tina Bay (DHS) was also invited but declined to participate.

The group found they had a lot in common, the heart of which is to see the needed services and supports provided for individuals with autism and their families. There is also much support for training and support for school personnel; for a payment mechanism for service provision; and for meaningful consumer, family, and stakeholder input into the service delivery mechanism.

There was huge progress made at the meeting and the group came to consensus on the following:

1. Expand the autism waiver (ages 3 through lifelong) and include needed services, such as behavior therapy, as written into SB 2193. The waiver is up for renewal this fall, so this is timely. The group would like to see reporting on the progress and status of this to the Legislature during the interim.
2. Change HB 1039 to reflect the implementation of a 'pilot voucher system' in addition to the expanded and refocused waiver. The group is intrigued by a voucher system but believes there are too many questions to go with this as a single system for service access at this time. The group would like to see the pilot up and running by January 2014 and reporting on the progress and status by DHS to the Legislature during the interim.
3. Training for school personnel should flow through the Regional Education Associations to ensure 'outreach' to all school personnel, not just those who might be able to attend a statewide conference.

4. Funds should be included specifically for autism service providers to conduct training and for family support/advocacy organizations (Federation of Families for Children's Mental Health, Family Voices of ND, and Pathfinder Parent Center) to provide training, family support, and advocacy.
5. A registry/data base should include mandated reporting while ensuring the confidentiality of consumers and families.
6. Consumers, families, advocates, and service providers should have ongoing input throughout all discussions, decisions, and implementation. This includes input into the hiring of an Autism Coordinator should this be funded for DHS. The group spoke strongly to the idea of a Steering Committee to work with DHS on the waiver and pilot voucher system. Because the existing autism waiver turned out to be NOT what parents and advocates supported, trust and communication needs to be built between DHS and other stakeholders.

While other related items were discussed, the group has not reached consensus on those. If I can be of assistance to you on this important matter, please feel free to contact me at any time.

Sincerely,

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**SB 2193 Appropriation Detail UPDATED 2-6-2013**

Section	Cost	Detail
<b>Section 2.</b>		
Database	\$ 391,464	Costs based on information received from Department of Health. Personnel and operating costs.
<b>Section 3.</b>		
Medicaid Waiver	\$ 2,576,473	DHS will need an appropriation increase of \$2,576,473 to expand the ASD Medicaid waiver, add 8 half time FTE for case management and expand the fiscal agent contract, of which \$1,284,355 is general fund. For the 15-17 bienium DHS will need an appropriation increase of \$3,540,139 of which \$1,770,070 is general fund.
<b>Section 4.</b>		
Coordinator & Assistant	\$ 494,135	Coordinator salary & fringe= \$242,122; assistant salary & fringe= \$132,769; operating to include stipends for attendance at regional meetings, annual conference expenses, website management, costs to facilitate meetings to develop standards = \$119,244
<b>Section 5.</b>		
Statewide Training	\$ 158,032	2 day Regional trainings including time of 2 trainers for a total of 48 days of training= \$98,832 Parent Training = \$6,400 Physician Training= on-line training includes continuing education units= 4,800.00 Statewide training fund for completing college coursework= \$48,000
<b>Section 6.</b>		
Behavioral Analyst Capacity	\$ 198,864	Provide funding support (2 in each region). To complete the St. Paul on-line BCBA program including supervision up through the test. $\$12,429 \times 16 = \$198,864$ . Costs will be dependent on whether studies are taken full or part time.
<b>Section 7.</b>		
ASD Diagnostic Teams	\$ 433,280	8 Regions/ 8 children each clinic- Diagnostic clinics range from \$1,725 to \$5,045 per child. This includes paying for the time of experienced parent, physician, occupational therapist, physical therapist, family support specialist. 5 - 15 children evaluated per region per year.



2/10/23

Department of Human Services  
Comparison of Proposed Bills related to Autism Spectrum Disorder

	<b><u>SB 2193</u></b>	<b><u>HB 1037</u></b>	<b><u>HB 1038</u></b>	<b><u>HB 1039</u></b>
Scope	Funds: Database/registry; Medicaid waiver; State coordinator and assistant; Statewide Training; Behavioral Analyst training; Diagnostic Teams	Instructs the Legislative management to study the current system for individuals with ASD	Funds: ASD Registry; Autism training for general education teachers and other school staff	Funds: Voucher system for ASD services and support
Funding Details	Database = \$391,464; Medicaid Waiver \$27,239 per person/year/additional 50 people for 18 months= \$2,042,925; Coordinator/assistant & training = \$494,135; Case Managers= \$508,152; Fiscal Agent= \$25,396; Statewide Training = \$158,032; Behavioral Analysts = \$198,864; Diagnostic Teams = \$433,280 * includes fiscal note changes. * 13- 15 costs	N/A	Registry: \$148,132; Educational Training \$198,000	up to 100 individuals - up to age 26; up to 50 individuals age 26 and older; Eligible services are assessments, medical care, mental health occupational therapy, speech therapy, assistive technology, case management, respite care, educational supports, executive and social skills training, behavioral intervention plans, housing, transportation, independent living services
Total Appropriation	\$2,767,289	N/A	\$346,132	\$4,500,000
Target Group	All Medicaid Waivers are restricted to those who meet institutional level of care criteria- regardless of financial eligibility. Statewide training is designed for doctors, parents, regional training, and assistance to complete college coursework.		All people with a diagnosis that falls under the category of autism. Education is targeted for general education and school personnel.	General Fund voucher is not restricted to institutional level of care criteria as is a Medicaid Waiver

#13

**Fiscal Note Summary**

Bill / Resolution No.

SB2193

	FTE	Total	General	Federal	Other	Project Number
Salaries and Wages	22.00	\$ 2,684,395	\$ 1,675,375	\$ 1,009,020		
Operating Expenses		1,095,766	1,052,593	43,173.00		
Capital Assets		-	-	-		
Capital Construction Carryover		-	-	-		
Grants		-	-	-		
HSC and Institutions		-	-	-		
Grants - Medical Assistance		6,945,945	3,459,775	3,486,170		S055
<b>Total</b>	<b>22.00</b>	<b>\$ 10,726,106</b>	<b>\$ 6,187,743</b>	<b>\$ 4,538,363</b>	<b>\$ -</b>	

**Salaries and Wages****2 FTEs for Dept of Health (DOH)**

HSPA III	145,732
Epidemiologist III	145,732
	<u>291,464</u>

**20 FTEs Dept of Human Services (DHS)**

Admin Assist I	132,769	section 4 in bill	
HSPA V	242,122	section 4 in bill	
DD Case Manager for increase caseload (2.5 FTE per region) 18 mx	<u>2,018,040</u>		2,536,060 24 mos
	<u>2,392,931</u>		

General	1,675,375	1,383,911
Federal	1,009,020	1,009,020
<b>Total Salaries and Wages</b>	<b>\$ 2,684,395</b>	

**Operating Expenses****DOH**

Operating costs for 2 FTE	20,000
Travel for Epidemiologist	5,000
Brochure/printing expenses	5,000
License for new module for autism database.	30,000
System maintenance costs	40,000
<b>Total DOH</b>	<b>\$ 100,000</b>

**DHS**

Operating for 2 FTEs	119,244	section 4 in bill	\$ 494,135
Training	158,032	section 5 in bill	
Behavioral Analyst Certification	198,864	section 6 in bill	
Diagnostic Teams	433,280	section 7 in bill	
Fiscal Agent (18 months for 50 new)	<u>86,346</u>		118,872 24 mos with 80 people
<b>Total DHS</b>	<b>\$ 995,766</b>		

General	1,052,593	952,593
Federal	43,173	43,173
<b>Total Operating Expenses</b>	<b>\$ 1,095,766</b>	

**Grants- Medical**

Currently budget 13-15 (30 people/month) \$ 2,011,178

Cost for expansion (30 to 200/month)

Recipients per month	170
DD traditional waiver avg yrly cost	27,239
for biennium (2yrs x 75%) (18/24=75%)	<u>1.5</u>
	<u>6,945,945</u>

Total for 170 recipients/month

Difference from current budget to projected need for expansion

\$ 6,945,945

**General Fund****Federal Fund (50.19% FMAP)****Total Grants - Medical**

Grants	Operating (50/F Total)	
3,459,775	1,052,193	4,511,968
3,486,170	1,052,193	4,538,363
<u>6,945,945</u>	<u>2,104,386</u>	

**Costs for 13-15 biennium**

General	6,187,743
Federal	<u>4,538,363</u>
<b>Total</b>	<b>10,726,106</b>

#14

**Projected Grants-Medical Assistance 15-17**

Total grant costs 13-15 (@ 24 months)	9,261,260	
Cost for 1 yr	4,630,630	
Inflation yr. 1 4%	4,815,855	
Inflation yr. 2 4%	5,008,489	
Total 15-17	9,824,345	
	Operating (50/50) 15-17	
General	4,912,172	1,327,466
Federal	4,912,173	1,327,466
Total	\$ 9,824,345	\$ 2,654,932

**DOH Appropriation**

	<u>13-15 General</u>	<u>13-15 Federal</u>	<u>15-17 General</u>	<u>15-17 Federal</u>
	<u>Fund</u>	<u>Fund</u>	<u>Fund</u>	<u>Fund</u>
Less amount included in bill	(200,648)			
For FTE	291,464		291,464	0
For Operating - (software for 13-15 only)	100,000		70,000	0
Total appropriation DOH	190,816		361,464	0

**DHS Appropriation**

For FTE	1,009,020	1,009,020	1,642,921	1,268,030
For Operating	43,173	43,173	968,856	59,436
For Grants	3,459,775	3,486,170	4,912,172	4,912,173
Total appropriation DOH	4,511,968	4,538,363	7,523,949	6,239,639
Total	\$ 4,702,784	\$ 4,538,363	\$ 7,885,413	\$ 6,239,639



Sen. Lee

SB 2193 relating to autism spectrum disorders February 10, 2013

Enact Sections 1 and 2 with requirements for

- 1) diagnostic assessment by an appropriately trained and licensed professional
- 2) current list of DSM 5 diagnoses
- 3) complete physical evaluation by a licensed physician
- 4) testing supervised and interpreted by a licensed PhD psychologist or psychiatrist, including intellectual testing

Delete Section 3 concerning the waiver because of regulatory issues (MA would be responsible for administration, although not all of those served are MA). Replace with modified voucher system covering:

1. Equipment/general educational
  - a. Assistive technology
  - b. Video modeling DVDs or equipment
  - c. Language generating devices
  - d. Training/educational materials for parents
  - e. Parenting education
  - f. Sensory equipment
  - g. Tutors
  - h. Safety Equipment
  - i. Travel tools
  - j. Self-care equipment
  - k. Timers
  - l. Visual representation systems
  - m. Language comprehension equipment
  - n. Registration and related expenses for workshops and training to improve independent living skills, employment opportunities, other executive or social skills

Make autism spectrum disorders services a core service of DHS.

Section 4 with just one coordinator, get new fiscal note

Enact Section 5 with training, but with more money and with the focus on schools, including teachers and support staff, such as custodians, secretaries, lunch crew, bus drivers, parents, etc. with more money--\$500,000?

Section 6 - delete Section 6 - no ABA (why would we train one class of provider & not others?)

Section 7 - Delete Section 7 re: diagnostic teams; better to aid families in connecting with experts around the state, rather than funding teams to go out



Dr. Fischer

SB 2193 relating to autism spectrum disorders February 10,  
2013

Enact Sections 1 and 2 with requirements for

~~1) diagnostic assessment by an appropriately trained and licensed professional~~

1) A valid and reliable diagnosis must be done by a doctoral level professional who is appropriately licensed, credentialed, and experienced in the field of Autism including intellectual testing and other formal evidenced based assessments for autism spectrum disorders.

The decision of who can provide a definitive diagnosis to the registry, should be determined at a later date by a panel of experts, who themselves are qualified and experienced in making the diagnosis of an ASD.

2) current list of DSM 5 diagnoses

3) complete physical evaluation by a licensed physician

~~4) testing supervised and interpreted by a licensed PhD psychologist or psychiatrist, including intellectual testing~~

5) The reporting should be mandated.

Delete Section 3 concerning the waiver because of regulatory issues (MA would be responsible for administration, although not all of those served are MA).

Replace with modified voucher system covering:

1. Equipment/general educational

b. Assistive technology

c. Video modeling DVDs or equipment

d. Language generating devices

e. Training/educational materials for parents

f. Parenting education

g. Sensory equipment

h. Tutors

i. Safety Equipment

j. Travel tools

k. Self-care equipment

- l. Timers
- m. Visual representation systems
- n. Language comprehension equipment
- o. Registration and related expenses for workshops and training to improve independent living skills, employment opportunities, other executive or social skills
- p. Community Access

## 2. Exclusions Section:

Any clinician working with ASD children should strongly encourage families to seek additional information when they encounter the following claims or situations: treatments that are based on overly simplified scientific theories; therapies that are claimed to be effective for multiple different, unrelated conditions or symptoms; claims that children will respond dramatically and some will be cured or approach “normal” behaviors; use of case reports or anecdotal data rather than carefully designed studies to support claims for treatment; lack of peer reviewed references or denial of the need for controlled studies; or treatments that are said to have no potential or reported adverse effects.

The following services are benefit exclusions and shall not be provided under the auspices of this voucher:

- . Early Intensive Behavioral Intervention (EIBI) in all its variations including, but not limited to, Applied Behavioral Analysis (ABA), Intensive Early Interventional Behavioral Therapy (IEIBT), Intensive Behavior Intervention (IBI), the Lovaas Method, Denver Model, LEAP, TEACCH, Pivotal Response Training, Discrete Trial Training and others.
- . For the following Complementary and Alternative Medicine interventions, there is not enough scientific evidence yet to support or refute their use for ASDs: Auditory Integration training, behavioral optometry, cranio-sacral manipulation, hyperbaric chambers,

dolphin assisted therapy, music therapy, and facilitated #16  
communication, immunoregulatory interventions (eg.  
Dietary restriction of food allergens or administration of  
immunoglobulin or antiviral agents),  
detoxification/chelation therapy, gastrointestinal  
treatments (eg. Digestive enzymes, antifungal agents,  
probiotics, “yeast free diet”, gluten/casein free diet, and  
vancomycin), dietary supplement regimens purported to  
act by modulating neurotransmission or through immune  
factors or epigenetic mechanisms (eg vitamin A,C, B6,  
magnesium, folic acid, folinic acid, B12,  
dimethylglycine and trimethylglycine, carnosine, omega  
3 FAs, inositol, various minerals and others.

Make autism spectrum disorders services a core service of  
DHS.

Section 4 with just one coordinator, get new fiscal note

Enact Section 5 with training, but with more money and  
with the focus on schools, including teachers and support  
staff, such as custodians, secretaries, lunch crew, bus  
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rather than funding teams to go out

13.0192.03001  
Title.

Prepared by the Legislative Council staff for  
Senator J. Lee

February 11, 2013

## PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "database" insert "and an autism spectrum disorder voucher program"

Page 1, line 2, replace "direct the department of human services to seek an autism spectrum disorder medicaid waiver" with "provide for a department of human services study and report to the legislative management"

Page 1, after line 7, insert:

"1."

Page 1, after line 13, insert:

- "2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.

## SECTION 2.

### Autism spectrum disorder voucher program.

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills.
2. The department shall adopt rules establishing the eligibility requirements and exclusions for this voucher program.

## SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT. During

the 2013-14 interim, the department of human services shall study autism spectrum disorder services, including whether it would be feasible and desirable to establish mandatory reporting to the autism spectrum disorder database and including the most feasible service delivery system for individuals with nondevelopmental disability autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study."

Page 1, remove lines 21 through 24

Page 2, remove lines 1 through 3

Page 2, line 6, replace "\$494,135" with "\$400,000"

Page 2, line 8, remove "and an assistant"

Page 2, line 12, replace "two" with "one"

Page 2, line 13, replace "positions" with "position"

Page 2, line 17, replace "\$158,032" with "\$500,000"

Page 2, line 19, after the second comma insert "school staff training,"

Page 2, remove lines 21 through 30

Page 3, remove lines 1 and 2

Renumber accordingly



**Testimony  
Human Services Interim Committee  
Department of Human Services  
Representative Alon Wieland, Chairman  
August 2, 2011**

Chairman Wieland and members of the Human Services Interim Committee, I am JoAnne Hoesel, Director, Division of Mental Health & Substance Abuse Services, for the Department of Human Services. I am here today to provide comments regarding the committee's study of the autism spectrum disorder (ASD).

My comments focus on four areas: 1) background information on the autism spectrum disorder, 2) information on the developmental disability (DD) system and the mental health system and their interactions with individuals with disorders on the spectrum, 3) the ASD Task Force of which I am chairperson, and 4) general issues for consideration.

**Background information on ASD**

In order to provide context to my comments, I will describe the conditions that fall on the ASD spectrum and define commonly used terms.

- **Intellectual disability (previously referred to as mental retardation)** is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability is sometimes referred to as a cognitive disability or mental retardation.



- **Developmental disabilities** are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living.
- **Autism Spectrum Disorders** are a group of developmental disabilities that can cause significant social, communication, and behavioral challenges.

The diagnoses that are on the ASD spectrum are:

- Autism
- Asperger's Syndrome
- Rett's Syndrome
- Pervasive Developmental Disabilities, Not Otherwise Specified
- Childhood Disintegrative Disorder

The Center for Disease Control estimates a range between about 1 in 80 and 1 in 240, with an average of 1 in 110 children in the United States have an ASD.

There is currently no cure for ASDs. However, research shows that early intervention treatment services can greatly improve a child's development. Early intervention services help children from birth to three years old learn important skills. Services can include therapy to help the child talk, walk, and interact with others.

We do not know all of the causes of ASDs. However, we have learned that there are likely many causes for multiple types of ASDs. There may be many different factors that make a child more likely to have an ASD including environmental, biologic, and genetic factors.

- Most scientists agree that genes are one of the risk factors that can make a person more likely to develop an ASD.
- Children who have a sibling or parent with an ASD are at a higher risk of also having an ASD.
- ASDs tend to occur more often in people who have certain other medical conditions. About 10 percent of children with an ASD have an identifiable genetic disorder, such as Fragile X syndrome, tuberous sclerosis, Down syndrome, and other chromosomal disorders.
- Some harmful drugs taken during pregnancy have been linked with a higher risk of ASDs, for example, the prescription drugs thalidomide and valproic acid.
- We know that the once common belief that poor parenting practices cause ASDs is not true.
- There is some evidence that the critical period for developing ASDs occurs before birth.

Services for individuals with ASD are provided by varied sources both public and private: education, mental health, primary health care, developmental disabilities, advocacy organizations, and vocational rehabilitation.

The Department of Human Services administers the early intervention programs in North Dakota for children birth through three years old. This program, referred to as Infant Development, is contracted to private agencies. Children are served by the education system after early intervention services end.

The regional human service centers provide services to individuals through the DD system, the vocational rehabilitation system, and the mental health system.

In the DD system, individuals need to have a developmental or intellectual disability, must be in need of institutional level of care, and diagnosed with mental retardation. Services are delivered through a Medicaid waiver in the community or through Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IDs). For those who are not eligible for the DD system and/or have a mental health condition, individual, group, or family therapy are provided in addition to care coordination, residential, medication therapy and psychiatric and psychological services. The regional human service centers do not provide specific ASD services nor does the Department consider this a core service even though we do have professionals skilled in this area. Many individual professionals in the mental health system have received additional specific training for ASD and provide appropriate care, but this must be determined by the professional and not by the profession. The majority of specific ASD therapies are provided by private providers in the state. The term Applied Behavior Analysis (ABA) is one therapy method often referred to in a discussion about ASD.

Depending on the individual, severity of condition, and diagnosis, services are delivered in varied settings. It can be confusing and frustrating to access services due to the eligibility criteria of a program, level of training of the professional, and availability of trained providers. We are aware of young children discharged from their daycare services due to behaviors associated with ASD.

**ASD Waiver**

The Department of Human Services was appropriated funds during the 2009 Legislative Session to develop and implement a specific Medicaid waiver for children ages birth through four years of age who have ASD or have significant delays in the areas affected by ASD. The intent of this waiver is to provide interventions early to mitigate the effects of these conditions. The waiver has a capacity for 30 children and there have been 14 children served since services began in November 2010. The waiver includes the following services: intervention coordination, in-home supports, equipment & supplies, and environmental modifications. Early detection and early diagnosis do lead to better outcomes according to the Center for Disease Control. Minot State Center for Persons with Disabilities serves as the evaluation and consultation team for this waiver. The 2011 Legislature continued the funding for the waiver.

**ASD Task Force**

The ASD Task Force was formed in 2009 but was preceded by the work of a Minot State University-led work group formed in 2008. The ASD Task Force distributed a survey in the spring of 2010 which provided insight into the current status of ASD services and support. Responders confirmed what task force members had suspected in that they felt services are lacking, there are limited comprehensive services, there is a need for training, and they recommended earlier identification. An initial plan was written and the Task Force continues work on the plan's recommendations.

**Issues to Consider**

- 1) Consistent service delivery, provider expertise, and public awareness options,
- 2) Methods to increase access to services,

- 3) Financial impact on families receiving effective services,
- 4) Potential incentives for individuals to encourage the pursuit of educational degrees and certifications to address the lack of well trained workforce,
- 5) Include all age groups in the scope of the study, and
- 6) Public policy needs to support an effective and comprehensive service delivery system for individuals in need of support.

We are pleased that a comprehensive review of the needs of individuals with ASD is occurring, and we look forward being involved and being a resources to achieve a successful study result.

I am available to answer any questions you may have.

**Testimony**  
**House Bill 1039 – Department of Human Services**  
**House Human Services Committee**  
**Representative Weisz, Chairman**  
**January 15, 2013**

Chairman Weisz, members of the House Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Division, for the Department of Human Services (Department). I am here today to discuss House Bill 1039.

House Bill 1039 instructs the Department to implement a voucher system for up to 100 individuals up to age 26 and up to 50 individuals aged 26 and older with autism spectrum disorders.

If this bill is adopted, the Department will need clarification on a number of items in order to ensure that we honor legislative intent and implement a successful program.

A voucher program is a program where, once eligible for the program, a person receives "vouchers" to "purchase" services.

The Department would need staff resources to run a voucher program, which would include establishing the mechanisms of the voucher program, developing prior authorization criteria, and monitoring the services received and payments made. The program would need management and monitoring of the infrastructure, service agreements, and utilization. We would expect that the legislature would want the Department to reconcile vouchers issued with vouchers used and attend to the issues that arise in the development and implementation of the program and services.

Some questions for which answers would be helpful so the Department understands legislative intent include:

Who decides that the services a family requests are approved?



Who would determine which services are allowable and unallowable?

Who are the appropriately trained individuals to make these decisions?

Is the voucher funding intended to be used last if an eligible person had other resources or assistance available such as eligibility for Medicaid or other insurance?

Who would be qualified to provide the services?

Who decides if a requested service is tied to the autism diagnosis or another medical condition?

As some of the services mentioned do not exist, is it the intent that the Department establish the parameters of the provider qualifications and reimbursement levels?

Is the intent that the Department makes the final decision on these items?

Would providers be required to enter a vendor agreement in order to become an approved vendor?

In Section 1, Number 4, House Bill 1039 lists a wide variety of services ranging from medical care to housing, to transportation. The Department requests clear criteria on what the vouchers would cover to avoid the Department being more lenient or more prescriptive than intended. Due to the potential magnitude of the program, the development of administrative rules would likely be necessary.

In Section 2, the appropriation states that up to \$30,000 per year per person is available for a total of \$4,500,000 for the biennium. The Department would like clarification on the appropriation. According to the information proposed in the bill: \$30,000 per person X 2 (years) X 150

individuals = \$9,000,000. The \$4,500,000 would be appropriate if the intent is that it would take 12 months to develop a voucher program; therefore only one year of vouchers would be issued. If this is the case, the Department recommends a delayed effective date be added to the bill.

We pose these questions so you may consider them in your discussions on this bill because the Department wants to follow the intent and be able to fulfill the scope of intended outcomes of this program.

I am available to answer any questions.

13.0192.03002  
Title.

Prepared by the Legislative Council staff for  
Senator J. Lee

February 12, 2013

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3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's diagnostic and statistical manual of mental disorders, fifth edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.

## SECTION 2.

### Autism spectrum disorder voucher program.

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age eighteen who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills.
2. The department shall adopt rules addressing management of the program and establishing the eligibility requirements and exclusions for this voucher program.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including whether it would be feasible and desirable to establish mandatory reporting to the autism spectrum disorder database and including the most feasible service delivery system for individuals with nondevelopmental disability autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study."

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# HB 1039 ASD Voucher Services and Supports

## Vignettes - Funding Possibilities

<u>Name</u>	<u>Service Plan</u>	<u>School/Education</u>	<u>Insurance/Medicaid</u>	<u>Voucher</u>	<u>Other Source</u>
A. Deven	1) Membership fee			X	
	2) Specialized equipment to meet sensory needs	X	X	x	
	3) Travel expenses for Deven and mother			X	
	4) Travel toolkit including fidgets			X	
	5) Educational materials for parents and hockey coach			X	Training Funds
B. Eric	1) Enrollment in social skills program - group therapy	X	X	X	
	2) Sensory equipment for daycare and home		X	X	
	3) Payment for specialized daycare			X	
	4) Respite Care			X	
	5) Parenting Education			X	Training Funds
	6) Follow-Up Supports			X	
	7) Safety features to prevent elopment at daycare/home		X	X	
C. Tiffany	1) Enrollment in independent skills class			X	VR or Independent Living Centers or Transition to Independence Program (TIP)
	2) Transportation to employment			X	VR
	3) Handheld assistive technology for skill development and job search			X	VR or IPAT or TIP

\* Education Individual Education Plan ( IEP) teams decide what is necessary to access a free and appropriate public education. If team agrees a service is necessary for FAPE, then education is required to pay for that service.



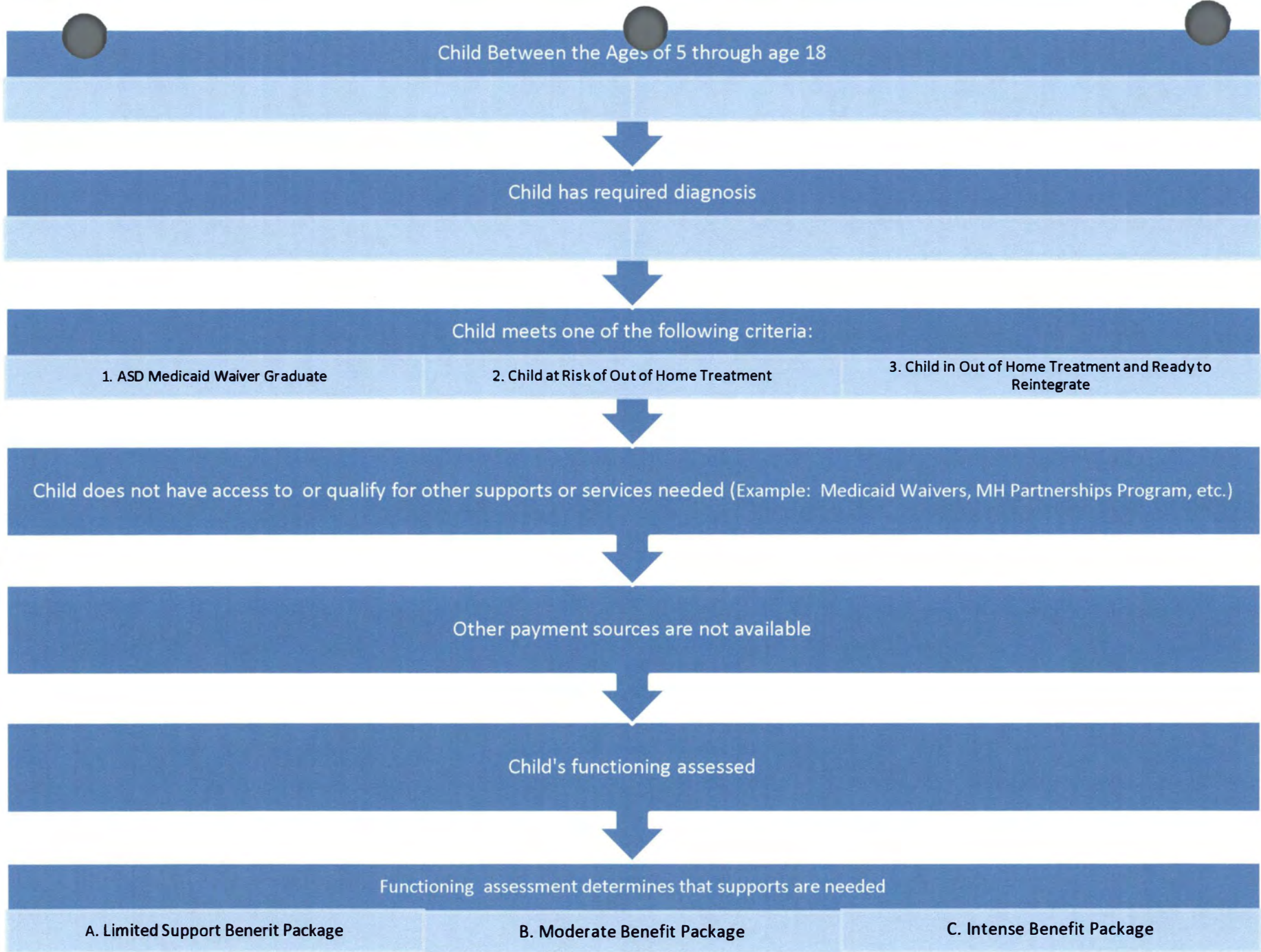
**ASD Medicaid Waiver****ASD Voucher- General Fund**

Birth through age of 4		Ages 5 through age of 18
------------------------	--	--------------------------

<i>Environmental Modifications</i>	needed for safety	Assistive Technology
<i>Equipment &amp; Supplies</i>	Needed to implement evidence based interventions	Video modeling videos or equipment
<i>In-Home Support</i>	Assistance in the consistent implementation of evidence based interventions.	Language-generated devices
<i>Intervention Coordination</i>	Provided by Early Intervention Professionals who will support families through coaching and problem solving to implement strategies within daily routines. During home visits Intervention Coordinators will also provide training for Family members, In-Home Support staff, and other care givers to support consistent implementation and data collection of evidenced based interventions.	Training and education materials for parents
		Parenting education
		Sensory equipment
		Tutors
		Safety Equipment
		Travel tools
		Self-care equipment
		Timers
		Visual Representation systems
		Language comprehension equipment
		Registration and related expenses for workshops
		Training to improve independent living skills
		Employment opportunities
		Executive and social skills

Attachment #22





February 12, 2013

## PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "database" insert "and an autism spectrum disorder voucher program"

Page 1, line 2, replace "direct the department of human services to seek an autism spectrum disorder medicaid waiver" with "provide for a department of human services study and report to the legislative management"

Page 1, line 7, after line 7, insert

"1."

Page 1, after line 13, insert:

- "2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:

  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep all records of the database which could be used to identify a reported individual confidential; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

**SECTION 2.****Autism spectrum disorder voucher program.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age eighteen who have



been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills.

2. The department shall adopt rules addressing management of the program and establishing the eligibility requirements and exclusions for this voucher program.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals with nondevelopmental disability autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study."

Page 1, remove lines 21 through 24

Page 2, remove lines 1 through 3

Page 2, line 6, replace "\$494,135" with "\$400,000"

Page 2, line 8, remove "and an assistant"

Page 2, line 12, replace "two" with "one"

Page 2, line 13, replace "positions" with "position"

Page 2, line 17, replace "\$158,032" with "\$500,000"

Page 2, line 19, after the second comma insert "school staff training,"

Page 2, remove lines 21 through 30

Page 3, remove lines 1 and 2

Renumber accordingly

13.0192.03004  
Title.

Prepared by the Legislative Council staff for  
Senator J. Lee  
February 12, 2013

PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a department of human services study and report to the legislative management; and to provide an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1.

**Autism spectrum disorder database - Rulemaking - Confidentiality.**

1. The state department of health shall establish and administer an autism spectrum disorder database. The database must include a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable research and analysis of the autism spectrum disorder, and provide services to individuals with an autism spectrum disorder.
2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the

receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

## **SECTION 2.**

### **Autism spectrum disorder voucher program - Appeal.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age twenty-two who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills.
2. The department shall adopt rules addressing management of this voucher program and establishing the eligibility requirements and exclusions for this voucher program.
3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.

**SECTION 4. APPROPRIATION - STATE DEPARTMENT OF HEALTH - AUTISM SPECTRUM DISORDER DATABASE.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the sum as may be necessary, to the state department of health for the purpose of establishing and administering an autism spectrum disorder database, for the biennium beginning July 1, 2013, and ending June 30, 2015. The state department of health is authorized one full-time equivalent position for this purpose.

**SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$400,000, or so much of the sum as may be necessary, to the department of human services for the purpose of hiring a state autism coordinator who would be responsible for implementing a resource and service center to provide information and services for individuals with autism spectrum disorder, developing a statewide outreach plan, conducting regional meetings and an annual conference, and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and ending June 30,

2015. The department of human services is authorized one full-time equivalent position for this purpose.

**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$500,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015."

Renumber accordingly



13.0192.03005  
Title.

Prepared by the Legislative Council staff for  
Senator Axness  
February 12, 2013

PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a department of human services study and report to the legislative management; and to provide an appropriation.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

**SECTION 1.**

**Autism spectrum disorder database - Rulemaking - Confidentiality.**

1. The state department of health shall establish and administer an autism spectrum disorder database. The database must include a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable research and analysis of the autism spectrum disorder, and provide services to individuals with an autism spectrum disorder.
2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the

#26

receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

## **SECTION 2.**

### **Autism spectrum disorder voucher program - Appeal.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age twenty-two who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language-generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self-care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills. In determining the amount of a voucher for which an applicant may be determined eligible under this section, the department shall consider the applicant's level of functioning.
2. The department shall adopt rules addressing management of this voucher program and establishing the eligibility requirements and exclusions for this voucher program.
3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.

**SECTION 4. APPROPRIATION - STATE DEPARTMENT OF HEALTH - AUTISM SPECTRUM DISORDER DATABASE.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the sum as may be necessary, to the state department of health for the purpose of establishing and administering an autism spectrum disorder database, for the biennium beginning July 1, 2013, and ending June 30, 2015. The state department of health is authorized one full-time equivalent position for this purpose.

**SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATE AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$400,000, or so much of the sum as may be necessary, to the department of human services for the purpose of hiring a state autism coordinator who would be responsible for implementing a resource and service center to provide information and services for individuals with autism spectrum disorder, developing a statewide outreach plan,

conducting regional meetings and an annual conference, and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and ending June 30, 2015. The department of human services is authorized one full-time equivalent position for this purpose.

**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$500,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015."

Renumber accordingly



February 13, 2013

## PROPOSED AMENDMENTS TO SENATE BILL NO. 2193

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a department of human services study and report to the legislative management; and to provide an appropriation.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:****SECTION 1.****Autism spectrum disorder database - Rulemaking - Confidentiality.**

1. The state department of health shall establish and administer an autism spectrum disorder database. The database must include a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable research and analysis of the autism spectrum disorder, and provide services to individuals with an autism spectrum disorder.
2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the

receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

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2. The department shall adopt rules addressing management of this voucher program and establishing the eligibility requirements and exclusions for this voucher program. The program may not provide a voucher for early intensive behavioral intervention, including applied behavioral analysis, intensive early interventional behavioral therapy, intensive behavioral intervention, the Lovaas method, the Denver model, LEAP (learning experiences - an alternative program for preschoolers and parents), TEACCH (treatment and education of autistic and related communication handicapped children), pivotal response training, or discrete trial training.
3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.

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**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$500,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015."

Renumber accordingly



*Anne Hansen*

C E N T E R

Nurturing abilities. Changing lives.

## **Autism Voucher Program**

*Compiled 1/18/13*

The Autism Voucher Program will provide a mechanism for people who have Autism Spectrum Disorders and their families to secure services critical to assuring health, safety, well-being, educational success, vocational fulfillment and maximum independence. The voucher system will include an individualized plan of supports and services designed to meet the needs and goals of individuals who are living with an autism spectrum disorder. The plan is based on the preferences, interests, talents, attributes and needs of each individual.

The vouchers will enable individuals on the autism spectrum and their families to access goods and services to cover a range of home and community-based services that will benefit the individual with autism spectrum disorder to function successfully in their home, school, job and community.

Services in voucher program will be provided to individuals on the spectrum regardless of ID/DD designation including individuals who only qualify for DD case management.

### **Structure of North Dakota's Autism Voucher Program**

#### **Administering Agency/Case Management Services:**

- Case managers will be identified and appropriately trained to understand the needs of individuals with an Autism Spectrum Disorder and how to effectively work with them and their family, caregiver, or guardian. Adequate financial support will be given to train and provide resources for these case managers.

Available Funds:

- Each person who participates in the Autism Voucher Program will receive up to \$30,000 annually to access supports and services that are available within the voucher program.

Age Ranges:

- Two age groups are identified for focused interventions:
  - Birth – 18 years of age (children and young adults)
  - 19 years of age – end of life (adults)

Available Slots:

- **50** voucher slots will be available for those from birth – 18 years of age.
- **25** voucher slots will be available for those from 19 years of age – end of life

\*Slots in both age groups will be made available to those who do not qualify for funding under any other state autism waiver services program.

Covered Services for Children and Young Adults:

- Diagnostic services
- Program evaluations and assessment to determine appropriate interventions
- Program planning and development
- Direct treatment and intervention
- Behavior support plan development and implementation
- Mental health services
- Occupational therapy and equipment
- Speech and language services
- Assistive technology
- Program management
- Transportation

Covered Services for Adults:

- Diagnostic services
- Program evaluations and assessments
- Mental health services
- Occupational therapy and equipment
- Employment counseling and job readiness supports
- Life skills education and coaching/independent living services
- Transportation

Eligibility for the Autism Voucher Program:

- The individual must have been a resident of North Dakota for a minimum of six months. (If a child younger than 6 months of age is referred, the child must be a resident of North Dakota at the time of referral.)
- A current diagnosis of Autism Spectrum Disorder as confirmed by a qualified clinician.
- A referral must be made for diagnostics to determine eligibility.
  - Individuals referred for diagnostics must be screened through a local healthcare provider or school personnel utilizing standard screening tools to determine if they are at risk of carrying the diagnosis.
  - Criteria for diagnostics:
    - Qualified clinician(s) must complete the diagnostic evaluation. A diagnostic team approach is preferred and includes a clinical psychologist or pediatrician, a behavioral specialist, a speech and language pathologist, an occupational therapist, and an early interventionist or special educator, as appropriate.
    - Formal diagnostic assessments or tools utilized will be based on industry standards for best practices.
    - The tests used must be considered valid for the age of the individual and diagnosis given.
    - The evaluation must support that the individual is a candidate for services identified within the voucher program.
    - The evaluation must have been completed no more than one year prior to application for Autism Voucher funding for services.
- The diagnostic evaluation results must identify that the individual has a diagnosis of an Autism Spectrum Disorder in order to be determined eligible for continued services under this voucher program.
- The evaluation must include supporting documentation that includes a DSM-IV-R diagnosis (or DSM-5 diagnosis once published) and identification of testing tools utilized during evaluation.

Plan of Care:

A Plan of Care will be developed with the individual who has an Autism Spectrum Disorder and/or their family, caregiver or guardian. The Plan of Care must contain the following information:

- Specific services to be provided, utilizing evidence-based services as appropriate
- The frequency of each service
- Who will provide each service
- The cost of each service

Intervention and Treatment including Behavioral Services:

- The treatment and intervention program is person-centered and includes direct service support for the individual and family.
- The environment for services may be center or clinic-based, home and community based, or a combination thereof.
- The center or clinic-based program consists of the individual activity and group activity.
- The home and community based program consists of individual activity embedded in structured routines within the natural environments and natural routines to teach skills.
- The basis of interventions and treatments utilized employ established evidence-based programs.
- The interventions and treatment will offer curriculum that addresses behavior supports, social skills, vocational skills, adaptive living and pre-academic or academic skills.
- Other emerging evidence-based treatments and interventions may be incorporated into the individual's program plan, based on the individual needs and as deemed appropriate to meet the needs of the individual and their family.
- Occupational, physical, and speech therapy may be provided.
- Programs are integrated and followed consistently in order to provide the maximum benefit for the individual and their family.

Provider Qualifications:

- Provider qualifications and provider selection will be completed through an application process similar to current ND Medicaid provider requirements.
- Intervention and treatment services are provided through entities licensed as a provider in the state of North Dakota.
- Providers must have a substantive program business plan identifying specific intervention, services and treatment utilized.
- The services must adhere to evidence-based treatments and interventions and may be provided in individual or group sessions, in a clinic setting or an individual's home.

- The provider personnel may be a psychologist, pediatrician, early interventionist specialist, speech and language pathologist, occupational therapist, or hold a bachelor's degree in an education or human services related field, and must be licensed in the state of North Dakota, pertinent to their area of expertise and service provision.
- All intervention and treatment programs must have oversight by a clinical psychologist licensed at the doctoral level.

#### Outcomes:

Outcomes will be measured through routine review of the individual's Plan of Care which will include individualized goals and objectives that are measurable and address areas including:

- Increased social competencies
- Increased competencies in academic and pre-academic areas
- Increased competencies in adaptive and independent living skills
- Reduction in challenging behaviors

#### Quality Indicators:

- Quality of the services will be measured through evidence of outcomes achieved per individual plans.
- Clinical oversight of the program by a licensed clinical psychologist will assure integrity of the services.
- Client satisfaction surveys will indicate level of success as a result of services.

#### Cost of the Autism Voucher Program for the 2013-2015 biennium:

- Total cost is \$4,500,000.
- The per unit cost (cost of 1 hour of service) is \$45.00 for direct intervention services.

2-19-13

## SB 2193

Chairman Holmberg and Members of the Senate Appropriations Committee:

I am Senator Joan Heckaman from New Rockford and I represent District 23.

I am here this morning to introduce SB 2193 to you. This bill started from the culmination of 3 ½ years of work by the Governor's Autism Task Force established by SB 2174 during the 2009 Legislative Session.

Since its organization, the Task Force has met quarterly to determine the current services available in North Dakota, survey the needs in the state and develop a comprehensive plan for services to individuals with autism.

The work of the Task Force resulted in North Dakota's first State Autism Plan. This plan was presented to Governor Hoeven in the summer of 2010. Following the development of that initial 1st plan, the Task Force continued to meet and develop recommendations for legislation that were presented during the 2011-2012 Interim.

The bill before you today has undergone some changes in committee and I would like to thank the Human Services Committee for their attention to this bill as well as their extensive work on the bill.

Intervention at any stage is important for individuals with Autism. But early evaluation, diagnosis, and intervention prove significantly more successful.

I ask for your support and careful attention to SB 2193.



Chairman Holmberg and Members of the Senate Appropriations Committee:

I am Dr. Barbara Stanton. I am employed at Prairie at St. John's as an outpatient therapist specializing in autism spectrum disorders (ASDs). I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I also conduct trainings and workshops about autism for mental health professionals, educators, law enforcement, early childhood educators, daycare providers, religious organizations, and the community at large.

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families.

I speak in favor of **Senate Bill 2193** which provides appropriations for the establishment of a database for autism spectrum disorders, a voucher program, an on-going study of ASDs, a coordinator, and funding to train physicians, school staff, regional trainings and parents.

#### Continuing Study on Autism Spectrum Disorders: Section 3

\*Autism is a complicated neurological disorder that impacts communication skills, social interactions, and behavior. It is a lifelong disorder. There is a genetic basis to autism.

\*Every week new research studies are published. It is important to continually monitor this research and advances in evidence based assessments and interventions.

\*The Center for Disease Control reported in May of 2012 that 1 in 88 children meet the criteria for an autism spectrum disorder; 1 in 54 boys. Of those, 30 – 40% are considered to have high functioning autism. Autism is more prevalent than childhood cancers, multiple sclerosis and cystic fibrosis combined.

\*Autism is a spectrum disorder in which there is great variation in individual differences.

While there have been advances in research there are gaps in our understanding of autism such as causation, public concerns of health and safety including issues ranging from obesity to mental health, legal issues, efficacy of interventions, transitions to independence, employment and building public private partnerships; just to name a few. Continuing to study this complicated issue is essential. It will

be critical to include professionals with expertise and experience working with individuals with an ASD, individuals with an autism spectrum disorder and families impacted by autism.

#### Autism Database: Section 1

A registry is a necessary element to better understand the number of individuals diagnosed with an autism spectrum disorder. There is currently no tracking system in the state. Having accurate data is essential to plan future services, access funding, and give us the opportunity for data sharing. It will benefit families and the state.

By having professionals who are qualified to make a medical diagnosis of autism mandated to provide data is an effective means to monitor the numbers of individuals in the state who are impacted by autism. Safeguards will be put into place to guard the privacy of individuals registered. Mandating this process is essential to insure that we have an accurate input of data.

#### Autism Spectrum Disorder Training and Support: Section 6

Adequate training of professionals is essential in understanding how to appropriately identify individuals with an ASD as soon as possible. Physicians are often the first to see children and it is critical for them to be able to recognize the signs of autism. The Center for Disease Control and the American Academy of Pediatrics have excellent materials for physicians. I have attached a copy of a flow chart from the American Academy of Pediatrics to identify autism and steps to take.

Assessments for ASDs need to be done by someone who is qualified to make diagnoses based on training and credentials and are familiar with ASDs. These are the professionals who can use evidence based assessments to identify an ASD and provide evidence based interventions. They also must be able to differentiate between symptoms that are a part of the autism or may be a separate diagnosis;

someone who can make appropriate referrals for additional evaluations when necessary.

Two of the most important groups who need training are those who work in schools and parents.

Autism spectrum disorders are present from birth or very early in development. Although the exact neurobiological mechanisms have not yet been established, it is clear that autism spectrum disorders reflect differences in the developing brain. Autism is unique in the pattern of deficits and areas of strengths. It has lifelong effects on how children learn to be independent and to participate in their community. In many cases, autism can occur along with intellectual disabilities, language disorders, and other medical and mental health issues. For individuals with high functioning forms of autism the disability is hidden but severe none the less. Thus, educational planning must address both the needs typically associated with autistic disorders and needs associated with accompanying disabilities. Educational goals for these students, as part of addressing independence and social responsibility, often need to address language, social, executive skills and adaptive goals that are not part of standard curriculum. Without intending it to be so, the educational setting is currently the primary location of treatment for children with autism spectrum disorders.

One of the biggest challenges facing children on the autism spectrum is attending school. This includes pre-school to high school. As I work with school staff, I hear about the struggles they have in understanding and providing services to children with autism spectrum disorders. Parents are caught in these struggles. They get frequent, sometimes daily, calls from the school as their children show challenging behaviors that impact the learning of their child and other children in the school. Without proper interventions these children can be delayed in their learning and suffer stress that leads to overwhelming anxiety and depression.

Many children with autism are gifted in math, science and the arts. Due to the neurological differences inherent in individuals with autism they often learn differently, struggle with sensory issues, mental

flexibility, cannot navigate the social environment, cannot establish relationships with others, and have trouble communicating their needs. Many problems arise due to delays in emotional development and trouble expressing their emotions. These are children who love to learn but hate school.

In order to make informed decisions for their children parents need accurate information and an understanding of their options.

### Voucher System: Section 2

In 2011 The Autism Society of America stated in a memo to congress:

“Moving to a voucher-based system will significantly improve the quality of services and care, eliminate fraud and abuse, and improve access to the ever-shrinking pool of healthcare providers willing to accept Medicaid reimbursement rates. A voucher-based system would allow people to receive care on the private market, decreasing the financial burden on federal and state governments.”

There are many essential services for children and adults with autism spectrum disorders that are not covered by insurance nor are they provided in school. There are many adults, and some children, who do not have insurance to access critical medical and mental health care. Many need equipment such as educational materials, sensory equipment, visual aids, safety equipment, assistive technology, and speech generating devices. This equipment must be purchased by the family.

Every day I hear the stories from families who are desperate to find services for their children with autism. Many of them drive for hours from both urban and rural areas of North Dakota to see me. And as difficult as it is to get services for children, for adults the situation is even more dire. These are not services to make life easier or more convenient. These are services that can determine success or failure; life or death.

It is my belief that a voucher system will encourage providers across the state to receive appropriate

training and offer services to individuals with autism. Many of my colleagues in North Dakota, who are licensed mental health practitioners, do not have the training to work with autism nor are they Medicaid eligible providers. Many children and adults with an autism spectrum disorder have co-morbid mental health issues so access to care is essential. I recently had a 13 year boy, who is intelligent and talented, tell me that he'd rather be dead than have autism. I wish I could tell you that this is an isolated situation. It is not. Every day is a struggle for individuals on the spectrum as they try to fit into a world that does not understand them. There is an 80-90% divorce rate for parents of children with special needs. Many families do not get services because they can't afford the transportation. Specially trained childcare and respite services are scarce and those that exist are expensive.

In a study by the Harvard Department of Public Health it was found that the direct medical and non-medical costs of autism ranged from \$38,000 – 100,000 for each autistic individual per year. This does not include costs to the school system which can be around \$40,000 per student per year. The indirect costs which include lost productivity/wages can range from \$40,000 – 130,000 per family per year. The total cost of autism can be \$3.2 million over their lifetime. The fiscal note of this bill reduces these costs as less expensive institutional care will be required.

Of the 34 appointments that I had scheduled last week, 30 appointments were with children under age 18. Of those, 3 are in therapeutic foster care, 1 is in a family foster care situation, 4 are involved in the judicial system, 1 is being referred to an out of state residential program, 1 is in a partial hospitalization program (after being inpatient), 28 are receiving special education services and 1 was under age 5. With the proper supports most of them could have been maintained at home or require a lower level of care. Of the 4 young adults I saw; 3 are in residential/group home placements, 1 is in partial hospitalization, 2 of them are involved in the legal system, and 2 are unemployed. (I have attached a page listing the cost of services.)

It will be cost effective to be pro-active in providing access to services. Without appropriate interventions that are provided in a timely and efficient manner these individuals are more likely to become a part of the legal, mental health or disability system thereby adding to the cost of these programs. For children the costs include additional educational services and out of home placements at the expense of the state.

By providing proper services from trained professionals and giving supports to individuals and families thereby decreasing the demand on public services there will be significant financial savings. The benefits to individuals with autism and their families are immeasurable.

The funding left in the bill will not meet the full need in North Dakota. However it will point us in the right direction as we develop other services and supports and we learn more because of the services outlined in this bill. I ask you to vote yes on Senate Bill 2193.



**Costs Associated with Services to Children with an Autism Spectrum Disorder:**

Therapeutic Foster Care:	\$97.11 per day or \$2910 per month or \$34,920 per year
County Foster Care:	\$23-26 per day or \$695 – 875 per month (depends on age)
Dakota Boys and Girls Ranch	\$302 per day or \$9060 per month or \$108,720 per year
Prairie Learning Center	\$174 per day or \$5220 per month or \$62,640 per year
Lake Oahe Group Home Of Standing Rock Nation	\$164 per day or \$4920 per month or \$59,040 per year
Inpatient hospitalization:	\$1,618 per day or \$11,326 per week
ASD Specialized Residential Out of State placement	\$762 per day or \$22,860 per month or \$278,130 per year (more for 1:1 staffing)

# Surveillance and Screening Algorithm: Autism Spectrum Disorders (ASDs)

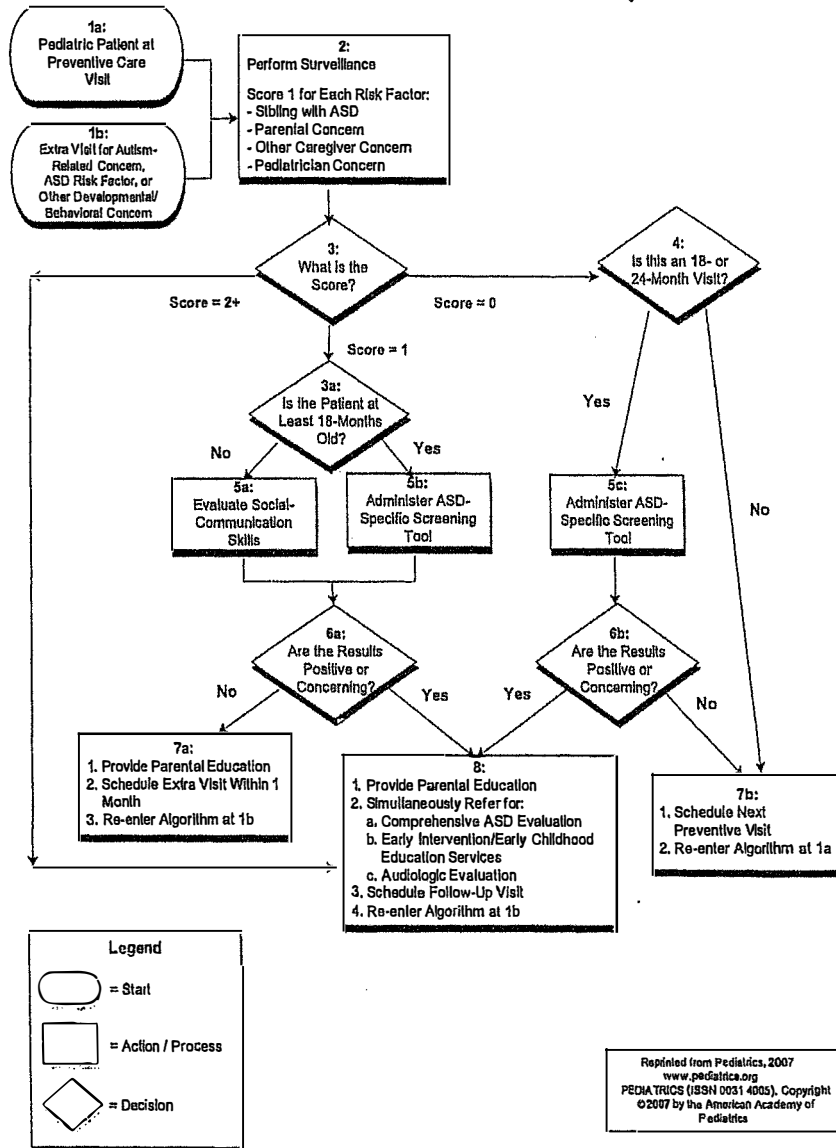


FIGURE 1  
Surveillance and screening algorithm: ASDs.

## **Senate Appropriations**

**February 19, 2013**

**SB 2193**

Good morning. Chairman Holmberg and members of Senate Appropriations, I am Christine Hogan, a lawyer for the Protection & Advocacy Project (P&A), an independent state agency that advocates for the rights of individuals with disabilities.

P&A has been very involved with the Governor's Task Force, families, and service providers in addressing the issue of services for individuals with diagnoses on the autism spectrum disorder (ASD) and their families. Children ages three up to age five may be covered under the ASD Medicaid waiver. Once they "age out," these children may or may not be covered by the traditional Developmental Disabilities Medicaid waiver. In my own experience representing these 5 year-olds, they are determined not to be eligible for the DD waiver. Ones who are not covered are left with no services available to them outside of the school system. The school system does not look at service needs beyond what the child might need in order to benefit from education. The school does not address what a child and family might need outside of the school day.

While the current bill, as amended by Senate Human Services, continues to need some changes, we are pleased at the progress being made. We hope to have continued discussions with the House Human Services Committee on policy issues. This includes the list of services that may be covered by the voucher system (which needs to include behavior therapy and respite) as well as removing the list of excluded "intensive behavioral interventions" and substituting that the therapies must be "evidenced-based" or "promising practices."

We have not yet seen the revised fiscal note for this bill. As a result, we do not yet know the specifics included for either voucher funding or whom it is intended to cover. While discussions seemed to focus on serving so-called ASD waiver "graduates," this would address the needs of a very small group of children. Following a two-year Legislative interim study, families need to see a more comprehensive outcome.

We ask that you support SB 2193 so the bill may move forward and receive further discussion and scrutiny. Thank you for your interest in this important issue.

3

**Testimony**  
**Senate Bill 2193**  
**Senate Human Services Committee**  
**Senator Ray Holmberg, Chairman**  
**February 19, 2013**

Chairman Holmberg 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 children and youth with an Autism Spectrum Disorder and their families. I am also the parent to a young man with Pervasive Developmental Disorder (NOS) which is an Autism Spectrum Disorder.

NDFFCMH supports the establishment of the following:

- Autism spectrum disorder database
- Autism spectrum disorder pilot voucher program
- Study for a department of human services.
- Comprehensive training effort.

The autism spectrum disorder database will enable the state to better understand and provide services to individuals with an ASD. Having a comprehensive training effort in our state will be very helpful. Individuals have many missed opportunities due to the lack of training and understanding. Families need to understand autism and how it impacts their family member. As well as providers that individuals come in contact with.

A pilot voucher program will allow us to serve children who are graduating from the current autism waiver. We believe it should be expanded to include others not just children coming off



the waiver. We also believe that DHS should establish a process to determine evidence based practices and promising practices and we should not list exclusions. Finally NDFFCMH supports a study from the DHS to look at the best way to provide services to individuals with ASD.

To truly help individuals with ASD all people involved in their lives must understand the uniqueness of ASD in order to meet their needs. The way we always do it simply will not work for individuals with an ASD.

Thank you for your time.

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

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Email: [carlottamccleary@bis.midco.net](mailto:carlottamccleary@bis.midco.net)

SB 2193

<b>National Autism Center's National Standards Report Reference Sheet for Established, Emerging, &amp; Unestablished Interventions for Autism Spectrum Disorders (2009)</b> From: <a href="http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf">http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf</a>		
<b>Type of Intervention</b>	<b>Ages</b>	<b>Diagnostic Classification</b> (Autistic Disorder (AD), Aspergers Syndrome (AS), Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS))
<b><u>Established Treatments</u></b>		
Antecedent Package	3-18	AD
Behavioral Package	0-21	AD; PDD-NOS
Comprehensive Behavioral Treatment for Young Children	0-9	AD; PDD-NOS
Joint Attention Intervention	0-5	AD; PDD-NOS
Modeling	3-18	AD; AS; PDD-NOS
Naturalistic Teaching Strategies	0-9	AD; PDD-NOS
Peer Training Package	3-14	AD; PDD-NOS
Pivotal Response Treatment	3-9	AD
Schedules	3-14	AD
Self-management	3-18	AD
Story-based Intervention Package	6-14	AD; AS
<b><u>Emerging Treatments</u></b>		
Augmentative and Alternative Communication Device	3-9	AD
Cognitive Behavioral Intervention Package	6-18	AD; AS
Developmental Relationship-based Treatment	0-5	AD; PDD-NOS
Exercise	3-14	AD
Exposure Package	3-5	AD
Imitation-based Interaction	0-14	AD
Initiation Training	6-14	AD; AS; PDD-NOS
Language Training (Production)	3-9	AD
Massage/Touch Therapy	3-5	AD
Multi-component Package	0-9	AD; AS; PDD-NOS
Music Therapy	N/A	AD
Peer-mediated Instructional Arrangement	6-9	AD
Picture Exchange Communication System	0-9	AD; PDD-NOS
Reductive Package	N/A	AD
Scripting	6-14	AD
Sign Instruction	3-9	AD
Social Communication Intervention	0-5	AD
Social Skills Package	3-18	AD; AS; PDD-NOS
Structured Teaching	0-18	AD; PDD-NOS
Technology-based Treatment	6-14	AD
Theory of Mind Training	6-14	AD; AS



<b><u>Unestablished Treatments</u></b>		
Academic Interventions	N/A	N/A
Auditory Integration Training	N/A	N/A
Facilitated Communication	N/A	N/A
Gluten- and Casein-Free Diet	N/A	N/A
Sensory Integrative Package	N/A	N/A

#1

SB 2193

Chairman Weisz and Members of the House Human Services Committee:

I am Senator Joan Heckaman from New Rockford and I represent District 23.

I am here this morning to introduce SB 2193 to you. This bill is the culmination of 3 ½ years of work by the Governor's Autism Task Force established by SB 2174 during the 2009 Legislative Session.

Since its organization, the Task Force met quarterly to determine the current services available in North Dakota, survey the needs in the state, and develop a comprehensive plan for services for individuals with autism.

The work of the Task Force resulted in North Dakota's first State Autism Plan. This plan was presented to Governor Hoeven in the summer of 2010. Following the development of the initial plan, the Task Force continued to meet and develop recommendations for legislation that were presented during the 2011-12 interim.

The bill before you today has undergone some changes in committee and I would like to thank the Senate Human Services Committee for their attention to this bill as well as the many stakeholders who have spent a significant amount of time working to get services to individuals and families across the state.

Intervention at any state is important for individuals with Autism. But early evaluation, diagnosis, and intervention prove significantly more successful.

I ask for your support and careful attention to SB 2193.

#2

SB 2193  
House Human Services Committee  
March 12, 2013

Good afternoon Chairman Weisz and members of the House Human Services Committee. I am Teresa Larsen, the Director of the Protection and Advocacy Project (P&A). I am also a member of the Autism Spectrum Disorder (ASD) Task Force. I am testifying on behalf of P&A in support of SB 2193.

That being said, there have been a number of issues causing consternation amongst stakeholders with regard to ASD legislation. As Senator Judy Lee said when the bill left Senate Human Services, it is a work in progress.

Since February 1<sup>st</sup>, a diversified group has met numerous times to work towards achieving consensus on language for SB 2193. Participants include: Dr. Barbara Stanton (Prairie St. John); Kris Wallman (Autism Society ND); JoAnne Vieweg (Red River Valley Asperger-Autism Network); Carlotta McCleary (Federation of Families for Children's Mental Health); Donene Feist (Family Voices ND); Vicki Peterson (parent); Eric Monson, Lorena Poppe, and Marcia Gums (Anne Carlsen); Cathy Haarstad (Pathfinder Parent Center); and me. Many, if not all, of these individuals are here today.

We have achieved success in reaching consensus on language on many sections of the bill. Our 'marked up' version provides the details, which I will walk through with you.

- SECTION 1.
  - Paragraph 1. In response to reported individual and parental concerns with the database, our group recommends removing "research" as one of the identified purposes. Adding the word "data" makes it clearer that this is what is being analyzed – not people. Our consensus group strongly recommends that the Department provide outreach and education to families with regard to confidentiality and the database.
  - Paragraph 2. We recommend removing the word "reporter" and replacing it with "diagnostician". Many individuals are evaluated out-of-state where the physicians will not be aware of the database in ND.

The diagnostician will need to meet the established criteria but the actual reporter will not.

- SECTION 2. This is the section where the group did not come to full consensus.
  - Paragraph 1. The revised paragraph (in green) provides broader language that allows an individual's team to develop a plan for needed supports and services, including evidence-based behavior intervention and treatment. The individual's assigned case manager would ensure that any services, supports, and treatment modalities are individualized and appropriate. It excludes incorporation of any aversive or abusive therapies or treatment. The intricacies can be determined through DHS rule promulgation. Opponents of this new language have expressed not wanting any behavior intervention or treatment covered by the voucher.
  - Paragraph 2. The proposed changes to this paragraph eliminate the list of excluded behavioral intervention modalities, leaving necessary details to DHS and the rule-making process. Opponents of the change believe the specific list to be necessary, removing the ability for the voucher system to provide for any behavior intervention or treatment.
- SECTION 3. The group is in agreement in removing the language entirely from this section and replacing it with the language from HB 1037, which the House has already passed. HB 1037 is more inclusive in its involvement of stakeholders in the study, which would be done by Legislative Management.
- SECTION 6. At the hearing on HB 1038 yesterday, a question was posed by Senator Lee about the funding for training. She asked how the funds in SB 2193 might be divided by DPI and DHS. Our group discussed this yesterday and recommends that \$200,000 be appropriated to DPI, which approximates the \$198,000 originally in the fiscal note for HB 1038. It is recommended that the remaining \$300,000 be appropriated to DHS. We encourage strong collaboration by these two agencies in planning and implementing training activities.

P&A supports all of the changes as 'marked up' in the hand-out. We also support the expansion of the Medicaid waiver for ASD, which we will be testifying for in the hearing for the DHS budget (HB 1012).

I am happy to answer any questions you might have for me. Thank you.

Teresa Larsen  
[tlarsen@nd.gov](mailto:tlarsen@nd.gov)  
328-2950

*Handled out  
by Teresa Larsen*

*#3*

March 12, 2013

PROPOSED AMENDMENTS TO SENATE BILL NO. 2193 (AS PASSED BY THE HOUSE)

~~Red stricken font~~ = remove    Green underlined font = insert    ☐ = consensus not achieved

A BILL for an Act to provide for the establishment of an autism spectrum disorder database and an autism spectrum disorder voucher program; to provide for a ~~department of human services~~ legislative management study ~~and report to the legislative management~~; and to provide an appropriation.

**BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:**

**SECTION 1. AUTISM SPECTRUM DISORDER DATABASE - RULEMAKING - CONFIDENTIALITY.**

1. The state department of health shall establish and administer an autism spectrum disorder database. The database must include a record of all reported cases of autism spectrum disorder in the state and any other information determined relevant and appropriate by the department in order to complete epidemiologic surveys of the autism spectrum disorder, enable research and analysis of the autism spectrum disorder data, and provide services to individuals with an autism spectrum disorder.
2. The state department of health shall establish criteria regarding who is qualified to report a case of autism spectrum disorder to the database. In establishing this criteria, the department shall require that the reporter diagnostician be a doctoral-level professional and be appropriately licensed, credentialed, and experienced in the field of autism spectrum disorder, including intellectual testing and other formal evidenced-based assessments for autism spectrum disorders. The department shall consult with experts in establishing this criteria.
3. The database established under this section must:
  - a. Include the reported individual's diagnoses under the American psychiatric association's Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition; and
  - b. Include a complete physical evaluation of the reported individual, performed by a licensed physician.
4. The state health council shall adopt rules to provide for mandatory reporting to the autism spectrum disorder database and to establish reporting requirements, including timeliness requirements.
5. The state department of health shall keep confidential all records of the database which could be used to identify a reported individual; however, the department may provide these records to other state agencies as necessary to



effect the purposes of this database without regard to the confidential nature of the records. If the department provides confidential records of the database to a state agency, the department shall notify the receiving agency of the confidential nature of the records and the receiving agency shall treat these records as confidential.

## **SECTION 2. AUTISM SPECTRUM DISORDER VOUCHER PROGRAM - APPEAL.**

1. The department of human services shall establish a voucher program to assist in funding equipment and general educational needs related to autism spectrum disorder for individuals under age twenty-two who have been diagnosed with autism spectrum disorder. The program may include funding for assistive technology; video modeling videos or equipment; language generating devices; training and educational material for parents; parenting education; sensory equipment; tutors; safety equipment; travel tools; self care equipment; timers; visual representation systems; language comprehension equipment; and registration and related expenses for workshops and training to improve independent living skills, employment opportunities, and other executive or social skills. In determining the amount of a voucher for which an applicant may be determined eligible under this section, the department shall consider the applicant's level of functioning.

1. The department of human services shall establish a voucher program to assist individuals with autism spectrum disorder from birth through age twenty-two. Through a plan developed by a team, the program will provide individualized appropriate services, therapies, and other supports designed to enable individuals with autism spectrum disorder to participate more fully in family and community life, as well as reduce the risks of school failure and institutionalization. The program may include funding for behavior intervention and treatment through evidence-based and promising practices, as well as in-home supports, respite care, case management services, assistive technology, and other services and supports as needed. Under this section, 'evidence-based treatments, services, and interventions' means those treatments, services, and interventions that are the result of the integration of researched evidence and clinical judgment with patient values. The program may not include aversive or abusive therapies or treatment.

2. The department shall adopt rules addressing management of this voucher program and establishing the program's eligibility requirements. The program may not provide a voucher for early intensive behavioral intervention, including applied behavioral analysis, intensive early interventional behavioral therapy, intensive behavioral intervention, the Lovaas method, the Denver model, LEAP (learning experiences—an alternative program for preschoolers and parents), TEACCH (treatment and education of autistic and related communication handicapped children), pivotal response training, or discrete trial training.

3. A decision on a voucher application which is issued by the department under this section may be appealed as provided under chapter 28-32.

**SECTION 3. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER STUDY AND REPORT TO THE LEGISLATIVE MANAGEMENT.** During the 2013-14 interim, in consultation with clinicians who have expertise in the evaluation, diagnosis, and treatment of autism spectrum disorder, the department of human services shall study autism spectrum disorder services, including the most feasible service delivery system for individuals not served in the developmental

~~disability system who have an autism spectrum disorder. Before August 1, 2014, the department of human services shall report to the legislative management the outcome and recommendations of this study.~~

**SECTION 3. LEGISLATIVE MANAGEMENT STUDY – AUTISM SPECTRUM DISORDER.** During the 2013-14 interim, the legislative management shall consider studying the current system for the diagnosis of, early treatment of, care for, and education of individuals with autism spectrum disorder. The study must continue the work of the legislative management during the 2011-12 interim on the study of the autism spectrum disorder, consider the recommendations of the autism spectrum disorder task force, and seek input from stakeholders in the private and public sectors. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-fourth legislative assembly.

**SECTION 4. APPROPRIATION - STATE DEPARTMENT OF HEALTH - AUTISM SPECTRUM DISORDER DATABASE.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$200,648, or so much of the sum as may be necessary, to the state department of health for the purpose of establishing and administering an autism spectrum disorder database, for the biennium beginning July 1, 2013, and ending June 30, 2015. The state department of health is authorized one full-time equivalent position for this purpose.

**SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES -STATE AUTISM COORDINATOR.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$400,000, or so much of the sum as may be necessary, to the department of human services for the purpose of hiring a state autism coordinator who would be responsible for implementing a resource and service center to provide information and services for individuals with autism spectrum disorder, developing a statewide outreach plan, conducting regional meetings and an annual conference, and developing a protocol for use after screenings, for the biennium beginning July 1, 2013, and ending June 30, 2015. The department of human services is authorized one full-time equivalent position for this purpose.

**SECTION 6. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - STATEWIDE AUTISM SPECTRUM DISORDER TRAINING EFFORT.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of ~~\$500,000~~ \$200,000 to the department of public instruction and \$300,000 to the department of human services, or so much of the sum as may be necessary, ~~to the department of human services~~ for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training, regional training, school staff training, and parent training, for the biennium beginning July 1, 2013, and ending June 30, 2015.

Renumber accordingly



Testimony March 12, 2013

Chairman Weisz, members of the committee, my name is Colin Vieweg. I am a 13 year old boy. I have Asperger's syndrome, an autism spectrum disorder. I am very smart and plan to be a scientist, astro-physicist, or robotics inventor when I graduate from college. I do pretty well in school, but I need help in figuring out what to do in certain social situations. Dealing with a lot of noise and commotion is also hard for me. And sometimes handling my anger is really hard. It helps a lot when teachers understand me and can help me use my calming strategies. It also helps when I can learn how to calm myself down and how to understand what people are telling me. I need help learning how to do this. I was able to talk about this at the Interim Human Service Committee last year and at the House Human Services Committee in January.

Thank you for learning about living with autism and caring about helping kids like me. My family helps me a lot, but not everyone can do that. Please pass SB2193 so that we can get more help and services.

The voucher will help us get the services our families have trouble affording. At my age, I need help getting technology that helps me calm myself and stay organized. I also need help with calming strategies. My mother tells me occupational therapy and communication therapy would help me a lot. I didn't really get the right help until I was 11 going on 12 and I still need it now. Other kids need a lot more help than I do. The voucher will really help us.

In January I got to meet Temple Grandin. She is a famous scientist who has autism. I think she helped teachers understand autism better. It helped them to hear from a person who has autism how to help and understand us.

I wish people knew this about me and Aspergers: that we're different than everybody else. We're different, but, at the same time we're the same. All of us have things that make us unique. Some people are different on the outside; others are different on the inside. My mom says that 'normal' is just a setting on a washing machine. My teacher said that maybe the kids with Aspergers are the 'normal' ones. I think that maybe both of them are right.

I have learned a lot about how a bill gets written. I really hope this bill will become law.

March 12, 2013

#5

Chairman Weisz, members of the committee, my name is JoAnne Vieweg. I am the grandmother of Colin Vieweg, a 13 year old boy with Asperger's Syndrome, a form of high functioning autism. You have met him today and previously. He and I have both had the privilege of testifying before the Interim Human Services Committee, the House Human Services Committee and the House and Senate Appropriations Committees. Colin has learned a great deal about himself over the past several years. He can better recognize the stressors that cause him trouble and he has learned to advocate for himself when he needs help or accommodations in school. While this is an on-going learning process, he feels strongly that it is his responsibility to advocate for others with autism who may not be able to speak up for themselves. We are very proud of his recognition of the value of civic responsibility.

I am a retired educator, special education teacher, school counselor, and licensed professional counselor. I am also president of the Red River Valley Asperger-Autism Network. We currently are in contact with over 98 families and individuals with a child or adult who is on the autism spectrum; and the number keeps growing. Our organization is able to provide support groups, community education, a speaker's bureau, and help with advocacy, but families still cannot afford services for their children. Adults with autism need support as well.

I am speaking today in support of SB2193 that provides for several critical opportunities to help people on the autism spectrum. A registry or data base will provide important information about how many people in the state are accurately diagnosed with autism spectrum disorder and how the needs are distributed across the state. This data base defines the professionals who are qualified to make diagnoses, thus insuring accuracy. Levels of confidentiality are guaranteed and protect the privacy of individuals.

I am particularly interested in the training component and the voucher system in this bill. My grandson's experiences in the school system have been varied. Despite good intentions, Colin had to leave the public school system in order to find a place that could best meet his needs. It is clear to us that teachers, the first line of intervention for him during the day, need good training and on-going professional development in order to know how to meet his needs. He is very smart, but learns differently and often needs extra time to process what has been asked of him and time to formulate his answer. Paraprofessionals, cafeteria aides, attendance persons, custodial staff and office personnel all have contact with him. They also need training in how best to understand him and meet his needs. Right now Colin is in an ideal situation at middle school in Fargo with an Asperger Teacher Coach who helps him and his teachers. But this service is not available in all schools.

But beyond school, there are family challenges. It has not always been easy for Colin's mother to accept the level of help that she and Colin need. I am proud to say that all of us have

worked hard to find a positive relationship that keeps Colin's needs as the focus. It took counseling and personal insight to reach this goal. We actually are living the extended family lifestyle that used to be more common.

Additionally, Colin needs a calm place to relax after a taxing day at school. Underlying his autism is a high level of anxiety over changes in schedule, unexpected events, unclear motives in social interactions, not knowing how to respond to situations, and worry when sensory things like loud noises are overwhelming. It takes all his concentration and effort to "hold it together" at school where expectations change frequently, there is a lot of noise in the halls, and each teacher has different rules and methods. When he has a "good day" at school, that means he needs time at the end of the day to decompress because it has taken all of his energy. I love being able to provide that for him, but it means I stop my other activities every weekday at 2:30 so I can pick him up from school and spend time with him until his mother finishes work.

In addition to after school care, my husband and I help with medical expenses, transportation and purchasing learning materials for him to use at home. His mother fears that if she did not have this much support she might not be able to work because of the demands of caring for her child. He could benefit from therapy for language processing and understanding what people mean, as well as occupational therapy to better manage his responses to sensory overload, but there is not enough money for that. As he gets older he will need help with transitioning to high school, college and beyond, as well as help learning to live independently. Colin is not eligible for respite care or other services outside of the school day, or supervised care over the summer because of the way the regulations are currently written. He cannot benefit from the Developmental Disability waiver for help with services because he does not have an intellectual disability even though he does have a developmental disability—autism spectrum disorder. My husband and I are spending our retirement money to insure his well being. We will continue to live nearby until Colin finishes high school, and we will have a smaller retirement fund to live from.

The voucher would help with funding the services Colin needs. The voucher needs to be a clearly focused means of providing services beyond what insurance provides, be measurable so that we have definitive evidence of its effectiveness, and be available to a wide range of people on the autism spectrum.

Training for school personnel, community providers, parents and others in contact with people in the autism spectrum is critical to "our kids". Family support organizations continue to provide service to families but the demands are increasing.

I appreciate the attention you are giving to the needs of people with autism and strongly support SB2193. I urge you to pass this bill and send it forward.

#4

Testimony in favor of SB 2193

From Chris McEwen; Board Member of the Red River Valley Autism-Asperger Network

Phone: 701-793-3528 email: chris.m.mcewen@gmail.com

This is from Chris McEwen, and I am not able to make it here today. I am having a designated representative still present this testimony though because I feel, as an adult with Aspergers Syndrome that has worked with other adults and children affected by autism spectrum disorders, that it is absolutely critical that SB 2193 gets passed.

As I stated previously when I spoke, in person, to the House Human Services Committee in support of related autism bills, I went through many issues that could have been better addressed had there been something in place like the voucher program provided for in SB 2193. I was very fortunate to have been able to adapt and adjust, but I still needed professional assistance along the way to make it through my bachelors degree. Without it, I may have had to drop out and I may not have been as able to contribute to society as well I can today.

There's also a need to make sure our teachers are trained to better approach autistic students. I was also very fortunate to have patient, tolerant teachers in high school for the most part. Others may not be as fortunate, and I strongly feel that even a modest attempt at educating our public instructors on basic autism issues can really go a long way towards bridging critical gaps. Students may be able to better adapt to the classroom environment, and teachers may be able to prevent many issues from occurring in their classrooms.

The provisions in SB 2193 will give others an opportunity that they may not have otherwise had. This could really save individuals from having to drop out of high school and college. This could help autistic individuals on disability readapt to where they can stay regularly employed.

While I, regretfully, am not able to be there, I strongly support this bill and I hope this testimony is still beneficial. Should there be questions that legislators would like to ask me directly, they would be invited to reach me via phone or email.

Thank you.



#7

Testimony on SB2193  
2013 Legislative Session  
March 12, 2013  
Rep Weisz, HS Committee Chairperson

Rep. Weisz and Members of the House Committee on Human Services

My name is Donene Feist and I am the Director for Family Voices of North Dakota. I rise today in support of the sections of SB 2193 that you have already heard testimony on today provided through Protection and Advocacy.

Family Voices of North Dakota provides emotional and informational support to many families across North Dakota who has a child with an autism spectrum disorder. Family Voices staff has provided assistance to these families through assisting them access and navigate services, providing emotional support and educational information to assist them with their various needs.

Because we are a health information and education center for all families who have a child with special health care needs and disabilities, we feel it in the best interest of the families we serve to continue to discuss the expansion of the waiver originally in 2193.

We fell there is a need for both the voucher and the expanded waiver. We feel removal of the waiver expansion is a huge mistake with unintended consequences and as such we would like the expansion of the waiver returned to the bill.

Voucher services across the country are primarily educational in nature. Voucher services may be helpful for children who are not diagnosed before the age of five of which is when the current Autism Waiver ends.

Since voucher services have an educational focus, they will not address the medical needs of children with autism spectrum disorders. There is empirical evidence that children with ASDs usually have co-occurring conditions.

A 2005 paper in Pediatrics, *Factors Associated With Age of Diagnosis Among Children With Autism Spectrum Disorders*, by David S. Mandell, ScD, Maytali M. Novak, MA, Cynthia D. Zubritsky, PhD (Vol. 116 No. 6; 1480 -1486) that reports children who reside in rural areas and children whose family income is less than 100% FPL are often diagnosed with ASDs later than other children are.

According to the National Survey of Children with Special Health Care Needs, 93.2% of children and youth with an Autism Spectrum Diagnosis have at least one other health condition. (Reference: National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH. Found at <http://childhealthdata.org/docs/drc/asd-data-brief 4.2.12.pdf>). (Enclosed handout)

Two papers below report evidence-based research about the medical care costs of children with ASDs who have co-occurring conditions.

J Dev Behav Pediatr. 2012 Jan;33(1):2-8. doi: 10.1097/DBP.0b013e31823969de.

**Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions.**

Peacock G, Amendah D, Ouyang L, Grosse SD. (enclosed handout)

96% of 3 – 17 year old children with ASDs were reported to have a co-occurring developmental condition. The most common conditions were learning disability, ADD/ADHD, mental retardation, and stuttering. Medical disorders, included: tuberous sclerosis, Down Syndrome, Fragile X, other genetic or chromosomal disorders, and birth defects) and neurologic disorders (e.g., encephalopathy, cerebral palsy, seizures or epilepsy, brain injury, vision or hearing loss, tics or Tourette syndrome).

Through the National Survey on Children with Special Health Care Needs documentation sites that children with ASDs have higher medical costs and would benefit from expanded Medicaid waiver services.

These children have medical needs and costs that will continue beyond the age of 5, which just makes sense to expand the current Medicaid autism waiver. These services pay for therapies, PT, OT, Speech, medication, nutrition, hospital and clinic services, Additionally, those who are on the current Autism waiver receive the federally mandated Early Periodic Screening Diagnostics and Treatment benefit.

Many of the children currently on the Autism Waiver will be exiting it soon, if they have not already. Many of those who will be exiting or have exited, their child's needs have not changed, but they may not screen eligible for other waived services.

Those who have exited have lost vital services that they will not find the assistance they need necessarily through the voucher nor through their private insurance plans. For an example, they may have access to a toothbrush etc to meet the child's oral needs through the voucher. However they have lost the ability to access to oral care as they are no longer on the waiver and able to access a dentist through Medicaid, and the family may be unable to afford the oral health expense they will incur through personal funds as they are drowning ongoing medical expenses for the child/youth.

Many families continue to need the in home support and respite care not currently the way voucher is currently written. These families will fall into a huge gap of services that they were able to access previously. Families lose the vital medical services through the state Medicaid plan, which they can only access if they are income eligible for Medicaid or are able to access through another waiver. For many families access to those vital core services is keeping them sustainable and afloat.

FVND fully believes discussion of expanding the ASD Medicaid Waiver needs to continue. Since the waiver was implemented not that long ago, for those who began with initial implementation, their child will age out soon. The current ASD waiver ends for children at age 5, unfortunately ASD does not end at age 5.

There are also some families who will not receive a diagnosis for their child until they have almost aged out of accessing the current waiver. They may receive a diagnosis after the age of 5 but need the vital services of the waiver and the Medicaid state plan. And yet some, may only need the services that are offered through the voucher. Hence we believe a two pronged approach is needed.

91.6 percent of children and youth with ASD have 4 or more functional limitations as compared with children with special health care needs in general. Less than 50% of families who have a child with ASD have the adequate health insurance for needed services. Many of these families are underinsured and need assistance to meet the needs of their child.

CSHCN (Children with special health care needs) with ASD generally experience a greater burden of illness in terms of types of special health care needs they have as well as the number of functional limitations and co-morbid conditions they experience compared to CSHCN without ASD. The impact for families is greater as compared to those CSHCN without ASD diagnoses.

You have heard the many statistics on costs associated for families of children with ASD. To often these children don't fit into any one criterion. The autism waiver expansion beyond the age of 5 would assist many families who fall in the gaps of obtaining services and children advancing to the best of there ability.

Waiver services also provide an additional funding stream for the state. North Dakota receives 52.27% FMAP for Medicaid services, including waiver services. Keeping the existing waiver or expanding it will generate \$1.095 in federal funds for each \$1 that ND spends.

North Dakota schools that participate in the school-based Medicaid program would be eligible to receive the federal match for Medicaid-eligible services they provide to any Medicaid eligible child including Medicaid-eligible children with ASDs. I've attached a paper that lists the Medicaid services ND provides, which include respite and targeted case management.

FVND suggests expanding the waiver to meet the ongoing needs of these children, youth and families. At minimum we would like to see the waiver expanded for those who will age out at 5 years of age. Additionally, for those who have yet to be diagnosed at the age of 5 and need the additional assistance that they can only achieve through a program such as the autism waiver.

Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child's most basic human rights.

We thank you for your consideration.

We are happy to answer any questions that you may have.

Donene Feist  
FVND Director  
701-493-2634

Part of #7

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J Dev Behav Pediatr. 2012 Jan;33(1):2-8. doi: 10.1097/DBP.0b013e31823969de.

## **Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions.**

Peacock G, Amendah D, Ouyang L, Grosse SD.

National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 1600 Clifton Road, Atlanta, GA 30333, USA.

gpeacock@cdc.gov

### **Abstract**

**OBJECTIVE:** Children with autism spectrum disorders (ASDs) often have co-occurring conditions, but little is known on the effect of those conditions on their medical care cost. Medical expenditures attributable to ASDs among Medicaid-enrolled children were calculated, and the effects of 3 commonly co-occurring conditions--intellectual disability (ID), attention deficit/hyperactivity disorder (ADHD), and epilepsy--on those expenditures were analyzed.

**METHODS:** Using MarketScan Medicaid Multi-State Databases (2003-2005) and the International Classification of Disease, Ninth Revision, children with ASD were identified. Children without ASD formed the comparison group. The 3 co-occurring conditions were identified among both the ASD and the comparison groups. Annual mean, median, and 95th percentile of total expenditures were calculated for children with ASD and the co-occurring conditions and compared with those of children without ASD. Multivariate analyses established the influence of each of those co-occurring conditions on the average expenditures for children with and without ASD.

**RESULTS:** In 2005, 47% of children with ASD had at least 1 selected co-occurring condition; attention deficit/hyperactivity disorder was the most common, at 30%. The mean medical expenditures for children with ASD were 6 times higher than those of the comparison group. Children with ASD and ID incurred expenditures 2.7 times higher than did children with ASD and no co-occurring condition.

**CONCLUSION:** Medicaid-enrolled children with ASD incurred higher medical costs than did Medicaid-enrolled children without ASD. Among Medicaid-enrolled children with ASD, cost varied substantially based on the presence of another neurodevelopmental disorder. In particular, children with ID had much higher costs than did other children with ASD.

PMID: **22157409** [PubMed - indexed for MEDLINE]

## Publication Types, MeSH Terms

## LinkOut - more resources

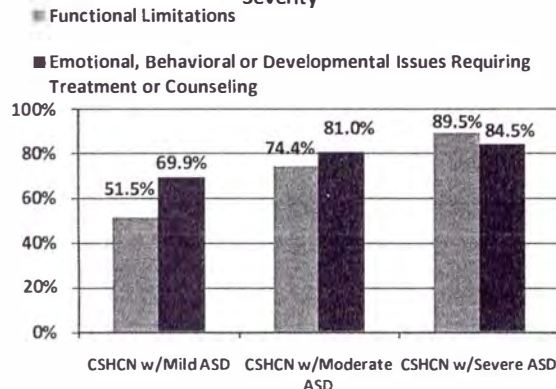


## National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH

### Who Are Children with Autism Spectrum Disorders?

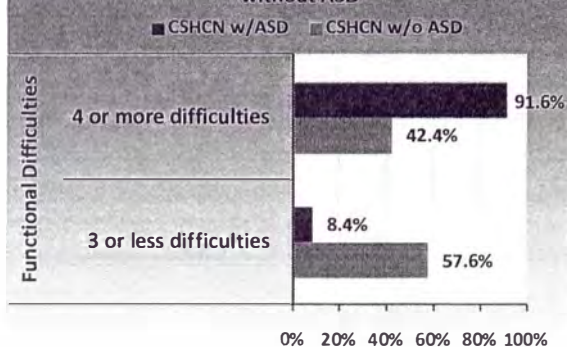
According to the Centers for Disease Control and Prevention (CDC), "Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. ... ASDs are 'spectrum disorders.' That means ASDs affect each person in different ways, and can range from very mild to severe."<sup>1</sup> Consequently, nearly all children with ASD qualify as children with special health care needs (CSHCN), because they experience at least one type of ongoing condition that results in an above routine need for health and related services.<sup>2</sup> The CSHCN Screener, which operationalizes this definition, was used in both the 2007 National Survey of Children's Health (NSCH) and 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) to identify CSHCN. Based on findings from the 2007 NSCH and 2009/10 NS-CSHCN, 4.8% to 7.9% of U.S. CSHCN age 2-17 years had current ASD.<sup>3</sup> Among CSHCN age 2-17 years, prevalence of ASD ranges across states from 4.5% in Mississippi to 14.3% in New Jersey according to data from the 2009/10 NS-CSHCN.

**Figure 1. Prevalence of Functional Limitations and Emotional, Behavioral or Developmental Issues among CSHCN with ASD by ASD Severity**



Data Source: 2009/10 NS-CSHCN

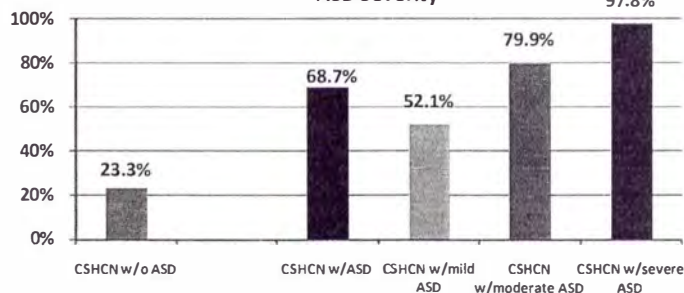
**Figure 2. Prevalence of Functional Difficulties among CSHCN with ASD Compared to CSHCN without ASD**



Data Source: 2009/10 NS-CSHCN

Four in five (80.6%) CSHCN with ASD are boys, and 71.6% of CSHCN with ASD were diagnosed between 0 – 5 years of age. Among CSHCN with ASD, parents described approximately half (49.5%) as having mild ASD, 36.2% as having moderate ASD and 14.3% as having severe ASD. Positivity bias in parent reports of child functioning may lessen the severity of conditions described.<sup>3</sup> A larger proportion of CSHCN with moderate or severe ASD experience functional limitations in their ability to do things that other children their age can do and/or emotional, behavioral or developmental (EBD) issues requiring treatment or counseling compared to CSHCN with mild ASD (Figure 1). While 65% of CSHCN with ASD experience functional limitations along with any other type of special health care need, 91.6% of CSHCN with ASD experience four or more functional difficulties from the list of 14 specific difficulties related to bodily functions, activities or participation, and emotional or behavioral factors asked about in the 2009/10 NS-CSHCN (Figure 2). Only a subset of functional difficulties lead to functional limitations. Most CSHCN with ASD (93.2%) additionally have at least one other condition from the list of 20 conditions asked about in the 2009/10 NS-CSHCN.

**Figure 3. Daily Activities Consistently Affected among CSHCN without ASD Compared to CSHCN with ASD and by ASD Severity**



Data Source: 2009/10 NS-CSHCN

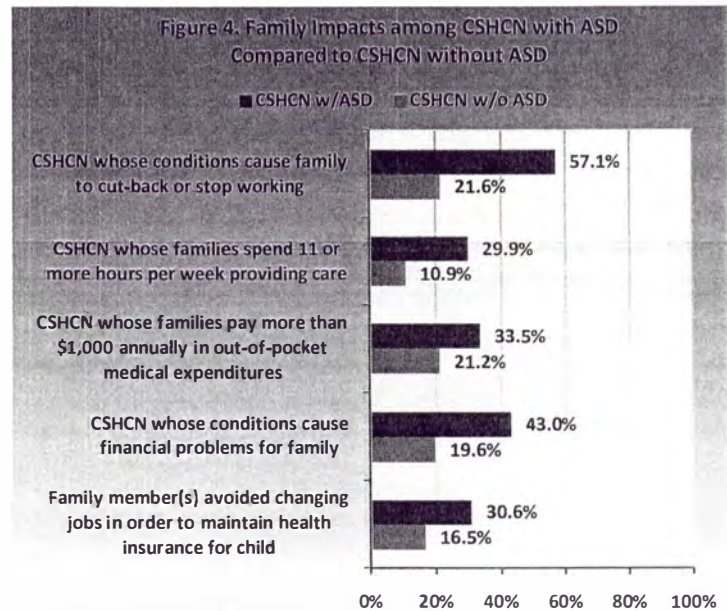
CSHCN with ASD experience complex health care needs that may influence their overall health status and daily activities. Based on 2007 NSCH data, a lower proportion of CSHCN with ASD (54.6%) were reported by their parents to have excellent or very good overall health status compared to CSHCN without ASD (70.3%) and non-CSHCN (87.4%). Further, in the 2009/10 NS-CSHCN, over two-thirds (68.7%) of CSHCN with ASD had health conditions that consistently affected their activities, often a great deal, compared to only 23.3% of CSHCN without ASD (Figure 3). Among CSHCN with severe ASD, 97.8% had conditions that consistently affected their daily activities, often a great deal, relative to 79.9% of CSHCN with moderate ASD and 52.1% of CSHCN with mild ASD.

<sup>1</sup>Variations in sampling and administration between the 2009/10 NS-CSHCN and 2007 NSCH lead to expected variations in prevalence.

Suggested Citation: Child and Adolescent Health Measurement Initiative (2012). "National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at [www.childhealthdata.org](http://www.childhealthdata.org). Revised 4/2/12.

### Impact on Families

Families of CSHCN with ASD are also impacted by their children's health care needs (Figure 4). Across all measures used to assess the impact of health system performance on families in the 2009/10 NS-CSHCN, a higher proportion CSHCN with ASD had families who were impacted by their children's special health care needs compared to families of CSHCN without ASD. Moreover, based on 2007 NSCH findings, over half (54.2%) of CSHCN with ASD had parents who reported feeling aggravated with their child once or more during the past month compared to CSHCN without ASD (18.6%) and non-CSHCN (8.2%) age 2-17 years. Parental stress varied by disease severity: 42.9% of CSHCN with mild ASD had parents who reported feeling aggravated with their child in the past month versus 63.7% of CSHCN with moderate or severe ASD.



### System of Care Performance

The federal Maternal and Child Health Bureau (MCHB) assesses health system performance for CSHCN with six core outcomes (for more information on the core outcomes, please see the [System of Care for CSHCN](#) data brief on the DRC Web site). Table 1 displays how CSHCN with ASD compare to CSHCN without ASD on each of the six core outcomes based on 2009/10 NS-CSHCN data. Among CSHCN with ASD, only 7.4% met all age-relevant core outcomes compared to 18.7% of CSHCN without ASD.

**Table 1. Health System Performance by Core Outcome\***

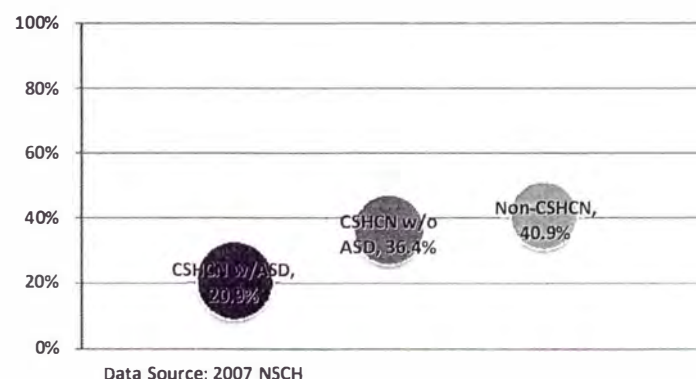
MCHB System of Care Core Outcomes	CSHCN w/ASD	CSHCN w/o ASD
Outcome #1: Families of CSHCN are partners in decision-making	56.7%	71.2%
Outcome #2: CSHCN receive care within a medical home	23.9%	44.7%
Outcome #3: CSHCN have adequate health insurance for needed services	49.4%	61.3%
Outcome #4: CSHCN are screened early and continuously for special health care needs	78.5%	80.2%
Outcome #5: Community-based service systems are easy for families of CSHCN to use	42.8%	67.1%
Outcome #6: Youth with special health care needs receive transition to adulthood services	21.1%	41.4%

\*Data Source: 2009/10 NS-CSHCN

### Minimum Quality of Care

A minimum quality of care summary measure was derived from the following three measures of health system performance in the 2007 NSCH: (1) adequate health insurance coverage; (2) receipt of coordinated, ongoing, comprehensive care within a medical home; and (3) had at least one preventive medical visit in the past 12 months. Only one in five (20.9%) CSHCN with ASD met the quality of care summary measure criteria, a lower proportion compared to CSHCN without ASD and non-CSHCN age 2-17 years (Figure 5). Among CSHCN with moderate or severe ASD, an even smaller proportion (12.9%) met the minimum quality of care summary measure criteria according to 2007 NSCH data.

**Figure 5. Children Meeting All Minimum Quality Summary Measure Criteria by CSHCN and ASD Status**

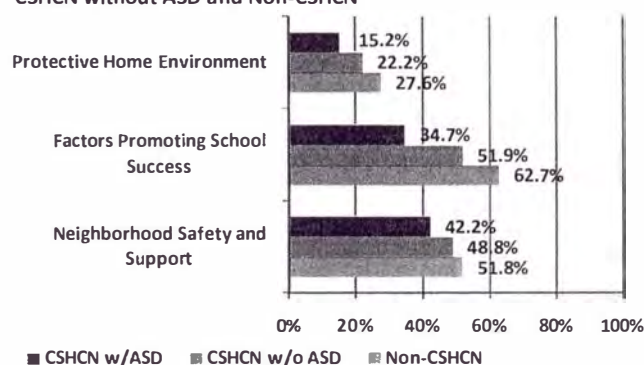




## Home, School and Neighborhood Environments

The health and well-being of each child is influenced by his or her interconnected home, school and neighborhood environments. Contextual factors from these environments and other child level factors may interact during certain periods of a child's lifespan ultimately promoting resiliency and healthy development or increasing risk for adverse health outcomes. Together, several summary measures from the 2007 NSCH provide a more comprehensive picture of how CSHCN, including those with ASD, compare to non-CSHCN in terms of their home, school and neighborhood environments.

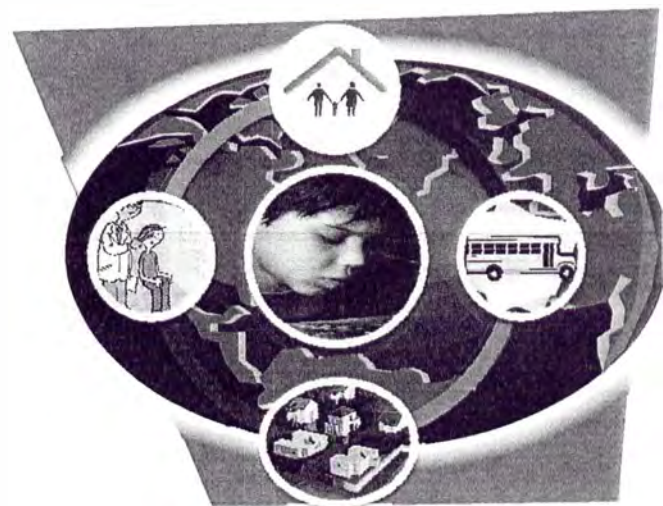
**Figure 6. Proportion of CSHCN with ASD Meeting Protective Home, Factors Promoting School Success and Neighborhood Summary Measure Criteria Compared to CSHCN without ASD and Non-CSHCN**



Data Source: 2007 NSCH

### Takeaways

- CSHCN with ASD generally experience a greater burden of illness in terms of the types of special health care needs they have as well as the number of functional difficulties and comorbid conditions they experience compared to CSHCN without ASD.
- The impact on families of CSHCN with ASD is greater than that experienced by families of CSHCN without ASD.
- CSHCN with ASD are less likely to meet each system of care core outcome and all age-relevant core outcomes compared to CSHCN without ASD.
- CSHCN with ASD are also less likely to experience a protective home environment, factors promoting school success and neighborhood safety and support compared to CSHCN without ASD and non-CSHCN.
- **System-wide improvements are needed to enhance the health and well-being of CSHCN with ASD.**



CSHCN with ASD were less likely to meet age-relevant criteria for a protective home environment<sup>a</sup> compared to CSHCN without ASD and non-CSHCN (Figure 6). CSHCN with ASD age 6-17 years were also less likely to experience factors promoting school success<sup>b</sup> than school-age CSHCN without ASD and non-CSHCN. On the neighborhood safety and support summary measure<sup>c</sup>, CSHCN with ASD were less likely than CSHCN without ASD and non-CSHCN to meet all age-relevant criteria.

### Protective Home, Factors Promoting School Success and Neighborhood Safety and Support Summary Measures Criteria

<sup>a</sup>Protective home environment was measured using the following age-relevant criteria: (1) no exposure to household smoking; (2) family shares meals on four or more days per week; (3) children watch less than two hours of television per day (age 1-17); (4a) children are read/sung to every day (age 0-5); (4b) children have no television in bedroom (age 6-17); (5a) children were breastfed ever (age 0-5); (5b) children usually/always do required homework (age 6-17); and (6b) parents of children have met most/all of child's friends (age 6-17).

<sup>b</sup>Factors promoting school success were measured only among children age 6-17 years using the following criteria: (1) children were usually/always engaged in school; (2) children participated in extracurricular activities; and (3) usually/always felt safe at school.

<sup>c</sup>Neighborhood safety and support were measured using the following age-relevant criteria: (1) neighborhood is usually/always safe; (2) neighborhood is supportive; (3) neighborhood includes three or more amenities essential to childhood; and (4) school-age children attend safe schools (age 6-17).

## References

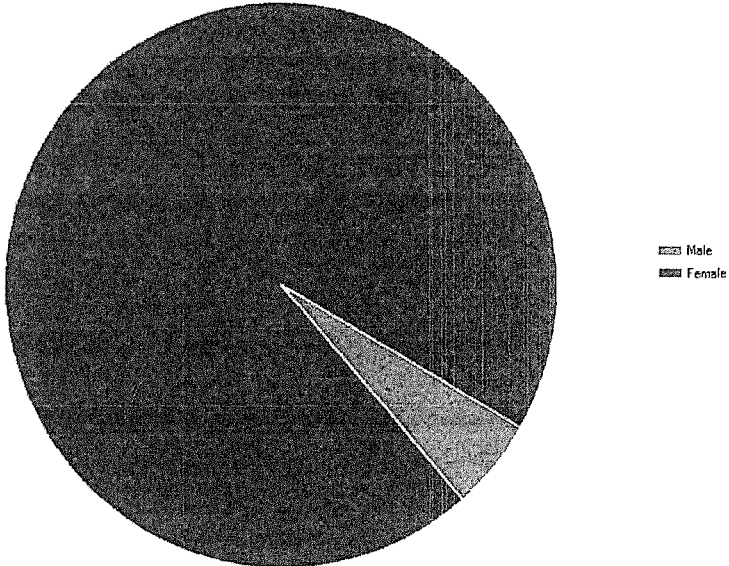
- <sup>1</sup>CDC, 2010. Autism Spectrum Disorders (ASDs). "Signs and Symptoms" Web page. Available at <http://www.cdc.gov/ncbddd/autism/signs.html>. Accessed March 21, 2012.
- <sup>2</sup>McPherson, M, Arango, P, Fox, H, et al. "A new definition of children with special health care needs." *Pediatrics*, 1998;102:137-140.
- <sup>3</sup>Simon, AE, Chan, KS, & Forrest, CB. "Assessment of children's health-related quality of life in the United States with a multidimensional index." *Pediatrics*, 2008;121:118-26.

Suggested Citation: Child and Adolescent Health Measurement Initiative (2012). "National Profile of Children with Special Health Care Needs and Autism Spectrum Disorders: Key Findings from the 2009/10 NS-CSHCN & 2007 NSCH." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at [www.childhealthdata.org](http://www.childhealthdata.org). Revised 4/2/12.

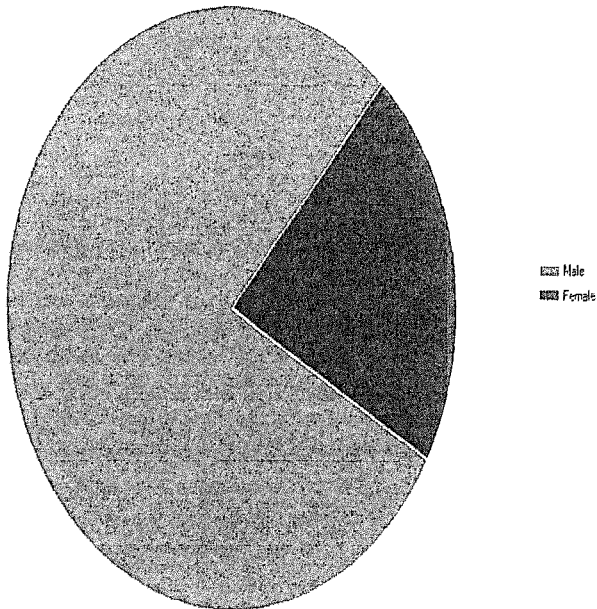
Part of #1

**Autism Survey of Families 2012**  
**SAND Grant in partnership with Family Voices of North Dakota**  
**44 Families responded**

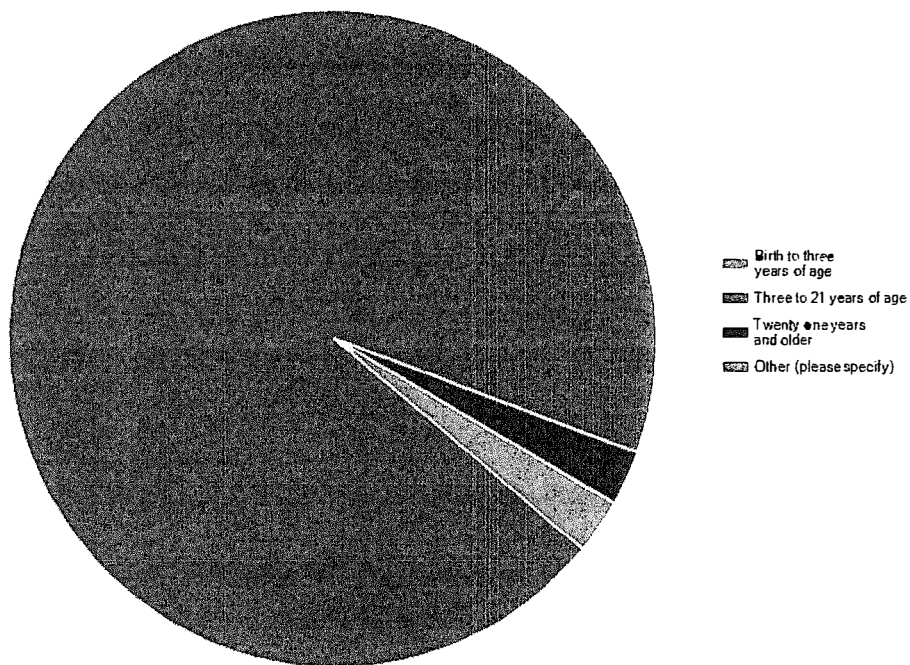
1. Please tell which of the following words best describes you.



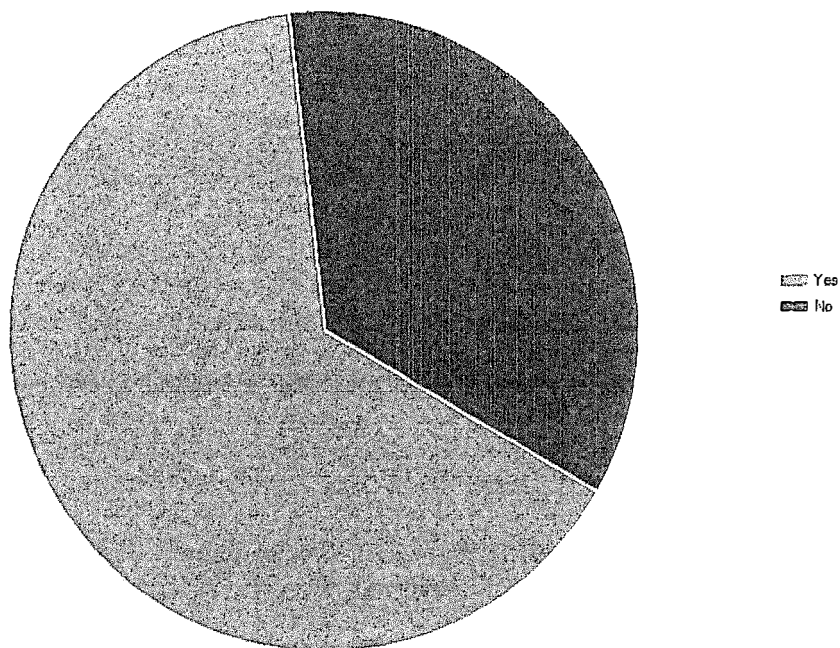
2. Please indicate the gender of your son or daughter.



3. Please indicate the age of your child



Did or has your son or daughter or foster child receive a screening such as (M-CHAT) for Autism Spectrum Disorders (ASD or Autism)?

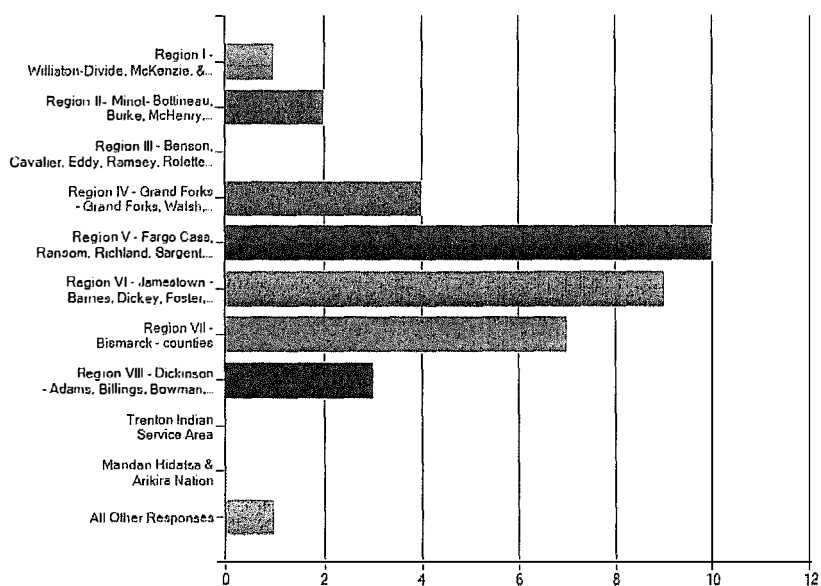


**5. If your child received a screening, share with us where this was done such as physician office, school or other**

- Prairie of St John's Fargo - Psychologist
- Early Intervention person
- We had several screenings and multiple diagnoses. What the final consensus arrived at was moderate to severe autism with an improvement in diagnosis if his language could be improved.
- School
- Anne Carlson through GPAST
- Physician never did the screening. I had to ask school to do it.
- Physician
- Developmental psychologist office
- It was done at the Dr office only by my request I think
- It was done at a WILMAC building in Williston through that District Cooperative - by Dr. Dion Darveaux
- 3 different Physician's offices
- GPAST, Psychologist, and a Psychiatrist offices'
- Dr Katherine Yeager and Dr Ellen Feldman
- MCHAT, CARS, ADOS
- My child received screening through early intervention.
- was done at the ACC thru the GPAST
- physician IHS
- Our son was not screened and was 9 before he was finally diagnosed. The Catholic School referred him and only then did he get diagnosed.
- Mayo clinic
- Dr. Porter-Sanford Neuroscience
- at a counseling center by a psychologist
- physician office
- through the GPIC program at NDCPD
- Mayo Clinic in Rochester Minnesota
- Physician Office



5. Where does your child currently live or receive services?



7. If you reside in one of the major cities: Fargo, Bismarck, Grand Forks, Minot, Williston, Dickinson please indicate in what city you reside. If you live in rural North Dakota, indicate this by saying: Rural

Rural-9

Fargo-7

Dickinson-3

Bismarck/Mandan-5

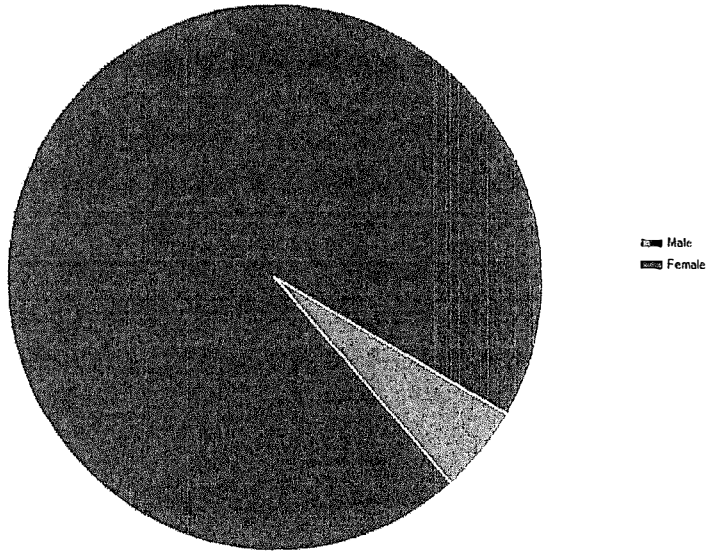
Grand Forks-2

Jamestown-3

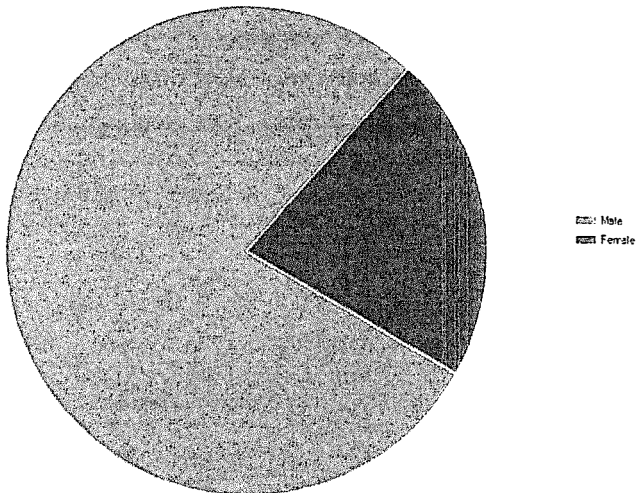
Rural -reservation border town

Minot-2

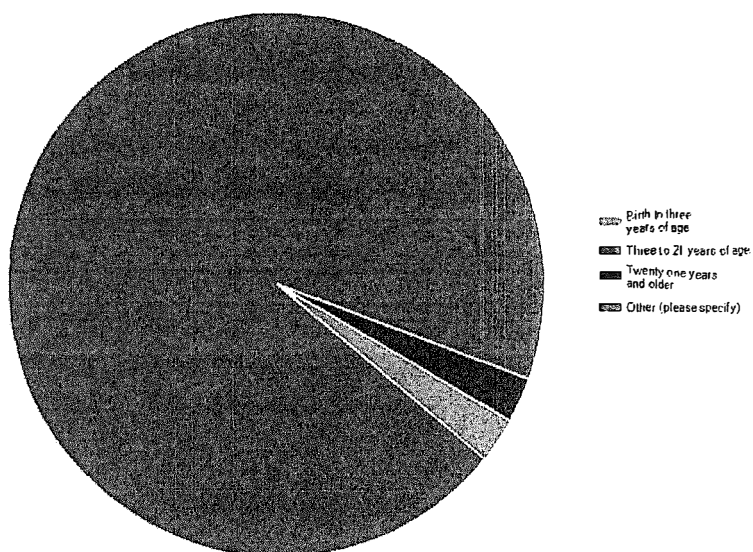
1. Please tell which of the following words best describes you.



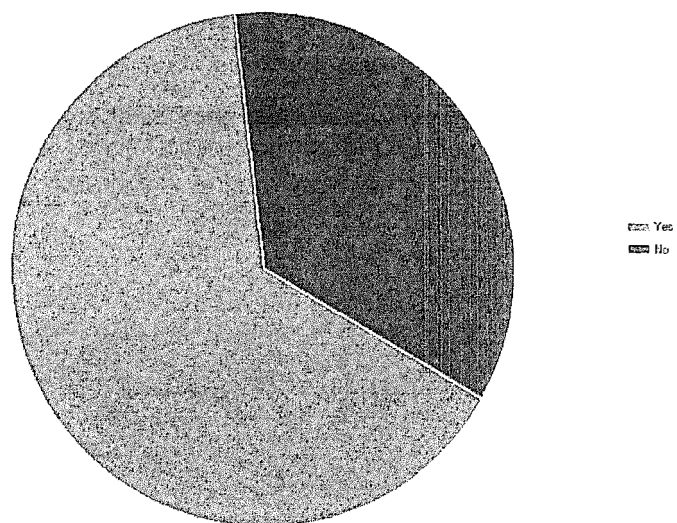
2. Please indicate the gender of your son or daughter.



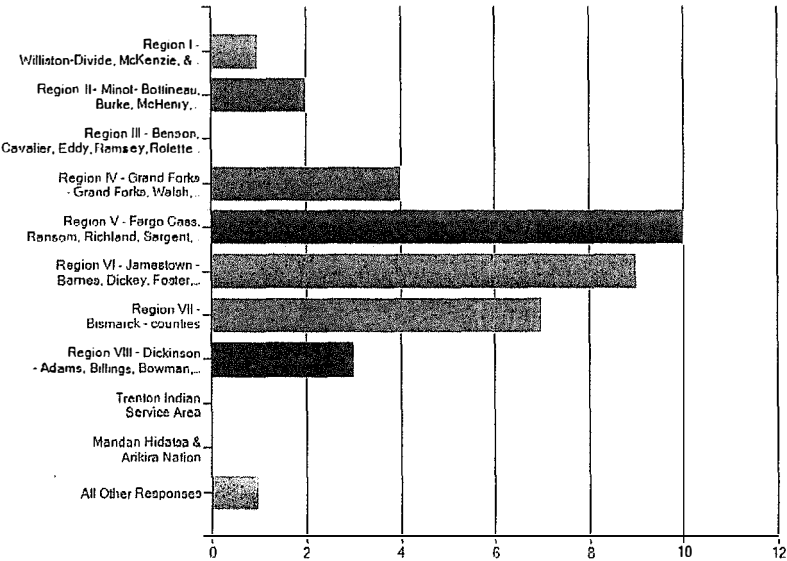
3. Please indicate the age of your child



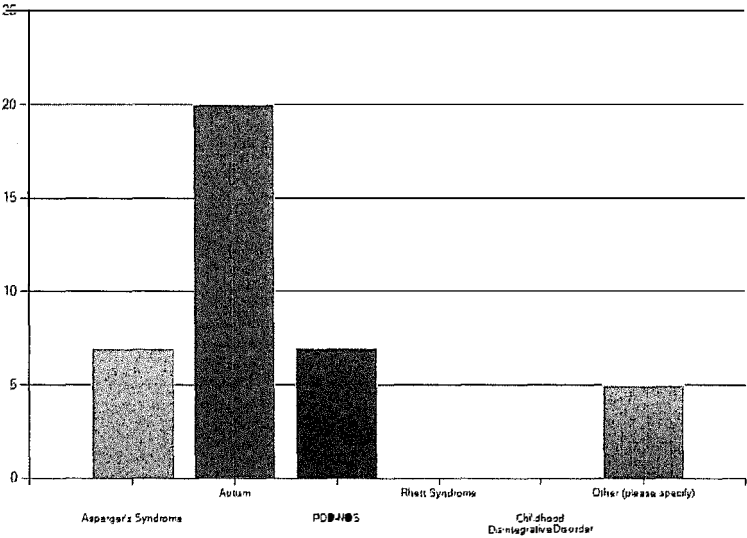
Did or has your son or daughter or foster child receive a screening such as (M-CHAT) for Autism Spectrum Disorders (ASD or Autism)?



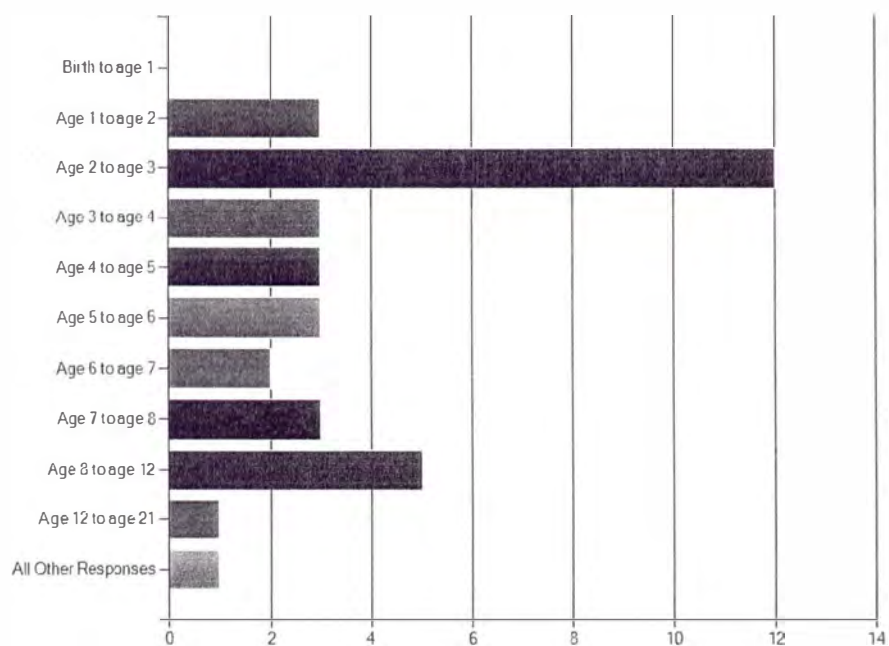
6. Where does your child currently live or receive services?



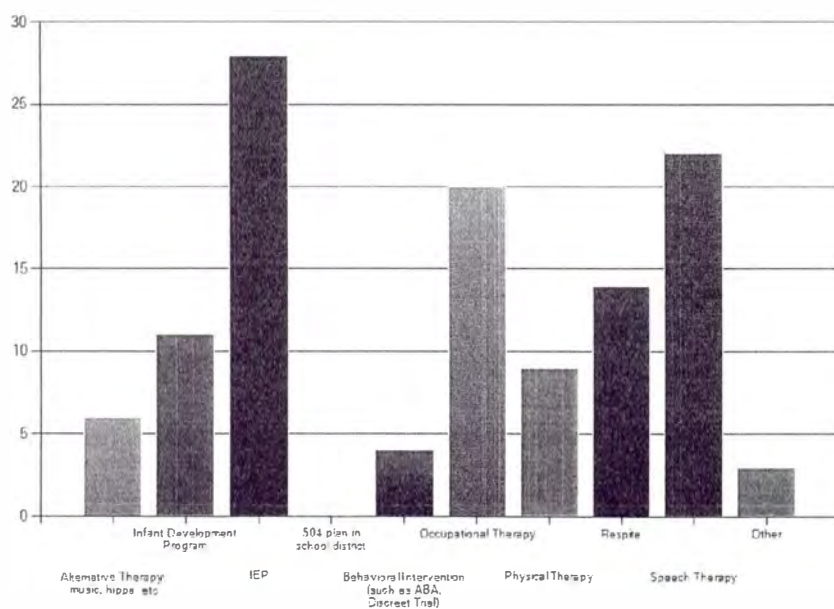
1. Please indicate your child's medical diagnosis.



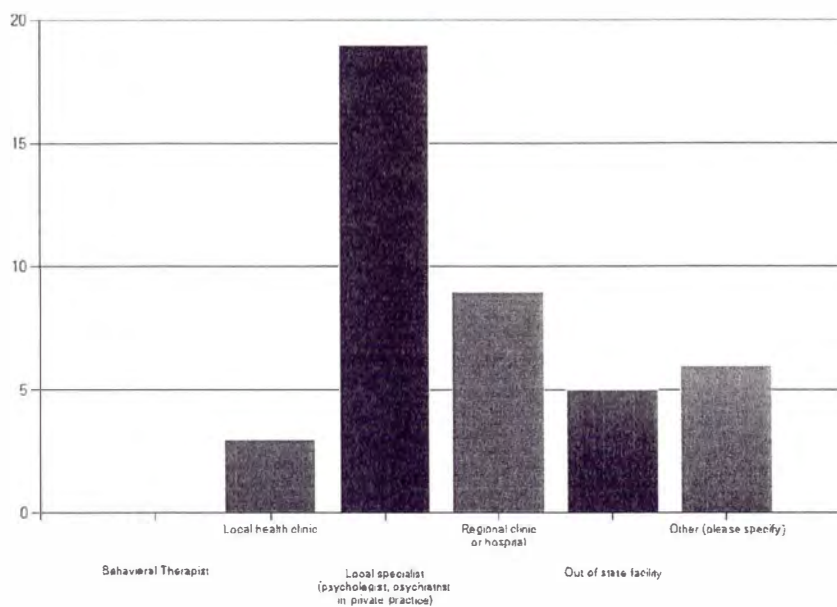
## 2. How old was your child when he or she received this diagnosis?



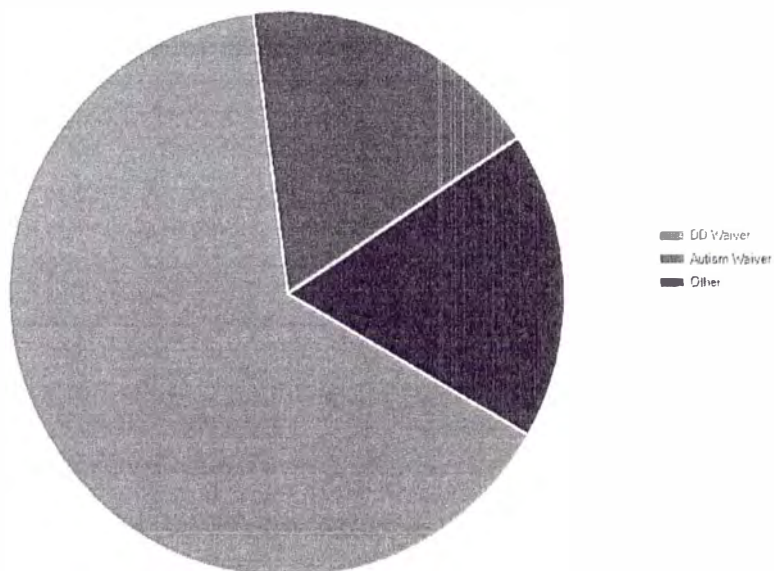
## Does/Did your child receive any of the following services?



Where did you go to get a diagnosis for your son or daughter or foster child?



Is your child on the DD Home and Community Based Waiver or if your child is on the new autism waiver



### Other Categories:

None-3

We moved - waiver services were withheld from us. Our son had a DD waiver, but did not get to use services.



Not sure what you mean by Community Based Waiver

Didn't qualify for Waivers

Of Course not....he is home with us without services.

Does not qualify due to family income.

### **Share with us your experience from diagnosis to interventions and treatment**

- ❖ Human Service Center Early intervention detected problems and played a critical role through age 3. The University of Minnesota for eye exams and MRI. ND School for the Blind played critical role by working with early intervention and providing many early therapies such as little room, OT etc. The first diagnosis was PDD/NOS MR with visual impairment from psychologist at Prairie in Fargo. Anne Carlson Center was critical 1-3 years old with therapies. Taught him to walk at the age of 2. Local Special Education Unit was critical for special needs kindergarten placement, school therapies and then through elementary school. IEP team gave us the Autism diagnosis. Anne Carlson Center was critical for extended summer school, continued therapies, and 1/2 day school as day student for 5th grade. Now full time day student at Anne Carlson with all therapies. School for the Blind is providing Music Therapy which has been very effective. We traveled to Mayo in Rochester for pediatric neurologist and psychologist for behaviors. Now working with local psychiatrist, Dr. Roblis, through Anne Carlson for behavior meds. Respite care through Easter Seals of Good Will is CRITICAL. We work with Sanford Healthcare Accessories for all of our freshening product needs.
- ❖ I actually have two children on the spectrum. I am answering these questions based on his information. My son is our second child on the spectrum. We have known the services this time around and who to ask. It was challenging with my daughter (our first child). I had her at the doctor's office numerous times because of concerns (extreme colic, delays in speech, etc). I was treated by her primary care physician like I didn't know what I was talking about because she was my first child. I heard about early intervention through a friend. Once I got in contact with early intervention things got a lot easier. Our family has been involved with two early intervention workers. Both have been very helpful, supportive, and knowledgeable. My son is currently 3. It has been an on-going debate about whether or not a diagnosis is beneficial and at what age is an appropriate to diagnose on the autism spectrum. My son has had very significant speech delays so a lot of his services are based on his challenges with communicating. He has been involved with early intervention since the age of 10 months due to having delays in multiple areas. He has had to been taught things that most kids just learn. Early intervention has been an amazing service.
- ❖ The first diagnosis was horrible. A physician took 15 min at the end of his day to snap his fingers and clap his hands in my son's face and then proceeded to tell me that my son had classic autism and if we wanted to have any hope of him living a mainstream and independent life that we would need to move to the east coast where the best services were available. His nurse then dropped of a binder and my child and I were left to cope with the news while the other medical professionals all went home to their "normal" lives for the day. I had no recommendation of supports, no idea what autism really was, and no idea what my next step even was. We didn't

move, we found services through the Human Service Center. We have had an amazing speech therapist, and while the Fargo early education program was good, the men on board there just didn't seem to be involved in anything but themselves. This included a preschool teacher who tried to push my son into a kindergarten class before he was ready because his teacher didn't want to listen to me about his needs, but instead only to push his own expertise. When he was set to move on to kindergarten, we moved to the West Fargo school district because of the better services available within the schools, including smaller class size. We have lost some of our supports along the way, including the most recent cuts to respite, which has been a life-line to us for helping my son with working on his social and routine development. My son has also tested out of OT services twice, even though he still doesn't have enough core strength to ride a bike. On the up side, there is a school that needs to be highlighted. Horace elementary has been nothing short of a God-send to our lives! The staff, from the principal, to the lunchroom staff, the teachers, the paraprofessionals, and everyone in between have embraced my son in a way that I will NEVER be able to express kind enough words for or enough gratitude towards. The staff shows him so much respect and patience that the students have picked up on that and continued to show that respect, whether in school or out in the community. It is so profound that it brings me to tears just reflecting on what a gift they all are. If you need examples of what schools SHOULD look like, look to Horace Elementary. Not every school in our district has a spotless reputation; in fact I worry about what will happen when he leaves Horace for middle school. But for the time being, we are very happy, very grateful, and VERY impressed!

- ❖ My son has seen a couple of different doctors and it has been split on whether he has asperger's or autism. I researched information and different facilities that could assist us. Family Voices was very helpful in guiding us on the path that was best for my family.
  
- ❖ Difficult time getting her diagnosed other than PDD.
- ❖ Lots of road blocks and steps backwards
- ❖ School requested diagnosis, Prairie St John suggested Asperger's but Mayo neurologist did not confirm it & the state would not pay for neuropsychologist
- ❖ It was hard to receive the diagnosis but once we did the services were easy to receive because my son has a awesome team serving him.
- ❖ It took 9 months for diagnosis once I suspected so strongly that he had autism and was seeking for diagnosis - being turned down at every turn. I was told "If he is autistic, he'll get even fewer services." At age 3 coming out of Infant Development - he was only getting an hour and 40 min of education a week when his SPECIAL EDUCATION PEERS were getting 8 hours a week. Once he was diagnosed - he did get 6 hours a week of education due to ESY over the summer - the SAME as his special education peers. Mileage reimbursements were withheld, respite was withheld - I have Asperger's and there is no compassion for the socially stupid. Though I was not socially stupid, I do not read social cues well - so people who have services to offer take advantage of me. Because I don't act "normal" or know how to pull at their heart strings in just the right way - my child does not get services. I have far more than just Aspergers - it is autism and is pervasive and affects my persistence and pace in doing everyday tasks. The system destroys "normal" people - I am a shell. I was a productive parent - working and active in the community - a professional with a 4 year college education. Now I am nothing. My death sounds good, and best for everyone involved - especially my children because I don't exist anymore. If families aren't entitled to services, then for Jesus' sake - don't pretend to offer them! And honestly

I mean for Jesus' sake! Whatever we do to the least of our brethren we do unto Him. Who ranks as "least" on the totem pole in comparison to one of Jesus' precious disabled children? The treatment that began to work best right off the bat (once I knew he was autistic) was heavy metal chelating using NCD Zeolite through Waiora. My sons color vision returned (or was maybe there for the first time!) after 6 months of use. Mercury can cause color blindness - and he'd gotten lots of mercury through vaccinations, starting with an out-dated hepatitis shot before he went home from the hospital just after being born. Within a week or 2 of using the chelation, behaviors had improved - and the behavior of running away from home naked dropped drastically.

- ❖ I am so thankful for other parents and support groups to help me.
- ❖ It was a very, very long 1.5 years before we received our son's diagnosis of autism. We were told by one specific group, GPAST team, that he didn't have anything wrong with him. He wasn't developing like he should be because he wasn't around kids his own age, put him in daycare and he'll be fine. We knew that was false. We pushed further and went to Sanford in Fargo. We were told again, we don't know what is wrong with him but we want to order many more tests for him and it isn't autism. We again disagreed and pushed further. We went to Bismarck in October 2011. We finally received his autism diagnosis then. It was a long struggle, still is. He has been receiving speech, physical and occupational therapies at Anne Carlson Center for one year next month.
- ❖ After we got a diagnosis, the doctors just left us hanging. I had to search things out for my daughter.
- ❖ Diagnosis extremely frustrating. I said something was wrong at birth and the pediatrician kept telling me to relax and everything was fine. Working with BCBS was extremely frustrating. Our son is non-verbal but insurance would not assist with any assistive technology or any alternative type therapies such as music therapy. Interventions such as respite became extremely frustrating. We had some respite workers on the way that were an absolute God Send. Trying to work and balance therapies was more intensive with a "special needs" child/individual.
- ❖ Before diagnosed we had issues with the school and our daughters social skills and behaviors. They thought she was just being lazy and defiant. Even at times we were told to be better parents. She missed out on most of her schooling in the classroom due to behaviors. She was not in the room for most of k-2nd grade. She is very high functioning so that is why we were told that the school expected better of her and she kept falling further and further behind. Once diagnosed, we got an autism specialist on board and started getting people to understand and get to know our child. She needs a lot of support thought her day but can stay in the normal class with her peers and is getting good grades and works really hard. There was a time in 2nd grade that my child told me she wanted to die as know one listened to her and she felt worthless and hated school. She now is enjoying school and with all the supports in place and a great IEP. She is learning how to understand herself and her emotions to the best that she can. It is very important the she has the support staff, and a good plan. Without this she would not be functioning well in the school system. Every day is really hard for her and she works so hard. She comes home from school and shuts down for some time to recompose. I hope that the services she is getting will not be taken away or cut back as they are very crucial to her and others that have aspergers. They are the ones who seem to take the longest to get the services they need. It took us several years and many wrong diagnosis before we finally got the right one.
- ❖ It has been isolating. Autism waiver is a joke. ND has poor psychiatric options to treat young children. Forced to go out of state for help.
- ❖ Interventions didn't change as we received services while living in another state. Interventions greatly improved upon moving to ND.
- ❖ The interventions for my son started before a diagnosis through early intervention. The diagnostics were multi-disciplinary and it was an obvious diagnosis of regressive autism. After the testing I was in a room with the specialists and they told me to go back to ND and do ABA (which at the time I did not know what it was and hire as many therapists as possible. I was

extremely overwhelmed at that time but with the help of Early Intervention that decreased over time.

- ❖ A very long road...
- ❖ Grief
- ❖ Failed.....no services...treated at school like he was developmentally delayed and a behavior problem. He is so turned off with adult and doesn't trust. He has lost all interest in learning or moving forward to transitioning. We FINALLY had a transitional counselor at SE and she is now gone. He trusted her also. He will be 19 in May.....
- ❖ We have had bad experiences in Middle School. We were told at Grace Lutheran School that they could not teach him there.
- ❖ Since my child is very high functioning, it took a long time to get her an IEP, despite her diagnoses of Aspergers, ADD and non-verbal learning disorder. She had a 504 for three years, but it wasn't until this last year that I was able to get her an IEP, and that only after I complained to the State Special Ed. office. She has struggled with school since entering Jr. High, due to the change in routine (she does much better in a very structured setting and Jr. High and High School are simply not structured enough. She has been barely passing since 6th grade and that with only a great deal of struggle and stress, not only on her but on the rest of the family as well. Since getting her IEP, things are better and she is less stressed and has fewer breakdowns at home. She has not received any therapies, as she is considered too high functioning to qualify for them.
- ❖ We have an extremely difficult time obtaining any services due to family income and our daughter has a normal IQ which disqualified her from DD services. We pay an enormous amount of money out of pocket for her care.
- ❖ Difficult; diagnosis was given in 2004; ND did have the knowledge and programming now available
- ❖ It took us a couple of years to get a diagnosis, despite our son being in Head Start for 2 years & us repeatedly saying there was something not quite right with him. He had an IEP with a diagnosis of PDD-NOS, but no mention of autism. His 2nd year of Head Start they first put him into a severely disabled classroom from reading his assessment, but then put him in a regular classroom after a couple months. His one therapist there kept comparing his behaviors to a normal 3 year old even though he was 5, like this was ok! One pediatrician said we just weren't disciplining him properly! It was so frustrating, we just wanted an explanation. We finally made him an appointment with a psychologist ourselves & that's when we got the diagnosis of Asperger's. After that we had a name to put to his condition. They had some interventions in place at Head Start like speech & OT all ready, so not much changed with his diagnosis. After a few months we did take him to a psychiatrist & started him on Abilify, which helped with his tantrums. After about a year the Abilify wasn't as effective so he was switched to Risperadone. We have had him in a social skills group but that wasn't carrying over outside of the group so we stopped going. He does have sessions with a social worker at North Central, which does seem to help. And the IEP team finally seems to be on the same page with us now that we have an advocate from Independence Inc. attending the meetings with us.
- ❖ First diagnosed with ADHD, dietary modifications (eliminating Red food dye and salicylates) helped immensely with the hyper behaviors, however he's still quirky with some motor issues
- ❖ The diagnosis part was easy for us as we had a team of doctors that felt very confident in giving the diagnosis which is not always the case. Prior to the diagnosis we had started with Southeast Human Services Infant and Development in which we had an OT visit us once a week. This was a joke because the OT didn't actually work with our son, she just observed him, and the visit served no purpose. We also started speech therapy because our son was still non-verbal but here too our local pediatrician felt there was no need to be concerned about the lack thereof any speech. After enough pressure he submitted the authorization for a speech evaluation and we began speech shortly after. Soon after that we brought OT in but the provider had no pediatric experience. When our son turned 3 he qualified for a special needs preschool. When meeting with the teacher

and the rest of what became the IEP team we weren't given the whole truth about how many days per week our son could attend school. At first they tried to say only 2 but luckily enough we learned that he was entitled to everyday that the facility was open. Since then he has attended school 4 days/week and does well but the staff is very uneducated in dealing with kids with autism and not very willing to get educated. They feel that they can teach all special needs kids the same way which is not the case. Along with speech and OT we also found a provider for ABA services that we do in-home and have been doing for just over 2 years. We tried to convince the school to implement ABA but they weren't even willing to consider it. We've also tried music therapy for a few weeks and our son seemed to enjoy it and plan to add it back into his treatment plan. This type of therapy was requested to be brought in to the school but again denied. Since there no medical doctors in the state of ND that are willing to look at the underlying issues that occur in most kids with autism, we have to travel out of state for those services. We see wonderful results with what she is having us do to help heal his entire body. Autism is considered a neurological disorder but it also affects the rest of the body as well.

- ❖ Felt like we were navigating in the dark. I took my child to a preschool screening and he was placed from there. He did well in preschool and was diagnosed prior to starting Kindergarten. We did not know about the autism or DD waiver. His services have been provided by the school or through private providers.

**Share with us if it was easy to locate services or if it was quite difficult. Share your experience**

- ❖ It has been very difficult the entire journey to locate services. I thought more information would come to us but we had to research and ask for everything. Going out of state for pediatric neurology, psychologists, ophthalmologists, etc was very hard with insurance etc. but in state ones did not have the knowledge or expertise. 13 years later I still don't know where to turn. Our case manager at the Human Service Center has been our guiding light. She is the only one that seems to be there for us every step of this journey.
- ❖ Difficult the first time.
- ❖ Our services came into place through a domino effect. One therapist would recommend an additional service or therapy, and then a different service would ask if I had checked with something or someone else, and things slowly fell into place, with some services staying and others going. It wasn't fast, it wasn't hard, but it wasn't an easy, comprehensive start-up either.
- ❖ It was and still is difficult to find services for my son.
- ❖ Difficult as we are rural.
- ❖ Very difficult
- ❖ Services limited to what school provides
- ❖ It has been easy to receive services due to the team that works with him ( DD case management respite and support services)
- ❖ Services were extremely difficult to locate because the people with "powers that be" lie. He had a year's worth of regression due to things such as not getting to start school at the same time as the other Special education peers - undoing the work Infant Development had done with him.
- ❖ At the time of my son's diagnosis, it seemed that there was not much known to public and medical. it was up to me to find what I needed
- ❖ It was difficult.
- ❖ Once I knew what services she needed, then it was easy to get them. They were all in one place and they were so helpful.
- ❖ Locate services was not difficult. Overwhelming is more of an accurate term vs difficult. Especially in the last few years. Technology is growing up leaps and bounds and it's very hard to stay informed and keep abreast of all the newest developments. The internet has so much information it's hard to know where to begin or sift through all of it.



- ❖ We searched and found the ones we have, and keep looking for others that may help her, it is the expense of these that is hard and some of them we cannot do as the expense is too great
- ❖ Difficult for psychiatric help. Easy for PT, OT (Sensory), Speech
- ❖ Services were difficult out of state due to the rural area. Services in ND were easy to set up due to all the community supports in place.
- ❖ In Bismarck Early intervention was already in place so those services were easy to attain. Respite and alternative therapies such as music therapy were more difficult. I also wanted therapy beyond early interventions services in my home and that was also difficult.
- ❖ Not easy.. But finally found a doctor in Fargo who rocks.. But he did referrals for specialist and right now those appointments are not for months as they are that booked.. We still can't find an ABA therapist..
- ❖ Difficult with tribal=state connections
- ❖ There is nothing for our son. He can speak his mind but he can't deal with others or multitask. I am so sick of these surveys and needing data to get things changed. WE NEED HELP. Our son is a beautiful person but because of the lack of services and the terrible actions of the school district their total disregard to his individualism it will be years before he is one his own.
- ❖ Difficult- very lonely and often feel like we are the only ones dealing with the issues.
- ❖ Services are not available.
- ❖ It's been quite difficult since moving to rural ND in 2009. We have had to travel to Jamestown for any services, and that has been quite disappointing, as they are not doing anything that they promised us they would do.
- ❖ We receive NO SERVICES through any agency - we pay privately for physical therapy because her insurance ( ND CHAND) will no longer cover because she also has Saethre-Chotzens syndrome, insurance won't cover therapies for it because it is a degenerative syndrome.
- ❖ Services have been great once they were in place
- ❖ It is very difficult at times. We really felt like we had nowhere to turn for some things and also had several times where it felt like it was us vs. the school at our IEP meetings. Thankfully we heard about Independence Inc. through our friends at the local autism support group (which has since disbanded). It was a major breakthrough when our advocate started attending the meetings. It was also our friends at the support group who recommended therapy at North Central. We tried contacting the autism clinic at Minot State, but never got anywhere. All of our resources were found through friends who had kids with autism. Our child's providers never gave us any advice in that department except to try for respite care through Partnerships (which was denied).
- ❖ Rather difficult, but easier because we have another child with a disability and know the systems pretty well
- ❖ Coming from a small town in rural ND it was very difficult to find people who were qualified to work with a child with autism. We do not have anyone in our town that provides those kinds of service so we are required to travel to get the services. We need to develop a network that will help point parents in the direction of where these services are located and who the provider is. We need pediatricians more on board as to proper therapies that work for these kids. Our local pediatrician has yet to give us any suggestions on types of therapies to do for our son, we have been the ones to request the speech and OT consults. They are just as uninformed about autism as our education department is. ABA providers are the most difficult to find since most insurances don't want to pay for those services so they go to the states that have insurance companies that are willing to pay. In our state we have 1 person that is qualified to do this and luckily enough we have insurance thru BCBS of MN and they cover these services as BCBS of ND does NOT cover it. As I said before we have a local pediatrician that we use for bumps, bruises and minor ailments, but we have to travel out of state to see a physician that is willing to treat our sons underlying issues.
- ❖ Not easy to begin with. Now that I am plugged in it is better.



**When your child received their diagnosis, what resources did you have?**

- ❖ Special education unit; Human Service Center; ND School for the Blind; Parent to Parent; Anne Carlson Center.
- ❖ When my son was given the diagnosis of having behaviors and symptoms consistent for a pervasive developmental delay I was given a book about autism, referred to OT, speech, and behavioral psychologist. I was also seen by a nutritionist that was not helpful. This process was through the child screening board at Sanford.
- ❖ Speech and early intervention (we knew there was a speech delay)
- ❖ I only had the info that I had researched. One doctor did give me a book to read. Otherwise it was us and Family Voices.
- ❖ Had much in place already...IEP, therapy all on own.
- ❖ We really were offered very few except for accommodations at the school
- ❖ Total ignorance of Aspergers
- ❖ EI then BECEP speech and occupational therapy
- ❖ DD services - but the services it had to offer were withheld. He did get to use a psychologist, but that was covered under Medicaid which he already had anyway without DD services.
- ❖ I found other parents, support groups and Family Voices on my own.
- ❖ Thankfully he was already in therapy services. I received helpful information from Family Voices.
- ❖ I had some prior knowledge to the diagnosis before hand, but we had no other resources. We had to advocate for our daughter.
- ❖ We basically had West Central to relay.
- ❖ A case manager from North East and a Protection and Advocacy.
- ❖ Medical Home, Anne Carlson Center
- ❖ He was receiving OT, PT, and SLP in the home.
- ❖ I had a resource of an experienced parent and then had a Parent2 Parent match and that led me to Family Voices of ND which helped me as a parent identify more resources throughout the state to include family support and opportunities.
- ❖ Family Voices and the KIDS program.. Family Voices rocks!
- ❖ None
- ❖ Dr. Stanton gave emotional support but there has been NO resources given. He doesn't have classic autism.
- ❖ None. And the doctor didn't even tell us that asperger's = autism!
- ❖ None
- ❖ None.
- ❖ We lived in Rapid City, SD at the time, so there were more resources available. She was able to be in a contained classroom for high functioning kids like herself for one year, with was ideal. However, funding was lost and they were unable to provide this after the first year. She was in counseling in Rapid City, as well.
- ❖ Private insurance. She capped out her lifetime max on her insurance by age 7.
- ❖ We had to seek most of our resources
- ❖ When we first got the diagnosis, we lived in Bismarck but traveled to Minot for medical treatment because that was where my husband's medical insurance was through (required us to use Trinity). But shortly afterwards we moved to Minot. In Bismarck, we really didn't access any resources and we felt fairly lost when we first moved to Minot. Eventually we made contact with the autism support group who gave us lots of places to go for help.
- ❖ I don't understand the question

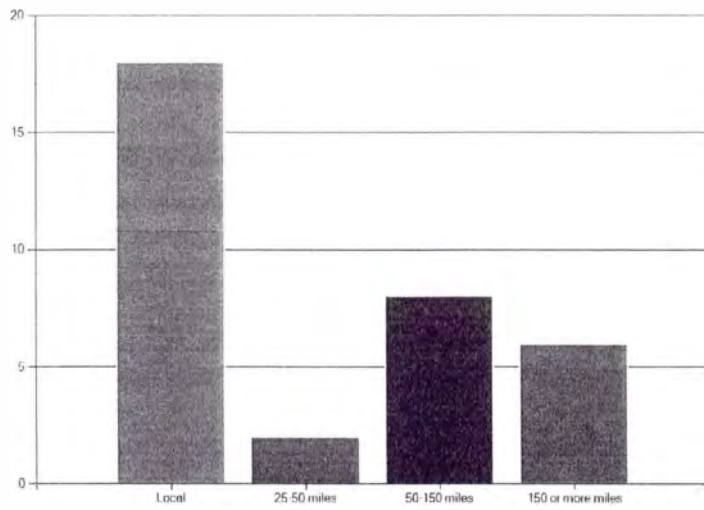
- ❖ Since we had already initiated speech and OT prior to the diagnosis we were only give 1 suggestion of therapy to add in to our schedule and that was ABA. Again, only 1 provider of this type of therapy in the entire state!
- ❖ My own training but very little beyond that. The school but that is about it.

**What type of support did you receive? What type of support do you wish you had received?**

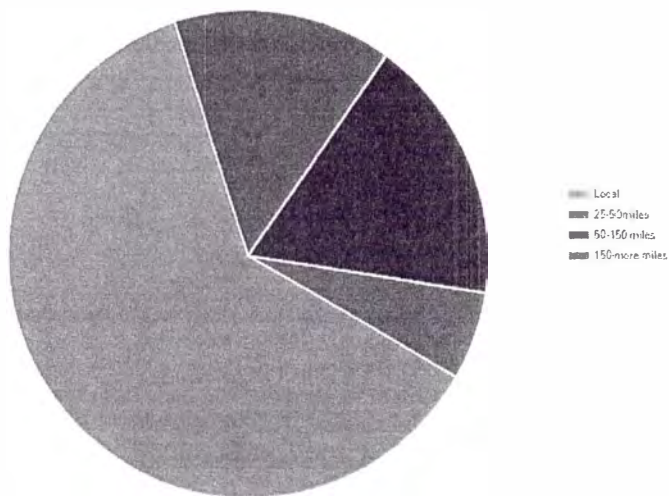
- ❖ We received help with therapy options, an education plan, and some emotional support from the parent to parent program. It is hard to know what support we wished we would have received because you don't know what you don't know. I wish my son would have seen a DAN doctor, someone to look at the whole autism picture, diet etc. I wish we would not have been misled by so many inexperienced ND pediatric neurologists who act like they know about autism. I wish there were more pediatric doctors of every kind in ND. You feel like you are floundering around trying to piece things together yourself. Wish we would have had a parent support group.
- ❖ Continued services with early intervention and speech therapy. We later started services with OT. It would be helpful to be connected with other families going through the same thing.
- ❖ I wish I could have found the Sanford diagnostics clinic from the start. It wasn't until much later that we found that and in their one day program you get all of the support-finding out of the way. It would have really cut down on our family stress to have that from the start.
- ❖ All of our support came from Family Voices. We were able to receive a few therapy sessions but then insurance ran out. I wish I had more connections to others in the area that we could speak and play with to know what was happening was normal. Maybe a place to exchange tips and ideas. Even someone to tell you what to expect at visits and not to get overwhelmed or worry. A feedback center on different hospitals, clinics or therapy places. You could rate your visit, the facility and how well the bedside manner was. If you were provided information.
- ❖ Someone trained in ABA
- ❖ More intensive services and out of school therapy. Not enough services for all children. Only those that can afford private services receive it.
- ❖ Fargo school (Kennedy) resistant to helping but Wahpeton (current school) very helpful
- ❖ Speech, OT, respite and mentor
- ❖ Independent Living Services had to intervene to get a little help for us. I wish the support we had received were anything we were entitled to - because if we're not entitled to it, then the effort to get anything outweighs the service. Things we were entitled to were withheld. Since stuff gets withheld I wish the service we had gotten was "Look lady, you need to quit your job and care for your kid yourself because your disabilities will not be able to handle this extra multi-tasking, and only parents with more abilities get to use these services for their disabled children. And, if something happens to your husband's meager income - you're gonna have to get rid of your kid (if that involves you getting jailed for abandoning the kid at a hospital) - and your oldest Asperger child can eventually get someone better to take care of him, too. I wish I had gotten the service of being told I wouldn't get to work ever again - so I wouldn't have struggled to get that back (I never did get it back) and lose my abilities because of all the effort I did trying to do that.
- ❖ Other parents, support group, and Family Voices were the best sources
- ❖ We did not qualify for any support. I still do not agree and have appealed the claim several times. I think we should have gotten Respite care or an Easter Seals worker.
- ❖ We received the DD in-home support services. The support that was lacking was family and friends. Family did not know how to respond. They were uncomfortable being left alone with our son. This made it difficult at family events. Family didn't understand why the holidays were so

- stressful for us. It was easiest for our child to just me at home. Always felt like I was disappointing someone and the holidays were stressful and sometimes depressing.
- ❖ Respite, better reimbursements for travel and equipment reimbursements, better and closer psychiatric care
  - ❖ NO parent support as it didn't exist.
  - ❖ I received very good support and my family was supportive so that helped. I would have liked to have more support from specialists as my son has chronic health conditions as well as autism.
  - ❖ Family Voices parent to parent match.. Wish though that I would have more guidance from my DD program manager..
  - ❖ Transition and service changes age 2
  - ❖ Occupational, Speech, Para at school, individualize class education.
  - ❖ None
  - ❖ We needed respite care much sooner. We were offered overnights thru a different company, but we didn't want to send him away overnight.
  - ❖ I sought out a counselor. We had a psychologist that evaluated medications.
  - ❖ None. Resources and education would have been helpful.
  - ❖ Not a lot, but did get some help from the school she was attending. I wish there had been someone available to help me figure out what exactly she needed and how to get it. Was basically very uneducated about Asperger's Syndrome at that time.
  - ❖ None. We have been told we don't qualify.
  - ❖ Did receive OT and speech wish we could have had behavior therapy
  - ❖ In Bismarck, we had no support other than 1 friend who had kids with similar diagnoses. There was no support group that we knew of. Even now we feel like we are on our own with the support group here breaking up due to the flood. We really had to become our own advocates & find stuff on our own.
  - ❖ It would have been nice for him to have some information saying "this is what these people think, and this is what this means." When I told him the team thought he had high functioning autism he thought they were wrong, likely because he didn't understand what that diagnosis meant. He was more familiar with classical autism, and knew that didn't fit him. A label really doesn't matter; he's the same kid today as he was before he had a diagnosis. Now we have more understanding as to why he is the way he is, and what things may/may not be in his control (echolalia, fidgets, poor sleep, certain fascinations, etc.)
  - ❖ When we met with our DD case manager she was able to help us get reimbursed for some mileage for traveling to our appointments. She was also instrumental in helping us get setup with respite care. As for other support, we luckily found a support group called TACA (Talk about Curing Autism) in Grand Forks. They have been the biggest help in whole ordeal. We get no support from our local pediatrician or schools. It's almost as if they are ignoring that autism even exists. We wish the school would have been better educated on dealing with kids with autism and that they would have received our recommendations for implementing therapies such as ABA and music therapy into the classroom for our son but they felt there was no evidence based data on either one which in fact there is. We would have liked to see our local pediatrician be more interested in treating our son with his other medical issues but again they don't see kids with autism has having other issues in their body, they believe it's all in the head, so not the case! We would love to see more community support. Many people don't have clue as to what autism is or what it's like live with it. Better educating the public is very much needed so they have an idea as to what to expect from these kids, and what may be causing the tantrums or meltdowns. It's not because the kid is a spoiled brat, they have autism and this is just a couple of the issues that the families have to deal with. The ND Dept of Health has a Resource Booklet for Children with Cardiac Conditions; they need to do the same type of resource book for autism!
  - ❖ Support group, maybe a counselor to help with the process

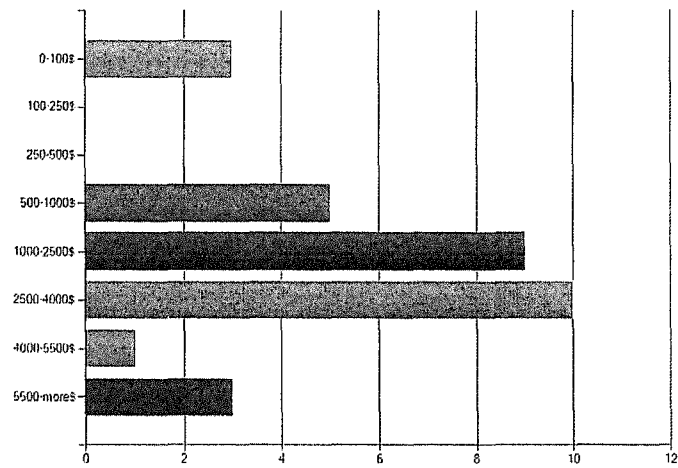
How far did you have to travel to get an accurate diagnosis?



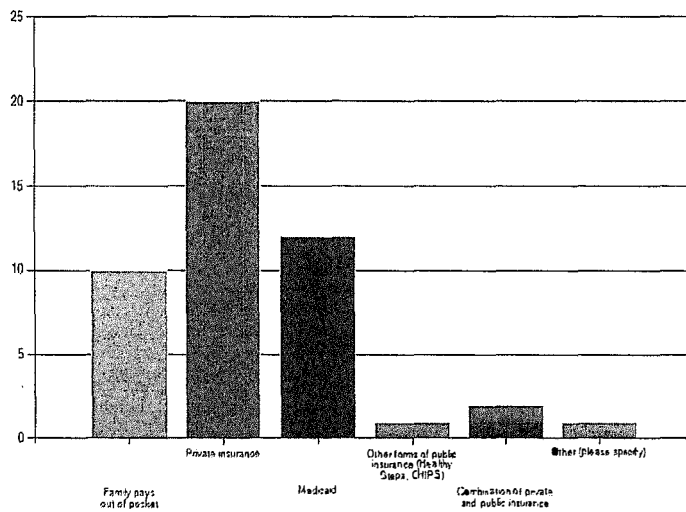
How far do you need to travel to continue to receive services for your child?



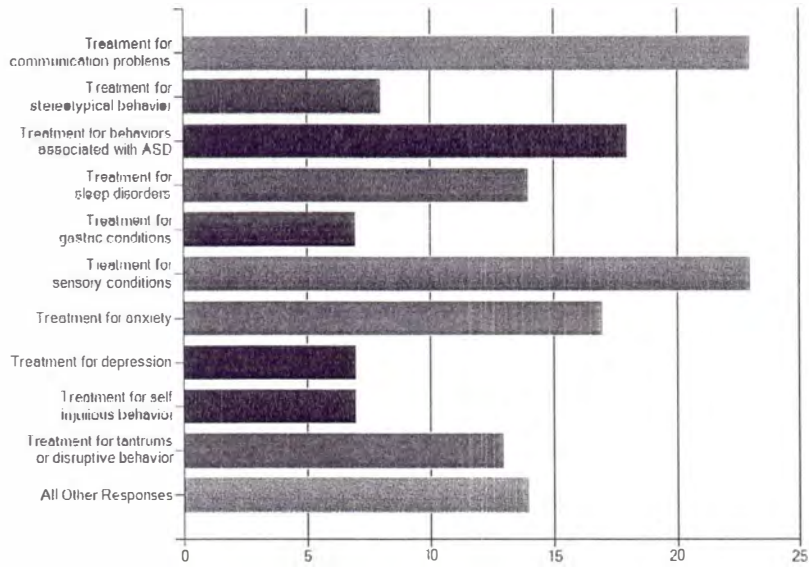
How much out of pocket costs do you incur for your child per year? Include travel, medications, therapies, etc.



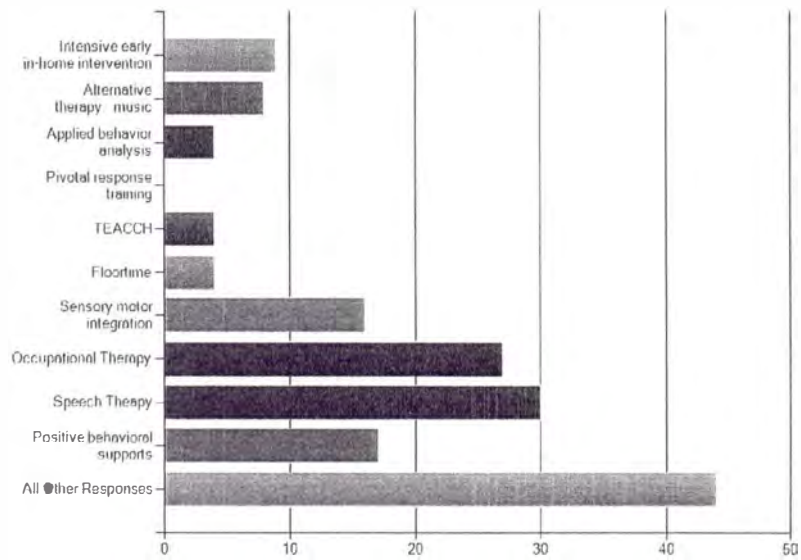
If medical services for treatment for autism are provided, what is the primary method used to pay for the treatment?



Has your son or daughter or foster child received any of these medical services sometimes prescribed for treatment of ASD? Check all that apply.

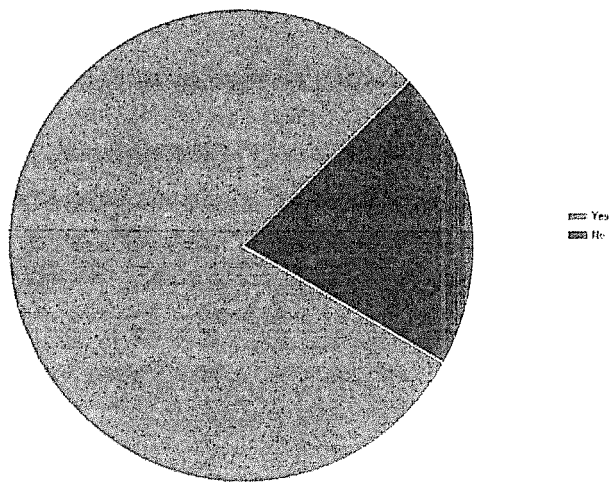


Has your son or daughter or foster child received any of the following services for treating ASD?

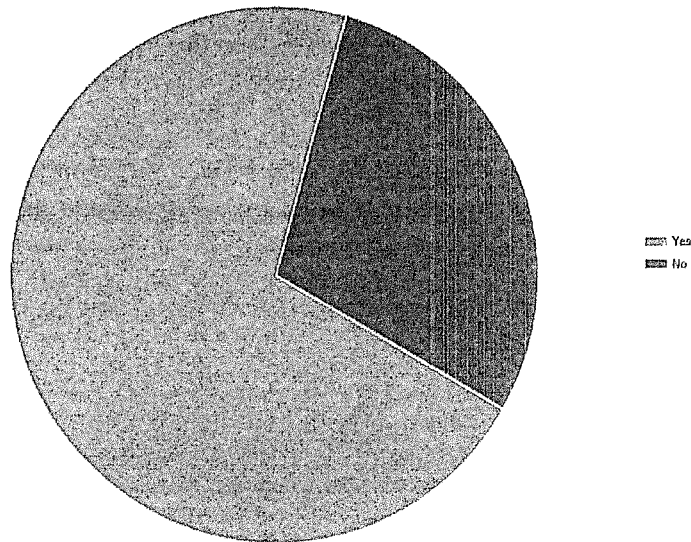




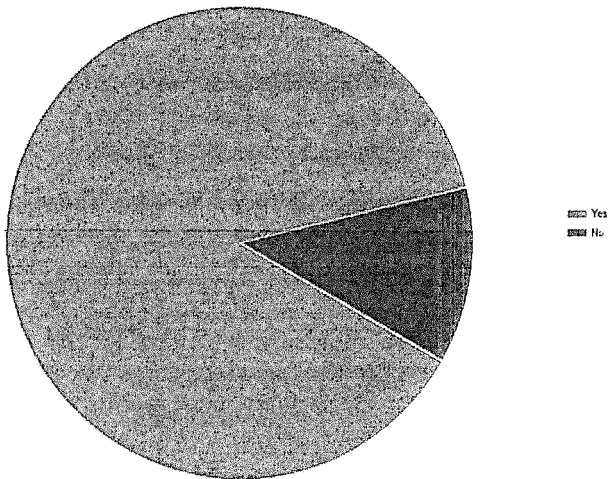
Is your son or daughter receiving medical treatment for ASD now?



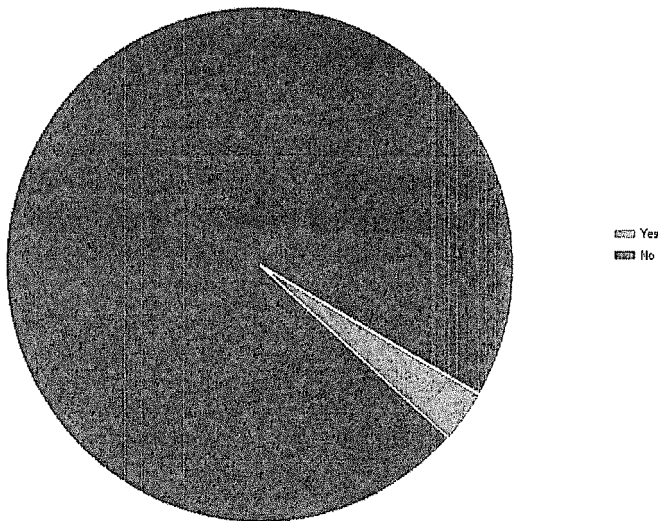
Did your child receive an educational diagnosis of Autism?

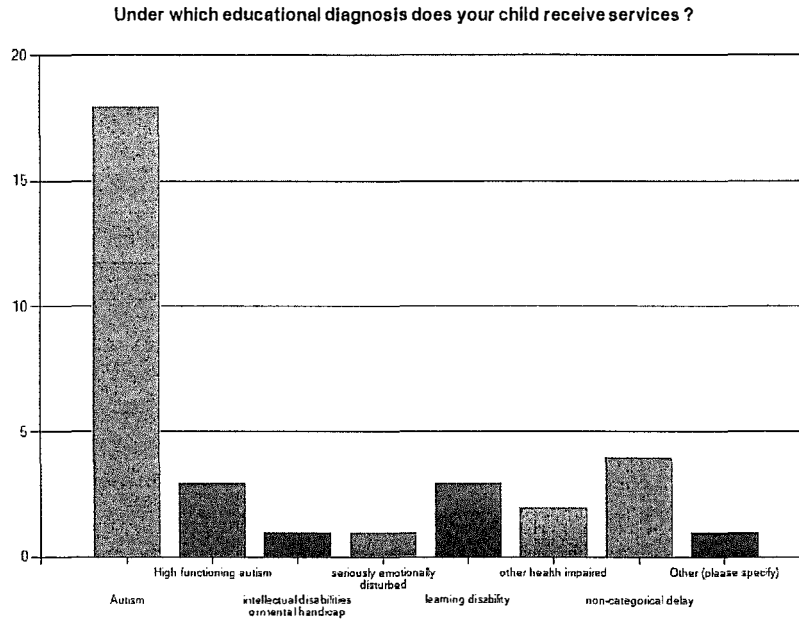


Does your child receive any special education services under an IEP?



Does your child receive individualized educational services under a 604 plan?

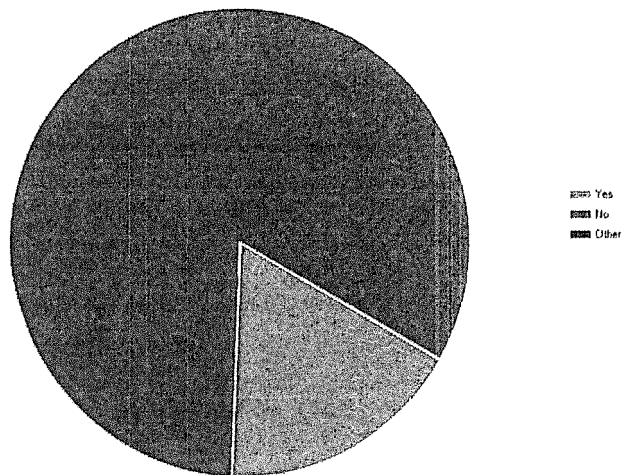




Other:

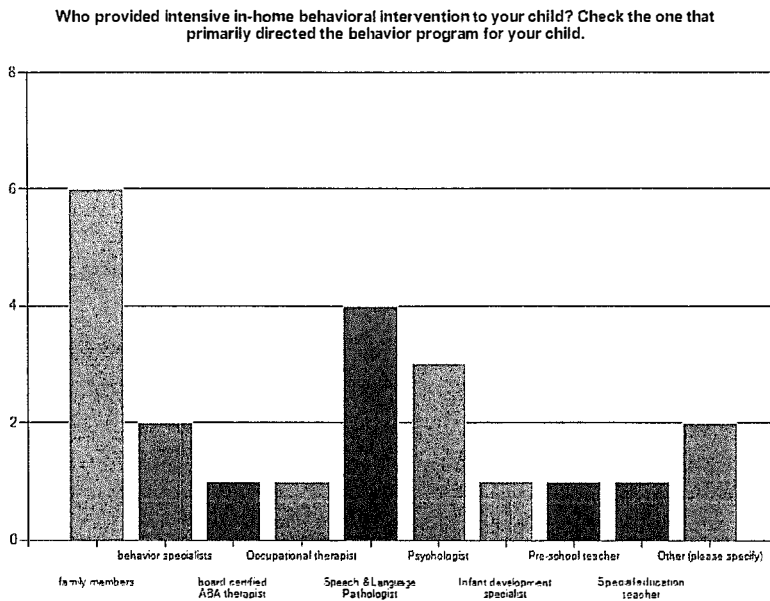
- ❖ ADHD
- ❖ Severe communication disorder
- ❖ Emotionally disturbed
- ❖ Not on IEP yet
- ❖ When his IEP was written he didn't yet have an autism diagnosis, but the team knew he needed services so at the principal's suggestion he was placed on an IEP for ADHD under the OHI category (even though his ADHD wasn't the primary concern) Non-categorical delay wasn't applicable due to his age (nearly 9) and we thought he might have a learning disability but he tested too high

Did or does your child with ASD receive early intensive behavioral intervention as a treatment option?



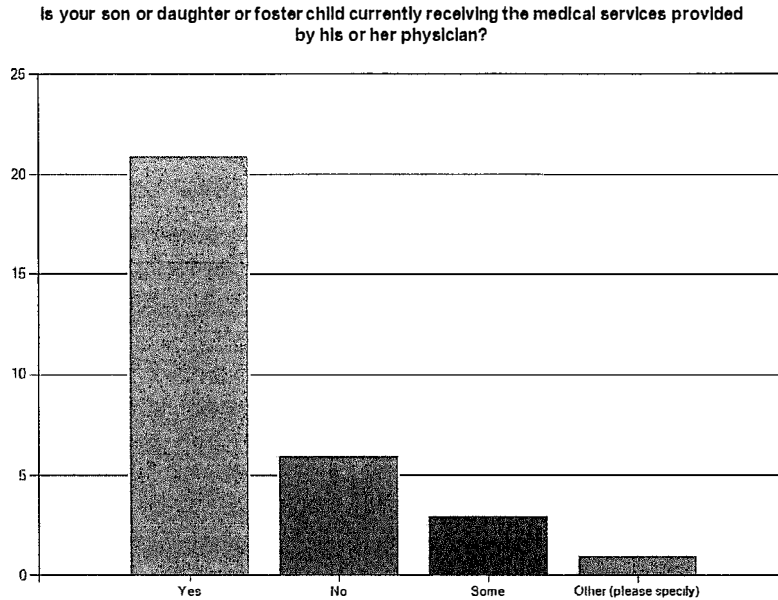
## Other:

- ❖ I'm not sure I know what that is.
- ❖ Just last week we began getting some behavior support. When he was diagnosed with PDD NOD (now is moderately mentally retarded on top of it all due to parental neglect because of the efforts the parent put forth trying to get supports) at 3 years 9 mo. he did get 4 or 5 sessions with a psychologist that instructed us to use 1-2-3 Magic



## Other:

- ❖ None - no intensive In-home training
- ❖ no one...
- ❖ Nobody
- ❖ It is NOT providing FAPE. The IEP is poorly written and the IEP staff avoids answering questions or even getting out report cards or progress reports. However, we are living in Iowa right now, and I can't stand the culture here. The schools are poor. ND schools have high standards.
- ❖ Graduated Last Year 2011
- ❖ Most of the time, Yes. Occasionally not being followed.
- ❖ Most of the time, but not always!



**What primary barriers to obtaining either medical or educational services for your son or daughter or foster child have you encountered?**

- ❖ We have had many barriers with education K-5. Those working with our son just did not have the training or expertise to work with our son in the most basic of needs with autism. We have transportation issues when it comes to school as well. We also have faced a barrier with Medicaid not working for the freshening products we need for our son. We use \$500-\$600/month of freshening products. The main diaper we use is not covered by Medicaid. This has been a great cost to our family. Medicaid should not be able to dictate what product works for which child. In home supports is also a big thing for our family. Our son would not be living in our home right now if we did not have respite. With recent budget cuts, respite has been affected. With a surplus in our state budget this should not be happening. It would cost the state more money if our son did not live with us!
- ❖ The whole process is overwhelming. It is very challenging to bring my son places. Every transition is a battle. It is very draining to have to take to other places for services.
- ❖ We have seen already overwhelmed teachers with too large of classrooms in Fargo trying to prepare for taking on special-needs kids on top of it all. Teachers are lacking the tools and training to help these kiddos & their families and so they can pass on the support that they don't have themselves. Medically, the medical professionals that are the initial ones to look for autism are either really in-tune or else they proclaim to know it all already and don't actually have any tools to help besides an Rx pad and the ICD-9.
- ❖ Medical professionals don't understand treatment options for autism.
- ❖ Rigidity of school to changes necessary
- ❖ Getting a diagnosis was the most difficult
- ❖ My disabilities. I need accommodations for my disabilities - help identifying my needs. Instead I'm lied to - and resources are withheld. It takes me hours to write simple one page emails. A psychologist once told me I'm addicted to advocacy (we moved and my older son never saw her again). I don't think I do anymore than the "regular person" but it takes me far longer - and people take advantage of me and withhold services.
- ❖ Out of pocket expenses and insurance covering what is needed. We do not qualify for Medicaid.

- ❖ Our school district doesn't think they need to provide services to him.
- ❖ Doctors leave you with a diagnosis and no follow up. They just tell you that your kid has a diagnosis and to have a nice day. I think they should give parents options on what to do next and where to find services.
- ❖ Augmentative communication funding has been the primary barriers.
- ❖ Understanding of his diagnosis
- ❖ Getting people to listen and understand and getting training for teachers and staff in the school
- ❖ None, both have been excellent!
- ❖ Community supports around recreation
- ❖ Finding the right doctor and location of doctor and the fact that other specialists are so booked you can't get in for months!
- ❖ Cost out of pocket for travel/lodging
- ❖ Direction for parent and support for our son
- ❖ We did not know the options available to us and the school district, for providing an education for our son. We realized later that having an IEP can really be almost a blank check.
- ❖ Cost of medication, availability of adolescent psychologists, school personnel uneducated in the needs of our son or any other student. Especially, Ben Franklin general ed teachers. Also our ability to receive some services for him to give us a break. We love him but some days.....
- ❖ Lack of providers.
- ❖ Lack of local services, lack of money to pursue them elsewhere.
- ❖ Financial has been the primary problem. Social services say we make too much for her to qualify for services and she doesn't qualify for DD services.
- ❖ Travel requirements
- ❖ There are medical doctors that are specialized in treating children with special needs and in our case autism. Unfortunately there is not a single doctor in ND that looks at treating other underlying medical issues in kids on the spectrum and since most medical doctors don't believe there is such things as GI problems, heavy metal toxicity, mitochondrial issues or deficiencies in vitamins and minerals, they aren't willing to refer patients out-of-state to a doctor that does treat those issues. And even if you do find a doctor that is willing to write a referral it is denied by MA as they see no warrant to leave the state as we have medical doctors in our state. Yes we do have doctors in our state but they aren't willing to treat other conditions in these kids. We've initiated the only 2 referrals we've asked for and both times they've been turned down because we the parents made the request, not the doctor. If the State truly wants to get these kids the best kind of help then let us go to these doctors who are willing to treat these kids. We thought our son was having seizures so we asked to see a pediatric neurologist. At the time we only had 1 in the state and she was booked 6 months out. So what are we as parents suppose to do, wait those 6 months and hope that our child doesn't have a full blown seizure or should we get seen by another pediatric neurologist that could see him in 3 weeks? Apparently ND MA felt waiting 6 months was ok. As for our educational services, in rural ND it's an absolute joke. Our school district is the biggest joke. We have IEP members that don't show up for meetings, we have a principal that sits and plays Angry Birds on his iPad during the meeting and is constantly in and out of meeting. The director of the district has parents, teachers and staff members scared of her because it's her way or the highway and is not open for suggestions. Building is not safe for children to even enter. We have resource teachers in our school that think it's too difficult to enroll a child in aerobics because all you have to do is enter their name into the computer, and that's too much work. We have a speech pathologist that is not open to suggestions for using different methods for helping our son communicate. We even went to the extent of asking the school speech pathologist to consult with our private speech pathologist so they kind of had the same treatment plans and she flat out told us absolutely not. Our school program for summer school isn't designed to help the kids make progress in school, it's designed to help the maintain. That's the silliest thing I've ever heard. We need a complete overhaul in our school program.



- ❖ We really had to fight to get him an OT evaluation in the Minot school system & even now he doesn't receive any OT therapy, but yet he struggled with holding a pencil & to this day his writing is very poor. At one point the IEP team just handed us a summary of his last few months of school without any discussion (because it was at the end of an IEP meeting for his brother). The summary described how he was having terrible behaviors (which were news to us) and since it was at the end of the school year, we had no time to schedule an IEP meeting to discuss it! It ended up having to wait until fall!
- ❖ He's too smart to qualify for services that he needs

**What changes to the service system would make it more likely for your son or daughter or foster child to receive services?**

- ❖ This question is too hard to answer.
- ❖ More specific guidelines for professionals for diagnosis. What age is a proper diagnosis? Early intervention is extremely important. My daughter lost her speech at the age of 18 months, currently she is in mainstream kindergarten with minimal supports. I believe it is because of early intervention that she is doing so well. I am optimistic that my son will do as well because of early intervention
- ❖ Better funding for better support to the professionals. As a parent, I don't want to spend time hunting for the right professional to provide the right treatment, I want to get the right treatment up and running ASAP.
- ❖ Professionals trained to work with autistic kids
- ❖ More flexibility of school - more education & support of teachers
- ❖ Insurance coverage for other medical issues that may be related to his autism dd. For example out of state services that are not approved by Medicaid
- ❖ A change in cultural language. Operate like WIC does (though Williston WIC doesn't do this well at all) - and thank parents for doing the right thing by seeking services and treat the child like they are getting services they are entitled to. Put things in a positive light so parents feel good about continuing to contribute to community and work jobs - despite the high cost of their child on the system. Because costs are FAR higher if we don't help these families and children - or if ANYTHING is done to withhold services that exist, it costs everyone FAR more.
- ❖ More services covered under insurance plans.
- ❖ Lots more education for everyone about autism.
- ❖ There is nothing available for middle school age children! He is too old for a babysitter yet still needs supervision!
- ❖ Some type of plan to be in place. If you get this diagnosis, you go here. If you get that diagnosis, you go there, and so forth. Also, with DD Case managers, there needs to be a finer screening process. We have been denied for DD several times, and they have yet to give me a valid reason why.
- ❖ I have always been frustrated when we have tried to secure services with programs such as Big Brother and Big Sister. Yes, I am married but, that DOES NOT mean we are equal partners in the care and responsibility for our son. We have always worked opposite shifts or adjusted our work schedules around our child's needs. But, by staying married, saving and working hard we/son have been disqualified for some financial services. I don't know how many times I have heard/thought that we should divorce and stop saving. But, I thought that was the American Dream; being married, having children and saving for the future.
- ❖ Understanding by the system of the broad range of this spectrum and that a child can be on the spectrum without having the intensive social avoidance
- ❖ More training. Educate!!!!!!!!
- ❖ Difficulties with the human service center

- ❖ None
- ❖ An open opinion of autism and more cross training within school systems
- ❖ I'm not sure there is much that can be done except by moving to a bigger city with more services..
- ❖ streamlined services from IFSP to IEP, no gaps
- ❖ Specialty services and coordination of services. If we could afford we would have him in an intensive program for transition services and education.
- ❖ More interaction between county, school, and medical.
- ❖ More local services or help with expenses to travel to get them elsewhere.
- ❖ Qualification criteria for obtaining affordable services
- ❖ More local services
- ❖ We need all health insurance companies in the state to start covering autism services whether it be ABA, speech, OT, sensory integration, hippo therapy. We need to get our education people better educated and better equipped in working with kids on the spectrum. We need more speech pathologists in our school system. We have an overabundance of kids receiving speech services so kids aren't receiving adequate amount of time for speech therapy in the school. In our case we have to pull him out of school 3 days per week so that we can get extra services. We need MA to approve the requests to see doctors out of state so we can get the proper medical services that are need for kids on the spectrum. We need more ABA providers. If insurance covered the expenses as well as MA covering the expenses that aren't covered by insurance, we wouldn't be in situation we are currently in and our kids would be getting better services. MA needs to start paying service providers better. They pay such minimal amounts back to the providers it's insulting. We can't expect these providers to work for free. We need more funds allocated to the schools specifically for kids with special needs. We need more teachers that care about kids with needs. Often times special needs kids just get shoved to the side because nobody knows how to deal or wants to deal with them. Our doctors and schools need to be held accountable for helping these kids and currently they are not doing this!
- ❖ Feel like there is no "link" to bind all the services together or even one location to find out what services are available. Having one place to look would be wonderful. I only recently came across the Autism Resource booklet from the Dept of Health. Something like this should be given out immediately when you receive a diagnosis! I also think there should be more training for teachers regarding autism so they are more familiar with behaviors & how to respond appropriately.
- ❖ change in the evaluation criteria, more available service providers and staff in the school
- ❖ Better communication. more coverage for services
- ❖ Linkages to family support organizations such as Family Voices and Pathfinders from day one.

#8

Handed in  
by  
Gunnarist



## Testimony

SB 2193

### House Human Service Committee

Chairman Weisz and Members of the Senate Appropriations Committee.:

My name is Toby Cherney and I am the parent of a wonderful little boy named Alexander. Alexander has autism. He turned five years old on January 26<sup>th</sup>, 2013. He is no longer eligible for the Autism waiver that exists in the state of ND right now which has caused regression and difficulty within our family life. I feel very strongly that the ND Autism Wavier needs to be expanded and refocused for those specific reasons.

Alexander was the first child on the Autism Waiver and even with its glitches it was still better than what we have now, minimal services at the Anne Carlsen Center, but have lost in-home supports, respite and access to Medicaid. Alexanders' therapies, in-home supports, opportunities for equipment and supplies that would assist him to be independent, and certain environmental changes adapting social skills, opportunities for in-home supports and respite. Are no longer available.

Ever since my son was diagnosed when he was 2 ½ it has been a constant battle to get help. We have fought and kicked and screamed and sent emails to get help for our son. The only way we found out about what services were available was from Family Voices and other parents. Once we found some help, it was quickly gone in a very short period of time. Alexander turned 5 and services stopped, he did not qualify for the traditional developmental disability waiver as his substantial functional limitations did not meet their criteria, I feel that they should spend a day with our family and see what we really live through each and every day .. The amount of time a child may be on the wavier is too short to gain progress, to access therapies for speech and occupational therapy, to allow in-home supports to help Alexander and help our family thrive as community members. Early Intervention supports families who have children birth to 3 so very few would be on autism wavier before age 3. Alexander receives speech and physical therapy thru the Anne Carlson Center, which I will have to stop due him not being eligible for Medicaid anymore. It is so important for him to continue these services while he is still young to help him continue on the path of independence. I believe and hope you would agree that early intervention is the key. Right now we are dealing with regressions already. His behaviors have changed dramatically. He will not sleep in his own bed anymore and has to sleep on the floor next to our bed to know where I am at because

he has a fear of me leaving and not coming back and this comes from the loss of his respite care. He is waking up every couple of hours just to check where I am. He is backsliding in preschool due to lack of energy from being tired. He is more aggressive now. Functioning on 4-5 hours of interrupted sleep every night is taking its toll. I can't afford to lose my job. My husband and I have not had an evening alone since the loss of the respite care and the constant stress of fighting to get our son help and fighting the behaviors is taking its toll on our marriage. I also have 2 other children that I have missed activities for that we can no longer attend due to the fact that Alexander cannot tolerate being in the crowd situations.

Alexander has co-existing medical needs along with his autism. The need to have a Medicaid waiver is critical for Alexander and my family. Alexander has issues with possible sleep apnea, issues regarding food, possible seizures, immune problems and a bump on his head that we still haven't received a clear diagnosis yet. Without Medicaid we will no longer be able to afford doctors visits.

Hearing comments such as "It's not our responsibility to take care of your son after he turns five, it is the schools." Is very disturbing to hear. My son has autism, a neurobiological disorder, he has medical concerns each and every day. As parents, we look to you for guidance. we are looking to you for understanding and compassion. Parents are looking for ways to help our children. We are not asking for handouts, we are looking for assistance so that our children can become independent and productive community members. To do that our family needs to be whole and we need the help of others to achieve this. We need the waiver expanded, the age group that it covers is wrong for ND, we have an early intervention program that can help our youngest of children from birth to 3, now help our children from 3 to life. Remember autism is a life-long disability.... We need Behavioral intervention and therapies. We as a state need to increase the access to the professional staff in the area of behavioral issues and concerns. We need ways to help parents access training so that we do can continue to help our children on the autism spectrum. As a parent, I have had a constant struggle to get help for our son, but an Autism Waiver that is designed for the consumer will work. There are families in ND that a year without services will make a huge difference in the progress made by our children. Just ending services and expecting that there will not be any regression and setbacks to the progress that has been made is being unrealistic. As parents we will have to start the process all over again from step one.

I would like to see an Autism Coordinator in the state that has knowledge of autism and not someone just put in that role, someone with hands on experience for persons with autism.. We need hold stakeholder meetings with parents and professionals at the table. The professionals need to hear parents and self-advocates as we live autism 24-7 everyday. To be able to understand the emotionally roller coaster families have and how that affects the whole family.. To better understand how to help our children the need to have co-training, stakeholder meetings and knowledge of the autism spectrum disorders and how it affects the child, family life and the future is a necessity. They need to walk in our shoes, spend a day with our children.

I am asking this committee as a parent and as a mother, as a community member to please address autism in our state, and please pass a comprehensive autism bill that will work for families, a new and improved autism waiver for families.

Please help my son as I am trying to help him..

Thank you for your time:

Toby Cherney, Mother to Alexander Cherney



Email address: [chernfamily5@centurylink.net](mailto:chernfamily5@centurylink.net)

Phone number 701-320-3104

Testimony SB 2193

#9

House Human Services Committee

Chairman Representative Robin Weisz

March 12<sup>th</sup>, 2013

Chairman Weisz and Members of the House Human Services Committee, I am Vicki Peterson a single mother of a child with autism and a Family Consultant for Family Voices of ND, the Health Information and Education Center in ND. As a parent of a child with autism, I live autism every day, as a consultant for families; I work and have contact with many families across the states that have children and youth with **Autism Spectrum Disorders** (*which I will refer to as ASD*). I am here today to provide testimony and information on SB 2193.

In section 1 of SB2193 concerning the Autism Database and the language that is stated, many parents have contacted myself and have expressed real concern over language stated of “research and analysis” as well as the” department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records.” Many also have high concerns over the language of “a complete physical evaluation.”

I would like to direct you to Section 2, paragraphs 1 and 2. Here is where lists of what may be covered and what would be excluded from a pilot voucher for ASD are written. Key services and supports are missing and the exclusion of behavioral interventions as treatment is excluded. Behavioral treatment is a priority for families having children and youth with ASD and was presented to the interim committee on the Study of Autism Spectrum Disorders as a high need and is the number one issue I hear from parents. Many parents tell the story of after a confirmed diagnosis of ASD, the diagnostician recommends Behavioral Interventions, yet many have no access to or can afford such services. Families feel isolated from communities, children are being removed from daycare settings, participation in inclusionary activities is non-existent for some and greatly hindered for others, a sense of self-worth for many including young adults with ASD is occurring. Children and youth with ASD are being seen as “naughty, or the bad child” and experience bullying and feelings of being an outcast and strange. Behavior is a form of communication for some of those with ASD and intervention and treatment is key for those to have quality of life and engage in social activities, in family environment, school and communities. I once attended an IEP meeting for a child with Aspergers who stated to his team, ***“I do not have autism today, because I have been good today”*** The National Autism Center’s *National Standards Report (2009)*, which I have provided with this testimony, recognizes Behavioral Treatment as an established treatment for ASD. In a recent report that Autism Speaks featured from the journal of *Current Opinion in Pediatrics (02/2013)*, Geraldine Dawson Ph.D. chief Science officer of Autism Speaks and professor of psychiatry at University of North Carolina and Karen Burner Ph. D. of University of Washington, found evidence of benefits from behavioral intervention and treatment to improve social communication, parent-child interactions, enhanced and improved social skills and reduced anxiety and aggression, which can be core deficits of those with ASD. For persons with ASD, it is necessary to make sure behavioral treatment is attainable for those who need.



Respite and In-Home supports are not included in the current version of SB2193. Two more key services families are in need of in ND. For families of children with autism and other special needs, daily living demands are a constant planning and juggling. High health-care costs can leave few funds for daycare. And many parents, who know their kids' challenges so intimately, struggle with the idea of leaving them with strangers. It has been estimated that the divorce rate is in the 80% range in families with children who have autism (*Bolman, 2006*). Lack of respite is a major reason. Autism is an emotional roller coaster ride that begins before diagnosis and continues throughout life. According to a study published in the journal *Pediatrics* (2010), ***mothers of children on the autism spectrum frequently rated their mental health status as "poor" or "fair." They had a much higher stress level than the general population.*** In addition to the higher stress level, many parents of children with autism experience the following emotions:

- Feelings of being overwhelmed
- Relief at having a name for the challenges their child faces
- Anger at their spouse, the doctors, or themselves
- Resentment of the child and guilt for that resentment
- Despair at the incurable nature of the disorder
- Guilt that something they did may have caused their child's challenges
- Frustration that the parenting experience they have is not what they envisioned
- Feelings of social isolation
- Embarrassment at child's behavior in public

In-Home supports need to be in place to support the need of daily and community routines, within their family home and community. ***In-Home supports support the primary caregiver, allowing the rest of the family to live as much like other families as possible with the intent of preventing or delaying unwanted out of home placement. (Defined as ND DHS Developmental Disabilities Services Policies and Procedures Manual).***

In conclusion I am in favor of a "pilot voucher program for persons with ASD" to be able to report back to the legislators if a voucher system may work for those with ASD that are not accessing a waived service in ND. For those young adults with ASD whom are in need of training of social skills and training towards independence and employment opportunities and to add behavioral treatments and the opportunity to evidenced-based and promising practices for ASD, and to have access to respite and in-home supports.

Thank you for your time and attention to Autism Spectrum Disorders.

Vicki I Peterson

Parent/ Family Consultant Family Voices of ND [vickiasdc@bis.midco.net](mailto:vickiasdc@bis.midco.net) 701-258-2237

**National Autism Center's National Standards Report Reference Sheet for Established, Emerging, & Unestablished Interventions for Autism Spectrum Disorders (2009)**  
 From: <http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf>

Type of Intervention	Ages	Diagnostic Classification (Autistic Disorder (AD), Aspergers Syndrome (AS), Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS))
<b><u>Established Treatments</u></b>		
Antecedent Package	3-18	AD
Behavioral Package	0-21	AD; PDD-NOS
Comprehensive Behavioral Treatment for Young Children	0-9	AD; PDD-NOS
Joint Attention Intervention	0-5	AD; PDD-NOS
Modeling	3-18	AD; AS; PDD-NOS
Naturalistic Teaching Strategies	0-9	AD; PDD-NOS
Peer Training Package	3-14	AD; PDD-NOS
Pivotal Response Treatment	3-9	AD
Schedules	3-14	AD
Self-management	3-18	AD
Story-based Intervention Package	6-14	AD; AS
<b><u>Emerging Treatments</u></b>		
Augmentative and Alternative Communication Device	3-9	AD
Cognitive Behavioral Intervention Package	6-18	AD; AS
Developmental Relationship-based Treatment	0-8	AD; PDD-NOS
Exercise	3-14	AD
Exposure Package	3-5	AD
Imitation-based Interaction	0-14	AD
Initiation Training	6-14	AD; AS; PDD-NOS
Language Training (Production)	3-9	AD
Massage/Touch Therapy	3-5	AD
Multi-component Package	0-9	AD; AS; PDD-NOS
Music Therapy	N/A	AD
Peer-mediated Instructional Arrangement	6-9	AD
Picture Exchange Communication System	0-9	AD; PDD-NOS
Reductive Package	N/A	AD
Scripting	6-14	AD
Sign Instruction	3-9	AD
Social Communication Intervention	0-5	AD
Social Skills Package	3-18	AD; AS; PDD-NOS
Structured Teaching	0-18	AD; PDD-NOS
Technology-based Treatment	6-14	AD
Theory of Mind Training	6-14	AD; AS

<u><b>Unestablished Treatments</b></u>		
Academic Interventions	N/A	N/A
Auditory Integration Training	N/A	N/A
Facilitated Communication	N/A	N/A
Gluten- and Casein-Free Diet	N/A	N/A
Sensory Integrative Package	N/A	N/A

#18

Senate Bill NO. 2193

Mr. Chairman and members of the committee,

My name is Craig DeGree and I would like to comment regarding this bill. Specifically, I am not in favor of the exclusion of early intensive behavioral interventions as identified in SECTION 2 (2).

My rationale for the above is as follows: First, the excluded services are considered the **best-supported interventions** for treatment of autism spectrum disorder. This is not just my opinion or speculation but also that of many in this field. Specific reference is invited to the summary of research and recommendations contained within the National Standard Project sponsored by the National Autism Center. A total of 775 peer-reviewed treatment studies were amassed. The behavioral interventions were described as offering "**compelling scientific evidence to show these treatments are effective**" (pp. 11).

Secondly, I am a licensed North Dakota psychologist with 30+ years of experience dealing with children and adolescents, many of whom have significant learning and developmental needs. I provide consultation and other services to a number of school districts and special education units in the Bismarck and surrounding area. I have seen the developmental outcome of many of our special needs children over the years. Despite the best efforts, intentions, and resources of those providing services to these children, I have concluded that more needs to be done and that efforts should start at an earlier age.

Consequently, it my recommendation that early intensive behavioral interventions as identified in SB 2193 be included as with other interventions that are evidence-based or offering promise.

Thank you.



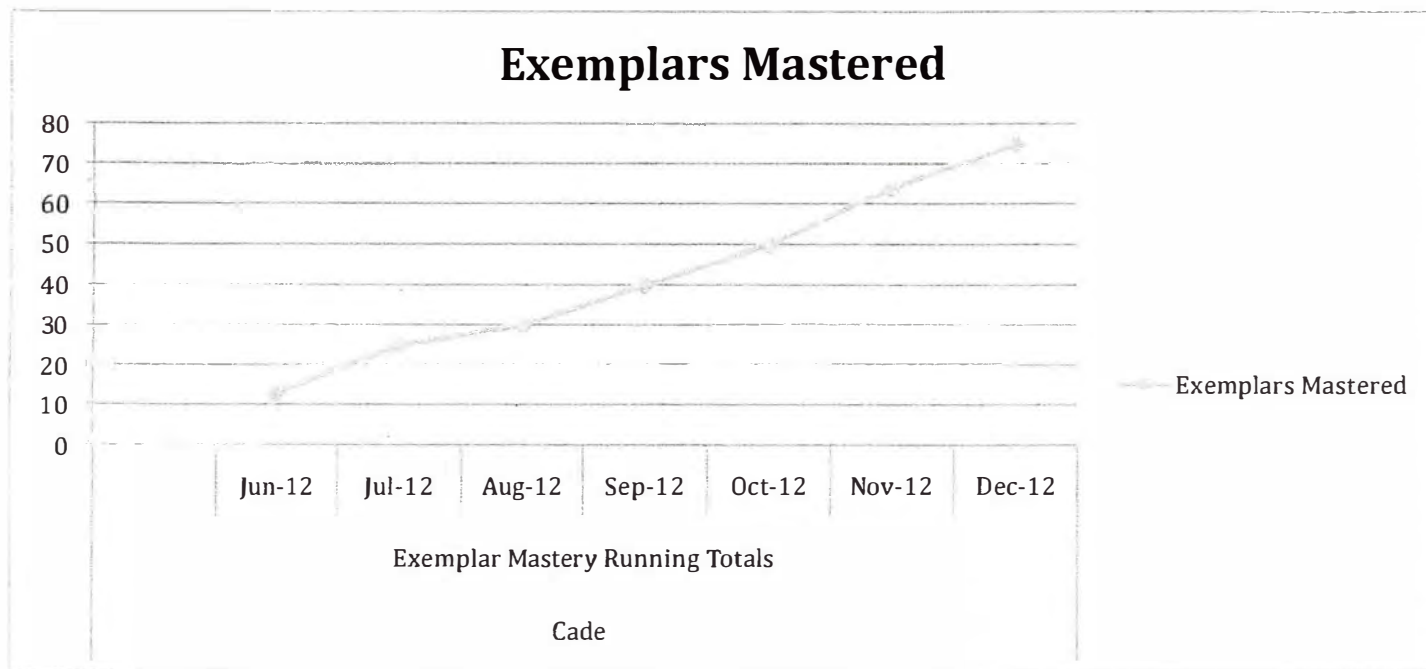
Craig DeGree, Ph.D.

cdegree@primecare.org

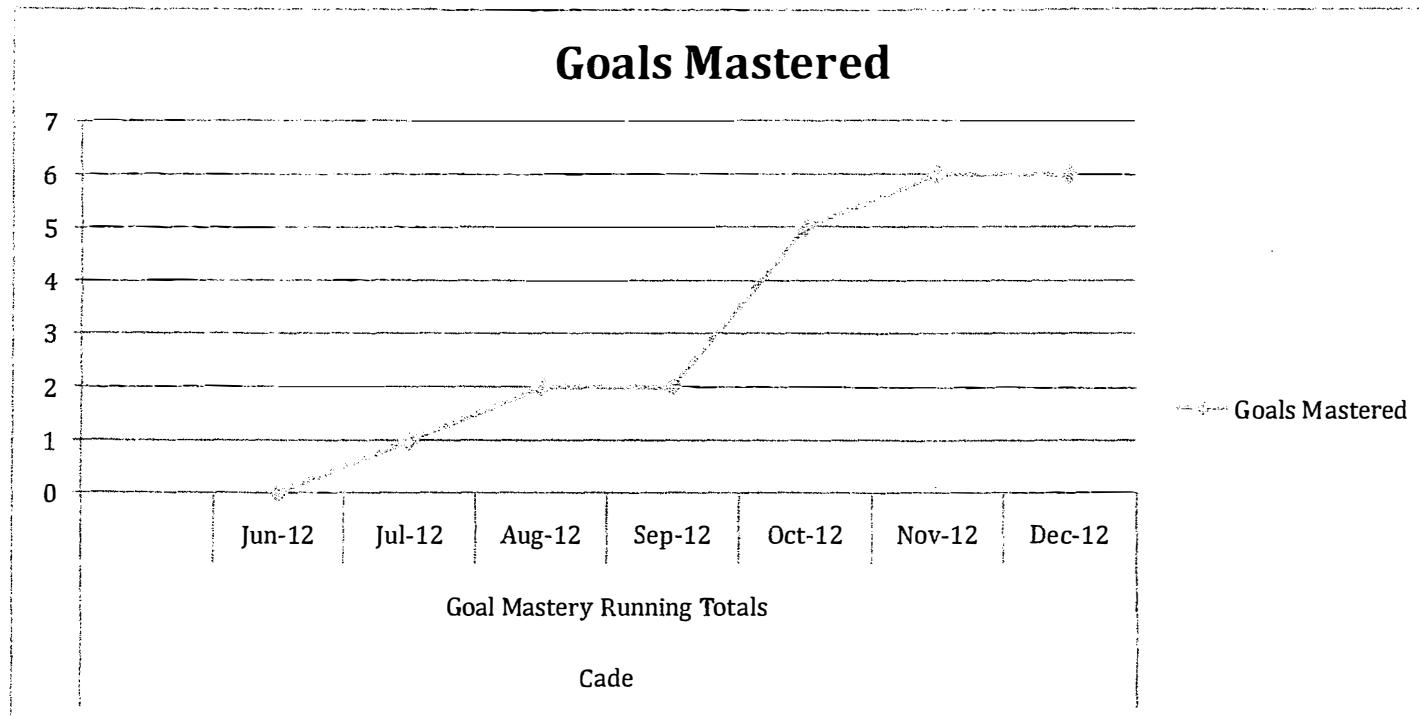
Missy

c/dmb@drtel.net

In June 2012 Cade began participating in an applied behavioral analysis treatment program designed by the Center for Autism and Related Disorders. Cade received an average of 7 to 9 hours a week in the summer months of June, July, and August, and 12 to 15 hours a week during the regular school year months of September, October, November, and December, of one to one therapy.



During this time period, Cade mastered 75 exemplars, and averaged over 10 exemplars mastered per month. His graph shows a nice increase, demonstrating the steady progress he is making in his work.



Cade also mastered six goals completely during this time period. That is an average just shy of 1 goal mastered per month.

This data does not reflect any of the Cade's prior knowledge. During the instructional phase, known as probing, any exemplars or goals that the students were able to complete at mastery level were marked as "known" into the skills curriculum. This information does not appear on any of the exemplar or goal mastery data. This was necessary to ensure they were working on meaningful goals and exemplars.



Cade Brademeyer

## Current Program

### All Curricula

Curriculum: [Show All](#) Filter By: [In Progress Only](#)

#### Actions

Present Tense Tacts

2 5 Fm

5/11/2012

[In Progress](#)

**SD:** The therapist presents a picture of an action or points to an action occurring in the natural environment and presents the vocal stimulus, "What is / am / are (pronoun / person) doing?"

**Response:** "(Action-ing)."/ "(Pronoun / Person) is (action-ing)."

#### Categories

Receptive

3 38 Fm

5/11/2012

[In Progress](#)

**SD:** The therapist presents a field of objects / pictures of objects and the vocal stimulus, "Give me (category)."

**Response:** The child gives the appropriate item(s) from the category.

#### Community Helpers

Naming

U 3 Fm

3/6/2013

[In Progress](#)

**SD:** The therapist presents a community helper and the vocal stimulus, "Who is it?"

**Response:** "A / An (community helper)."/ "It's a / an (community helper)."

#### Compliance

In the Community

0 2 Fm

5/11/2012

[In Progress](#)

**SD:** "(Compliance instruction)."

**Response:** The child responds to compliance instruction within (#) seconds.

#### Echoics

Echoic Sounds

0 1 Fm

5/11/2012

[In Progress](#)

**SD:** "Say, '(sound).'"

**Response:** The child imitates the sound.

#### Finger Skills

Object Manipulation

5 6C Fm

1/15/2013

[In Progress](#)

**SD:** The therapist gives the child a piece of paper and presents the vocal stimulus, "Fold the paper in half / diagonally" with or without using gesturing or modeling to promote a correct response.

**Response:** The child folds the piece of paper (and may or may not use a pincer grasp to crease it).

#### Following Instructions

One-Step Instructions

U 2 Fm

8/27/2012

[In Progress](#)

**SD:** "(One-step instruction)" + distraction.

**Response:** The child follows the instruction.

<b>Handwriting and Penmanship</b> <b>SD:</b> The therapist presents a prewritten uppercase letter, a writing utensil, and the vocal stimulus, "Trace uppercase ( <u>letter</u> )." <b>Response:</b> The child traces the uppercase letter.	Writing Uppercase Letters	4 1 Bb	9/14/2012	<u>In Progress</u>
<b>Objects</b> <b>SD:</b> The therapist presents a field of comparison objects, hands the child a sample picture of an object, and presents the vocal stimulus, "Put with same." <b>Response:</b> The child matches the sample picture to a nonidentical object in the field.	Matching	U 8 Fm	5/11/2012	<u>In Progress</u>
<b>Objects</b> <b>SD:</b> The therapist presents an object and the vocal stimulus, "What is it?" <b>Response:</b> "(Object)." or "It's a / an (object)." <b>Personal Information</b> <b>SD:</b> The child is asked a personal information question. <b>Response:</b> The child answers the question correctly.	Tacts	1 15 Fm	5/11/2012	<u>In Progress</u>
<b>Quantitative Concepts</b> <b>SD:</b> The therapist presents the child with at least two groups of objects and the vocal stimulus, "Touch the group that has ( <u>quantitative concept</u> )." <b>Response:</b> The child touches the corresponding group.	Receptive	2 2 Fm	1/15/2013	<u>In Progress</u>
<b>Safety Awareness</b> <b>SD:</b> The therapist contrives a situation for the child to apply the rule. <b>Response:</b> The child complies with the safety rule.	Following Safety Rules	3 2 Fm	5/11/2012	<u>In Progress</u>
<b>Safety Awareness</b> <b>SD:</b> The therapist presents a field of safety signs and the vocal stimulus, "Give me ( <u>sign</u> )." <b>Response:</b> The child gives the correct safety sign.	Identifying Safety Signs	5 11 Bb	1/15/2013	<u>In Progress</u>
<b>Waiting</b> <b>SD:</b> The therapist contrives or captures a naturally-occurring situation in which the child wants or needs an object / person / action / to go to a location or to engage in an activity <b>Response:</b> The child indicates desire or need for the object / person / action / location / activity (e.g., reaches for the object, requests the object / person / location, or attempts to engage in the activity)	Basic Waiting	1 1 Fm	5/11/2012	<u>In Progress</u>

Cade Brademeyer  
**Current Program**

**All Curricula**

Curriculum: [Show All](#) : Filter By: [Mastered Only](#)

**Basic Mands**

EO: The child has not recently had access to a highly preferred object.

Response: "(Object)" or "I want (object)."

Mands for Objects

1 3 Fm

11/19/2012

[Mastered](#)

**Colors**

SD: The therapist presents a color card comprised of a single color and the vocal stimulus, "What color?"

Response: "(Color)."

Naming

3 7 Bb

10/19/2012

[Mastered](#)

**Desires**

SD: The therapist looks at an object, reaches toward it (but can't get it), and presents the vocal stimulus, "Can you give it to me?"

Response: The child gives the therapist the desired item.

Inferring Others' Desires

U 7 Fm

10/12/2012

[Mastered](#)

**Eye Contact**

SD: "Look at me."

Response: The child makes eye contact with the therapist for (#) seconds.

Responding to Requests for Eye Contact

0 2 Fm

1/10/2013

[Mastered](#)

**Eye Contact**

SD: "(Child's name)."

Response: The child makes eye contact with the therapist for (#) seconds.

Responding to Requests for Eye Contact

0 3 Fm

1/17/2013

[Mastered](#)

**Finger Skills**

SD: The therapist gives the child a paper clip and a piece of paper and presents the vocal stimulus, "Put the clip on the paper" with or without using gesturing or modeling to promote a correct response.

Response: The child fastens the paper clip onto the paper using his / her preferred / nonpreferred hand.

Object Manipulation

4 7 Fm

8/9/2012

[Mastered](#)

**Following Instructions**

SD: "(One-step instruction)."

Response: The child follows the instruction.

One-Step Instructions

0 1 Bb

7/27/2012

[Mastered](#)

**Quantitative Concepts**

Representing

3 48 Fm

1/9/2013

Mastered

**SD:** The therapist presents the child with a group of objects and the vocal stimulus, "Give me (quantitative concept)."

**Response:** The child gives the therapist the requested quantity of objects.

**Yes / No**

Mands

0 1 Fm

10/23/2012

Mastered

**SD:** The therapist presents an object or food and the vocal stimulus, "Do you want (object / food)?"

**Response:** The child says, "Yes" or "No" with or without nodding or shaking his / her head.

[Previous](#)

1-877-9-Skill-9

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#11

**Testimony  
Senate Bill 2193  
House Human Services Committee  
Senator Robin Weisz, Chairman  
March 12, 2013**

Chairman Weisz 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 children and youth with an Autism Spectrum Disorder and their families. I am also the parent to a young man with Pervasive Developmental Disorder (NOS) which is an Autism Spectrum Disorder.

NDFFCMH supports the establishment of the following:

- Autism spectrum disorder database
- Autism spectrum disorder pilot voucher program
- Study for a department of human services.
- Comprehensive training effort.

The autism spectrum disorder database will enable the state to better understand and provide services to individuals with an ASD. We do have concerns with the language in the bill that requires the reporter to be a "doctoral level". My son was evaluated out of state at the University of Minnesota. Therefore, the Neuropsychologist from out of state would not be under the requirements to report to North Dakota. We would be concerned under the current language that children would have to be reevaluated in North Dakota. Having a comprehensive training effort in our state will be very helpful. Individuals have many missed opportunities due to the

lack of training and understanding. Families need to understand autism and how it impacts their family member. As well as providers that individuals come in contact with.

A pilot voucher program will allow us to serve children who are graduating from the current autism waiver. We believe it should be expanded to include others not just children coming off the waiver. We also believe that DHS should establish a process to determine evidence based practices and promising practices and we should not list exclusions. Finally NDFFCMH supports a study from the DHS to look at the best way to provide services to individuals with ASD. However, we feel that the study is not inclusive of family members and individuals with ASD.

The NDFFCMH supports the amendments offered by Protection and Advocacy as they address our concerns with this bill.

The NDFFCMH is also in support of expanding and refocusing the current Medicaid waiver for children with ASD from birth through 22.

To truly help individuals with ASD all people involved in their lives must understand the uniqueness of ASD in order to meet their needs. The way we always do it simply will not work for individuals with an ASD.

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](mailto:carlottamccleary@bis.midco.net)



#12

# Autism Legislation in North Dakota

A Supplement to Anne Carlsen Center Testimony

3/12/2013



*Anne Carlsen*

C E N T E R

Nurturing abilities. Changing lives.

## 2013 AUTISM LEGISLATION IN NORTH DAKOTA

### INTRODUCTION

Legislation has been introduced in North Dakota that addresses the need for support and services for those who have an Autism Spectrum Disorder (ASD) diagnosis. While the legislation is a good start, there is much work to be done. Specifically, there is a need to carefully look at recommended bill language to assure that the needs of all children and families are being addressed. Our state needs to assure an array of service delivery options so that people who are in need of support are not excluded. Among the considerations as legislation is formed are: process for diagnostics and services to be included in a pilot voucher.

### PROBLEM

The current ASD Waiver through the Developmental Disabilities (DD) Division of the DHS has been in existence since 2009. Though available for consideration by families, there are major flaws.

- There is no provision for direct intervention or behavior support services.
- Environmental modifications and equipment options are not specific to those with ASD.
- For the first 2 ½ years of the ASD Waiver being in place, applications for the Waiver were minimal and the majority of the slots (30) remained open until late 2012.
- If a child “ages out” of the Waiver, that slot is not made available to another child who might be found eligible. Therefore, slots are left open and, despite indications that the current Waiver slots are all full, there actually are not currently 30 children benefiting from the Waiver.

### SUGGESTED SOLUTIONS

Further review of evidence-based methods for determining the presence of an ASD diagnosis and provision of services is needed so that an expanded Medicaid Waiver or Voucher Program will be meaningful and beneficial for those seeking help through those avenues. The following should be considered:

- 1) Interdisciplinary Team Diagnostics:** The process for completing ASD diagnostics should be done through an interdisciplinary team, which includes a clinical psychologist or pediatrician, a behavioral specialist, a speech and language pathologist, an occupational therapist, and an early interventionist or special educator, as appropriate.
- The North Dakota Center for Persons with Disabilities (NDCPD) through Minot State University utilizes the team model and states it is effective because it is truly a team approach. Each member of the team has the benefit of observing assessments done through other disciplines (i.e. a Speech-Language Pathologist can observe an Occupational Therapy Assessment as well as the medical evaluation. The team is able

to provide specific feedback regarding each critical area. At each diagnostics clinic, a minimum of two people score ADOS for inter-rater reliability. This is best practice, per NDCPD. An approach other than one involving an interdisciplinary team would not allow for inter-rater reliability.

- Involving a medical provider who can review records prior to the actual diagnostics evaluation ensures that any prior medical conditions that might be causing some of the child's challenges are ruled out. Additionally, the team conducts pre-assessments together to ensure each team member's individual concerns (based on discipline) are addressed prior to scheduling the evaluation.
- The interdisciplinary approach gives the child more flexibility. If the child is having a difficult time in the first hour of the evaluation, that professional has a later opportunity to conduct evaluation through observation. The team approach is flexible and fluid, allowing for the child to dictate which activities are conducted and when (providing for a truly person-centered process).
- The interdisciplinary approach truly involves the family. Family members are present for much of the evaluation and every attempt is made to obtain the most thorough and comprehensive view of the child as possible.

#### Eligibility for Diagnostics:

Individuals referred for diagnostics must be screened through a local healthcare provider or school personnel utilizing standard screening tools to determine if they are at risk of carrying the diagnosis. Individuals must have been a resident of North Dakota for a minimum of six months.

#### Criteria for Diagnostics:

- Formal diagnostic assessments or tools utilized must be based on industry standards for best practices.
- The tests used must be considered valid for the age of the individual and the diagnosis given.
- The evaluation must support that the individual is a candidate for services identified within the voucher program.
- The evaluation must have been completed no more than one year prior to application for Autism Voucher or ASD Waiver funding for services.

- 2) Provision of Evidence-based Intervention and Treatment including Behavioral Services:** The treatment and intervention program must be person-centered and include direct service support for the individual and family. The basis of interventions and treatments utilized employ established evidence-based programs as indicated in the National Autism Center's findings, 2009. Other emerging or promising evidence-based treatments and interventions may be incorporated into the individual's program plan, based on the individual needs and as deemed appropriate to meet the needs of the individual and their family. Occupational, physical, and speech therapy may be provided. Programs are

integrated and followed consistently in order to provide the maximum benefit for the individual and their family.

It bears noting that within the current bill draft, great care has been taken to include language that insures evidence-based practice in the diagnosis of ASD. Why would the same standard not be applied to the treatment options for children on the Autism Spectrum?

### **Description of the Efficacy of Evidence-based Models Currently Excluded from Bill Draft Language:**

- The Early Start Denver Model (ESDM) is a model which employs social skills training along with applied behavioral analysis intervention in order to increase children's cognitive and language skills. New research on this intervention model has demonstrated remarkable outcomes for infants and toddlers. ESDM was developed by Dr. Sally Rogers, researcher and professor for the University of California, Davis, Dept. of Psychiatry and Behavioral Sciences; along with Geraldine Dawson, Chief Science Officer for Autism Speaks. (See **Appendix A**)
- Pivotal Response Treatment (PRT) is specifically listed in the National Autism Center's National Standards Project as an established, evidence-based intervention or treatment model. It is a behavioral treatment derived from applied behavioral analysis (ABA) and is play-based and child-initiated. The goal of PRT is the development of communication, language and positive social behaviors and the reduction of self-stimulatory behaviors of children on the spectrum. Its philosophy is to target key areas of child development thus resulting in improvements across social, communication, behavior and academic domains of development. It is one of the best studied and validated treatments for children on the spectrum. The model was developed by Dr. Robert Koegel, researcher and professor of Clinical Psychology and Special Education, Gervitz Graduate School of Education, and Director of the Koegel Autism Center, all at the University of California, Santa Barbara, CA; and Dr. Lynn Koegel, researcher and clinical director of the Autism Services, Koegel Autism Center, Gervitz Graduate School of Education, University of California, Santa Barbara, CA. (See **Appendix B**)
- A 2007 clinical report of the American Academy of Pediatrics states that the benefit of ABA-based interventions in ASDs "has been well documented" and that "children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior." (See **Appendix C**)



**\*\*The National Standards Project (NSP) sponsored by the National Autism Center (NAC)  
2009**

Description of the NAC

The NAC's primary purpose is to provide reliable information to families and professionals, promote best practices in treatment and interventions for individuals with Autism Spectrum Disorders (ASD), and advocate for these individuals and their quality of life. The NAC operates with oversight of a professional advisory board.

NSP Overview:

The NSP was a primary initiative of the NAC. The purpose was to address the need for evidence-based practice guidelines for ASD. Beneficiaries are the parents, educators, and service providers who make decisions about treatment selection for individuals on the spectrum.

Three primary purposes of the project:

1. To identify the level of research support available for educational and behavioral interventions used with individuals 22 years of age and under. The interventions address the core characteristics of the neurological disorders.
2. To help parents, caregivers, educators and service providers understand utilize key information to make decisions regarding treatment decisions.
3. To identify limitations of existing treatment research.

Process:

- A rigorous model was developed for evaluating the scientific literature working with a pilot team and outside consultation from methodologists.
- A model-based examination of evidence-based practice guidelines from other health and psychology fields, several experts in the field of ASD, and an additional 25 experts who have expertise in diverse fields of study and theoretical orientations was used.
- Reliability of the research reviewers' coding was completed with an acceptable level of agreement (>80%).

Research results:

Treatments and interventions were classified into four categories:

- 1) **Established.** Sufficient evidence supports that the treatment as having favorable outcomes and thus are effective.
- 2) **Emerging.** Some efficacy in the treatment has been demonstrated and more high quality studies must consistently confirm its effectiveness.
- 3) **Unestablished.** Little or no evidence exists that confirms the effectiveness of the treatments.
- 4) **Ineffective/Harmful.** Sufficient evidence exists that determines the treatment is ineffective or harmful.

*Listing of Established treatments:*

- **Antecedent Package** – treatments utilize applied behavioral analysis (ABA), behavioral psychology, and positive behavioral supports.
- **Behavioral Package** – treatments utilize applied behavioral analysis, behavioral psychology, and positive behavioral supports
- **Comprehensive Behavioral Treatment for Young Children** – treatment utilizes applied behavioral analysis, discrete trial training, incidental teaching and can be delivered in a variety of settings
- **Joint Attention Intervention** – intervention involves teaching children to respond to nonverbal social cues of others or to initiate interactions
- **Modeling** – interventions rely on adult or peer demonstrating behaviors and the imitation of the behavior by the individual with ASD
- **Naturalistic Teaching Strategies** – interventions utilize child-directed interactions to teach functional skills, i.e., play, conversation, choice-making, etc.
- **Peer Training Package** – intervention involves teaching without disabilities strategies for facilitating play and social interactions with children on the spectrum
- **Pivotal Response Treatment (PRT)** – intervention targets areas of motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues. Use parental involvement and the natural environment.
- **Schedules** – intervention involves presentation of a task list to communicate a series of tasks required to complete a specific task or series of task.
- **Self-management** – interventions involve promoting independence by teaching self-regulation of behavior. Reinforcement is a key component.
- **Story-based Intervention Package** – Treatments that involve written description of situations and specific behaviors that are expected to occur, i.e., how to act when shopping. Involves prompting, reinforcement, discussion.

\*\* This description was taken directly from NAC's NPR report titled "Findings and Conclusions: Addressing the Need for Evidence-based Practice Guidelines for Autism Spectrum Disorders." (See Summary Chart - **Appendix D**)

## **CONCLUSION**

As legislation is currently written, Anne Carlsen Center (ACC) would not be able to provide services to children with ASD and their families. Services to rural North Dakota children and families would not be possible as services would need to be provided in a major North Dakota city. ACC provides direct intervention services through the use of a specialized curriculum all under the direction of a clinical psychologist. The curriculum utilized incorporates applied behavioral analysis approach with positive behavioral supports and naturalize environments to not only assist children in the mastery of skills but in the generalization of those skills. Data from ACC's outcomes study indicates children are making gains in their skill development. This may not be a longitudinal study, but the early outcomes indicate reduced behaviors, increased communication and social skills, and increased quality of life. (See **Appendix E** and **Appendix F**)



## **Appendix A**

### **Early Interventions for Children with Autism**

**A new study examined Early Start Denver Model (ESDM)**, an early intervention method for young children with autism, finding that the interventions decreased children's autistic symptoms and improved their social skills. Furthermore, the study found that ESDM normalized the brain activity of children with autism. This is in addition to a previous study finding that this particular intervention model was effective for increasing children's cognitive and linguistic skills. ESDM is an intervention method developed by Sally Rogers (an author on this new study) and Geraldine Dawson, chief science officer for Autism Speaks. The model employs a relationship-based approach using the teaching methods of applied behavioral analysis.

The study participants included 48 autistic infants and toddlers in addition to a control group of children without autism. Half of the autistic children were randomly assigned to receive ESDM intervention for 20 hours a week over a two-year period while the other half of the experimental group received similar amounts of other types of interventions. Children who received early interventions using ESDM for two years had greater brain activity, as assessed by using electroencephalograms (EEGs), when viewing social stimuli such as faces than when seeing non-social stimuli like toys, a response in line with the typically developing children. Children who received the ESDM intervention were more likely to exhibit this type of brain activity than children whose therapy included other interventions, with 73 percent of the ESDM group showing this activation while only 5 percent of the other interventions group did. The study was funded through the National Institute of Mental Health as well as Autism Speaks, and its results can be found in the *Journal of the American Academy of Child & Adolescent Psychiatry*.

Meanwhile, an ongoing study in Canada also involves infants and toddlers who have autism - or who show autistic symptoms but have not been officially diagnosed yet - and early interventions. This study is examining the use of a parent-coaching intervention model known as Social ABCs, which focuses on techniques based on applied behavior analysis. Funded by Autism Speaks Canada and the Sinneave Family Foundation, this study will compare children who receive the intervention earlier to a group of children who receive it six months later. Preliminary results have been promising about the effectiveness of the Social ABCs intervention model.

## Appendix B

### **Overview of Pivotal Response Training (PRT)**

Pivotal Response Training (PRT) is a method of systematically applying the scientific principles of applied behavior analysis (ABA) to teach learners with autism spectrum disorders (ASD). PRT builds on learner initiative and interests, and is particularly effective for developing communication, language, play, and social behaviors. PRT was developed to create a more efficient and effective intervention by enhancing four pivotal learning variables: motivation, responding to multiple cues, self-management, and self-initiations. According to theory, these skills are pivotal because they are the foundational skills upon which learners with ASD can make widespread and generalized improvements in many other areas.

#### **Evidence**

PRT meets the criteria for an evidence-based practice with nine single subject design studies supporting its teaching practices. PRT constitutes an efficient and effective mode of intervention for promoting appropriate social communicative and adaptive behavior for children at the preschool and elementary school levels and for adolescents and young adults at the middle and high school level.

#### **With what ages is PRT effective?**

According to the studies that form the evidence base for PRT, children from 2 to 16 years of age have benefitted from PRT intervention. Research has shown that the use of motivational techniques inside PRT's teaching framework can lead to 85-90% of children with autism, who begin intervention before the age of 5, developing verbal communication as a primary mode of communication. More recently, though, researchers have identified specific behavioral characteristics associated with favorable responses to the teaching practices. Precursors related to positive outcomes thus far, include increased use of social initiations, less social avoidance, more toy play, and stereotypic language.

#### **What skills or intervention goals can be addressed by PRT?**

The focus of PRT is to teach children and youth with ASD certain pivotal behaviors through a set of specific training procedures, which, when learned, will lead to the development of new behaviors. The pivotal behaviors targeted in PRT are: motivation, responding to multiple cues, self-management, and self-initiations. By acquiring these behaviors children can learn skills in the areas of academics, social, language/communication, and self-management. Improvements in these areas will promote a variety of social-communicative behaviors, such as communication, imitation, play skills, joint attention, and will reduce inappropriate, maladaptive behaviors.

#### **In what settings can PRT be effectively used?**

The ultimate goal of PRT is to provide learners with autism with the social and educational skills to participate independently in enriched and meaningful lives in inclusive settings. PRT emphasizes the importance of training parents as primary intervention agents; however, other family members (e.g., siblings, secondary caregiver), staff (e.g., teachers, school personnel, consultants), and typically developing peers are also included as intervention agents. As a result, PRT has been successfully implemented in a variety of naturalistic settings, including school, home, and community. Further, teaching in varied and more naturalistic environments has been demonstrated to promote generalization of skills.

*(From the National Professional Development Center on Autism Spectrum Disorders – a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders)*

**Excerpt from Report:**

## **Management of Children with Autism Spectrum Disorders**

1. Scott M. Myers, MD,
2. Chris Plauché Johnson, MD, MEd,
3. the Council on Children With Disabilities

### **Applied Behavior Analysis**

Applied behavior analysis (ABA) is the process of applying interventions that are based on the principles of learning derived from experimental psychology research to systematically change behavior and to demonstrate that the interventions used are responsible for the observable improvement in behavior. ABA methods are used to increase and maintain desirable adaptive behaviors, reduce interfering maladaptive behaviors or narrow the conditions under which they occur, teach new skills, and generalize behaviors to new environments or situations. ABA focuses on the reliable measurement and objective evaluation of observable behavior within relevant settings including the home, school, and community. The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology<sup>21,25,27,28</sup> and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings.<sup>29-40</sup> Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.<sup>31-40</sup>

Highly structured comprehensive early intervention programs for children with ASDs, such as the Young Autism Project developed by Lovaas<sup>35,41</sup> at the University of California Los Angeles, rely heavily on discrete trial training (DTT) methodology, but this is only one of many techniques used within the realm of ABA. DTT methods are useful in establishing learning readiness by teaching foundation skills such as attention, compliance, imitation, and discrimination learning, as well as a variety of other skills. However, DTT has been criticized because of problems with generalization of learned behaviors to spontaneous use in natural environments and because the highly structured teaching environment is not representative of natural adult-child interactions. Traditional ABA techniques have been modified to address these issues. Naturalistic behavioral interventions, such as incidental teaching and natural language paradigm/pivotal response training, may enhance generalization of skills.<sup>13</sup>

Functional behavior analysis, or functional assessment, is an important aspect of behaviorally based treatment of unwanted behaviors. Most problem behaviors serve an adaptive function of some type and are

reinforced by their consequences, such as attainment of (1) adult attention, (2) a desired object, activity, or sensation, or (3) escape from an undesired situation or demand. Functional assessment is a rigorous, empirically based method of gathering information that can be used to maximize the effectiveness and efficiency of behavioral support interventions.<sup>42</sup> It includes formulating a clear description of the problem behavior (including frequency and intensity); identifying the antecedents, consequences, and other environmental factors that maintain the behavior; developing hypotheses that specify the motivating function of the behavior; and collecting direct observational data to test the hypothesis. Functional analysis also is useful in identifying antecedents and consequences that are associated with increased frequency of desirable behaviors so that they can be used to evoke new adaptive behaviors.

## Appendix D

National Autism Center's National Standards Report Reference Sheet for Established, Emerging, & Unestablished Interventions for Autism Spectrum Disorders (2009) From: <a href="http://www.nationalautismcenter.org/pdf/NAC%20standards%20report.pdf">http://www.nationalautismcenter.org/pdf/NAC%20standards%20report.pdf</a>		
Type of Intervention	Ages	Diagnostic Classification (Autistic Disorder (AD), Aspergers Syndrome (AS), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS))
<b>Established Treatments</b>		
Antecedent Package	3-18	AD
Behavioral Package	0-21	AD; PDD-NOS
Comprehensive Behavioral Treatment for Young Children	0-9	AD; PDD-NOS
Joint Attention Intervention	0-5	AD; PDD-NOS
Modeling	3-18	AD; AS; PDD-NOS
Naturalistic Teaching Strategies	0-9	AD; PDD-NOS
Peer Training Package	3-14	AD; PDD-NOS
Pivotal Response Treatment	3-9	AD
Schedules	3-14	AD
Self-management	3-18	AD
Story-based Intervention Package	6-14	AD; AS
<b>Emerging Treatments</b>		
Augmentative and Alternative Communication Device	3-9	AD
Cognitive Behavioral Intervention Package	6-18	AD; AS
Developmental Relationship-based Treatment	0-5	AD; PDD-NOS
Exercise	3-14	AD
Exposure Package	3-5	AD
Imitation-based Interaction	0-14	AD
Initiation Training	6-14	AD; AS; PDD-NOS
Language Training (Production)	3-9	AD
Massage/Touch Therapy	3-5	AD
Multi-component Package	0-9	AD; AS; PDD-NOS
Music Therapy	N/A	AD
Peer-mediated Instructional Arrangement	6-9	AD
Picture Exchange Communication System	0-9	AD; PDD-NOS
Reductive Package	N/A	AD
Scripting	6-14	AD
Sign Instruction	3-9	AD
Social Communication Intervention	0-5	AD
Social Skills Package	3-18	AD; AS; PDD-NOS
Structured Teaching	0-18	AD; PDD-NOS
Technology-based Treatment	6-14	AD
Theory of Mind Training	6-14	AD; AS

<b><u>Unestablished Treatments</u></b>		
Academic Interventions	N/A	N/A
Auditory Integration Training	N/A	N/A
Facilitated Communication	N/A	N/A
Gluten-and Casein-Free Diet	N/A	N/A
Sensory Integrative Package	N/A	N/A



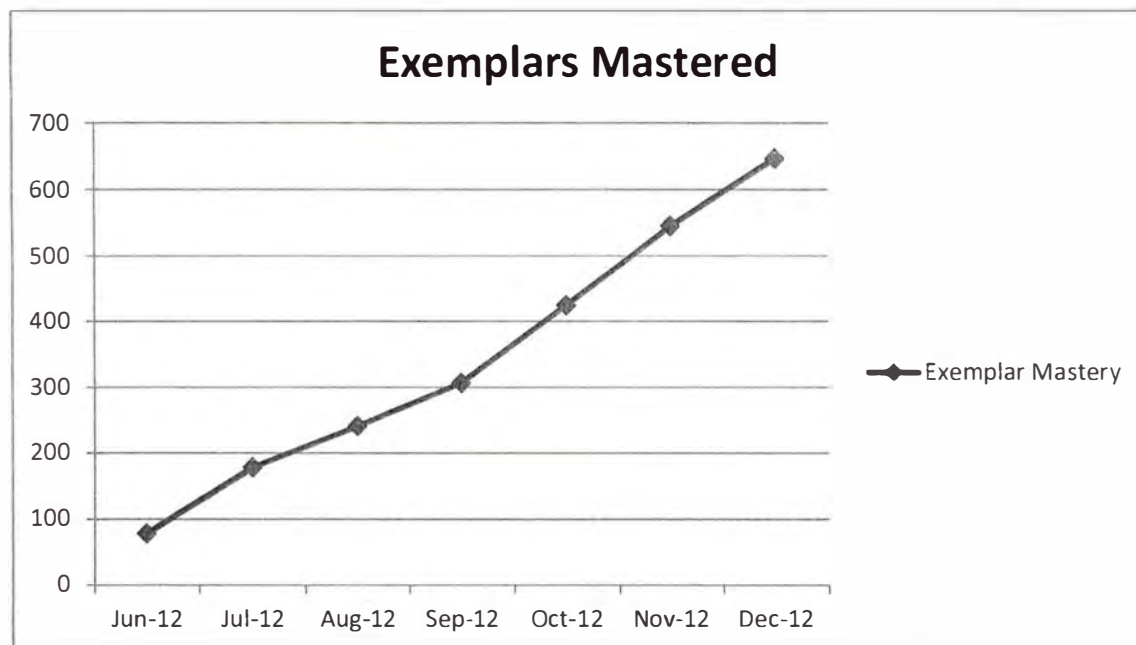
## Appendix E

### **Anne Carlsen Center Classroom CARD Data 2012**

In June 2012 data was collected from 9 students participating in an Applied Behavioral Analysis program, utilizing curriculum developed by the Center for Autism and Related Disorders (CARD). The students' ages ranged from 5 to 17 years old, and each has been diagnosed with a variety of developmental disorders. Prior to beginning the program, an assessment was completed on them by members of their teams including teachers, therapists, and direct services personnel.

The students participating in the program received an average of 10 to 15 hours a week of one-to-one instruction and worked on goals from all eight domains of the CARD curriculum. These include: Language, Play, Adaptive Skills, Motor Skills, Executive Functions, Cognition, Social Skills, and Academic Skills. Team members, based on the results of each student's skills assessment, chose goals.

This data does not reflect any of the student's prior knowledge. During the instructional phase, known as probing, any exemplars or goals that the students were able to complete at mastery level were marked as "known" into the skills curriculum. This information does not appear on any of the exemplar or goal mastery data. Some of the students have required considerable probing into the individual goals. This was necessary to ensure they were working on meaningful goals and exemplars.



The exemplar mastery data refers to the individual parts of an objective. If one were to examine the goal "Receptive Identification of Colors," the individual exemplars would be red, blue, green, yellow, etc. Depending on the goal, there could be as little as one exemplar, or numerous exemplars as in the case of numbers or sight words.

The nine students mastered a total of 647 exemplars (an average of 107 exemplars a month for this seven-month period).

The students' individual exemplar mastery ranged from a low of 17 exemplars to a high of 179 exemplars. The students' averaged a low of around 3 exemplars a month to a high of around 30 a month.



The goal mastery data refers to the goal in its entirety. If one were to again utilize the goal "Receptive Identification of Colors," the goal would be mastered after all of the individual exemplars are mastered. In this example, a student has mastered the goal when they can receptively identify red, blue, green, yellow, pink, purple, black, white, gray, orange, and brown. If they are not able to identify even one of the abovementioned colors, the goal would not be considered mastered.

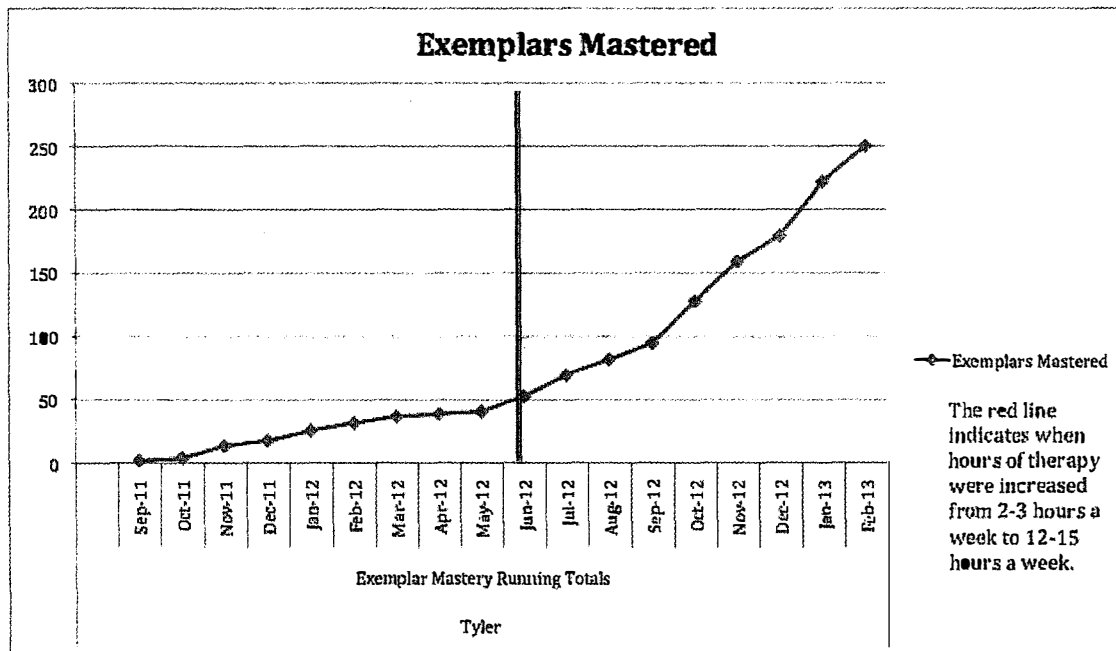
The nine students mastered a total of 67 goals (an average of over 11 goals a month during this seven-month period).

The students' individual goal mastery ranged from a low of 1 goal mastered to a high of 17 goals mastered.

The data has also shown that an increase in the amount of hours of one to one applied behavioral analysis treatment, has led to higher acquisition rates for both exemplars and goals.

In September 2011, we began using applied behavioral analysis strategies with one student for his IEP goals. The goals for the IEP were taken from the CARD curriculum and worked on for an average of 2 to 4 hours a week. During this time we did see positive results on the goals he was working on.

In June 2012 the student began participating in the applied behavioral analysis program for an average of 12 to 15 hours a week. His data graphs show dramatic increases in acquisition of both exemplars and goals.



This graph demonstrates the gains made after increasing the hours of treatment. Prior to the red line, the student was participating for an average of 2 to 4 hours a week of therapy. After the red line is the data for 12 to 15 hours a week of therapy.

In the nine months, from September 2011 to May 2012, the student was receiving 2 to 4 hours a week of applied behavioral analysis therapy and he mastered 41 exemplars and 4 goals.

In the subsequent nine months, from June 2012 to February 2013, the student was receiving 12 to 15 hours a week of applied behavioral analysis therapy and he mastered 205 exemplars and 14 goals. That is an increase of 400% in exemplar mastery, and an increase of 250% in goal mastery.



Although some students had slower acquisition rates for exemplars and goals, all of the students did make gains. Many of these goals have increased the students' ability to communicate. This has allowed the students to not only complete IEP goals with greater accuracy and consistency, but it has also increased their quality of life.

Patrick Kellam

Evidence Based Curriculum Coordinator

Anne Carlsen Center

January 14, 2013

## Appendix F

### **Anne Carlsen Community-Based Autism Services**

Data Summary: June 2012 to February 2013

#### **Background:**

The first Community-Based Autism Services client began receiving services in June 2012. The services combine Applied Behavioral Analysis, Positive Behavior Supports, and Natural Environment Training through utilization of the Skills Curriculum developed by the Center for Autism and Related Disorders (CARD).

Throughout the remainder of 2012, Autism Services were expanded in Grand Forks, Fargo, Jamestown, and Bismarck. Children are served in home and community-based settings, and urban and rural areas. Data in this document reflects 10 children receiving services through the Autism Services Program.

Age ranges of children receiving services through Anne Carlsen's Community-Based Autism Services Program are 2 ½ - 7 years old. Since June 2012, new children have been added to the program on a monthly basis. Children receive varying hours of service per week (between 10-40, with the average being 25).

Of the 10 represented in this data sample, numbers in the program each month were:

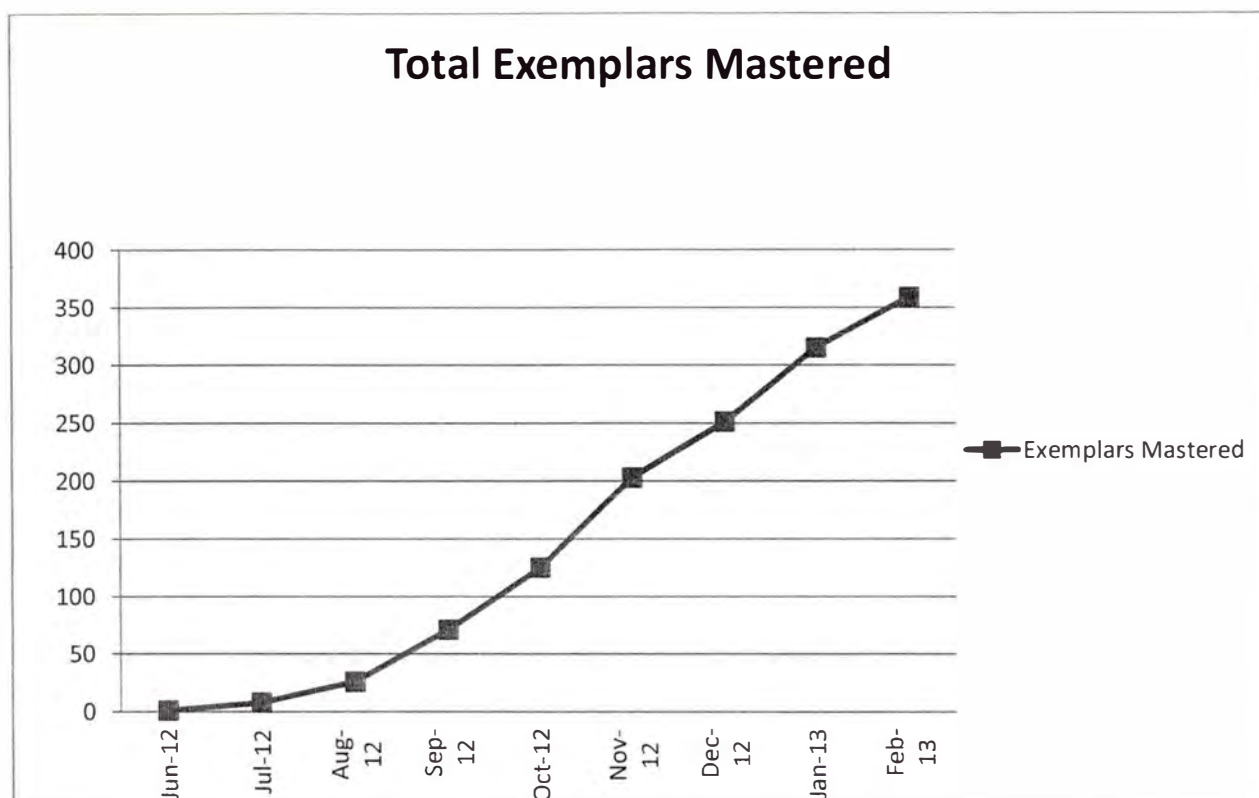
June 2012 -	1 child
July 2012 -	2 children
September 2012 -	3 children
October 2012 -	4 children
December 2012 -	6 children
January 2013 -	9 children
February 2013 -	10 children

#### **Program Overview:**

The CARD Skills Curriculum is designed so that the children in the program are working toward goal and exemplar mastery. As with CARD Curriculum data from the Anne Carlsen Center CARD classroom in Jamestown, community-based data does not take into account any of the child's prior knowledge. There is a thorough assessment and probing

phase which takes place prior to beginning the program. During assessment and probing, extensive time is spent assessing each child's current level of skills in all 8 developmental domains (to ensure that programming is meaningful with individualized goals built upon current skill level). The 8 domain areas include Language, Play, Adaptive, Motor, Executive Functions, Cognition, Social and Academic Skills.

### Progress:

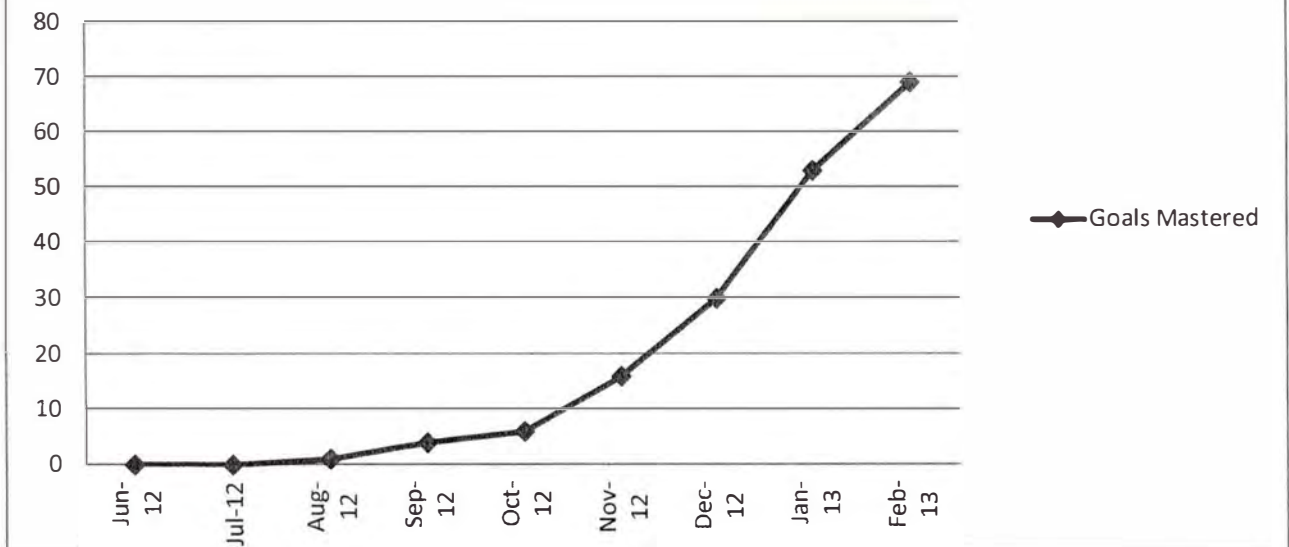


The exemplar mastery data refers to the individual parts of an objective. If one were to examine the goal "Receptive Identification of Shapes," the individual exemplars would be square, circle, triangle, etc. Depending on the goal there could be as little as one exemplar, or numerous exemplars as in the case of numbers or sight words.

In the graph above, it is indicated the 10 children mastered a combined total of **359** exemplars. The children's individual exemplar mastery ranged from a low of 10 exemplars mastered to a high of 181.



## Total Goals Mastered



The goal mastery data refers to the goal in its entirety. If one were to again utilize the goal “Receptive Identification of Shapes,” the goal would be mastered after all of the individual exemplars are mastered. In this example, a student has mastered the goal when they can receptively identify square, circle, triangle, and rectangle. If they are unable to identify any of the above mentioned shapes, the goal would be considered unmet and the child would continue work on meeting all exemplars.

In the graph above, it is indicated that the 10 children mastered a combined total of **69** goals.

The children’s individual goal mastery ranged from a low of 2 goals mastered to a high of 30 goals mastered.

Although some children had slower acquisition rates for exemplars and goals, all of the children made gains. Mastery of goals and objectives has been reflected, for example, in increased communication and decreased behavioral issues.

Jess Oswald, Autism Specialist and Lorena Poppe, Autism Services Director  
Anne Carlsen Community-Based Services  
March 8, 2013

Chairman Weisz and Members of the House Human Services Committee:

I am Dr. Barbara Stanton. I am employed at Prairie St. John's as an outpatient therapist specializing in autism spectrum disorders (ASDs). I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I also conduct trainings and workshops about autism for mental health professionals, educators, law enforcement, early childhood educators, daycare providers, religious organizations, and the community at large.

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families.

I am here to speak in favor of **Senate Bill 2193** which provides appropriations for the establishment of a database for autism spectrum disorders, a voucher program, an on-going study of ASDs, a coordinator, and funding for regional trainings for physicians, school staff, other professionals, and parents.

Autism Spectrum Disorder Study and Report to Legislative Management: Section 3

This is similar to House Bill 1037 and I continue to support the need for a study.

Autism is a spectrum disorder in which there is great variation in individual differences. Currently there is a belief that there are multiple autisms that are due to chromosomal differences, singular or multiple genetic mutations, brain structure changes, and neurochemical differences.

There are many claims of "cures" and interventions that will alter the core symptoms of autism. In order to provide effective and appropriate diagnostic assessments and interventions we must stay apprised of changes in the research and how to apply it to individuals.

Allowing stakeholders to access the North Dakota Legislature to advocate and educate regarding their needs is critical.

#### Autism Spectrum Disorder Database: Section 1

This is comparable to House Bill 1038 regarding a registry which is critical to better understand the number of individuals diagnosed with an autism spectrum disorder. As you know, there is currently no tracking system in the state. Having accurate data is essential to plan future services, access funding, and give us the opportunity for data sharing. It will benefit families and the state.

By having professionals who are qualified to make a medical diagnosis of autism mandated to provide data is an effective means to monitor the numbers of individuals in the state who are impacted by autism. Safeguards protecting privacy of individuals registered is addressed. Mandating this process is essential to insure that we have an accurate input of data. The steps outlined in this bill follow the diagnostic guidelines of the American Academy of Pediatrics.

#### Autism Spectrum Disorder Training and Support: Section 6

This is also similar to House Bill 1038 but expands the professions who would receive funding for training.

As you heard in previous testimony, adequate training of professionals is essential in understanding how to appropriately identify individuals with an ASD as soon as possible. Physicians are often the first to see children and it is critical for them to be able to recognize the signs of autism. The Center for Disease Control and the American Academy of Pediatrics have excellent materials for physicians.

Assessments for ASDs need to be done by someone who is qualified to make diagnoses based on training and credentials and are familiar with ASDs. These are the professionals who can use evidence based assessments to identify an ASD and provide evidence based interventions. They also must be able to differentiate between symptoms that are a part of the autism or may be a separate diagnosis; someone who can make appropriate referrals for additional evaluations when necessary. We have a

limited number of professionals in the field who are trained and qualified to do this.

Two of the most important groups who need training are those who work in schools and parents.

Without intending it to be so, the educational setting is currently the primary location of treatment for children with autism spectrum disorders.

Students with autism are more likely than other special-need students to receive out-of-district placements. Educating autistic children can be a challenge in the best of circumstances. Many people with autism also have associated language delays and intellectual disabilities, while others have average or above-average intelligence but the same communication problems.

At school meetings I regularly hear that these children are rude, lazy, or manipulative. Instead of recognizing the atypical development of children and young people on the autistic spectrum, teachers tend to view them through a "typical lens", comparing their behavior with children who do not have autism. Some believe that all they need are behavioral interventions to force autistic children to behave as other pupils do, or that it is a condition that they will grow out of.

There is also often a general confusion about autism. Teachers do not realize, for example, that challenging behavior can be accompanied by high intelligence. They don't always understand that every behavior has a function and is a maladaptive means by which the child communicates.

The stress associated with school can lead to physical illnesses for the child such as headaches and gastrointestinal disorders or mental health problems from debilitating anxiety to suicidal ideation.

I am in schools every week to provide case management services, consultation, or work directly with students. As I work with school staff, I hear about the struggles they have in understanding and providing services to children with autism spectrum disorders. Parents are caught in these struggles. They get frequent, sometimes daily, calls from the school as their children show challenging behaviors that impact the learning of their child and other children in the school. The first step is to understand the cause of the behavior as it relates to the autism. This understanding then leads interventions. Without proper interventions these children can be delayed in their learning and suffer stress that can lead to multiple other problems.

Parents often are in the role of support person, detective, advocate and case manager for their children in school. In order to make informed decisions for their children parents need accurate information and an understanding of their options.

The challenges at school and/or home frequently lead to out of home placements which are financially expensive and emotionally devastating.

#### Voucher System: Section 2

There are many essential services for children and adults with autism spectrum disorders that are not covered by insurance nor are they provided in school. Many need equipment such as educational materials, sensory equipment, visual aids, safety equipment, assistive technology, and speech generating devices. This equipment must be purchased by the family.

What is different in the Senate version of the voucher as compared to House Bill 1039 is the specificity of services that would be funded. When an issue is new we need to wait for the research to demonstrate what is effective for interventions. It is sometimes difficult for people to wait but it is critical to insure appropriate care of vulnerable individuals. The list of excluded services is based on several sources including results of a review completed by The Agency for Healthcare Research and

Quality (AHRQ) which is the nation's lead agency for research on healthcare quality, costs, outcomes and patient safety. It is the health research arm of the US Department of Human Services and compliments the biomedical research mission of the National Institute of Health. They reviewed research studies after the year 2000, which is when there were evidenced assessments to insure an accurate diagnosis, and those that had more than 10 participants in the study. They included information from stakeholders and reviewed articles that presented original research. It is important to note that the services listed have not all been proven ineffective but there is not enough research at this time to claim that they are effective for more than some children in specific subpopulations. In time the list may change. Also, as Senator Lee stated in her introduction of the bill on the Senate floor, parents may access these services for their children but the state will not pay for it at this time.

The bill, as it was introduced in the Senate, had some additional services on both the inclusion and exclusion lists. I would ask that respite care and specialized daycare be added to the included services list in Section 2. These are two essential services for children and families. Raising a child with an autism spectrum disorder is extremely challenging and can place significant stress on a family. Using specially trained respite homes and daycare services benefits not just the family but also the child who will receive continued supports and opportunities to learn and practice executive and social skills.

The following interventions, which are not evidence based or are harmful, should be added to the exclusion list for the following complementary and alternative medicinal interventions as there is not scientific evidence yet to support or refute their use for ASDs. Those include auditory integration training, behavioral optometry, cranio-sacral manipulation, hyperbaric chambers, dolphin assisted therapy, music therapy, and facilitated communication, immunoregulatory interventions (eg. Dietary restriction of food allergens or administration of immunoglobulin or antiviral agents), detoxification/chelation therapy, gastrointestinal treatments (eg. Digestive enzymes, antifungal agents,



probiotics, “yeast free diet”, gluten/casein free diet, and vancomycin), dietary supplement regimens purported to act by modulating neurotransmission or through immune factors or epigenetic mechanisms (eg vitamin A,C, B6, magnesium, folic acid, folinic acid, B12, dimethylglycine and trimethylglycine, carnosine, omega 3 FAs, inositol, various minerals and others. There are individuals and organizations preying on families by promoting these interventions. Last week I received a flyer for workshop about the use of omega 3 for autism spectrum disorders. Omega 3 can be valuable for general health but there is no evidence that it impacts the core symptoms of autism.

It is my belief that a voucher system will encourage providers across the state to receive appropriate training and offer services to individuals with autism. Many of my colleagues in North Dakota, who are licensed mental health practitioners, do not have the training to work with autism nor are they Medicaid eligible providers.

Of the 34 appointments that I had scheduled in one week, 30 appointments were with children under age 18. Of those, 3 are in therapeutic foster care, 1 is in a family foster care situation, 4 are involved in the judicial system, 1 is being referred to an out of state residential program, 1 is in a partial hospitalization program (after being inpatient), 28 are receiving special education services and 1 was under age 5. With the proper supports most of them could have been maintained at home or require a lower level of care.

Of the 4 young adults I saw; 3 are in residential/group home placements, 1 is in partial hospitalization, 2 of them are involved in the legal system, and 2 are unemployed. (I have attached a page listing the cost of services.)

It will be cost effective to be pro-active in providing access to services. Without appropriate interventions that are provided in a timely and efficient manner these individuals are more likely to

become a part of the legal, mental health or disability system thereby adding to the cost of these programs. For children the costs include additional educational services and out of home placements at the expense of the state. I included these costs in an attachment to this testimony.

By providing proper services from trained professionals and giving supports to individuals and families thereby decreasing the demand on public services there will be significant financial savings. The benefits to individuals with autism and their families are immeasurable.

This bill will not meet the full need in North Dakota. However it will point us in the right direction as we develop other services and supports and we learn more because of the services outlined in this bill. I ask you to vote yes on Senate Bill 2193.

**Costs Associated with Services to Children with an Autism Spectrum Disorder:**

Therapeutic Foster Care:	\$97.11 per day or \$2910 per month or \$34,920 per year
County Foster Care:	\$23-26 per day or \$695 – 875 per month (depends on age)
Dakota Boys and Girls Ranch	\$302 per day or \$9060 per month or \$108,720 per year
Prairie Learning Center	\$174 per day or \$5220 per month or \$62,640 per year
Lake Oahe Group Home Of Standing Rock Nation	\$164 per day or \$4920 per month or \$59,040 per year
Inpatient hospitalization:	\$1,618 per day or \$11,326 per week
ASD Specialized Residential Out of State placement	\$762 per day or \$22,860 per month or \$278,130 per year (more for 1:1 staffing)

# 14

Testimony  
Senate Bill 2193  
House Human Services Committee  
Tuesday, March 12, 2013  
North Dakota Department of Health

Good afternoon, Chairman Weisz and members of the House Human Services Committee. My name is Tamara Gallup-Millner and I am Director of the Division of Children's Special Health Services for the North Dakota Department of Health. I am here to provide information regarding SB 2193.

Section 1 of the bill instructs the North Dakota Department of Health to establish and administer an autism spectrum disorder (ASD) database that includes a record of all reported cases of ASD in the state and any other information deemed relevant and appropriate by the department in order to complete epidemiologic surveys of the ASD, enable research and analysis of the ASD and provide services to individuals with an ASD. It instructs the department to establish criteria, in consultation with experts, on who is qualified to report cases of ASD in the database. It requires the department to include diagnoses from the Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition, in the database in addition to a complete physical evaluation of the reported individual performed by a licensed physician. It requires the State Health Council to adopt rules to provide for established mandatory reporting requirements to the ASD database. Lastly, it addresses confidentiality of identifiable database records, but allows the department to provide the records to other state agencies to carry out the purposes of the database after notifying the receiving agency of the confidential nature of the records. Section 4 of the bill provides an appropriation of \$200,648 from the general fund to the Department of Health for the purpose of establishing and administering the ASD database and authorizes one full-time equivalent position for this purpose.

If SB 2193 is adopted, the Department of Health requests clarification on a number of items bulleted below in order to ensure we establish and administer a successful database.

- Who is expected to establish and administer the registry and complete the epidemiologic surveys, enable research and analysis, and provide services to individuals with ASD? Language in lines 7 through 12 of the bill differs from what was communicated when the Department of Health was initially

contacted for information regarding the database. At that point, it was communicated that only an accurate number of individuals with ASD was needed. To carry out the responsibilities as currently written in the bill, individuals would need to understand the intricacies and complexities of ASD and have a background in public health informatics. Ongoing FTE would be needed to carry out this level of responsibility.

- The bill requires that the database include a complete physical evaluation of the reported individual, performed by a licensed physician. This component adds complexity to registry reporting and may not be useful unless it's autism-specific.
- The department concurs that reporting be mandatory to assure the database will provide a complete and accurate record of all ASD cases in North Dakota and that rules be adopted to address specific reporting requirements.
- As with other registries maintained in the Department of Health (e.g., HIV), confidentiality would be maintained and the data kept in a secure system. The department agrees that having the ability to provide records to other state agencies, as necessary, to effect the purposes of the database is beneficial as it supports coordination across agencies and enables families to be linked to educational opportunities or other services.
- The amount appropriated to the Department of Health in SB 2193 is \$200,648. This figure originated from an estimate provided by the State ASD Task Force to an interim legislative committee and was a proxy estimate based on costs of an Early Hearing Detection and Intervention Tracking System. Upon request of advocates, the Department of Health also provided an initial cost estimate for a simple autism registry. With that option, ASD was to be added to an existing system, the ND Electronic Disease Surveillance System, also known as Maven. With the additional requirements of SB 2193, the Maven system will need to be customized in order to use it for an ASD database. By the time staff is hired, the autism database is operational, and reporting initiated, it's realistic to anticipate a two-year time frame before the system is fully functional. In addition to the added staff, additional costs include such things as maintenance costs from the system vendor, staff travel, and educational resources to create awareness for registry reporting.

- In the fiscal note, estimated expenditures for the Department of Health total \$391,464, which requires an additional appropriation of \$190,816 in general funds from what is included in the bill. This includes two full-time equivalent positions at \$291,464 and associated operating expenses at \$100,000, which are comprised of \$30,000 in general operating expenses associated with the FTE, \$30,000 for the purchase and license of a new module for the autism database using our current Maven system, and \$40,000 for system maintenance and hosting fees (\$20,000 per year).

HB1038 contains similar instruction to the Department of Health and a similar fiscal note, but includes no appropriation or full-time equivalent positions.

This concludes my testimony. I would be happy to answer any questions you may have.



**Display Settings:** Abstract

J Dev Behav Pediatr. 2012 Jan;33(1):2-8. doi: 10.1097/DBP.0b013e31823969de.

## **Autism spectrum disorders and health care expenditures: the effects of co-occurring conditions.**

Peacock G, Amendah D, Ouyang L, Grosse SD.

National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, 1600 Clifton Road, Atlanta, GA 30333, USA.  
gpeacock@cdc.gov

### **Abstract**

**OBJECTIVE:** Children with autism spectrum disorders (ASDs) often have co-occurring conditions, but little is known on the effect of those conditions on their medical care cost. Medical expenditures attributable to ASDs among Medicaid-enrolled children were calculated, and the effects of 3 commonly co-occurring conditions--intellectual disability (ID), attention deficit/hyperactivity disorder (ADHD), and epilepsy--on those expenditures were analyzed.

**METHODS:** Using MarketScan Medicaid Multi-State Databases (2003-2005) and the International Classification of Disease, Ninth Revision, children with ASD were identified. Children without ASD formed the comparison group. The 3 co-occurring conditions were identified among both the ASD and the comparison groups. Annual mean, median, and 95th percentile of total expenditures were calculated for children with ASD and the co-occurring conditions and compared with those of children without ASD. Multivariate analyses established the influence of each of those co-occurring conditions on the average expenditures for children with and without ASD.

**RESULTS:** In 2005, 47% of children with ASD had at least 1 selected co-occurring condition; attention deficit/hyperactivity disorder was the most common, at 30%. The mean medical expenditures for children with ASD were 6 times higher than those of the comparison group. Children with ASD and ID incurred expenditures 2.7 times higher than did children with ASD and no co-occurring condition.

**CONCLUSION:** Medicaid-enrolled children with ASD incurred higher medical costs than did Medicaid-enrolled children without ASD. Among Medicaid-enrolled children with ASD, cost varied substantially based on the presence of another neurodevelopmental disorder. In particular, children with ID had much higher costs than did other children with ASD.

PMID: **22157409** [PubMed - indexed for MEDLINE]

**Publication Types, MeSH Terms**

**LinkOut - more resources**

# 15

**TESTIMONY ON SB 2193**  
**HOUSE HUMAN SERVICES COMMITTEE**  
**March 12, 2013**  
**By: Gerry Teevens, Director of Special Education**  
**701-328-2277**  
**Department of Public Instruction**

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Mr. Chairman and Members of the Human Services Committee:

My name is Gerry Teevens. I am the Special Education Director for the Department of Public Instruction. I am here today to provide information and request an amendment related to Section 6 of the Engrossed Senate Bill 2193. I provided testimony March 11, 2013 related to Section 1 of HB 1023. For your reference and at your convenience, I have included a copy of that testimony. Both sections of each bill address required training. HB 1023 requires the Department of Public Instruction to provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism. Section 6 of SB 2193 would appropriate up to \$500,000 to the Department of Human Services for the purpose of implementing a statewide autism spectrum disorder training effort, including physician training regional training, school staff training, and parent training. The reengrossment of HB 1023 does not include an appropriation for the training costs. The proposed appropriation of \$198,000 was removed from the original bill.

The IDEA, 34 CFR §300.162 - SUPPLEMENTATION OF STATE, LOCAL, AND OTHER FEDERAL FUNDS, forbids the use of IDEA funds to pay for staff, programs, or materials that are required under state law. Supplanting would be presumed to have occurred. There currently is not money in the Department's budget for the trainings as set forth in Section 1 of this bill. Without an appropriation from the general fund of the state treasury the Department of Public Instruction would not be able to carry out the training as set forth in Section 1 of HB1038.

The most recent December 1, 2012 ND child count data revealed that 786 (6%) of the 13,296 children receiving special education and related services were identified under the disability category of autism. It is important to note that these numbers do not include those children with a secondary disability of autism. Some students with autism may not be identified as having autism; rather they are identified as having a specific learning disability, other health impairment, speech language impairment or a non-categorical delay (a designation for children up to age 10). The December 1, 2012 data shows a steady increase for the previous decade in the number of children with an autism receiving special education services. Included with this document is the historical child count data for ND over the last decade.

It is the responsibility of the ND Office of Special Education to provide technical assistance to local special education units and districts to enhance their

services for all children with disabilities. Most recently our office has received an increased number of requests for funding professional development trainings for personnel serving children with autism. To specifically identify training needs, Staff in Special Education Office conducted on-site stakeholder visits in each region of the state and followed up with an on-line survey to the 31 special education unit directors. As a result, the following areas were determined to be the high priorities for training: Social Skills Instruction, Communication Systems or skills, and Behavior Supports.

The contracting of national experts to conduct trainings in the area of Autism carries an initial significant cost. The Office of Special Education has received an estimate of \$22,000 per training by national experts. These trainings use research-based strategies to address problem behavior and communication deficits of this population. This estimated cost does not include travel expenses for the school district staff that will be participating. Although the majority of the local unit directors indicated willingness to cover travel expenses for their staff, their ability to allocate funds for this may be impacted by the federal budget cuts.

Additionally, ongoing embedded professional development which requires a sustained funding stream must be established in order to maintain skills that were developed in these initial trainings. The Office of Special Education intends to use these initial trainings as the first step in developing trained regional autism support

teams which would be available to provide ongoing support to local districts, especially the rural districts in the state. These teams would work to build the school staff capacity to provide services and supports using evidence based practices with individuals having autism.

On behalf of the Department, I request that the committee please consider an amendment to HB 1038 or to SB 2193 to reinstate the appropriation for the Department of Public Instruction to provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism.

Mr. Chairman and members of the Committee, this concludes my testimony. I would be happy to answer any questions the committee may have.



Comparison by Disability for Dec. 1999 through Dec. 2012

Disability	Dec 1999	Dec 2000	Dec 2001	Dec 2002	Dec 2003	Dec 2004	Dec 2005	Dec 2006	Dec 2007	Dec 2008	Dec 2009	Dec 2010	Dec 2011	Dec 2012
Autism	112	135	160	197	240	278	320	375	444	514	586	627	718	786
Deaf	43	38	38	35		2								
Deaf/Blind	3	4	4	4	1	2	2	12	8	5	5	5	4	3
Emotional Disturbance	973	1,037	1,096	1,123	1,193	1,278	1,127	1,087	1,054	995	913	836	807	792
Hearing Impairment	111	106	102	102	147	137	139	126	109	120	125	131	125	133
Intellectual Disability	1,241	1,246	1,200	1,169	1,142	1,092	970	975	906	860	801	763	755	767
Non-Categorical Delay 3-5	216	271	305	325	397	423	451	504	567	615	740	803	780	804
Non-Categorical Delay 6-9		49	132	223	260	361	433	517	555	598	671	707	743	789
Other Health Impairment	542	640	781	960	1,086	1,236	1,296	1,388	1,417	1490	1606	1634	1715	1765
Orthopedic Impairment	177	158	159	158	137	182	148	132	124	118	115	110	111	100
Speech Impairment	4,416	4,251	4,204	4,262	4,301	4,619	4,307	4,245	4,032	3644	3439	3298	3237	3087
Specific Learning Disability	5,686	5,620	5,353	5,247	5,043	4,973	4,594	4,387	4,307	4224	4159	4143	4022	4161
Traumatic Brain Injury	31	35	33	35	41	46	51	32	37	43	50	58	57	55
Visual Impairment	61	60	63	61	56	52	45	45	46	52	51	55	49	54
<b>TOTAL</b>	<b>13,612</b>	<b>13,650</b>	<b>13,630</b>	<b>13,901</b>	<b>14,044</b>	<b>14,681</b>	<b>13,883</b>	<b>13,825</b>	<b>13,606</b>	<b>13,278</b>	<b>13,261</b>	<b>13,170</b>	<b>13,123</b>	<b>13,296</b>

*Part of  
Testimony  
#15*

**TESTIMONY ON HB 1038  
HOUSE HUMAN SERVICES COMMITTEE  
March 11, 2013  
By: Gerry Teevens, Special Education Director  
701-328-2277  
Department of Public Instruction**

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Madam Chairman and Members of the Human Services Committee:

My name is Gerry Teevens. I am the Special Education Director for the Department of Public Instruction. I am here today to provide information and request an amendment related to section 1 of the Reengrossed House Bill 1038.

The Department of Public Instruction/Office of Special Education has the responsibility as set forth in the federal law, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), to assure that a free appropriate public education (FAPE) is available to any individual child with a disability who needs special education and related services. These services must be designed to meet their unique needs and prepare them for further education, employment and independent living. Children with disabilities are to be educated with those who do not have disabilities to the maximum extent appropriate, and should attend and participate in general education classes unless it is inappropriate and otherwise indicated on a student's Individualized Education Program (IEP). An essential consideration in the development of the IEP is the extent to which the child's

instructional needs can be met by general education staff in all environments with or without assistance from special educators.

Over the last several years the number of children identified with autism and needing special education services has increased in North Dakota as well as nationally. Autism is the term used in the IDEA and that is the term that schools use when reporting Child Count data to the Department of Public Instruction. The December 1, 2012 ND child count data, revealed that there were 13,296 children receiving special education and related services in the state. Of this total, 786, (6%) were identified under the disability category of autism. It is important to note that these numbers do not include those children with a secondary disability of autism. Some students with autism may not be identified as having autism, rather they are identified as having a specific learning disability, other health impairment, speech language impairment or a non-categorical delay (a designation for children up to age 10). The December 1, 2012 data shows a steady increase for the previous decade in the number of children with an autism receiving special education services. Included with this document is the historical child count data for ND over the last decade.

It is the responsibility of the ND Office of Special Education to provide technical assistance to local special education units and districts to enhance their services for all children with disabilities. Most recently our office has received an

increased number of requests for funding for professional development training for personnel serving children with autism. During the annual Fall Leadership Conference which our office hosts for local Special Education Unit Directors and Program Coordinators, an emphatic request was voiced by the participants for state sponsored professional development for all school staff working with children with autism. Parents of children with autism have expressed concerns about this need to us as well. This need is reflected in currently proposed legislation. The State Autism Task Force has identified the need for training and support for general education teachers and other school staff as well.

In order to assess more specifically the training needs, the Office of Special Education carried out two activities. Staff in the Special Education Office conducted on-site stakeholder visits throughout the state to develop a statewide perspective on: the types of services currently being provided to children and youth with autism; the school district challenges related to providing those services; and the type(s) of training(s) needed for school staff working with these children. In addition, the Special Education Office disseminated an on-line survey to the 31 special education units in the state. This survey asked special education directors to identify and prioritize the specific types of training needed by the unit staff working with children with autism. Thirty of the thirty one Special Education Units responded. The most frequently requested trainings identified by the directors were

Social Skills Instruction, Communication Systems or skills, and Behavior Supports. Teachers also expressed these needs as well. The rural directors additionally expressed the need for assistance in training and supports to retain trained personnel.

The contracting of national experts to conduct trainings in the area of Autism carries an initial significant cost. Upon research for estimated cost, the Office of Special Education has received an estimate of \$22,000 to bring in national experts to conduct three sets of trainings during a one week period. These trainings use research-based strategies to address problem behavior and communication deficits of this population. This estimated cost does not include travel expenses for the school district staff that will be participating. Although the majority of the local unit directors indicated willingness to cover travel expenses for their staff, their ability to allocate funds for this may be impacted by the federal budget cuts.

Providing ongoing embedded professional development requires a sustained funding stream in order to maintain skills that were developed in these initial trainings. The Office of Special Education intends to work to develop trained regional autism support teams which would be available to provide ongoing support to local districts. These teams would work to build the school staff capacity to provide services and supports using evidence based practices with

individuals having autism. This is a significant need in the more rural districts in the state.

In the reengrossment of this bill, the appropriation to the Department for the training as set forth in Section I was removed. The IDEA, 34 CFR §300.162 - SUPPLEMENTATION OF STATE, LOCAL, AND OTHER FEDERAL FUNDS, forbids the use of IDEA funds to pay for staff, programs, or materials that are required under state law. Supplanting would be presumed to have occurred. There currently is not money in the Department's budget for the trainings as set forth in Section I of this bill.

On behalf of the Department, I request that the committee please consider an amendment to HB 1038 to reinstate the appropriation for the department of public instruction to provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism.

Madam Chairman and members of the Committee, this concludes my testimony. I would be happy to answer any questions the committee may have.



#16

Testimony SB2193  
House Human Service Committee  
Chairman Representative Weisz

Chairman Representative Weisz and Members of the House Human Services Committee,

My name is Amanda Lausch. I am a constituent as well as a parent to a child with Autism. I am writing this in reference to SB2193

My child was served under the current Autism waiver until she aged out at age 5. The current Autism waiver was a good start but needs much revision. We benefited and appreciated greatly some of the services we received under the current Autism waiver. Now that she has aged out, my child is lacking. I have reviewed SB2193 and have significant concerns. North Dakota does need another Autism waiver in place or an expansion and revision of the current waiver. However, I would prefer to see no waiver in place than for this one to pass!

My biggest concern is regarding the reporting database. I am a well-educated medical professional and I fully understand the HIPPA rules and regulations. Along with that, I also understand that under HIPPA a patient's health information is not to be shared unless it absolutely needs to be and then only the minimum is to be shared. The state does not need this information. Additionally, I find this unconstitutional. We should ask ourselves that why a child's information should be required to be reported just because they are different, because they have a disability, because they have Autism? Apparently the state feels that any information "determined relevant and appropriate", which is rather broad, they have a right to so they may complete their "surveys" and "analysis." When did our children with Autism become their property to study like wildlife? They are human beings with rights to keep their information private, not regulated by the government that they have to turn over their information just because they have Autism. Sex offenders must register and report to a database. Children with Autism should not. We have a duty to "look over" people and care for people with disabilities, not take away their rights and "look at them." Additionally, this is quite unethical. Whenever research and analysis is professionally performed, there is an ethics committee to insure that the research is performed ethically. Those the research is performed on must give consent. There is no consent about this. Thus it is unethical.

My second concern is with the voucher program. It excludes all forms of behavioral training. Most parents who have children with Autism struggle with some form of behaviors. This is a crucial piece to have excluded. Lastly, what a child can receive from the voucher is determined by the department's opinion of the child's level of functioning. Most of the time, those in the department hold a four-year degree that does not specialize in Autism nor do they know the specifics of the child. It is imperative that the language of the bill include "provider's recommendations" in addition to the "applicant's level of functioning.

Overall, I am very disappointed in this bill. I would strongly encourage you to take out the database registry as it is a clear violation of the rights of children with Autism to be required to register and be studied.

Thank you for your time.

Sincerely,

Amanda Lausch

1218 16<sup>th</sup> St SW, Jamestown, ND 58401

#1

13.0192.04004  
Title.

Prepared by the Legislative Council staff for  
Representative Fehr  
April 1, 2013

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2193

Page 1, line 1, remove "the establishment of an autism spectrum disorder database and"

Page 1, remove line 2

Page 1, line 3, replace "study and report to the legislative management" with "expansion of the autism spectrum disorder medicaid waiver"

Page 1, remove lines 5 through 23

Page 2, remove lines 1 through 31

Page 3, replace lines 1 through 20 with:

**"SECTION 1. DEPARTMENT OF HUMAN SERVICES AUTISM SPECTRUM DISORDER MEDICAID WAIVER.** The department of human services, during the biennium beginning July 1, 2013, and ending June 30, 2015, shall seek approval from the federal centers for medicare and medicaid services to expand the department's autism spectrum disorder medicaid waiver to cover thirty-five additional individuals from birth through age five. The expansion to the waiver must become effective on or after January 1, 2014, and must include appropriate behavior intervention and treatment services that may include evidence-based and promising practices, case management services, technology and technology-based support, in-home support, equipment and supplies, home monitoring, respite care, residential supports and services, and behavioral consultation."

Page 4, line 6, replace the first comma with a semicolon

Page 4, line 6, replace the second comma with a semicolon

Page 4, line 6, replace ", and parent training," with "; training to support behavior analyst certification; training to improve independent living skills, preemployment opportunities, and executive and social skills; training and educational materials for parents; and parenting education"

Renumber accordingly