2011 SENATE GOVERNMENT AND VETERANS AFFAIRS

SB 2268

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
February 3, 2011
13957

☐ Conference Committee

Committee Clerk Signature Katie Olsen

Explanation or reason for introduction of bill/resolution:

Relating to public employee retirement system medical benefits coverage for autism spectrum disorders.

Minutes: Testimony Attached

Chairman Dever called Government and Veterans Affairs to order and opened the public hearing on SB 2268.

Senator Wardner: Rich Wardner, District 37. I brought this forward for a constituent who lived right behind me. I would like to talk about the history and the situation; this bill did not get a recommendation from the committee and it was opposed by blue cross because of the mandate. People felt that they were unable to give the true numbers of what they would cost. 1) make sure that it doesn't cost as much as previously stated, in the meantime I had someone from the Ann Carlson school that was interested. See attached amendment #1. .

Senator Nelson: Carolyn Nelson Dist 21. I am lucky that child is not severely autistic. We worked together and we ran into people at state park. They did give an unfavorable recommendation in its current form, but they did recommend a study. When I was in the school board in Fargo during the 1980's there were only 4 kids that were diagnosed as autistic. We have come a long way in 30 years, the research I brought was from 2005 and the changes are happening so rapidly. He does not communicate well; his speech is a little hard to understand. The hardest thing that he had to do was take school lunch, he had to make decisions. His father came with him to work through the lunch line. There are kids out there with major problems. There are parents here that have been making decisions

Chairman Dever: PERS?

Senator Nelson: Several years ago we decided we have to try things out in PERS and then we move it into mainstream insurance.

Chairman Dever: PERS?

Senator Nelson: Several years ago we decided we have to try things out in PERS and then we move it into mainstream insurance.

Cal Rolfson: See attached testimony #1.

Chairman Dever: has the Department of Human Services seen these?

Cal Rolfson: Yes.

Chairman Dever: residential services

Cal Rolfson: Yes, that is what we are hoping.

Nick Gates: See attached testimony #2.

Chairman Dever: Are the services provided in the school inadequate?

Nick Gates: There are so many kids in the school that the services that he does get are good but just not enough. If you read the studies on early intensive behavioral intervention he should have started getting it at age 2 not at age 5 when he entered the school system.

Senator Berry: You mentioned about individuals with autism and obviously we are seeing an increasing in diagnosis which is a blend of awareness and some of that is an actual increase and as you said, 90% show improvement with intervention.

Justin Robinson: See attached testimony #3.

Penny Smith: Parent of twins with autism, a disease which is so very complicated. It looks different for every single child; we have heard stories of children being negatively punished under the misunderstanding. We were able to utilize someone coming to our week but it ended at age 3 when we were told that they were not 'bad enough'. It affects every aspect of their lives. For one of our sons we have a step by step checklist my husband and I are both working however in regards to speech therapy they are very literal and as they get older the social situations get more difficult. We have paid out of pocket 100% for the speech therapy for our twins. For our occupational therapy and physical therapy we only had access to 6 visits a year it was $720 a month per child for out of pocket costs only for the speech therapy. These therapies supply our children with the tools that they need to cope, integrate, build friendships, to fight loneliness and depression. I feel that when our children have access to these therapies it helps us focus on their strengths and not their disability.

Judith Ursitti: Autism Speaks, see attached testimony #4.

Senator Cook: When you say board certified, who certifies the board?

Judith Ursitti: It's a national credential and it recognized in 17 of the 23 states that have the laws, the remaining 4 states that pursue licensure.

Chairman Dever: Did the Federal Healthcare bill provide provisions for Autism.

Judith Ursitti: In other states what they are doing is adding language to the legislation. They would not be on the hook for having a state mandate for having things beyond the state benefit package.

Rod St Aubyn: See attached testimony #5.

Senator Cook: You explained that you did a study. This is a rather expansive piece of legislation compared to other states did you or could you do further studies to see where that number would come down to if you offered amendments.

Rod St Aubyn: we can have our actuaries look at anything but under the Fed hc law we cant put caps.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
February 4, 2011
13967

☐ Conference Committee

Committee Clerk Signature Katie Oliver

Explanation or reason for introduction of bill/resolution:

Relating to public employee retirement system medical benefits coverage for autism spectrum disorders.

Minutes: Testimony Attached

Chairman Dever opened the floor to committee work on SB 2268. Dr. Keith Fischer was teleconferenced in to speak on the proposed treatment for the bill.

Dr. Kenneth J. Fischer: See attached testimony #6

Senator Nelson: Regarding ABA, you said it was a spectrum of services and something better might evolve, wouldn't that something better become part of that spectrum of services?

Dr. Kenneth J. Fischer: Right now the way we approach these children is, by necessity, so multi-disciplinary it involves everything from a broad range of behavioral interventions educational approaches, alternative approaches and medication. It is so complicated because the kids are so complicated that is has to be done in a central integrated way. While we will always adopt changing ways of approaching these kids you will never be able to find a single therapy that works for every autistic child. As I said, ABA is a broad statement to include a whole host of disciplinary interventions some have better creditability than others but none have the kind of creditability that we would like as it relates to evidence based practice and randomized trials. Even so, because these kids are so unique it is best to do these things in the school.

Chairman Dever: It seems to me that we can agree on the fact that autism creates challenges particularly for the families affected. There are big holes in the services provided and we would like to do more. I think that the parents affected would like to see the bill as introduced but I think that alternatively they would agree with just about everybody else that the centers of excellence might be a step in the right direction.

Senator Nelson: I think part of the problem in this discussion is the definition of what Applied Behavior Analysis means and I don't think it is nearly as narrow as they are trying to draw it.

Chairman Dever: And I guess what the situation now is that we have the bill and the amendments and do we need additional amendments or information before finalizing consideration of the bill.

Cal Rolfson: The numbers were basically pulled out of the air at the time. We had to find a number and the people who put the numbers together came up with the concept that about $500,000 is what it would cost to build 1 regional center and if it was a 50% public funds/50% private funds.

Senator Cook: Can we switch it to $250,000 and build one.

Cal Rolfson: We probably could, but the problem with doing that now and not when it gets to conference committee is that we wouldn't have as accurate of numbers.

Senator Berry: is there a provision in this for private donations?

Cal Rolfson: The public private partnership thing would be. That is why the study is incorporated in the amendment.

There was no further information on SB 2268 at that time. Chairman Dever closed the committee work.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
February 4, 2011
14060

☐ Conference Committee

Committee Clerk Signature Katie Dirst

Explanation or reason for introduction of bill/resolution:

Relating to public employee retirement system medical benefits coverage for autism spectrum disorders.

Minutes: No testimony attached

Chairman Dever opened the floor to discussion on SB 2268.
Senator Nelson made a motion to adopt the amendments with a second by Senator Marcellais, there was no discussion, roll was taken and the motion passed 6-0-1. Senator Nelson then made a motion for a do pass with a re referral to Appropriations, there was no discussion, roll was taken and the motion passed 6-0-1 with Senator Nelson carrying the bill to the floor.

FISCAL NOTE

Requested by Legislative Council
04/06/2011

Amendment to: Engrossed SB 2268

1A. **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.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$200,000			
Appropriations						

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

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

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

The amended Bill states that the Department may establish & operate a regional autism spectrum disorder center of achievement pilot program & also provides for a study of the current system for the diagnosis of, early treatment of, care of, & education of individuals with autism spectrum disorder.

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 of the amended Bill states the Department may establish and operate a regional autism spectrum disorder center of achievement pilot program using up to $200,000 of funding from its legislative appropriation. The pilot program is to provide a matching grant to a qualified applicant that is to be a nonprofit intermediate care facility for the mentally retarded. The applicant is required to provide a dollar for dollar non-state cash match for each grant dollar awarded under the pilot program. The Department is required to report its findings to the Legislative Management before September 1, 2012.

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.*

The expenditures would consist of $200,00 for the grant program.

   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 Bill does not contain an appropriation. The Department may implement the provisions of the Bill up to $200,000 if the Department is able to find the funding within its legislative appropriation.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	04/06/2011

FISCAL NOTE

Requested by Legislative Council
02/11/2011

Amendment to: SB 2268

1A. **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.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures			$600,000			
Appropriations						

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

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts

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

The amended Bill requires the Legislative Management and the DHS to study the feasibility of establishing a network of regional autism spectrum disorder centers of achievement and requires the DHS to implement a regional autism spectrum disorder center of achievement pilot program.

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 of the amended Bill requires the DHS to establish and operate a regional autism spectrum disorder center of achievement pilot program. The pilot program is to provide a matching grant to a qualified applicant that is to be a nonprofit intermediate care facility for the mentally retarded. The applicant is required to provide a dollar for dollar non-state cash match for each grant dollar awarded under the pilot program.

In addition, Section 1 requires the DHS to work with public and private stakeholders to study the feasibility of establishing a network of regional autism spectrum disorder centers of achievement. The DHS is required to report its findings to the Legislative Management.

Section 3 of the Bill appropriates $600,000 from the general fund to the DHS for the study and the grant program. The DHS would need 1 FTE at a cost of $164,000 with the remaining $436,000 being utilized for the grant program and costs associated with the study.

Section 2 of the Bill requires a Legislative Management study of the current system for the diagnosis of, treatment of, care for, and education of individuals with autism spectrum disorder. There is no fiscal impact related to the study required of the Legislative Management since the study would be included in the list of studies to be prioritized by the Legislative Management.

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.*

The expenditures would consist of $164,000 for 1 FTE within the DHS and $436,000 for the study and grant program required of the DHS.

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 Bill provides a general fund appropriation of $600,000 to the DHS to implement the provisions contained within the Bill. The DHS would implement the provisions of the Bill within the $600,000 appropriation with the addition of 1 FTE.

Name:	Brenda M. Weisz	**Agency:**	DHS
Phone Number:	328-2397	**Date Prepared:**	02/14/2011

FISCAL NOTE

Requested by Legislative Council
01/21/2011

Bill/Resolution No.: SB 2268

1A. **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.*

	2009-2011 Biennium		2011-2013 Biennium		2013-2015 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures				$5,844,910	$2,771,954	$3,072,955
Appropriations				$5,844,910	$2,771,954	$3,072,955

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

2009-2011 Biennium			2011-2013 Biennium			2013-2015 Biennium		
Counties	Cities	School Districts	Counties	Cities	School Districts	Counties	Cities	School Districts
			$671,040	$362,520	$380,880	$671,040	$362,520	$380,880

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

The bill would expand coverage for the treatment of autism. BCBS has indicated that the average cost per contract would need to increase by $15 per month to support the additional benefits provided by this bill.

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 above cost is the additional premium BCBS has indicated would be required to provide this coverage. The average increase is $15 per contract per month. The additional premium is not in the budgeted premiums for 2011-2013. Therefore unless premiums are increased PERS will need to pay this additional cost from the PERS health fund for 2011-2013. Thereafter the cost would be built into future premiums.

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.*

Is the additional premiums payments to BCBS averaging $15 per contract per month.

   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.*

Is the additional premium payments to BCBS.

Name:	Sparb Collins	Agency:	NDPERS

Phone Number:	328-3900	Date Prepared:	01/27/2011

Date: 2-4-11
Roll Call Vote #: 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO.

Senate Government and Veteran's Affairs Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Do Pass as Amended & w Re Refer

Motion Made By Nelson Seconded By Marcellais

Senator	Yes	No	Senator	Yes	No
Chairman Dever	X		Senator Marcellais	X	
Vice Chairman Sorvaag	X		Senator Nelson	X	
Senator Barry					
Senator Cook	X				
Senator Schaible	X				

Total (Yes) 6 No 0

Absent 1

Floor Assignment Senator Nelson

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

11.0032.01003
Title.03000

Prepared by the Legislative Council staff for
Senator Nelson
February 4, 2011

2-8-11
1 of 2

PROPOSED AMENDMENTS TO SENATE BILL NO. 2268

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

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF ACHIEVEMENT PILOT PROGRAM - DEPARTMENT OF HUMAN SERVICES STUDY - REPORT TO THE LEGISLATIVE MANAGEMENT.

1. During the 2011-13 biennium, the department of human services shall establish and operate a regional autism spectrum disorder centers of achievement pilot program.

   a. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for the mentally retarded which is licensed by the department of human services.

   b. A qualified applicant shall establish the availability of one dollar of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds may not be a gift or grant, but must be funds of the applicant.

   c. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of achievement in a city with a population of more than ten thousand.

   d. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

2. During the 2011-13 biennium, the department of human services shall work with public and private stakeholders to study the feasibility of establishing a network of regional autism spectrum disorder centers of achievement. The study must include:

   a. Consideration of funding needs and sources for startup as well as ongoing financial sustainability of a network of regional autism spectrum disorder centers of achievement;

   b. Evaluation of the unmet needs in the state related to the regional delivery of skilled services to individuals with autism spectrum disorder, consideration of the most effective and efficient delivery

system for these skilled services, and evaluation of whether the skilled services provided by the qualified applicant under subsection 1 is part of a viable plan to increase availability of these services; and

c. Evaluation of the funding, development, and delivery of the skilled services provided by a qualified applicant under subsection 1, including recommendations regarding the feasibility and desirability of implementing the pilot program on a broader scale.

3. During the 2011-13 biennium, the department of human services shall provide regular status reports to and work in cooperation with the legislative management as the legislative management conducts the study provided for under section 2 of this Act.

4. Before September 1, 2012, the department of human services shall report to the legislative management on the preliminary findings and recommendations of the regional autism spectrum disorder centers of achievement pilot program and study. During the 2013 legislative session, the department of human services shall introduce any legislation that may be necessary to implement the study recommendations.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT. During the 2011-12 interim, the legislative management shall conduct a comprehensive study of the current system for the diagnosis of, treatment of, care for, and education of individuals with autism spectrum disorder and shall make recommendations regarding how this system can be improved to better meet the needs of individuals with autism spectrum disorder. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families impacted by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for the mentally retarded. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly.

SECTION 3. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $600,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing the regional autism spectrum disorder centers of achievement pilot program and study provided for under section 1 of this Act, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

Date: 2-9-11
Roll Call Vote #: 2

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO.

Senate Government and Veteran's Affairs Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken Adopt Amendments .0103

Motion Made By Nelson Seconded By Marcellais

Senator	Yes	No	Senator	Yes	No
Chairman Dever			Senator Marcellais		
Vice Chairman Sorvaag			Senator Nelson		
Senator Barry					
Senator Cook					
Senator Schaible					

Total (Yes) No

Absent

Floor Assignment

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

REPORT OF STANDING COMMITTEE

SB 2268: Government and Veterans Affairs Committee (Sen. Dever, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (6 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2268 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 a regional autism spectrum disorder centers of excellence pilot program; a department of human services report to the legislative management; and an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EXCELLENCE PILOT PROGRAM - DEPARTMENT OF HUMAN SERVICES STUDY - REPORT TO THE LEGISLATIVE MANAGEMENT.

1. During the 2011-13 biennium, the department of human services shall establish and operate a regional autism spectrum disorder centers of excellence pilot program.

   a. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for the mentally retarded which is licensed by the department of human services.

   b. A qualified applicant shall establish the availability of one dollar of nonstate, cash matching funds for each grant dollar awarded under this section.

   c. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of excellence in a city with a population of more than ten thousand.

   d. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

2. During the 2011-13 biennium, the department of human services shall work with public and private stakeholders to study the feasibility of establishing a network of regional autism spectrum disorder centers of excellence. The study must include:

   a. Consideration of funding needs and sources for startup as well as ongoing financial sustainability of a network of regional autism spectrum disorder centers of excellence;

   b. Evaluation of the unmet needs in the state related to the regional delivery of skilled services to individuals with autism spectrum disorder, consideration of the most effective and efficient delivery system for these skilled services, and evaluation of whether the skilled services provided by the qualified applicant under subsection 1 is part of a viable plan to increase availability of these services; and

   c. Evaluation of the funding, development, and delivery of the skilled services provided by a qualified applicant under subsection 1, including recommendations regarding the feasibility and desirability of implementing the pilot program on a broader scale.

3. Before September 1, 2012, the department of human services shall report to the legislative management on the preliminary findings and recommendations of the regional autism spectrum disorder centers of excellence pilot program and study. During the 2013 legislative session, the department of human services shall introduce any legislation that may be necessary to implement the study recommendations.

SECTION 2. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $600,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing the regional autism spectrum disorder centers of excellence pilot program and study provided for under section 1 of this Act, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

2011 SENATE APPROPRIATIONS

SB 2268

2011 SENATE STANDING COMMITTEE MINUTES

Senate Appropriations Committee
Harvest Room, State Capitol

SB 2268
02-15-2011
Job # 14542

☐ Conference Committee

Committee Clerk Signature Alice Delzer

Explanation or reason for introduction of bill/resolution:

A BILL to provide for a regional autism spectrum disorder centers of achievement pilot program

Minutes: You may make reference to "attached testimony."

Chairman Holmberg called the committee to order on Tuesday, February 15, 2011 at 9:00 am in reference to SB 2268. Joe Morrissette, OMB and Brady Larson, Legislative Council were also present.

Senator Wardner, District 49, Dickinson, ND I am here to introduce SB 2268 to you. I am the prime sponsor. The subject deals with Autism. The Bill has been amended and it's different than it was when it was originally introduced. In this Bill the part we will be interested in this committee is section 3 of the amendment. I didn't bring the Bill up as it's been, it's kind of a hoghouse, but section 3 the appropriation really tells it all. There is an appropriation out of any monies in the general fund from the State Treasury and the amount is $600,000.00 and it's to go for the purpose of implementing a regional Autism Spectrum Disorder Centers and it's a pilot program to get it started plus there would be a study done on Autism. Autism is becoming more and more of an issue in our society and it's something we are going to have to deal with. There is a couple of people that want to speak and we also have another sponsor here, Senator Nelson and I am going to turn it over to them and I can answer any questions.

Chairman Holmberg: We do want to focus on the appropriations because the committee is well aware of Autism Spectrum Disorder, so we don't need a lot of that kind of testimony today.

Senator Carolyn Nelson, District 21, Fargo: I was the sponsor of this bill during the interim, I got together with Senator Wardner on the proposal that's brought before you. We have some folks with us here today who helped us design the amendment and they are here to answer your questions dealing with the appropriation that's requested in the section but I do endorse this Bill.

Cal Rolfson, Anne Carlson Center: I will honor the chairman's suggestion that we don't go into the details of Autism. You know it is a devastating disease, it impacts medical, social,

financial, educational issues significantly for families that suffer with children that have that disease. The original bill that was 2268 had a total of $5.7M to create a mandated insurance coverage, and in addition to that I think there ws $2.9M of state dollars and that created a problem for some in the policy committee and so I was asked to design a concept that would both respond to the governor's task force on Autism that urges recommendations that the state stepped forward to help support this devastating issue for families. But at the same time the governor's task force regrettably didn't have any money in the recommendation, it was just a recommendation. It was an unqualified recommendation that something needs to be done. With that, Eric Monson, who is the CEO for the Anne Carlson Center, who has the majority of it's kids there are on the Autism Spectrum Disorder or ASD and they care for them in a fantastic, loving way and a competent professional way. Because of that the Anne Carlson Center has a great deal of experience in that and that is why I thought Eric could be the one to share that and he developed this concept. The trouble you might be facing if you are facing it, is the $600,000.00 doesn't give you any details and so if I may I'd like to ask Mr. Monson to come forward and give the concept of the details.

Eric Monson, CEO of Anne Carlson Center with operations in Jamestown, Devils Lake, Grand Forks and Fargo; we have students throughout the state of ND. For the record I am not a lawyer. In 2007 the Anne Carlson center commissioned a study of service needs in ND for intellectual disabilities. The study was conducted for us by Center for Persons with Disability at Minot State and joined by a national behavioral services firm. From that we developed a list of priorities for our organization and since we are nonprofit, nonprofit needs to focus on families and children with intellectual disabilities. We always keep that at the center of our strategy discussions and our implementation of those strategies. From that study in 2007 we developed community services, because we did not want to have a one solution that tried to fit all the particular needs so we developed the community services because we were willing to bring services as close as possible to families to children that are given a type of assistance. Another priority was community based services for children on the spectrum. The idea behind the amendment here was to be able to rather than an insurance mandate, we could develop centers across the state, so that families with children with Autism if it was possible to stay in the community, to continue to participate in public school, in special education units, continue to be a part of the family rather than transport the child someplace else, if it was possible given the individual needs of the child we would be able to support that. The governor's task force on Autism that Cal mentioned earlier also concluded that community based services would be the right thing to do. We are ready, willing and able to allocate the dollars and the organization resources to develop a series of centers across ND for the families and children on the Autism Spectrum.

Senator Warner: We are always so careful to speak of these as children, but I assume that autistic children grow into autistic adults. What kinds of services are we able to provide to these adults, how much self efficiency can some of the attain, what kinds of guidance are some of them going to require for a lifetime and how does your organization coordinate that with other providers?

Eric Monson: All the planning and the work that is done with any individual, and I might add I have a tendency to concentrate on children because most of our clients are children and under the age of 18 and then we do serve young adults and we also serve through our infant development programs, we are also involved in early identification of children on the spectrum

and we think that has got to be a strong emphasis is because if you can enumerate some of the issues for a child, early identification, early intervention, early treatment, the long term stability of those behavioral changes is very important. We coordinate with a lot of providers. We have some children and young adults in a day program, a residential provider provides that residential service but all the work is done is built around a team developed individual plan for that particular person. Independence is one of our main goals. Be able to participate inclusion in community activities, inclusion in school is another strong objective in the programs. So it depends on the particular individual but we are looking for appropriate behavioral interventions so they can live, work , earn in their own ordinary environments.

Senator Wanzek: The dollars must be matched dollar for dollar, the source of the matching funds may not be a gift or grant but the funds of the applicant, does that work for you?

Eric Monson: Yes, we are prepared to allocate the dollars appropriately. I assume there would be others that are interested in developing centers. We are not opposed to that at all. That's what we need to do. That's what we exist for is to meet needs and so however, we can do that through collaborations, partnerships, partnerships with the state, other providers, the answer is yes.

Dan Ulmer, BBCC testified in favor of SB 2268. I think one of the issues with Autism there is another bill we are working on, 2155, and Senate Human Services recently working on that bill. Autism has been a fairly large issue for us. One of the problems most of those type of costs get sloughed off on insurers. The real issue behind Autism happens to be whether or not this is a developmental disability in educational as well as a human service issue. We are quite pleased to see this bill come along. We pay a substantial amount for drugs to treat these kids as well as housing them and whatever they basically need. We don't mind taking care of the medical needs. There is a real question of taking care of the developmental and educational needs which is out of our realm. As this bill originally came out $5 to $7M of insurance money was set aside to take care of this issue. They're really not medical issues, they are developmental issues. So with that we support 2268 and hope you will take us in the path we need to go.

Chairman Holmberg: SB 2155 is not a bill coming to this committee.

Senator Fischer: Would autism spectrum also includes aspergers? Could you tell me the percentage of diagnosis of both and is aspergers treated on an outpatient basis?

JoAnne Hoesel, Director of Mental Health/Substance Abuse Dept., DHS: I don't' have the breakdown. I could get it for you. I think the biggest thing it is a continuum, it has to be very individualized. The thing that is an important issue and goes back to Senator Warner's question earlier is I believe the state does a very good job in treating individuals that have autism spectrum disorders along with mental retardation. That is a requirement in our waiver. But if you have an individual of which many are often considered to be high functioning, which means outside of the asperger syndrome that they have; they do not have a cognitive disorder, they're not mentally retarded. They get lost in our system because they are not able to be served in the developmental disability system because they don't qualify for the waiver and our mental health system doesn't do very well, because they are not positioned to handle individuals with that condition because they are different than a person that has a depressive

disorder and that kind of thing. So, it's that individual that this bill and other autism targeted bills would get at; the individuals that really have no home in the service system because of some of those details that get us to be very silo-ed. On an outpatient basis, yes. Individuals that have autism spectrum disorders are often better served in their environment. In early intervention and in other services the providers actually go into their homes because they are not able to, if they've learned something here, they are not able to translate it in a new environment so If they go to someone's office they're not able to take what they've learned there in the school or home, they can't transfer that knowledge very well. So if you work with them in their environment they can do very well. But there is also a continuum, we absolutely have some people that need more ongoing 24 hour support because they need to be guided and they need to be cued so that they don't make decisions that are not in theirs or anybody else's best interest to keep them safe. We have many people in the state that function quite well and they receive services on an outpatient basis. If you recall during the overview during the Department of Human Services budget, Jan Eggan, who is the Director of the Aging service Division, when she was giving her overview she was speaking of a document we had produced, it is now printed. It is called Aging is Everyone's Business. Our research unit has worked extensively to identify the population shifts in ND, the numbers of children that live in different communities which has implications for the future, and it is a document we want to make available to the committee. We will make sure you get a copy of that.

Chairman Holmberg: Why don't you bring down 14 copies and we will distribute them.

JoAnne Hoesel: It is also online on the Department website.

Chairman Holmberg: Does anyone else want to testify on the Bill? If not we will close the hearing on 2268.It is very straight forward Bill. Are you ready to act on it?

Senator Wardner: We don't need to put in subcommittee on this Bill.

Senator Wardner moved a DO PASS AS AMENDED on SB 2268. SECONDED BY Senator Robinson

Chairman Holmberg: Would you call the roll on a DO PASS AS AMENDED on SB 2268.

A Roll call vote was taken on a DO PASS AS AMENDED: YEAS; 11; NAYS: 0; ABSENT: 2. Senator Carolyn Nelson from GVA will carry the Bill.

Chairman Holmberg: Closed the hearing on SB 2268.

Date: 2-15-11
Roll Call Vote # 1

2011 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

Senate 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 Ben Wardner Seconded By Jerry Robinson

Senators	Yes	No	Senators	Yes	No
Chairman Holmberg	✓		**Senator Warner**	✓	
Senator Bowman	✓		**Senator O'Connell**	✓	
Senator Grindberg	✓		**Senator Robinson**	✓	
Senator Christmann	✓				
Senator Wardner	✓				
Senator Kilzer	✓				
Senator Fischer	✓				
Senator Krebsbach	✓				
Senator Erbele	✓				
Senator Wanzek	✓				

Total (Yes) 11 No 0

Absent 2

Floor Assignment Back to Nelson

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

REPORT OF STANDING COMMITTEE

SB 2268, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman) recommends **DO PASS** (11 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2268 was placed on the Eleventh order on the calendar.

2011 HOUSE HUMAN SERVICES

SB 2268

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2268
March 8, 2011
Job # 15119

☐ Conference Committee

Committee Clerk Signature Marilyn Kienzle

Explanation or reason for introduction of bill/resolution:

Provide for regional autism spectrum disorder centers of achievement pilot program; Provide a department of human services report to the legislative management and to provide a legislative management study and an appropriation

Minutes: See attached Testimonies #1,#2,#3

Vice Chairman Pietsch: Opened the hearing on SB 2268.

Sen. Warner from District 37 in Dickinson: I bring before you SB 2268. This bill has been Hog housed. It went through Employees Benefit Committee over the interim. It is a bill that children with Autism would be covered under the health insurance. It was change in the Government and Veterans Affairs Committee in the Senate and this is how it came to your committee. What it does is sets up a Centers of Autism, a pilot study, 600,000 dollars associated with this bill and also an Autism Study that will be a part of this over the interim. The player in bring this amendment forward was the representatives of the Anne Carlsen School.

Cal Rolfson: Representing the Anne Carlsen Center for Children testified in support of the bill in its Engrossed version. (See Testimony #1)
Before question I would like to review briefly what the Engrossed bill does. The essentials behind this bill are to have a public/private partnership match of cash non-profit dollars of 50/50 with state match to create these centers of achievement around the state. That is whether there be one or two or if the funds will provide more we are unsure as of now but the conservative need right now is the $600,000 that is being appropriated for that purpose. The application of that bill will go under the Department of Human Services with standards created for the application. There will be conditions established and an interim study that will call for a report of the success or lack of success of this process to be given at the next Legislative session. The appropriation of $600,000 is a guess. It was based on approximately the cost to build two regional facilities. The idea is that the 8 largest cities in the State each have one of these facilities so families would be able to have access to these services. He noted that families have begged for this support.

Sen. Carolyn Nelson from District 21: It started out as a bill last April. I have a grandson who is autistic and it is emotional for families. What we were looking for was the inclusion of costs that vary. Many people realized we need to look at this and how we pay for this. It

all came down to we needed money. The school is responsible for education not medical and much of the service that can be done before the age of 3. Autism can impact families. My daughter has 5 children and the 4th child has autism. They have all been trained how best to treat their younger brother. The hardest thing for him was going to hot lunch because it was too hard to choose from all those choices. These children need a very strict standard on how they live. It took a long period of time for him to have the structure that these children need to function. The committee's recommendation was to study this a little bit more and perhaps take a look at a pilot program and see if we can find something that will work, keep the cost down and keep all of the share holders involved. We didn't want this to be a battle between insurance companies and families or the parents and the schools. We wanted all the stake holders to come together. This includes volunteers to assist in caring for these children as there is a 24/7 need to care for these children. You will hear from some today that will tell you how important this is. We are delighted that an outside source came in and made an offer to help us with project and hope you will give favorable consideration to this bill.

Rod St. Aubyn: Introduced Dr. Kenneth Fischer. He also noted that he was in support of the bill as it was engrossed. Many of the struggles for parents have are the ability to find resources to assist them.

Dr. Kenneth Fischer: Testified in support of the bill. (See Testimony #2)

Rep. Paur: Hasn't this problem been multiplying many folds over the past few years?

Dr. Kenneth Fischer: Yes and that really needs a 4 hour answer. On one hand more cases are more appropriately identified because there are more consistent criteria and understanding and awareness being applied. More people know what to look for. The difficult thing about autism that affects the amount of people that are being diagnosed is like saying all Martians are green but not everything that is green is a Martians. If you are on the spectrum, by definition you would have issues with language impairment, social skills deficits, executive function and attention deficits, obsessive/compulsive tendencies and narrow interests. This does not mean that everyone with a language delay or obsessive/compulsive is autistic. It is like the parable of the blind man and the elephant, you might have a child presenting with one thing and you are grabbing the snout and not realizing that you are touching an elephant. There is the tendency that if the child is on the spectrum because they look a lot like that. It is not uncommon that diagnosis are delayed for years because it is one thing to diagnose an autistic child who has the very clear impairments that are obvious from birth but the further you go along the spectrum to a higher functioning child, there delays don't become obvious until later on in their development. It can look like a lot of different things making it very confusing for everyone. All of the interventions in the school settings are tied to diagnosis whether it gets covered or not under the IAP and the IDEA. That is why diagnosis is very important. A Center of Excellence that can identify which clinicians out there are the best in making the diagnosis because diagnosis has to precede treatment or you will not get a very result. There is a varying degree of willingness and ability of primary care clinicians and specialty physicians and even physiologists to want to engage in this difficult area. So you may want to send your child who might be on the spectrum to the wrong person and they are not getting diagnosed because it is a very difficult diagnosis to make. Yet the earlier it is diagnosed

and we intervene the more important it is. So having coordination centers around the state knowing the resource that a parent can call and be told this is where you can go.

Rep. Paur: No, absolutely not but I don't want to continue.

Rep. Holman: There are stereo types by our pop culture that are attached to autism, what can be done and what are you and the industry doing to destroy those stereo types?

Dr. Kenneth Fischer: I think there are stereo types with anyone that has emotional difficulties. It is stereo type because it is rooted in the person looking at them. The children in the spectrum see the world very differently. They often see it very concretely and very literally. Often see in school setting where there aren't enough resources, training and sophistication for the teachers and staff about the spectrum. This is improving but the Center of Excellence could assist schools identify their needs. The motives of kids on the spectrum get miss interrupted. An example: a patient's teacher will get very frustrated as the child sees the world very literally and differently. So the teacher will say you are assigned problems in your math book from 11 through 24. The student will do problems 11 through 13 and then 19 through 24. The next day the teacher will say what about the problems 14 through 18. He will say I already know how to do those. The teacher will say yes but the assignment was all of them. The student say but I already know how to do those and why would you want me to do those. They then are seen as being oppositional when they are not. These kids define adapted solutions. The more we can find the strengths out there and raise awareness and the resources.

Rep. Louser: We hear all the time of the increase in the diagnosis of autism. Can that spectrum be broadening over the time?

Dr. Fischer: Yes and no. No in the sense that the spectrum is pretty clearly defined in what terms diagnosis fall under the spectrum but with the diagnosis there are studies that show that diagnosis is increasing and the differential diagnosis that goes into autism is very broad. There are genetic components, environmental components and it won't surprise me if we find environmental toxins. These are not just diagnoses that are going up in this country alone. They are going up across the world. This is not to say that people with this spectrum are over diagnosed or under diagnosed. But I don't think that autistic children are getting over diagnosed. Where it is over diagnosed is when the children are at the end of the spectrum that is higher functioning where they have some of the features of Autism but not all of them.

Dorothy Pudwill: Testified in support of the bill. Personal testimony (See Testimony #3)

Alison Dollar: Assistant Director of Special Education for the Dept. of Instruction testified in support of the bill. (See Testimony #4)

NO OPPOSITION

Vice Chairman Piesch: Closed the hearing on SB 2268.

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2268
March 21, 2011
Job #15753

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Minutes: You may make reference to "attached testimony."

Chairman Weisz: 2268 is our pilot project for autism. I talked to Rep. Louser and he said he has found some specific language having to do with definition. It is a public-private partnership with a grant to ICMFR. Exactly what do they plan to do with (drops sentence). Is this project going into the school system or one on one with the person who is autistic or develop programs within the school system? The language is so vague. I have phone calls with the assumption this is going to the school system and to the client.

Rep. Holman: My experience with a couple of cases; it was a partnership between the client and the medical community and the school with the special ed programs. It isn't well defined. Bismarck does a nice job with it, but some places don't.

Chairman Weisz: I had a conversation with someone from Minot over the weekend. I didn't realize (inaudible) with funds. There were the stimulus funds that were available to these providers to use in the school system and Souris River or Valley, the one in Minot, hired five people who went out and helped develop curriculums and help train the teachers how to deal with violence in some cases. They did that for the past two years and now that money is gone so their question was, it that where this money is going to go? The testimony was they want them in the normal class setting and not in special ed and there are a lot of issues and the teachers aren't prepared. So, they thought the money was well used to train teachers.

Rep. Holman: It is like any other disability. There is a wide range of functionality. Just saying it is not special ed does not apply. It does apply in some situations depending on the degree of the disability. We are in a process of learning about this in the last 8-10 years.

Chairman Weisz: Nobody really testified on, you give us this $600,000 and this is the program and this is how it is going to be? They are going to play it by ear?

Rep. Pietsch: They talked about it being a matching grant. The community has to have up to 50% of it. Cal Rolfson can explain if they have the money to match.

Chairman Weisz: My question is, did anybody really testify that this is the program, where will the money be used? School system or direct client services?

Cal Rolfson: Representing the Anne Carlson School in Jamestown. The bill originally called for mandated insurance coverage. All the sponsors knew with this environment that would never make it past first base. The original intent was to have it a public-private partnership match in intermediate care facilities for the mentally retarded (ICFMR). They are the ones that are called upon do directly and indirectly deal with autism in either onsite daycare services or support services. After we became involved my understanding is that the schools suggested to you that they provide educational services through federal and state education dollars for those in the school system. The Ann Carlson Center is K - 12 school licensed by the Dept. of Public Instruction. We do A-Z for autism around the state. I can't speak to why the schools wanted have an involvement in this, but our original intent was to have it done through ICFMR facilities because the Governor's taskforce had identified this urgent need. Not to enhance the school system, but enhance the support that go well beyond that because of the spectrum aspect of it.

Chairman Weisz: What kind of support would you have?

Cal: We would compete with anyone else that wanted to participate. The thought was that would build regional facilities or have regional presence like Fargo or Dickinson and that would be staffed by appropriate persons. Whether the money would go to build an actual facility, pay rent to staff it or have some facility out of which there could be staffing. In some cases you might have in-patient services for those families that could not deal with autism without breaking up the family. They have autism students who go to the Jamestown public schools. The thought was to respond to something to do trial projects. The need was identified in the Governor's task force in having to do something. I was disappointed that other people weren't supporting the concept. The concept was to be 50/50 and to build or rent a facility.

Chairman Weisz: Not going to deal with this today. We are adjourned.

2011 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

SB 2268
March 23, 2011
Job #15907

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Minutes: You may make reference to "attached testimony."

Chairman Weisz: I don't know what to do with this piece of legislation. Usually I have an opinion and I don't even have that much. We can send over to appropriations as is or we can kill it. If we are going to fix it we have to decide what we want the money to be used for. There is $1.8 million in the DHS budget for autism and got a breakdown in uses from Brenda. One is strictly from birth – 4 years of age. There is four things it I used for. Environmental modifications that are needed for safety. The fiscal agent will pay the vendor on behalf of the family. Equipment and supplies specifically needed to implement evidence based intervention. In this case the fiscal agent will pay the vendors. In-home support staff. The family hires to assist in the consistent implementation of evidence based intervention that was mentioned up above. The fiscal agent in this case would pay the employee for the family. The last one is intervention coordination will be provided by early intervention professionals who will support families through coaching and problem solving. To implement strategies within daily routine. During home visits intervention coordinators will also provide training for family members in home support staff and other caregivers to support consistent implementation and data collection of evidenced based intervention.

Rep. Schmidt: How many dollars is that?

Chairman Weisz: Roughly $1.8 million.

Rep. Schmidt: When did they get the 1.8?

Chairman Weisz: That's in the budget.

Rep. Schmidt: How much of the 1.8 have they spent?

Chairman Weisz: They are using it. DPI came in and made a case that this pilot project be maybe more directed at K-12. Mr. Rolfson said it might be more in the intent area. The other option is do we want to expand in this program and raise the age and give them more money? I don't know. Everyone does agree that early intervention is the key.

Rep. Porter: Did you ask or have we found out how money is in DPI's budget for this very same thing in special education and Title I dollars that come into the state? It seems to me we have had a great amount of money that has flowed through Title I through special

education units out there for this very same thing too. I don't know that the gap exists inside of the public education system.

Chairman Weisz: I had some conversation with DHS on it. They felt there were plenty of services available and funding in schools program.

Rep. Porter: Inside of this bill is there an age specific that I am not seeing?

Chairman Weisz: There is nothing in here. That is part of my problem is the bill is broad for $600,000 for a pilot project. It seemed like it's open for whoever got up in support of the bill.

Rep. Paur: I don't like this bill and would just as soon kill it. To me it is a kind of a mess.

Rep. Kilichowski: I don't remember during the presentation if we got much information on early intervention on autism and how that is dealt with. I agree with you, if anything should be studied should be early intervention. Can Cal answer that?

Cal Rolfson: From Anne Carlson Center: The question is, is early intervention a crucial issue in autism and all the information I'd garnered from medical and other experts is that is the key to identify. The earlier you can intervene the less cost in the long run to deal with autistic services. There is no cure for autism, but the earliest intervention possible is crucial.

Rep. Porter: Having said that earlier intervention is the key, how then is this pilot program targeting toward that early intervention?

Cal: It doesn't. You could certainly put something in there as an amendment. I understand this bill is here because the Governor's task force urged that something to support additional services for autism. The bill that was identified for that purpose was going to die so we created this process and would respect anything this committee comes up with, but I think there should be something that goes over to the Appropriations Committee.

Chairman Weisz: Based on what you said on early intervention is the key. We hand you the money then what would the Anne Carlson Center do with that money to address the issue you just talked about?

Cal: The primary funding would be spent in regional areas. Let's use Dickinson as an example. Develop direct services. The same services that are urged in the 50 plus page Governor's task force that are needed in the state. Most of those are dealing with earlier intervention of autistic children.

Chairman Weisz: You would be going into the home and provided direct services to the families?

Cal: We do that now and they would do that at the regional.

Chairman Weisz: You would put staff in Dickinson and they would go out and provide direct services to families in that area.

Cal: That is my understanding.

Rep. Hofstad: At the present time does your school work in conjunction with the $1.8 million that is appropriated to DPI right now? Is there any collaboration or coordination with those services that are provided now?

Cal: Yes. Anne Carlson is a K-12 school licensed by DPI, in the center they would have special education teachers that deal with special education issues and would do the education part. They do and would work with them.

Rep. Hofstad: I'm trying to follow the money. Are those Title I funds or those funds appropriated through the state?

Cal: My understanding is they are Title I funds that every school is required in the State of ND.

Chairman Weisz: The $1.8 million is in addition to the Title I funding.

Rep. Porter: The center, assuming that Anne Carlson would get the grant and have the match, there wouldn't be a need to have this pilot in Jamestown because of the structure of the existing school and the interventions and programs available there. You are looking at going out into other underserved areas of a population greater than 10,000?

Cal: That is exactly correct.

Rep. Damschen: A different thought goes through my head. We know the intent of Cal's organization, but if it didn't go there it is still kind of open ended as far as the pilot project. I have mixed feelings about the pilot project. I do feel the place that needs a lot of work is the early screening, detection and treatment of autism. If recommend a study it should be very specific to what we would study.

Chairman Weisz: The clients you are serving now, if they come in for autism, are you providing the services for free?

Cal: The Anne Carlson Center while it donates a lot of money does not provide it free. They have to pay their staff, physicians and anyone else that works closely with these people. Virtually all of Anne Carlson Center's funding comes through the DHS. I think 97-98% is through Medicaid. Through the FMAP it is 45, 55 or whatever it will end up being now. That is how it is funded.

Chairman Weisz: If you were to do one of these grants, you would provide the services for free based on the fact that it is being funded through the grant?

Cal: If it was funded through the grant, that is how it would be funded, but the pilot project would identify and have a trial period, maybe one year. Then we would identify any

prospected needs and the study would report to the management committee as well as to the department what that experience has created.

Rep. Schmidt: The $1.8 million in the budge to do those 4 items for kids 0 – 4 years of age and we have $600,000 over here. It seems to me if we are talking about early intervention as key, is not the program with $1.8 million doing those 4 items, early intervention?

Cal: I don't believe so. They are doing the public education part. As soon as the child gets into public education which is 5 years old, they would be provided those services in the school system. I don't think they are providing them before that or not to the significant level all the medical experts seem to urge.

Rep. Schmidt: So this 0-4 of age is not intervention?

Cal: That would be early intervention, but I don't think it is funded through the school system.

Chairman Weisz: This is funding through DHS.

Rep. Schmidt: To me we are just putting $600,000 into $1.8 million.

Cal: From my personal opinion, the $600,000 suggested in here and you think it should be $100,000 or zero, but still pass the bill; I would hope they would still provide some of the grant possibilities. This was to provide a pot so that we could do a trial project in response to the Governor's recommendation through their task force. If there is a better way of doing it, I would support whatever this committee thinks.

Rep. Porter: In looking through this bill, I would move an amendment. On page 1, line 9 after the of, we would insert "early intervention and". That would read, "operate a regional autism spectrum disorder centers of early intervention and achievement pilot program". Then down on page 1, line 19, the same thing and would read the same thing. On page 2, line 8 after the word disorder, we would insert, "early intervention and". That would read, "skilled services to individuals with autism spectrum disorder, early intervention and consideration of the most effective and efficient delivery system for these skilled services". On the bottom of page 2 on line 27 after the first of, insert "early". That would read, "the diagnosis of early treatment of, care for and education of individuals with autism spectrum disorder". That would be my motion. I think it is very clear that the focus of this is to be early intervention. I think adding this changes the focus to where I was hearing the committee wanting to be.

Rep. Pietsch: Second.

Voice Vote: Motion Carried

Rep. Schmidt: I'd still like a better definition where the $600,000 is going to go. I understand it has been pulled from the sky and could we do the same thing with $200,000?

Chairman Weisz: Yeah the number is pulled out of the sky. The bill doesn't limit the number of centers so whatever we put in for dollars would most likely determine how many of these would go into the pilot project.

Rep. Porter: I do agree the $600,000 is arbitrary number, but knowing this has to go to appropriations and they have to make it plug into the existing human service budget, I'm not afraid to send it over there like this and let them (drops sentence). We fixed the problem and are directing it toward early intervention.

Chairman Weisz: I believe that within the pilot project there should be a sliding fee scale or something as far as the payment of services.

Rep. Porter: The way the Medicaid program is set up with special needs kids, you don't think this falls under those?

Chairman Weisz: I don't. I don't think anything we have in here specifies that they would have to be Medicaid eligible.

Rep. Porter: It being a 50/50 match from the nonprofit to the state funds. Maybe your language needs to be added to the legislative management autism study so that is a key component of that.

Chairman Weisz: Do we need like we do for (inaudible) a fee scale like that? If we expand this do we look at Medicaid eligible and the rest pay out of their pockets? The original intent was the insurance companies pay then they looked at if the state should help pay for all these services. If the state is going to go down this road, some sort of sliding scale fee should be developed. I don't believe the state should pay the services regardless of income or ability to pay.

Rep. Hofstad: Further more it seems to me it leaves some sort of a disconnect between the $1.8 million right now and this pilot program. We have the money appropriated and have specific goals within that dollar amount off to the side and now developing another pilot program. I don't see how we are really tying those two together. We should tie these two together somehow.

Chairman Weisz: I'm not sure I disagree with you. I look at this as the same services doing the same things that we are doing with the $1.8 million only we are going to do it in regional center. You are right. It isn't specific there either.

Rep. Porter: I would move to further amend 2268 to include in the study language in section 2, a payment schedule and sliding fee schedule as part of that study.

Rep. Devlin: Second.

Rep. Schmidt: Do any of these types of studies have a sunset clause to them?

Chairman Weisz: The studies are always to be done in that interim. It has to be done before next session.

Voice Vote: Motion Carried

Rep. Kilichowski: I'll move a Do Pass as amended and re-refer to Appropriations.

Rep. Damschen: Second.

VOTE: 6 y 6 n 1 absent – Rep. Conklin

Rep. Devlin: I move a Do Pass as amended and Re-refer to Appropriations.

Rep. Kilichowski: Second.

VOTE: 7 y 5 n 1 absent – Rep. Conklin
MOTION CARRIED

Bill Carrier: Rep. Porter

Date: 3-23-11
Roll Call Vote # 1

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2068

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. Porter Seconded By Rep. Pietsch

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ			REP. CONKLIN		
VICE-CHAIR PIETSCH			REP. HOLMAN		
REP. ANDERSON			REP. KILICHOWSKI		
REP. DAMSCHEN					
REP. DEVLIN					
REP. HOFSTAD					
REP. LOUSER					
REP. PAUR					
REP. PORTER					
REP. SCHMIDT					

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

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

Voice Vote

Motion Carried

Date: 3-23-11
Roll Call Vote # 2

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

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. Porter Seconded By Rep. Devlin

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ			REP. CONKLIN		
VICE-CHAIR PIETSCH			REP. HOLMAN		
REP. ANDERSON			REP. KILICHOWSKI		
REP. DAMSCHEN					
REP. DEVLIN					
REP. HOFSTAD					
REP. LOUSER					
REP. PAUR					
REP. PORTER					
REP. SCHMIDT					

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent: further amend. payment and sliding fee schedules.

Voice Vote

Motion carried

11.0032.03001
Title.04000

Adopted by the Human Services Committee 3/24/11

March 23, 2011

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2268

Page 1, line 1, after "of" insert "early intervention and"

Page 1, line 5, after "**OF**" insert "**EARLY INTERVENTION AND**"

Page 1, line 9, after "of" insert "early intervention and"

Page 1, line 19, after the second "of" insert "early intervention and"

Page 2, line 3, after "of" insert "early intervention and"

Page 2, line 6, after "of" insert "early intervention and"

Page 2, line 8, after the comma insert "early intervention and"

Page 2, line 22, after "of" insert "early intervention and"

Page 2, line 27, after the first comma insert "early"

Page 2, line 28, after "disorder" insert ", shall study a sliding fee scale for payment of services,"

Page 3, line 8, after "of" insert "early intervention and"

Renumber accordingly

Date: 3-23-11
Roll Call Vote # 3

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

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. Kilichowski Seconded By Rep. Damschen

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ		√	REP. CONKLIN	A	
VICE-CHAIR PIETSCH	√		REP. HOLMAN	√	
REP. ANDERSON	√		REP. KILICHOWSKI	√	
REP. DAMSCHEN	√				
REP. DEVLIN		√			
REP. HOFSTAD		√			
REP. LOUSER		√			
REP. PAUR		√			
REP. PORTER	√				
REP. SCHMIDT		√			

Total (Yes) 6 No 6

Absent 1

Floor Assignment _____

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

Date: 3-23-11
Roll Call Vote # 4

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

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. Devlin Seconded By Rep. Kilichowski

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN WEISZ		✓	REP. CONKLIN	A	
VICE-CHAIR PIETSCH	✓		REP. HOLMAN	✓	
REP. ANDERSON	✓		REP. KILICHOWSKI	✓	
REP. DAMSCHEN	✓				
REP. DEVLIN	✓				
REP. HOFSTAD		✓			
REP. LOUSER		✓			
REP. PAUR		✓			
REP. PORTER	✓				
REP. SCHMIDT		✓			

Total (Yes) 7 No 5

Absent 1

Floor Assignment Rep. Porter

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

REPORT OF STANDING COMMITTEE

SB 2268, 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** (7 YEAS, 5 NAYS, 1 ABSENT AND NOT VOTING). Engrossed SB 2268 was placed on the Sixth order on the calendar.

Page 1, line 1, after "of" insert "early intervention and"

Page 1, line 5, after "**OF**" insert "**EARLY INTERVENTION AND**"

Page 1, line 9, after "of" insert "early intervention and"

Page 1, line 19, after the second "of" insert "early intervention and"

Page 2, line 3, after "of" insert "early intervention and"

Page 2, line 6, after "of" insert "early intervention and"

Page 2, line 8, after the comma insert "early intervention and"

Page 2, line 22, after "of" insert "early intervention and"

Page 2, line 27, after the first comma insert "early"

Page 2, line 28, after "disorder" insert ", shall study a sliding fee scale for payment of services,"

Page 3, line 8, after "of" insert "early intervention and"

Renumber accordingly

2011 HOUSE APPROPRIATIONS

SB 2268

2011 HOUSE STANDING COMMITTEE MINUTES

House Appropriations Committee
Roughrider Room, State Capitol

SB 2268
3/29/11
16114

☐ Conference Committee

Committee Clerk Signature Meredith Trabolt

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for a regional autism spectrum disorder centers of early intervention and achievement pilot program; to provide for a department of human services report to the legislative management; to provide for a legislative management study; and to provide an appropriation.

Minutes: You may make reference to "attached testimony."

Chairman Delzer: SB 2268 on autism is next.

Representative Robin Weisz, District 14: The bill in front of you will establish a pilot project for early intervention, to set up centers in communities above 10,000 people. It's a matching grant, 50/50. We didn't do anything with the dollar amount in the appropriation, which came from the Senate, because we didn't have a basis to determine what was necessary. This was a very difficult bill. There seemed to be unanimous agreement that we need to deal with ASD (autism spectrum disorders), but not what we need to be doing. We thought it might be useful to develop a pilot project, and use the study spelled out in the bill to try to determine what we should be doing and how it should be paid for.

Chairman Delzer: Did you have discussion about early intervention? I think there is a fair amount of money in DHS (department of human services) for age four and under.

Representative Weisz: We did discuss that, there's $1.8 million in that budget currently for age four and under. The human services committee intent was preschool, which might be six years and under. It was a real struggle. There was no clear direction from any of the supporters or anybody else on where this should head.

Chairman Delzer: Your committee took it down to one pilot project, but you did not do anything with the fee scale?

Representative Weisz: Correct, we did talk about it, but we didn't know how to insert that in without further information. This is probably one of the few times when supporters have come in and haven't spelled out what they want and their plan to do it. Part of the reason was the bill started out as an insurance mandate in the Senate. It got switched to this, and then it came over to the House and to us.

Chairman Delzer: And it came out of your committee 7-5.

Representative Pollert: Are the human service centers screening already for autism for six and under?

Representative Weisz: I think it's four and under. This would go beyond the screening to early intervention services. That's why there was a debate about if they should be in the school setting, or community centers...I'm sorry I'm not giving the committee a lot of direction, but we didn't have a lot of direction on our committee, either.

Representative Pollert: Is there currently a sliding fee scale for administration of services, or would they have to establish it administratively as part of the study?

Representative Weisz: No, that's why we put it in the study. We thought if we would establish one of these centers, we'd look at the clientele that we're serving, and then the study should look at this clientele and say how we will treat them, should we have a sliding fee scale, should the state just be responsible for it, should we not be in it at all and just look at screening, etc. That's why our committee sent it forward with a pilot project. Hopefully we can get results from the pilot to determine if this should go forward, and if so, in what form.

Representative Pollert: The position we all seem to be in is, we know we want to do something, we don't know exactly what, we want to fund a pilot project, we don't know what the pilot will be, we don't know what the sliding fee scale will be. I see your frustrations as well. It doesn't seem like there's a direction.

Representative Weisz: When you say it that way, it doesn't sound good at all. The committee all agreed there's a real issue with ASD. Our argument would be, if there is a pilot project, the study is important to give us direction.

Chairman Delzer: This is just for the next biennium?

Representative Weisz: Correct. And we had no idea what funding level would be appropriate, which is why we didn't change it from what the Senate did.

Representative Pollert: Is the idea that the pilot project does the study, or the pilot is part of the study and then DHS will have their findings from the pilot project? It's almost like two studies in one.

Representative Weisz: The committee hoped to use the pilot project as the basis for answers in the study. Hopefully we could get some answers that would then give us some direction on how we should deal with this issue.

Representative Pollert: Are there multiple ICMFRs that could do this?

Representative Weisz: I think there are several that can, if they desire. Anne Carlsen School is one of them that has an interest in pursuing this. It requires a match, so they have to have that ability to product that.

Representative Skarphol: What's happening elsewhere, what's going on nationally with this issue?

Representative Weisz: I can't speak nationally. There has been a push to have insurance mandates to cover these types of services in many states. The issue comes down to, from a federal definition, most autism doesn't qualify under special needs. Unless they have severe emotional disturbance, they probably aren't special needs. The number of children with ASD is rising dramatically, and the question is why, are we just broadening the definition? Right now they say 1 in 91 have ASD.

Chairman Delzer: Further questions by the committee? Thank you.

2011 HOUSE STANDING COMMITTEE MINUTES

House Appropriations Committee
Roughrider Room, State Capitol

SB 2268
4/4/11
16294

☐ Conference Committee

Committee Clerk Signature Shirley Brenning

Explanation or reason for introduction of bill/resolution:

A BILL for an Act to provide for a regional autism spectrum disorder centers of achievement pilot program; to provide for a department of human services report to the legislative management; to provide for a legislative management study; and to provide an appropriation.

Minutes:

Chairman Delzer: We'll move to SB 2268. This has to do with funding for autism services. It came from Human Services as well. We heard that in full committee. Addressing **Representative Wieland** to distribute the Amendments.

Representative Wieland: I move amendment .03003.

Representative Kreidt: Second.

Representative Wieland: The original bill dealt with a regional autism spectrum disorder (ASD) center. The sponsors are looking for two areas, one in Dickinson and one in Fargo. SB 2268 hog houses the amendment into creating the centers. They can use up to $200,000 of funding if they can find it in their budget. It is a pilot project

Chairman Delzer: It is also a study so they come back with what these services would find in that period of time and it also sunsets...

Representative Wieland: It sunsets on December 31, 2012.

Chairman Delzer: Discussion on the motion to amend.

Representative Hawken: This is a massive topic. We know the early intervention piece makes a huge difference. I would like a better explanation. I'm not sure the $200,000 can do much to begin with, but I would like to know what that 'within their budget' means.

Representative Bellew: In the Department's budget currently there is $1.8 million in the budget for ASD for age 0 to age 4. The money that's in this bill should come out of that part of the funding in their budget.

Chairman Delzer: Currently we're looking at a 12.8 million turnback. If they can find $200,000 anywhere in their budget, they can do the pilot project. Because this is such a massive deal, we don't want to start something without knowing what we're doing, there was discussion of putting it that way, sunsetting it at the start of the next biennium with report to the next legislature and the study to tell us how to proceed with this with the slight increase. Addressing who receives the services, who doesn't and how you deal with them.

Representative Bellew: I see in the study you have an education, is that for when the kids go to school? Is that K-12?

Chairman Delzer: It says during the system of diagnosis, early treatment, care for, and education of Autism, See bottom of page 1of the Amendment. They would see what is currently being done and decide how to go from there.

Representative Skarphol: On page 1 subsection 3, the second sentence says this plan must establish a regional ASD center of early intervention and achievement with a population of more than 10,000 and if the expiration date of this is December 31, 2012 does that mean that they will they have funding only through that time period? After that the center will close, is that the intent?

Representative Wieland: That is correct, unless there are other dollars they can find out of some other area.

Chairman Delzer: That timeframe is figured so that information can be gathered for the next legislative body and if that body decided to expend money with their emergency clause they would be able to do it.

Representative Skarphol: There is potential for other money to be utilized to continue the center being open if it is needed during the time frame being considered.

Chairman Delzer: When you set up a pilot project with a deadline date, you would have to, in that emergency clause, reauthorize that. I do not believe that we would be authorizing that.

Voice Vote Taken: Motion Carried.

Chairman Delzer: We have the amended bill before us. Any other amendments?

Representative Glassheim: I would like to further amend that the expiration date in section 3 be moved to the end of March 2013, so there is not a closure, to give them authority to keep going through the beginning of the legislative session.

Chairman Delzer: There is a motion to further amend to change the deadline date to close on March 31, 2013.. Calling for a second.

Representative Hawken: Second.

Chairman Delzer: One of the reasons I felt that we should have the December 31 deadline so that we get them to get the information to us at the start of the next legislative session. I

Representative Glassheim: On page 1 section 5, they are instructed to report preliminary findings by September 1. If you wanted to change also that one to report secondary findings to by December 31, that is fine, too. It makes no sense to close it and then potentially reopen it after two months.

Chairman Delzer: Further discussion, hearing none ...All in favor of further amending with the March 31, 2013 expiration date.

Voice Vote: Indecisive.
Roll Call vote is taken: 10-11-0 Motion Fails.

Representative Wieland: Move the Amended Bill .03003.

Representative Kreidt: Second.

Roll Call vote is taken: 20-1-0 Motion Carries.

Carrier: Representative Wieland

11.0032.03003
Title.05000

Prepared by the Legislative Council staff for
Representative Wieland
April 4, 2011

VR
4/4/11
1082

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2268

In lieu of the amendments adopted by the House as printed on page 1115 of the House Journal, Engrossed Senate Bill No. 2268 is amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a regional autism spectrum disorder centers of achievement pilot program; to provide for a report to the legislative management; to provide for a legislative management study; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM - REPORT TO THE LEGISLATIVE MANAGEMENT. During the 2011-13 biennium, the department of human services may use up to $200,000 of funding from its legislative appropriation to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program.

1. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for the mentally retarded which is licensed by the department of human services.

2. A qualified applicant shall establish the availability of one dollar of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds may not be a gift or grant, but must be funds of the applicant.

3. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than ten thousand.

4. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

5. The department of human services shall report to the legislative management before September 1, 2012, on the preliminary findings and recommendations of the pilot program.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT STUDY. During the 2011-12 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 include a review of a sliding fee scale

for payment of services and the value of services provided. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families impacted by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for the mentally retarded. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly.

SECTION 3. EXPIRATION DATE. Section 1 of this Act is effective through December 31, 2012, and after that date is ineffective."

Renumber accordingly

Date: 4/4
Roll Call Vote #: 1

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

House Appropriations Committee

Legislative Council Amendment Number .03003

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			Representative Nelson		
Vice Chairman Kempenich			Representative Wieland		
Representative Pollert					
Representative Skarphol					
Representative Thoreson			Representative Glassheim		
Representative Bellew			Representative Kaldor		
Representative Brandenburg			Representative Kroeber		
Representative Dahl			Representative Metcalf		
Representative Dosch			Representative Williams		
Representative Hawken					
Representative Klein					
Representative Kreidt					
Representative Martinson					
Representative Monson					

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

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

Voice vote carries

Date: 4/4
Roll Call Vote #: 2

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

House Appropriations Committee

Legislative Council Amendment Number

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

Motion Made By Rep. Glassheim Seconded By Rep. Hawken

Representatives	Yes	No	Representatives	Yes	No
Chairman Delzer		X	Representative Nelson	X	
Vice Chairman Kempenich		X	Representative Wieland		X
Representative Pollert		X			
Representative Skarphol		X			
Representative Thoreson		X	Representative Glassheim	X	
Representative Bellew		X	Representative Kaldor	X	
Representative Brandenburg		X	Representative Kroeber	X	
Representative Dahl	X		Representative Metcalf	X	
Representative Dosch		X	Representative Williams	X	
Representative Hawken	X				
Representative Klein		X			
Representative Kreidt		X			
Representative Martinson	X				
Representative Monson	X				

Total (Yes) 10 No 11

Absent

Floor Assignment

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

section 3 expiration moved to 3/31/13

voice vote uncertain

motion fails

Date: 4/4
Roll Call Vote #: 3

2011 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2268

House Appropriations Committee

Legislative Council Amendment Number 03003

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	X		Representative Nelson	X	
Vice Chairman Kempenich	X		Representative Wieland	X	
Representative Pollert	X				
Representative Skarphol	X				
Representative Thoreson	X		Representative Glassheim	X	
Representative Bellew	X		Representative Kaldor	X	
Representative Brandenburg	X		Representative Kroeber	X	
Representative Dahl	X		Representative Metcalf	X	
Representative Dosch		X	Representative Williams	X	
Representative Hawken	X				
Representative Klein	X				
Representative Kreidt	X				
Representative Martinson	X				
Representative Monson	X				

Total (Yes) 20 No 1

Absent

Floor Assignment Rep. Wieland

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

REPORT OF STANDING COMMITTEE

SB 2268, as engrossed and amended: Appropriations Committee (Rep. Delzer, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (20 YEAS, 1 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2268, as amended, was placed on the Sixth order on the calendar.

In lieu of the amendments adopted by the House as printed on page 1115 of the House Journal, Engrossed Senate Bill No. 2268 is amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a regional autism spectrum disorder centers of achievement pilot program; to provide for a report to the legislative management; to provide for a legislative management study; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM - REPORT TO THE LEGISLATIVE MANAGEMENT. During the 2011-13 biennium, the department of human services may use up to $200,000 of funding from its legislative appropriation to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program.

1. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for the mentally retarded which is licensed by the department of human services.

2. A qualified applicant shall establish the availability of one dollar of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds may not be a gift or grant, but must be funds of the applicant.

3. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than ten thousand.

4. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

5. The department of human services shall report to the legislative management before September 1, 2012, on the preliminary findings and recommendations of the pilot program.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT STUDY. During the 2011-12 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 include a review of a sliding fee scale for payment of services and the value of services provided. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families impacted by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for the mentally retarded. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly.

SECTION 3. EXPIRATION DATE. Section 1 of this Act is effective through December 31, 2012, and after that date is ineffective."

Renumber accordingly

2011 SENATE GOVERNMENT AND VETERANS AFFAIRS

CONFERENCE COMMITTEE

SB 2268

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
April 12, 2011
16517

☒ Conference Committee

Committee Clerk Signature: Katie Dwel

Explanation or reason for introduction of bill/resolution:

Relating to public employees retirement system medical benefits coverage for autism spectrum disorders

Minutes: *No testimony attached.*

Chairman Berry called the conference committee on SB 2268 to order, roll was taken Representative Conklin was replaced by Representative Holman.

Senator Berry explained to the House members of the committee what the bill looked like in its original forum and the changes that were made in the Senate.

Representative Wieland: If you like we can go through out amendments and if other people would like to add things then they can. 03003 amendments what we did is made this into a pilot program what we were concerned about is that we were moving too fast and we really need to study so when we really do tackle the problem which can still be done in 2 places if they wish the $200,000 that is talked about is actually comes out of the department themselves. They can establish a regional autisms spectrum disorder. It does include a study, included in the study is talking about the sliding fee scale and the values of services provided. There is a taskforce and they would consider input from families,

Senator Nelson: The taskforce that existed is for education, are you looking at that being continuing taskforce or a whole new taskforce?

Representative Wieland: My thought was to continue with the same taskforce that is there now because we have made reference to the taskforce in the study.

Senator Nelson: Are we talking that it could be an up to $400,000 project?

Representative Wieland: My understanding is that it would be a match totaling up to $400,000

Senator Berry: Where would that extra come from?

Representative Wieland: An applicant, in this case it would be a nonprofit intermediate care facility which is licensed by the DHS.

Representative Holman: One of the testifiers on the bill indicated that the Anne Carlson school would help match $200,000 funds.

Senator Dever: The language with the match was brought in the Senate.

Senator Berry: Did the Human Services indicate that they had the money?

Representative Wieland: They do have if they want to use it.

Senator Berry: Was there any indication as to who the money would come from?

Representative Wieland: We don't get to hear the policy on that.

Senator Nelson: When it was $600,000 it said that $600,000 from the general fund.

Senator Berry: That is where the money got changed.

Representative Wieland: I can only tell you that we just looked at the amount of dollars and felt that you could do the same thing, albeit restricted, but if you are going to get some matching funds we thought that you could do it for this amount of dollars.

Senator Berry: Maybe we can have someone from the DHS to come talk to us.

Representative Wieland: That is your decision to make.

Senator Berry: Maybe talking this over and going forward we can do some further research and to find out what you think. For me the most important thing is to get out the best piece of legislation that arrives at the goals that we want to do

Representative Holman: The difference tends to be money. I t came out of our committee at 600k. The Purpose of this study is to see how we are affecting the people being affected.

Senator Dever: $200,000 we are not going to build 2 centers. If it is subject to the department finding the money we need to allocate the dollars.

Representative Wieland: I don't disagree now that we have defined what the situation is it would be interesting to me if the department said they didn't have the funds. I understand that they are confined to certain programs that they must do. If we need to determine what the dollar is I would hope that. I have no problems with adjourning and meeting after we had done some additional research.

The committee then adjourned and decided to do more research on the funds allocated for this project.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
April 14, 2011
16593

☒ Conference Committee

Committee Clerk Signature Katie Olsen

Explanation or reason for introduction of bill/resolution:

Relating to public employees retirement system medical benefits coverage for autism spectrum disorders

Minutes: *No testimony attached*

Chairman Berry: We had a chance to discuss where we are at. I have handed out copies. I think that it is very doable with 2 facilities at $400, 00 a piece.

Senator Dever: regarding that line on travel, that emphasizes travel

Chairman Berry: My understanding is that there would, it wasn't meant to be set up to be that those were estimates are that if they had to pick numbers that there is probably...it would come out of the existing budget, that is where section 3 there is an appropriation that can be matched. That would be equaled by the wording, page 1 line 15. This is one of the possibilities, depending on what is done or not done we would need to insert to provide for an appropriation. If we are not going to appropriate we need to replace may with shall and if we are asking them to come up with the budget of human services that

Representative Wieland: There are some things in here that we can agree to. Until we determine exactly where the money is going to come from replacing may with shall would be a problem.

Senator Berry:

Representative Wieland: We certainly would talk to them before we made a final decision. We had some folks who had a little concern about making them do it, the Appropriations part we would prefer to see the $400,000 coming from the department. With the stuff I think that after that we have a whole different ballgame.

Senator Berry: You preference would be to have page 1 line 8 say $400,000 leave it to say may. Giving them the option to use $400,000

Senator Dever: The use of the word may imply the use of the word may not.

Representative Holman: I think that asking the dept to find the money I assume their budget is already allocated for different things.

Representative Wieland: in the last 2 biennium they have had a lot of turn back, last session I believe that it was $20,000,000.

Senator Berry: When they turn it back does it go back to the general fund?

Representative Wieland: It can.

Senator Nelson: I feel better if I knew if somebody had talked to human services to find out where it is on the priority list.

Joann Hazel: Department of Human Services, caseload as it stands to use those funds to transfer people f

Senator Berry: Do you see with the language as we have in there do you see it getting done.

Joann Hazel: We base our budget on the caseload and utilization and the priority would be.

Senator Dever: When would you know about having money to turn back?

Joann Hazel: It takes time for the bills to come in and be paid.

Senator Dever: I see this as a problem.

Senator Berry I agree. There is only one way to know how it has been done.

Representative Wieland: It is going to be a tough see even though I think that some people see that there is a situation here that is becoming alarming. The big problem is that up until now we didn't know where to go. The study is the most import part to me, I would think that there will be people in the body that would support it and there will be people who don't support it, no matter what we do. My guess is that we have a conversation with them, the big problem is that some of the spending is about $40,000,000 over what was proposed. It makes it a little more difficult to find.

There was no further discussion, the members agreed to reconvene on SB 2268 at a later time.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
April 15, 2011
16677

☒ Conference Committee

Committee Clerk Signature Katie Olson

Explanation or reason for introduction of bill/resolution:

Relating to public employees retirement system medical benefits coverage for autism spectrum disorders

Minutes: *No testimony attached*

Senator Berry called the meeting to order, roll was taken and all members were present.

Senator Berry then handed out an amendment to SB 2268 and explained the differences to the committee.

Representative Holman: Section 1 in the description, do we have any assurance that since we are using the word 'may' that the department is going to work with this

Senator Berry: There is no guarantee.

Representative Wieland: The only thing that is of concern to me is having it run through the biennium is we won't have the information from that pilot project during the next session. I think that it is important to have it in there during the session itself. Maybe there is a way around that and I will think about that but other than that I have no problem with the amendment.

Senator Berry: There language does specify dates as it relates.

Representative Wieland: In the original one we asked that it's affective through December 31, 2012 and I see that but this takes it though June 2013 for the pilot project.

Senator Berry: It does ask for a report from legislative management. Would you like to move that date?

Representative Wieland: At this point I would like to think a little bit on this. On the other amendment where we had section 1 of this act is effective through December 31, 2012 and after that date is ineffective and the reason for that was so that we would have the information

and get a final report. I would like to think about that a little bit, other than that, I am very supportive

Senator Nelson: The study from legislative management, it needs to be done by legislative report time which would be mid November so they would have to then be in by November 1. There might be a way that we can make both of these at the same time. Preliminary in September would be fine because it gives you a couple of months to work out some things. Most of the reports and preliminary bills would come in during December.

Representative Wieland: The study I have no problem with it. That was why I need to think about how that one if there is some way we could word that. I appreciate what you have done here except for that one quirky item.

Senator Dever: I wonder if we put an emergency clause on that if they could use turn back dollars from this biennium to fund this program.

Representative Wieland: I will look into that.

There was no further discussion, the committee agreed to re convene at a later date and the meeting was adjourned.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
April 18, 2011
16707

☒ Conference Committee

Committee Clerk Signature Katie Dixon

Explanation or reason for introduction of bill/resolution:

Relating to public employees retirement system medical benefits coverage for autism spectrum disorders

Minutes: *No testimony attached*

Senator Berry called the conference committee on SB 2268 to order, roll was taken and all members were present

Senator Berry: There was a question regarding turn back money which I have had a chance to get answered. Representative Wieland do you have further thoughts?

Representative Wieland: I have had an opportunity to look at some things but I have not had a chance to run them by all the people. I wanted to explain why I am being so hardnosed on this. As you all know this is going to be a brand new program, from what I can see it maybe a large one and as a brand new program it is still an expansion of government. My concern is that we are trying to run before we are walking. That is why I have said all along is the important issue is the study itself. The idea of leaving the pilot program in there is enticing because maybe it can be accomplished that we can do two things in one in one fell swoop. But typically you would do the study and then you would do the pilot project and then you would go in to the full program and that is part of the reason for trying to hold this thing down a little bit. I am toying with the idea of extending that date but I don't like the idea of going beyond the session but maybe a month or 2 into the session maybe we can get that to work, that is one of the things that I need to go through. At this point in time I am not ready to make any changes.

Senator Berry: Which date are you referring to?

Representative Wieland: December 31, 2012.

Senator Nelson: I have a problem with section 3; I think what you want is the report but not the pilot program to end because then you have some kids into a program and all of a sudden

there is no program. What we are wanting is a report by a set date not the program to be cut off.

Senator Berry: Correct. The goal would be to have the report in by December 31 but I would like to see the pilot program go through the biennium so that we don't have people enrolled and then cut it off. In answering questions that you had Representative Wieland the fact that we are not appropriating new dollars but rather allowing the Human Services Department to use money that has been appropriated to them, the turn back money that was brought up last time, is not available.

Representative Wieland: A using turn back fund is the same as setting an appropriation.

Senator Berry: Where we are at with these is the idea of allowing DHS to use the $600,000 and that is money that is already there but to allow for a program that is already there and a match from a private applicant. With the full knowledge that it might not continue this is obviously a huge problem. Finding a proper way to deal with this is critical. Every 2 years the tension then the next 2 years that you come back and re evaluate it. A pilot program and a study if that can be done I have no problem looking at this again but with the nature of the problem and the size I do see the urgency.

Representative Louser: The autism center of North Dakota was formed in 2006, they have 501c3 tax exempt status as of June 2007, and they have a board; the vision is to be the provider for support for the ASD community.

Senator Nelson: We had a program presented by that group at one time. A parent started the group to help with her daughter and from what I have seen from that group I don't see it as competition.

Senator Berry: The Ann Carlsen center is roughly 40% of their population and they are the best equipped to handle something of this nature. I am all for private enterprise doing things but I don't think that they have it is all. My feeling is that for the state to get a sense of where we are at for this it is something that has blossomed in the last 20 years. Yes it has always been a pervasive delay and folks are looking for it more and most likely the prevalence is increasing. With the numbers that we are seeing getting a handle on it, not to say that the study is excellent to do that and having a little bit of experience with a pilot program would teach us something. This is money that will have to be out of a budget that is already there. From my standpoint I would like to see kids not get cut off and then the money gets found by the department.

Representative Louser: Senator Nelson answered my question and had mentioned that there was a proposal; was that during a different session?

Senator Nelson: Basically the plea was for money when they came to the group. A couple of kids needed services are very expensive. So their purpose in going around to the Kiwanis and the Rotary Club was a plea for funds it was not a legislative thing.

Representative Wieland: A onetime deal?

Senator Nelson: They were asking us, the retired teachers, for money and they were making the same programs available.

Senator Dever: I am a little confused when we are talking about the date. Are we talking about the date in 05000 version of the bill or the date in the 03001 version?

Representative Wieland: Section 3, expiration date. Section 1 of this act is effective through December 31, 2012 and after that date is ineffective.

Senator Berry: When I talked to legislative council the amendment was based on the version and that is why it is worded but it looks different.

Representative Wieland: To my way of thinking that is what we are a part of.

Senator Berry: If the House recedes then these amendments 03004 so you are saying what it is about of these amendments.

Representative Wieland: Section 3 should be added to 03004 or you can take it from 05000.

Senator Berry I had that deleted because I wanted the program to go through the biennium.

Representative Wieland: If you terminate it you know it is not around at the end of the biennium and it was the fact that we wanted to have all the information in time for the session.

Senator Berry: Having the report is critical; obviously something of this nature is going take a while to get implemented. To cutoff that service to folks who are already involved in it seems to me that it would be a more seamless transition that nothing further is going to be done knowing full well that it will stop June 30th.

Senator Nelson: If we are asking the applicant to match 1 for 1 up to whatever the DHS has and it takes this thing 6 months to a year to get running you may be asking someone for $600,000 and then telling them that they may have to stop their program 6 months from now. I don't see that as a sensible plan because an autistic kid needs structure and to have something go for 6 months and then to cut it off is not good for the kid. That is what we should be thinking about in the long run.

Senator Berry: I would like to see it continue and for people to see how it's going. Yet keep it going because once it starts and based on that fine tune what is happening. I just feel that we are looking at 6 moths verses a year

Representative Holman: In my mind we are already supporting these kids and it takes the kids that we are supporting and focusing on the problems and we are already putting money into their treatment.

Senator Nelson: Rather than have an expiration date on it, would it be possible to get a report in without closing off the program. Have that in section 1 so section 3 can become null and void after a certain date.

Representative Wieland: We won't get a final report before the end of the session so it would be an interim report. The other thing is that if you are going to stop the program at the end of the biennium or December 1 and it is terminated at the end of the biennium.

There was no further discussion; the committee was then in recess and agreed to meet at a later time.

2011 SENATE STANDING COMMITTEE MINUTES

Senate Government and Veteran's Affairs Committee
Missouri River Room, State Capitol

SB 2268
April 18, 2011
16745

☒ Conference Committee

Committee Clerk Signature Katie Dieterich

Explanation or reason for introduction of bill/resolution:

Relating to public employees retirement system medical benefits coverage for autism spectrum disorders

Minutes: *No testimony attached*

The conference committee was called to order by Senator Berry, roll was taken and all members were present.

Representative Wieland: what everyone wanted was to run the pilot project through the biennium if you look on the second page you will see that the expiration date is June 30, 2013. You will also see that there are some reports, September 30th a preliminary and in December 31, 2012 and then to the Appropriations committee during the next session there is to be a report given on this as well. The money that we had in there was reduced from $600,000 to $200,000 if it can be found within the department's appropriation for the year 2013. That is the changes that were made and I would make a motion that we adopt the amendment.

A motion was made by Representative Wieland for the House to recede and amend SB 2268 with a second by Senator Nelson

Senator Dever: With $200,000 would that mean only one center?

Representative Wieland: That is up to the department.

Senator Dever: Report to legislative management before September 30th, I understand that and whatever committee they would report to it would likely be at their last meeting. I am not sure of their opportunity of their ability to report to legislative management between then and December 3. It might be more appropriate to provide that final report to a legislative standing committee during the next session.

Representative Wieland: Not knowing what the committees will be I wouldn't want to identify that. If they presented to legislative management then they would know at that time would be

Senator Dever: Their last meeting would be before the session would be mid November.

Representative Wieland: I understand that but we can do one before December 31 to present early in the session and one later in the session.

Senator Nelson: You could put in language to say that when they give the first report they could make a ruling as to where that final report would go. They would still be using an appropriation.

Representative Wieland: Maybe give them some leeway and gives them opportunity. That would mean it would have to be sometime during the session.

There was no further discussion, roll was taken and the motion passed 6-0. Senator Berry then closed the conference committee on SB 2268.

2011 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

Committee: Goverment + Veterans Affairs

Bill/Resolution No. 2268 as (re) engrossed

Date: 4/12, 4/14, 4/15

Roll Call Vote #: _____

Action Taken

- ☐ SENATE accede to House amendments
- ☐ SENATE accede to House amendments and further amend
- ☐ HOUSE recede from House amendments
- ☐ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ page(s) _____

- ☐ Unable to agree, recommends that the committee be discharged and a new committee be appointed

((Re) Engrossed) _____ was placed on the Seventh order of business on the calendar

Motion Made by: _____ Seconded by: _____

Senators				Yes	No	Representatives				Yes	No
Berry	X	X	X			Wieland	X	X	X		
Dever	X	X	X			Lauer	X	X	X		
Nelson	X	X	X			Holman	X	X	X		

Vote Count: Yes _____ No _____ Absent _____

Senate Carrier _____ House Carrier _____

LC Number _____ . _____ of amendment

LC Number _____ . _____ of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

11.0032.03005
Title.06000

Prepared by the Legislative Council staff for
Representative Wieland
April 18, 2011

4-19-11
1 of 2

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2268

That the House recede from its amendments as printed on pages 1216 and 1217 of the Senate Journal and pages 1382 and 1383 of the House Journal and that Engrossed Senate Bill No. 2268 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a regional autism spectrum disorder centers of early intervention and achievement pilot program; to provide for a report to the legislative management; to provide for a report to the sixty-third legislative assembly; to provide for a legislative management study; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM - REPORT TO THE LEGISLATIVE MANAGEMENT - REPORT TO THE SIXTY-THIRD LEGISLATIVE ASSEMBLY. During the 2011-13 biennium, the department of human services may use up to $200,000 of funding from its legislative appropriation to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program.

1. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for individuals with intellectual disabilities which is licensed by the department of human services.

2. A qualified applicant shall establish the availability of $1 of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds must be funds of the applicant.

3. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than ten thousand.

4. As a condition of a grant award under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

5. The department of human services shall report to the legislative management before September 30, 2012, on the preliminary findings and recommendations of the pilot program. The department of human services shall provide a written report summarizing the status of the pilot program and any findings and recommendations to the legislative management before December 31, 2012.

6. The department of human services shall report to the appropriations committees of the sixty-third legislative assembly on the status of the pilot program and any findings and recommendations.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT STUDY. During the 2011-12 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 include a review of a sliding fee scale for payment of services and the value of services provided. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly.

SECTION 3. EXPIRATION DATE. Section 1 of this Act is effective through June 30, 2013, and after that date is ineffective."

Renumber accordingly

2011 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

Committee: Goverment + Veterans Affairs

Bill/Resolution No. 2268 as (re) engrossed

Date: 4-18-11

Roll Call Vote #: 1

Action Taken

- ☐ SENATE accede to House amendments
- ☐ SENATE accede to House amendments and further amend
- ☐ HOUSE recede from House amendments
- ☒ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ page(s) _____

☐ Unable to agree, recommends that the committee be discharged and a new committee be appointed

((Re) Engrossed) _____ was placed on the Seventh order of business on the calendar

Motion Made by: Wieland Seconded by: Olson

Senators				Yes	No	Representatives				Yes	No
Berry	X	X		X		Wieland	X	X		X	
Dever	X	X		X		Lauer	X	X		X	
Nelson	X	X		X			X	X		X	

Vote Count: Yes 6 No 0 Absent _____

Senate Carrier _____ House Carrier _____

LC Number _____ . _____ of amendment

LC Number _____ . _____ of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

REPORT OF CONFERENCE COMMITTEE

SB 2268, as engrossed: Your conference committee (Sens. Berry, Dever, Nelson and Reps. Wieland, Louser, Holman) recommends that the **HOUSE RECEDE** from the House amendments as printed on SJ pages 1216-1217, adopt amendments as follows, and place SB 2268 on the Seventh order:

That the House recede from its amendments as printed on pages 1216 and 1217 of the Senate Journal and pages 1382 and 1383 of the House Journal and that Engrossed Senate Bill No. 2268 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a regional autism spectrum disorder centers of early intervention and achievement pilot program; to provide for a report to the legislative management; to provide for a report to the sixty-third legislative assembly; to provide for a legislative management study; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM - REPORT TO THE LEGISLATIVE MANAGEMENT - REPORT TO THE SIXTY-THIRD LEGISLATIVE ASSEMBLY. During the 2011-13 biennium, the department of human services may use up to $200,000 of funding from its legislative appropriation to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program.

1. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for individuals with intellectual disabilities which is licensed by the department of human services.

2. A qualified applicant shall establish the availability of $1 of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds must be funds of the applicant.

3. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than ten thousand.

4. As a condition of a grant award under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

5. The department of human services shall report to the legislative management before September 30, 2012, on the preliminary findings and recommendations of the pilot program. The department of human services shall provide a written report summarizing the status of the pilot program and any findings and recommendations to the legislative management before December 31, 2012.

6. The department of human services shall report to the appropriations committees of the sixty-third legislative assembly on the status of the pilot program and any findings and recommendations.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT STUDY. During the 2011-12 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 include a review of a

sliding fee scale for payment of services and the value of services provided. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families affected by autism spectrum disorder, insurers, educators, treatment providers, early childhood service providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly.

SECTION 3. EXPIRATION DATE. Section 1 of this Act is effective through June 30, 2013, and after that date is ineffective."

Renumber accordingly

Engrossed SB 2268 was placed on the Seventh order of business on the calendar.

2011 TESTIMONY

SB 2268

2268 testimony #4

SENATE GOVERI FFAIRS COMMITTEE
ON

SENATE BILL NO. 2268

February 3, 2011

Chairman Dever, Committee members, my name is Cal Rolfson, I represent the Anne Carlsen Center for Children. I appear in support of SB 2268, with the amendments attached.

The Anne Carlsen Center is an ICF/MR facility licensed as such by the Department of Human Services. They care for some of the State's most medically fragile and behaviorally challenged children and young adults. They are like a step-down ICU unit and have facilities in Jamestown, Fargo, Grand Forks, and will soon have facilities in Bismarck and other regional cities providing day-support and community services care to those vulnerable clients we are called upon to serve.

The Anne Carlsen Center had a representative at the table for the Governor's Task Force on Autism. The Center is respected State-wide as providing care for those families that have children on the autism spectrum. The Center teaches and conducts leading workshops around the state on autism issues and is seen as a state leader in that area. That is why the Center supports this need.

I do not need to add to testimony that will discuss the devastating impact that families face with children on the autism spectrum. That impact is medical, social, financial and familial. Again, it goes without saying that the Governor's Task Force has identified the need and you, as policy makers for our State, are aware of that need. This Bill helps respond to the concerns identified by the Task Force.

The idea behind the amendments is three-fold. First, the Bill in its original form may have tough sledding and may have trouble passing with an insurance mandate at the center of the Bill. Second, the fiscal note calls for State general funding of $2.7 Million and total funding at $5.8 Million. Third, it only covers families that are insured under PERS, and therefore leaves out a majority of the State's population.

However, there is a vital need to still fulfill the urgings by the Governor's Task Force and begin with something to support families that suffer due to this issue. That is the function of the amendments. They cut the general fund fiscal note by over four times. The amendments provide a pilot project for regional centers that, if successful and able to properly fulfill this need, can be studied and expended in future Sessions. The concept in the amendments is to take the successes that have been documented in the Education Title of the Century Code (Title 15) and transplant that idea into a public/private partnership in this area.

With a 50/50 match, the non-profit entity has an investment into the success of the project. At the same time, the State and the tax payers that fund our government, have an investment as well and an equal need to follow up with success. It seems to be a wonderful team approach that has proven success through our State Department of Commerce and the Center's of Excellence projects through the state.

This amendment seems like a wonderful idea that helps meet devastating family needs, responds to the urgings of experts perhaps wiser than many of us in this room – certainly wiser than I am – and conservatively responds to the compassionate purposes of government to serve those that may need that support.

On behalf of the Anne Carlsen Center and CEO Eric Monson, I urge this Committee to amend the Bill with the suggested amendments and then give the Bill a "Do Pass as amended".

Thank you for the privilege of appearing before this Committee I am no expert in this area, but I will offer to respond to questions.

Cal Rolfson, for the Anne Carlsen Center
(Lobbyist #38)

Thank you for letting me speak on behalf of this bill today. I also want to thank Sen. Nelson and Senator Wardner for their continuing support of this bill. They know it is something that this state desperately needs and something the children of North Dakota deserve.

I want to talk to you today about some statistics that I found about North Dakota.

18.1% of the population of North Dakota are current smokers. This equates to approximately 90,000 people. That is almost one out of five. Centers for Disease Control and Prevention (CDC) In addition, approximately 330 people will die in North Dakota this year due to lung cancer. (American Cancer Association)

There are many horrible things that go along with smoking like emphysema, heart disease and lung cancer just to mention a few. It is a horrible habit that I encourage every adult to stop doing it they are currently using a tobacco product. Not only does it affect you but it affects the people in your life.

An autistic child has an effect on the people in their lives also. Accept instead of in five it's one 1 in 110.

Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Survey on Drug Use and Health conducted a survey in 2008 showing:

2,425 people were admitted into a treatment facility for substance abuse.

184 people were admitted for methamphetamine use.

I wanted to follow up on this statistic. I called and spoke with the New Freedom Center in Bismarck and told them I was a Methamphetamine Addict. I want to assure you that I am not but in any case it was for research purposes.

I asked them with my current North Dakota Blue Cross Blue Shield coverage, could be admitted to a long term treatment program. I wanted somewhere that I could stay for at least 90 days to ensure my addiction treatment was comprehensive because I wanted to show improvement or be "cured".

I asked them if my insurance plan would cover my stay. They told me yes and that they were a preferred provider. I told them that I wanted to stay for 90 days because I had tried shorter programs and they had not worked.

I asked them what it would cost out of my pocket and how much insurance would pay. They told me that they bill my insurance company at an astonishing $750.00 per day!!!!! That's $67,500.00 in 90 days! I was amazed that my insurance

company would cover it. I asked if my evaluation showed I needed to stay longer would that be possible? He said yes.

According to the Harvard School of Public Health, the total cost of caring for an autistic person over his or her lifetime can be as high as $3.5 million. This includes Direct and indirect costs.

Direct costs include direct medical costs, such as physician and outpatient services, prescription medication, and behavioral therapies and direct non-medical costs, such as special education.

Indirect costs equal the value of lost productivity resulting from a person having autism, for example, the difference in potential income between someone with autism and someone without. It also captures the value of lost productivity for an autistic person's parents. Examples include loss of income due to reduced work hours or not working altogether. Severely autistic children will never work, pay taxes, buy a home, a car or make a large donation back to their community.

You may be asking yourself why Mr. Gates is telling us this. I am telling you this because both of these things, smoking and addiction are choices people make but Autism is NOT!

People can choose to put. A two year old cannot choose to be autistic.

Even though an adult and knows all the consequences that go along with what will occur when they put a cigarette in their mouth; or put a bottle to their lips or a needle in their arm, their insurance company will help cover the cost of their treatment or care to get better.

This bill asks for a $25,000.00 per year maximum for Autism Treatment. According to the actuary study that was done prior to the previous meeting that is $3.08 per month. I spent almost twice that on my coffee this morning. It equates to less than a ½ percent increase in premiums.

I want you all to take a step back before voting on this bill and ask yourselves, do I really think that an autistic child deserves less treatment and coverage than a methamphetamine addict? Or a smoker dying of lung cancer who chose to smoke for 20 years?

SB 2268 February 3, 2011
Janna and Justin Robinson
701-265-3305
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Relevant Case Studies

Ganz(2007). *The Lifetime Distribution of the Incremental Societal Costs of Autism.* Archives of Pediatric Adolescent Medicine. 161(4):343-349 – "The study showed the lifetime per capita incremental societal cost of autism is $3.2 million"

Autism Speaks (2007) Arguments In Support of Private Insurance Coverage of Autism-Related Services. – "The report identified legislative mandates for autism benefits in ten states: Colorado, Delaware, Georgia, Iowa, Indiana, Kentucky, Maryland, New Jersey, New York, and Tennessee. The report assessed the incremental cost of state mandated benefits for autism in these ten states *as less than one percent."*

Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism-General Model and Single State Case. Jacobson, John W., Mulick, James A., & Green, Gina. (1998). Behavioral Interventions, 13, 201-226. – "Demonstrates that providing behavioral treatment to all children with autism for three years, delivered between the ages of 2 to 6 years, would save approximately $200,000 per child for ages 3-22 years and up to $1,000,000 per child for ages 3-55 years. The savings per child even takes into account that some children will not benefit at all from behavioral treatment and some will only make modest gains."

Behavioral treatment and normal educational and intellectual functioning in young autistic children. Lovaas, O. I. (1987).Journal of Consulting and Clinical Psychology, 55, 3-9. – "Original research in peer-reviewed journals indicating that 90% of children substantially improved when utilizing the Lovaas Model of Applied Behavior Analysis, compared to the control group. Close to half attained a normal IQ and tested within the normal range on adaptive and social skills."

Long-term outcome for children with autism who received early intensive behavioral treatment. McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). American Journal on Mental Retardation, 97 (4), 359-372. - "Follow-up research in early adolescence showed that children in the 1987 study maintained their skills and could succeed in life without costly special education and residential services."

Intensive Behavioral Treatment for Children with Autism: Four-Year Outcome and Predictors. Sallows, Glen O. & Graupner, Tamlynn D. (2005). American Journal on Mental Retardation, 110 (6), 417-438. –"Replication study of the Lovaas Model of Applied Behavior Analysis by an independent author. Dr. Sallows states, "We found that 48% of all children showed rapid learning, achieved average post treatment scores, and at age 7, were succeeding in regular education classrooms. These results are consistent with those reported by Lovaas and colleagues"

Early Intensive Behavioral Treatment: Replication of the UCLA Model in a Community Setting. Cohen, Howard, Amerine-Dickens, Mila, Smith, Tristram. (2006).Journal of Developmental & Behavioral Pediatrics, 27 (2), 145-155. "The most recent replication study of the Lovaas Model of Applied Behavior Analysis by an independent author. Children in behavioral treatment scored significantly higher in IQ and adaptive behavior scores than the comparison group. Further, 29% (6 of 21) children were fully included in regular education without assistance and another 52% (11 of 21) were included with support. This compares to only 5% (1 of 21) children in the control group who were placed in regular education."

SB 2268, February 3, 2011
Janna and Justin Robinson, Cavalier, ND
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Cost Effectiveness of Applied Behavior Analaysis

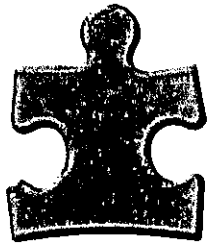
One of the main barriers to the implementation of Early Intensive Behavioral Interventions (EIBI) for Autism has been cost. Recently, researchers in Texas analyzed the overall cost of implementing an ABA program versus the overall cost of serving a child with Autism throughout their school years.

1 Babies Born in North Dakota - 3 year average	8,907	The costs associated with the implementation of an average of 3 years of Discrete Trial Training as an Early Intensive Behavioral Intervention (EIBI) in an effort to minimize the need for special education. Their results indicate that the state of Texas would save $208,500 per child across eighteen years of education with EIBI.
2 Occurrane of Autism Spectrum Disorder (ASD) in Children	1:100	
Projected number of children diagnosed with ASD in ND in 2011	89	
Projected number of children diagnosed with ASD at age 18	1335	
Approximate number of State Employees	40,000	
Employee benefit months/year # of employees x 12 months	480,000	
Monthly Cost to Each member in Montana	$0.83	
Monthly Cost to Each member in Minnesota	$1.00	
Monthly Cost to Each member in North Dakota - BCBS estimate	$4.00	
3 Chasson, Harris, and Neely, Cost Comparison savings/each child	$208,500 = $11,583.33 per year	

Cost/member in Montana/year	$398,400.00
Cost/member in Minnesota/year	$480,000.00
Cost/member in ND BCBS/year	$1,920,000.00
Cost/member in ND at $2.00/year	$960,000.00
89 ASD children cost savings/year	$1,030,916.37
Cost Savings at age 18	$15,463,745.55

Figures to the left are only for children ages 3-18. This does not show any cost beyond 18 years of age for assisted living, group homes or institutionalized individuals reliant on state funding.

1. North Dakota Division of Vital Records, 2007,2008, 2009
2. Untied States Center for Disease Control
3.Chasson, Harris, and Neely, Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism *Journal of Child and Family Studies* ,(2007) 16, 401-413)



AUTISM SPEAKS™
It's time to listen.

North Dakota SB 2268
Public Employees Retirement System
Medical Benefits Coverage for Autism Spectrum Disorders
(Senators Nelson and Wardner)

- Would require health plans to cover medically necessary autism treatments prescribed by a licensed physician or a licensed psychologist.
- Autism is a neurological disorder that affects 1:110 children. Access to medically necessary treatments endorsed by the American Academy of Pediatrics and the U.S. Surgeon General can dramatically affect the quality of life for people diagnosed with autism.
- Research indicates that 90% of children with autism improve when they receive evidence-based intensive interventions like applied behavior analysis (ABA). Almost half of these children enter public school indistinguishable from their peers. Children come to school ready to learn, needing fewer supports.
- The long term cost of caring for a person with autism is $3.2 million over their lifetime according to a 2007 study by the Harvard School of Public Health.
- Experience rates from states that have passed similar legislation indicate a minimum cost impact:
    - BCBS of Minnesota reported their coverage costs in 2007 at 83¢ per member per month. This included coverage of more than 2,100 individuals with ASD with no age or dollar caps.
    - Actual South Carolina cost for similar coverage in 2009 was $856,000, or approximately 20¢ per member per month. SC has a population of 4.5M, an enrollment in the state employee health plan of 350,000, and a dollar cap on ABA only of $50,000.
    - Actual South Carolina cost for similar coverage in 2009 was $2,042,392, or approximately 44¢ per member per month.
- Independent actuarial analysis prepared by Oliver Wyman (a leading, global actuarial firm) for multiple states considering similar legislation has indicated premium impact of less than 1%, generally falling within a range of $1.00-$2.50 per member per month.

- Similar legislation that was passed in Montana was projected to have a premium impact of a mere $1.00 per member per month. Fiscal impact per the state fiscal note was projected to be $766,465 in FY10 and $835,323 in FY11 for 9,600 dependent children.

- Provider growth has been experienced in the states that have passed similar legislation:

    - South Carolina and Louisiana have more than doubled the number of BCBA's providing treatment.

    - University Programs in Texas educating BCBA's have tripled in the past three years.

- Twenty-three states have passed similar legislation and many are currently considering it.

For additional information, please contact:

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Testimony on Senate Bill 2268
Senate Government and Veterans Affairs Committee
February 3, 2011

Chairman Dever and members of the Senate Government and Veterans Affairs Committee, for the record I am Rod St. Aubyn, representing Blue Cross Blue Shield of North Dakota.

SB 2268, an insurance mandate for Applied Behavior Analysis (ABA) for Autism Spectrum Disorder (ASD) as written, is one of the most costly health insurance mandates that I have seen during my years here. Our actuaries and medical management personnel put together 3 scenarios for estimates. The first estimate was very unlikely, but worst case scenario assuming all ASD children received the maximum recommended ABA therapy. That scenario showed an estimated cost of $81,712,922 per year. The second scenario assumed that 50% of the ASD children received the maximum recommended ABA therapy. That scenario showed an estimated cost of $40,856,461 per year. The third scenario assumed that 25% of the ASD children received the maximum recommended ABA therapy. That scenario showed an estimated cost of $20,428,230 per year. I will point out numerous troublesome components of this legislation and explain why this could have not only a significant financial impact for health insurers, but also for the State of North Dakota.

The first thing that I want to emphasize is the significant need that exists in our state in dealing with autism spectrum disorder. The legislature began the process during the 2009 Legislative Session by passing SB 2174, which established an ASD Task Force. This Task Force, which included Sen. Heckaman, met 8 times and:

- Reviewed legislation
- Reviewed other state's ASD information
- Reviewed State ASD plans
- Reviewed funding mechanisms

From their work they developed an initial state plan. From a survey that was completed through their work one of the most significant survey responses was **the need for more qualified individuals to deliver evidence-based services.** This is an important point as we discuss this bill.

It is important to note that private insurers such as BCBSND already provide reimbursement for ASD treatment services. In fact, in 2010 BCBSND provided reimbursement for ASD claims for institutional, professional and prescription services for NDPERS members in the amount of $479,750 and for other BCBSND members in the amount of $1,813,458.

What this bill basically does is mandates that all insurers including NDPERS must cover "applied behavior analysis" or ABA. However this bill skirts an existing law that requires that all health insurance mandates must apply toward NDPERS for 2 years first to ascertain the true cost/benefit. In addition there is a requirement that your committee must get an estimated cost/benefit analysis before taking action on this bill (NDCC 54-03-28). Another requirement is that any bill affecting NDPERS must first be considered by the Employee Benefits Programs Committee. This bill is significantly different than the one considered this summer and fall by that Committee.

You will note on page 1, lines 14 and 15, that an Autism spectrum provider means **ANY** person that provides treatment of any autism spectrum disorder. Insurers reimburse certified and licensed

providers. This bill requires **unlimited** reimbursement as ordered by a physician or psychologist to any autism spectrum disorder. This means that a doctor or psychologist could in fact have parents provide basic therapy and the insurer would be required to reimburse parents for those services, even if they were not certified or licensed.

On page 2, lines 6 – 14, include a separate definition for "medically necessary" that is not the same as in other parts of the Century Code. This expansive definition will certainly increase insurance costs. The proponents will quote estimated costs for these services which include ABA from other states that have adopted an ABA mandate. However, what is not told is none of those state laws are as expansive as this proposed bill.

I wanted to elaborate on the main purpose of this bill – mandating ABA coverage. This bill is based on a model act being pushed nationally by an autism advocacy group who are seeking medical reimbursement for a type of therapy that has not yet been proven to be medically effective called "applied behavior analysis" or also referred to as "Early Intensive Behavioral Intervention" (EIBI).

Autism is a complex, lifelong developmental disability that causes substantial impairments in social interaction and communication. Health care providers think of autism as a spectrum disorder, that is, a group of disorders with similar features. Historically, health plans have not reimbursed for services that are classified as investigational or experimental, until a treatment is scientifically proven to be effective for a specific type of medical condition. Reimbursing for experimental or investigational procedures only increases the cost of health insurance.

This bill will simply shift the costs for developmental disabilities **from** services typically required to be covered under special education **to** the health plans.

A study was contracted to evaluate all of the current studies completed on ABA therapy. I have a copy of that report that was printed in February, 2009. I did not want to burden you with the entire report, but I would be happy to make copies for those that want the entire report. I thought I would highlight some of the study's key statements below:

In recent years, public attention has focused on the number of children diagnosed with autism spectrum disorders or ASDs, which include autism, Asperberger's disorder, and "pervasive developmental disorder – not otherwise specified" or PPD-NOS.

Early Intensive Behavioral Intervention based on Applied Behavior Analysis or ABA (hereafter referred to as "EIBI" is among the most commonly cited and best-researched intervention for these children.

This Report systematically reviews the evidence on EIBI because it is important to know which interventions are most effective, especially for conditions like ASDs that have such a profound impact on peoples' lives. ***If we are not sure what works in treating any disorder and do not push forward with learning what does work, the people who are affected may potentially be deprived of benefit. (emphasis added)***

Three questions are addressed in this Special Report:

Question 1. How effective is EIBI in improving the functioning of children with autism spectrum disorders, and how does it compare to other early intervention approaches?

Question 2. Can patient characteristics be identified that predict better outcomes from EIBI?

Question 3. Does the effect of EIBI vary with the intensity of treatment?

Results – Sixteen studies were abstracted, including 2 randomized, controlled trials; 9 nonrandomized comparative studies; and 5 single-arm studies.

Overall, the quality and consistency of results of this body of evidence are weak. Consequently, no conclusions can be drawn from this literature on how well EIBI works. Weaknesses in research design and analysis, as well as inconsistent results across studies, undermine confidence in the reported results. It is important to distinguish between certainty about ineffectiveness and uncertainty about effectiveness. ***Based on the weakness of the available evidence, we are uncertain about the effectiveness of EIBI for ASDs.***

The results for each question are summarized below.

Question 1. How effective is EIBI in improving the functioning of children with autism spectrum disorders, and how does it compare to other early intervention approaches?

The evidence is insufficient to determine whether or not EIBI is more effective than alternative approaches for children with ASDs.

Question 2. Can patient characteristics be identified that predict better outcomes from EIBI?

Given the lack of a definitive answer to Question 1 on the relative effectiveness of EIBI, Question 2 on whether there are characteristics of children that predict a greater likelihood of success cannot be answered either.

Question 3. Does the effect of EIBI vary with the intensity of treatment?

The findings on whether more intense treatment leads to better outcomes were inconsistent.

Author's Comments and Conclusions

The variability of presentation and progression among children with autism spectrum disorders, as well as potential differences in delivery of behavioral interventions, make this topic challenging to study. Nevertheless, given the importance of caring for children with ASD, additional research is needed to identify those characteristics of treatment – content, technique, intensity, starting and ending age, etc. – that maximize its effectiveness.

The cost of continuing the current course of assuming that EIBI works may not be obvious. EIBI is costly financially for society and requires a large time commitment from children, their families, and their teachers or therapists. However, these programs may not appear to pose any harm for the children themselves. Nevertheless, the opportunity costs could be high, indeed, of providing suboptimal care to these children, simply because we as a society do not know what works best. The children may be treated with an intervention that is not as effective as the alternatives. And if we accept an intervention because it seems to work, without solid evidence, research on the alternatives or on how it can be improved is likely to be stifled.

While the state may elect to mandate specific benefits such as ABA it is important to note that state laws will only apply to "fully-insured" products. "Self-funded" products, such as those typically offered by larger employers, many cities, schools, and political subdivisions, are exempt from most state laws such as state health insurance mandates. Approximately 50% of BCBSND's business involves self-funded plans. As a result, if this bill were to pass, potentially half of our business would not need to comply and would likely not comply due to the significant increase in costs.

As I have shown, this mandate will potentially be very costly for health plans and for NDPERS. A final point that I wanted to bring to your attention is the potential cost that this mandate may have on the State. Under the new health care reform law called PPACA, beginning in 2014, any state mandate costs that are not part of the federally defined "essential benefits" must be paid by the state. The potential impact is unknown since essential benefits have not yet been defined. A federal entity is currently meeting trying to determine what those "essential benefits" will be that every health plan must provide in 2014.

Mr. Chairman and Committee members, for all the reasons identified, we strongly oppose SB 2268 and ask that you give it a Do Not Pass recommendation. I would be willing to answer any questions that the committee may have.

TESTIMONY

Senate Bill 2268—Senate Government and Veterans Affairs Committee

Senator Dever, Chairman

February 3, 2011

Chairman Dever, members of the Senate Government and Veterans Affairs Committee, I am a physician who specializes in Pediatric Psychiatry.

I have had the privilege of working with Autistic Spectrum Disorders (ASD) afflicted children and their families for over a decade now, in multiple settings (inpatient, outpatient, community, schools, etc). I am also the newly appointed Medical Director for Behavioral Health, Blue Cross Blue Shield of North Dakota.

I am also quite familiar with the findings of the North Dakota Autism Spectrum Disorder Task Force Initial State Plan-2010 and the published North Dakota *Guidelines: Identifying, Serving and Educating Children and Youth with Autism* .

I want to share some thoughts and concerns regarding Senate Bill 2268.

As written, the bill would define "Autism Services Provider" so broadly as to include "any person". In some states that definition would include a parent or parents who are then eligible for reimbursement. There need to be uniform standards, content and criteria included in the definition of Autism Services Provider that meet (1) the legal standards established through state, federal and case law, and (2) identify "best practice" and ethical standards of the behavior analysis profession and (3) develop eligibility standards to certify or recertify that professional.

The bill does not specify criteria that need to be met for evaluation and the fulfillment of 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. These individuals vary greatly with respect to their ability to benefit from any given treatment. Therefore, it is important that treatments be offered to these complex and vulnerable children and their families that have some scientific rather than anecdotal validity and are provided by qualified professionals. It must be remembered that "one size does not fit all" in these cases and that means that no one form of treatment has been shown to be superior to others although many have been shown to be useless or, as stated above, harmful.

Finally, the bill would seem to de-facto endorse one form of intervention, Applied Behavioral Analysis (ABA) above other forms of therapies, with the net result of moving the care of ASD afflicted individuals out of the setting where best practice guidelines and an emerging expert consensus believe they should stay: the school.

The first cornerstone of good medical practice remains, even in this age, Primum Non Nocerum: *First Do No Harm*. The second flows from the first: Proper Diagnosis Must Precede Treatment.

In the case of autism spectrum, a proper *Bio-Psycho- Social* diagnosis is highly nuanced and complicated, even for seasoned specialists . When I am asked by one of my pediatric colleagues (in General Pediatrics, Family Practice, Pediatric Neurology, and Child Psychology) to evaluate a child who may be showing signs of an ASD, I must (1)carefully rule out a myriad of medical illnesses that complicate or contribute to the primary complaint, including medical (laboratory, imaging studies, EEG's, others), neuropsychological (cognitive) , and psychological (autism related among others),(2) begin to address parental fears that interfere with their ability to even seek further services. We also evaluate issues intrinsic to the child that pose barriers to any treatment proposed and identify any siblings that might get neglected on account of their autistic brother or sister, and (3) assess whether the child is in a proper educational environment to optimize his/her adaptive behavior and the learning of verbal and non verbal communication.

As soon as an infant or toddler is suspected of having an ASD, he /she should be referred immediately to an early intervention program at a public school that is already mandated to serve children with special needs and developmental delays . There they can be further assessed while habilitative therapies, particularly Speech Therapy, can begin in earnest. Such immediate referral in the first three years of life is critical because ASD children often have language delays and the inability to "learn how to learn" by the condition's very nature. (Hence they need an integrated multidisciplinary approach that can be realistically provided only in a school setting given the intensity of the intervention required).

After age three, they should be immediately referred to their local school's special education department ; federal law mandates that all school districts have ready access to Autism Specialists, and other habilitative therapists such as Occupational, Physical and Speech and Language Therapists to continue and build upon the work already begun in the early intervention program.

A consensus among national experts is emerging regarding current best practices with ASD children, that validates the process that has been used within (adequately funded) school systems to integrate their multi-disciplinary approaches to teaching ASD children. School districts already have a federal mandate to offer education to autism affected children and usually teach them under an IEP (Individual Education Plan) when warranted. I have been helping draft such plans and have advocated for my autism affected patients and families in these matters for years.

Schools use the IEP to incorporate teaching and to engage the unique autistic child by both recording those methods (previously agreed to by the parents and the special education team) to be utilized for instruction, and the progress or lack thereof. The child's special education team in direct consultation with parents then continually determine, in ongoing fashion, what might be effective for both their learning and behavior (as they are intertwined). The IEP process, you can imagine, can become contentious at times, precisely because there are no "one size fits all" approved methods that address all the instructional needs a child with an ASD might have.

Most children with ASD unfortunately will remain within the spectrum as adults, and, regardless of their intellectual functioning, continue to experience problems with independent living, employment, social relationships and mental health. That is what we know from the current state of the science, and from the clinical experience of those of us clinicians who have followed these families along their Autism Journey over time.

The primary goals of treatment for these children (and eventually young adults) therefore, 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. We accomplish these by facilitating development and learning, promoting socialization, reducing maladaptive behaviors (usually by methods that are eclectic, incorporating some principles of operant learning theory, and other behavioral theories as appropriate), and educating and supporting the family and school system.

ABA therapy has been touted as the "most effective" method for autism intervention by a small chorus with loud voices. In essence, this is hope engaged upon by prominent professionals and groups, and lifted up as empirically validated science. To state, as some organizations have that purport "to speak" for the Autism community, that there is "one proven treatment" that can lead to "normal" or "near normal" functioning simply politicizes and polarizes the situation. All treatments for autistic children, including behavioral and educational interventions, should be based on sound theoretical constructs, rigorous methodologies, and empirical studies of efficacy. Anything less is simply an insult to these children and their families.

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. ABA in its purest form is intended to be the sole scientific study of an individual child, using the autistic child's unique pattern of behavior as the lone scientific control. Studying the child and his or her responses to different methods –in this way—results in a highly unique (and invasive) prescription of intervention—comprised of a variety of approaches that are tailored according to the child's responses.

Intervention intensity (ie.. 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.

The way that these "intervention ingredients" (for lack of a better term) interact with the hours of intervention per week, and characteristics of the children or their parents (ie the parents "buy in"), have not been addressed in the scientific literature. Understandably this would complicate any desire to mandate any one form of therapy out there for ASD, let alone ABA in particular.

Moreover, studies have not yet examined (or have done so woefully inadequately to date) the impact of changing from one therapeutic approach to another, (in real time) for children showing no/little progress; hence, there are no prescriptive formulas to help clinicians, parents and teachers select which types of treatment for ASD children who differ in their behavioral profiles after initial observation. Stated another way, since ASD is a complicated neurobiological disorder affecting multiple areas of their development, and since children with autism have different needs at different stages in their development, one size cannot by definition fit all.

Because these families are vulnerable, I often encourage them to seek additional information and the advice of trusted family, friends, and their primary care physician, whenever they encounter claims of treatments based on simplified scientific theories, therapies that are claimed to be effective for multiple, different, unrelated conditions or symptoms (which is often the case with ASD), claims that their child will respond dramatically and that some will be "cured to the point of being normal" (whatever "normal" means), the use of case reports or anecdote rather than carefully designed studies, etc.

Chairman Dever and Senators, this bill does not , I am afraid, resist the temptation to ask for simple answers to very complicated questions. It is essential to do all we can for autistic children. Autism Spectrum Disorders , similar to all neurodevelopmental disabilities, are not "curable" and chronic sophisticated management is required, and often best found at the local community level, in the school, and coordinated in the office of the child's physician and medical home.

But please make no mistake. Educational interventions (as early as possible after proper diagnosis or even sometimes before, when ASD is only suspected) and behavioral therapies (in the child's natural school environment) and habilitative therapies (PT, SL, OT) remain the cornerstone of treatment. Though schools may differ in philosophy and relative emphasis on particular strategies, they share common goals.

You see, Mr. Chairman and Senators of this Committee, no matter what economic, budgetary and educational models you must consider, it really comes down to family and community. There is a lot that funding and teaching can do. However, something I can affirm is the fact that 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. Such moments of grace then become something difficult but doable, something money can't buy.

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.

We are only at the beginning, and much additional research is needed to identify those characteristics of any behavioral treatment for kids on the autism spectrum (content, technique, how often, when to start and when to stop) to maximize the treatment's effectiveness. The overall quality of the studies in the field need to be vastly improved, including a greater emphasis on randomized controlled trials when possible, larger sample sizes (number of kids enrolled), uniform outcome measures (to see if what we're doing is making a difference), and finally, consistent treatments (by providers trained to the highest available standards) that don't vary so much across environments.

By pursuing one narrow form of treatment and enshrining it into law (if not directly then indirectly) the opportunity costs could be high, indeed, of providing suboptimal care to these children, just because we as "expert" clinicians of all stripes don't yet know what works best. If we accept an intervention because it "seems to work", without solid evidence, research on alternatives often gets stifled.

If we truly want to be most helpful and responsive to children with autism, their families, and the professionals (medical, therapeutic and teaching) who serve them, we need a broad based forum on the local level , where all the stakeholders in that locale can engage in thoughtful discussion , examine the real ground level issues of Autism in their local North Dakota communities, and not rely on un-rigorous and incomplete research findings, inappropriate economic models, and the all too often inflammatory words that may accompany such poignant discussions.

Chairman Dever, members of the committee, I submit these remarks with gratitude for your time and consideration.

Kenneth J. Fischer, MD

Board Certified Adult, Child and Adolescent Psychiatrist

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February 3, 2011

Mr. Jim W. Smith
Director
North Dakota Legislative Council
600 E Boulevard
Bismarck, ND 58505-0360

Re: Analysis of Senate Bill 2268

Dear Mr. Smith:

Thank you for requesting a cost-benefit analysis of the mandates included in Senate Bill 2268. In accordance with North Dakota Century Code (NDCC) 54-03-28, you asked that we provide information to help determine the following:

a. the extent to which the proposed mandate would increase or decrease the cost of the service;
b. the extent to which the proposed mandate would increase the appropriate use of the service;
c. the extent to which the proposed mandate would increase or decrease the administrative expenses of insurers and the premium and administrative expenses of insureds; and
d. the impact of the proposed mandate on the total cost of health care.

This letter is intended for use by North Dakota legislators and officials for the purpose of considering this proposed legislation. This letter should not be used for other purposes. To the extent that this letter is not subject to disclosure under public records laws, this document should not be distributed to third parties without Milliman's prior written consent. This document may only be released in its entirety. Milliman does not intend to benefit and assumes no duty or liability to other parties who may receive this work.

The results in this letter are technical in nature and are dependent upon specific assumptions and methods. No party should rely upon these results without a thorough understanding of medical insurance policies and how they are priced. Such an understanding may require consultation with qualified professionals.

In doing our work, we have relied on the data and information cited in this letter. This information includes the Senate Bill which is attached to this letter and provided with the email we received on January 20, 2010. If there are changes to the bill, the comments here may no longer be appropriate. This letter is subject to the Professional Services Contract between the State of North Dakota and Milliman executed on January 18, 2011.

This letter was prepared under certain time constraints, and, therefore, certain simplifying assumptions have been made.

Background

Senate Bill 2268 is for an Act to require health insurance coverage for autism spectrum disorders (ASDs) and to create a new section in NDCC 54-52.1 relating to North Dakota public employees retirement system medical benefits coverage for ASDs. Section 2 of the bill includes private insurance policies in the coverage mandate. As requested by the Legislative Council (in an email from Sheila Sandness dated January 20, 2010) we have performed a cost-benefit analysis related to this bill. Our analysis is focused on the impact that this proposed mandate will have on the total cost of health care.

ASDs are conditions that begin early in life and typically affect areas of a person's daily functioning. They are a group of developmental disabilities defined by uncharacteristic social interactions and communication (both verbal and nonverbal). The challenges associated with ASDs require collaboration between individuals, family members, professionals, and members of the community to meet the needs of people with ASDs.

The Centers for Disease Control and Prevention (CDC) currently estimates that an average of 1 in 110 children have an ASD[1]. More children than ever before are being classified as having an ASD. The CDC estimates that up to 730,000 people between the ages of 0 and 21 have an ASD and ASDs are more likely to occur in boys than in girls.[2]

There is no cure for autism, but it is a treatable condition. Most health professionals agree that early intervention treatment programs are important. Treatment options may include behavioral and educational interventions, complementary and alternative medicine, dietary changes, or medications to manage or relieve the symptoms of autism.

Senate Bill 2268 defines ASDs as "any of the pervasive development disorders as defined by the most recent edition of the diagnostic and statistical manual of mental disorders."

Pervasive development disorder (PDD) is characterized by a spectrum of behavioral problems commonly associated with autism. The *Diagnostic and Statistical Manual of Mental Disorder, 4th Edition (DSM-IV)*, which is published by the American Psychiatric Association, includes the following PDDs:

- Autistic Disorder;
- Rett's Disorder;
- Childhood Disintegrative Disorder;
- Asperger's Disorder; and
- Pervasive Development Disorder Not Otherwise Specified (Including Atypical Autism).

Under this bill all insurance companies, nonprofit health service corporations, or health maintenance organization in North Dakota "may not deliver, issue, execute, or renew any health insurance policy

[1] Rice, Catherine. "Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, Unites States, 2006." MMWR Surveillance Summary. 18 December 2009.

[2] 2011 Milliman *Health Cost Guidelines*

that does not provide coverage for the diagnosis of an autism spectrum disorder and the treatment of an autism spectrum disorder in an eligible individual."

Coverage for an eligible individual would be limited to "treatment that is prescribed by the eligible individual's treating physician in accordance with a treatment plan." Under this Senate Bill no benefit limitations would exist related to the diagnosis or treatment of an individual identified with an ASD. However, the coverage for an ASD may be subject to the deductible, copayment, and coinsurance to the extent that other medical services are covered by the health insurance policy are subject to those provisions.

Senate Bill 2268 specifies that treatment for an ASD includes the following medically necessary treatments prescribed, provided, or ordered by a physician or psychologist for an individual diagnosed with an ASD:

- habilitative or rehabilitative care;
- pharmacy care;
- psychiatric care;
- psychological care; or
- therapeutic care.

We understand from correspondence with individuals at the Legislative Council, that the coverage mandate should be interpreted to also apply to facility charges.

Some states require insurers to provide coverage for the treatment of autism. A total of 35 states and the District of Columbia have laws related to autism and insurance coverage. At least 23 states – Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Vermont and Wisconsin – specifically require insurers to provide coverage for the treatment of autism. Other states may require limited coverage for autism under mental health coverage or other laws, or just require coverage for the diagnosis process. Most of the legislation to provide coverage for autism has been enacted in the last three years. [3]

Results Summary

We estimate the 2011 claim cost impact of Senate Bill 2268 to range from $3.02 to $6.03 per member per month (PMPM). These estimates are before any reductions due to cost sharing and assuming there is no existing insurance coverage for ASDs. As described in more detail below, due to the large variation in treatment costs associated with treating autistic individuals and the estimated prevalence of autism, the actual cost impact may vary significantly from this estimate.

A major factor impacting the cost is the existence of insurance coverage. Treatment for autism can be expensive. Our estimate includes a significant amount of induced utilization due to the existence of insurance coverage.

[3] 2011 Milliman *Health Cost Guidelines*

These estimates were developed using assumptions for the number of individuals diagnosed with an ASD under current diagnosis criteria and assumptions for the average treatment costs at current cost levels for current treatment options. It is possible for these underlying assumptions to change over time. It is also possible that increased treatments due to a coverage mandate will result in decreasing future treatment costs.

Methodology and Assumptions

Two key assumptions were considered to develop the estimate stated above. The first was determining an estimate for the average cost associated with treating an individual with an ASD and the second was the prevalence of ASD. To develop these assumptions we researched numerous published ASD articles and reviewed internal Milliman research related to ASDs. As a result of our research our estimate for the average allowed cost associated with autism treatment ranged from $30,000 to $60,000 per individual per year. We are assuming this average represents the average across all individuals with ASD. The average cost per case represents the annual amount of expenditure at current cost levels for current treatment options. The range of treatment costs found in our research is discussed further below.

To develop the assumption for the prevalence of ASD we relied on two recent published articles. The first was a report published by the North Dakota Department of Public Instruction which indicated that approximately 539 students between the ages of 3 and 21 in the North Dakota special education administrative units have autism as their primary disability.[4] The second was statistics published by Easter Seals, Inc. which indicated that approximately 514 children between the ages of 3 and 21 who receive special education services in North Dakota have autism.[5] We used the average of these two estimates and assumed 527 children in North Dakota public schools have an ASD. Based on our research we found there to be approximately 102,233 students in North Dakota public schools.[6]

We also relied on North Dakota census information to develop our prevalence assumption.[7] The census information showed that there are approximately 551,758 individuals in North Dakota under the age of 65 and of that population approximately 144,246 (or 26.1%) are under the age of 18. Using this information, along with the assumption that children not in public schools and older than 3 years old will have a similar prevalence rate to those children in public schools, we estimated that approximately 610 children in North Dakota have an ASD.

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[4] Sanstead, Wayne. "Autism Spectrum Disorders in North Dakota Public Instruction." North Dakota Department of Public Instruction. 2 April 2009.

[5] "2010 State Autism Profiles NORTH DAKOTA." Easter Seals, Inc. http://www.easterseals.com/. 16 September 2010.

[6] North Dakota EducationBug. http://north-dakota.educationbug.org/public-schools/.

[7] U.S. Census Bureau Quick Facts for North Dakota. http://quickfacts.census.gov/qfd/states/38000.html.

In addition, we found in an internal claim data source that approximately 8.4% of the individuals identified with an ASD were adults; therefore, we grossed up the 610 children to account for adults with an ASD (666 total individuals).

This resulted in our estimate that approximately 1 in 237 children or 1 in 829 individuals under the age of 65 have an ASD in North Dakota. The prevalence estimate represents the current number of individuals that have been diagnosed using current diagnostic criteria.

The prevalence of autism was determined to be approximately 1.21 (= 666 / 551,758 * 1,000) per 1,000 individuals under the age of 65. Using this estimate and the assumption that autism treatment costs between $30,000 and $60,000 per individual per year, the additional cost due to autism treatment was estimated to be in the range of $3.02 to $6.03 (= 1.21 * $60,000 / 12,000 for the high estimate) PMPM. We did not include any provision for additional retention due to an autism mandate. As a percent of total cost we do not believe that covering autism would significantly increase the administrative costs. Also, this estimate is before any reductions due to cost sharing.

Note that results published by the CDC indicate the prevalence of autism to be approximately 1 in 110 children which is higher than the estimate used in this analysis. Using the CDC information, along with the other assumptions previously described, the PMPM cost impact of covering ASDs would range from $6.49 to $12.97 PMPM.

Senate Bill 2268 does not state that only children would be covered as a result of this legislation, but generally treatment is much more common in children who are maturing and developing, rather than in adults. Most adults with an ASD do require lifelong training, ongoing supervision, and reinforcement of skills. As previously mentioned we found that 8.4% of the individuals in an internal data source identified with an ASD were adults.

Discussion

Public Research –Treatment Costs

When researching ASD costs we found a wide range of estimates associated with treating autistic individuals. The ASD treatment estimates ranged from approximately $20,000 to upwards of $70,000 per year. ASD treatment costs can vary significantly depending on the method of treatment, cost of medications, and the severity of the diagnosis, among other things.

Below are several ASD treatment estimates we found:

- The Harvard School of Public Health estimated direct autism costs, on average, to be more than $29,000 per person per year.[8]
- A 2004 New York Times article stated that "parents say treatment costs often exceed $25,000 a year."[9]

[8] Ganz, Michael. "Autism Has High Costs to U.S. Society." Harvard School of Public Health. 25 April 2006.

- A 2008 article that appeared in the LA Times indicated that autism treatment costs are as much as $70,000 per year per child.[10]
- A November 2008 article from the Wisconsin Briefs from the Legislative Reference Bureau stated that treatment can cost anywhere from $30,000 to $70,000 per year.[11]
- A September 23, 2010 article from The Bismarck Star Tribune stated that extensive behavioral therapy can cost more than $70,000 for a year of treatment.[12]
- A September 22, 2010 article from The Dickinson Press stated that out-of-pocket costs for therapy can cost $60,000 per year.[13]

Medstat MarketScan Analysis

We performed an independent analysis using an internal claim data source to determine what percent of adults are diagnosed with an ASD.

Table 1 below shows the ICD-9 diagnostic codes we included in our analysis and the ICD-9 diagnostic codes we believe would be are covered under this Senate Bill. The ICD-9 diagnostic codes in Table 1 were identified using *The Diagnostic and Statistical Manual of Mental Disorder, 4th Edition (DSM-IV).*

[9] Freudenheim, Milt. "Battling Insurers Over Autism Treatment." *The New York Times.* 21 December 2004.

[10] Girion, Lisa. "In treating autism, the healthcare system isn't fully functional." *LA Times.* 6 July 2008.

[11] Eagan, Kinnic. "Autism Treatment." Wisconsin Briefs from the Legislative Reference Bureau. November 2008.

[12] Wetsel, Dale. "Advocates want ND insurance coverage for autism." *The Bismarck Tribune.* 23 September 2010.

[13] Finneman, Teri. "State considers autism parity." *The Dickinson Press.* 22 September 2010.

Table 1: ASD Diagnostic Codes Included

Diagnostic Code	Description
299.00	AUTISTIC DISORDER-CURRENT OR ACTIVE STATE
299.01	AUTISTIC DISORDER-RESIDUAL STATE
299.10	CHILDHOOD DISINTEGRATIVE DISORDER-CURRENT OR ACTIVE STATE
299.11	CHILDHOOD DISINTEGRATIVE DISORDER-RESIDUAL STATE
299.80	OTHER SPECIFIED PERVASIVE DEVELOPMENTAL DISORDERS-CURRENT OR ACTIVE STATE
299.81	OTHER SPECIFIED PERVASIVE DEVELOPMENTAL DISORDERS-RESIDUAL STATE
299.90	UNSPECIFIED PERVASIVE DEVELOPMENTAL DISORDERS-CURRENT OR ACTIVE STATE
299.91	UNSPECIFIED PERVASIVE DEVELOPMENTAL DISORDERS-RESIDUAL STATE

Using Milliman's 2008 Medstat MarketScan database we identified 28,880 individuals, 26,450 of whom were children, who had one or more claim identified with an ASD diagnostic code. The Medstat MarketScan data is a large database consisting of nationwide historical claim experience.

Cost Impact on Premium

As stated above we found that the cost impact on premium associated with treating an individual diagnosed with an ASD can vary significantly depending on a variety of factors.

One factor that can influence the cost impact on premium depends on whether or not the individual was diagnosed with an ASD as a primary or secondary condition; and whether their current insurance coverage would depend on a primary or secondary diagnosis. For example, an individual may have a primary diagnosis of bipolar and a secondary diagnosis of autism. Senate Bill 2268 does not specify whether or not coverage would extend to those individuals identified with a secondary diagnosis of ASD.

Prescription drugs also play a key role when estimating the cost impact on premium associated with expanding coverage to autistic individuals. While no drug has been developed to cure ASDs, many drugs are used to treat symptoms of ASDs. For example, prescription drugs may be used to treat autistic individuals with anxiety, depression, obsessive-compulsive disorder, seizures, inattention, or hyperactivity. The cost impact depends on the extent to which the current insurance carrier associates these drugs with ASDs and, therefore, excludes them from insurance coverage. The cost of ASD medications can vary significantly and be very expensive. Pharmacy care is included in the covered treatments under this Senate Bill.

Another factor to consider is the types of ASD treatments that would be covered under the mandate. The specific treatment options that would be covered as a result of this legislation are listed above. The types of treatment options that are included in the benefit mandate, and any associated treatment limits, have a significant impact on the projected costs. Common treatments include Applied Behavioral Analysis (ABA), floor time therapy, gluten free diet, casein free diet, speech therapy, occupational therapy, sensory integration therapy, relationship development intervention,

verbal behavioral intervention, and school-based training and education (TEAACH method). Some of these benefits may be covered under typical healthcare benefit plans, while others are likely excluded without the benefit mandate. Some estimate that ABA costs alone may amount to $50,000 or more per year, with the cost of a comprehensive evaluation of disease prevalence and the evaluation of disease prevalence ranging between $1,000 - $4,000, depending on the number of professionals involved in the assessment.[14]

Ultimately, the cost impact will vary from plan to plan, depending on how aggressively the health plan identifies claims and denies coverage in the absence of a mandate.

❖❖❖

This letter contains estimates of future experience, based on the assumptions described here. It is certain that actual experience will not conform exactly to the assumptions used in this analysis. If actual experience is different from the assumptions used in the calculations, the actual amounts will also deviate from the projected amounts.

Jim, I hope this letter is helpful to you as you consider these bills. If you have questions regarding this letter, or would like us to do additional analysis, please feel free to contact me at (952) 820-2474 or kent.roepke@milliman.com.

Sincerely,

Kenton J. Roepke, ASA, MAAA
Consulting Actuary

KJR/jad

Enclosure

[14] 2011 Milliman *Health Cost Guidelines*

Janna & Justin Robinson

Cavalier, ND

[redacted]one 701-265-3305

SB2268

We are Maddy's Voice. Our 2.5 year old daughter, Madalynn, was diagnosed with Autism Spectrum Disorder on July 15, 2010 and 25 months of age. On September 21, 2010, we began ABA treatment with a group of 7 volunteers. I would like to show you the cost effectiveness of ABA in the treatment of autism for children in the state of North Dakota, the science behind ABA, and the incredible journey we have taken with Madalynn through ABA.

Cost Effectiveness:

There are several studies that state the cost associated for a person with autism through their lifespan, such as, the 2006 Harvard Study, The Ganz Study, as well as Temple Grandin's own projections. All of these range from 3.2 to 5 million dollars.

The 2007 Autism Speaks Arguments in Support of Private Insurance Coverage of Autism-Related Services says that the report assessed the incremental cost of state mandated benefits for autism in ten states *as less than one percent of the medical benefits.*

If you look at the page in front of you, these figures are from a recent study in Texas. I used their savings figures and related it to North Dakota numbers to see if it was cost effective.

[redacted]nce behind ABA:

Applied Behavior Analysis is best known for the original Lovaas Study conducted in 1987 where a group of children with Autism were taught basic tasks in a systematic manner. Many independent studies have been done to repeat Lovaas' findings and many of them have found similar results and a few even had higher results. Many of these children from the original Lovaas study have been tracked down and were found to be leading regular lives. Holding jobs. Starting families. Contributing to society.

The Center for Autism and Related Disorders has stated in their recent November 2010 study that Recovery is possible from Autism with the use of ABA. They also state that ABA is not a cure and it will not recover every child, however, it will potentially teach them many valuable life skills to improve their lives.

The bottom line is that ABA doesn't hurt or make children regress. It helps them learn.

Journey:

Like we stated earlier, our daughter was diagnosed with Autism last July. She showed all the classic symptoms of Autism. She did not respond to her name, request anything, she would not even acknowledge our presence in a room with her. She did not play with her sisters. She had very specific stereotypical behavior. She would rock back and forth and moan. Flap her hands. Bang her head against the wall to sleep at night. She was totally engrossed in her own world. I knew we were losing her when one night at the dinner table as I called her name to get her attention and she continued to rock, [redacted]isters joined in and all 4 of us were waving our hands and shouting her name and nothing.

We started ABA in September and our first goals were simple. Sit Down in a chair, look at me, stand up, put your hands down, and come here. She fussed at first but quickly began to master these simple tasks and we continued adding motor imitation like clapping or waving to labeling objects to matching objects.

By the end of October, I knew it was working. At the end of a session, she reached up and grabbed my wife's hand, looked at her and said "hold hand" - Madalynn had never held her hand before this. Her sensory issues had prevented [redacted] from ever wanting her hand to be held. And she did it. On her own.

Maddy has quickly progressed through the program. Her results are unprecedented. Her psychologist is excited by how great Maddy is doing and we are now working on peer play. She has learned the entire alphabet, she can speak correctly in full sentences, knows her numbers, can properly play with all her toys and requests items. She can answer proper questions about objects. State her name. Tell you what her sister's names are and we are working on how old she is. She is truly amazing. All of this is because of ABA, our psychologist, and ALL of our wonderful VOLUNTEERS. We can't afford to pay any of them for all the hard work they do. It's working and they tell us the benefit is seeing her grow.

It's worked for us. We are very fortunate. We cannot expect other parents to do the same. To somehow find a group of willing volunteer stay at home mothers, a private preschool willing to let them try peer groups. To buy all the material themselves. To somehow pull out an ABA miracle. No. We can do better than this. BCBS can cover the costs of ABA. This allows ABA teachers to come to ND and make a living. It can be done on your own but Autism is hard enough.

Choice?

Maddy did not choose Autism. It chose her. Currently with the state employee benefit package, I could CHOOSE to severely destroy my body; I could smoke marijuana, do methamphetamine, or other drugs, I could even CHOOSE to beat my wife and even though these are chosen acts, there are treatments in place for them and they are covered under my benefits as a state employee, both behaviorally and medically. Autism is a bio-medical condition. My daughter did not choose it. This is a great state. And it is time to take care of our own. It's time to dictate to insurance companies and not let insurance companies dictate policies to us.

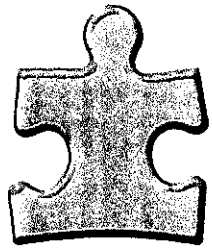
[redacted]Autism community is growing and we have an opportunity in the State of North Dakota to be a leader in the treatment of Autism. We have great resources available through the Anne Carlsen Center to bring ABA all throughout North Dakota. We could potentially increase our tax base by bring in families from other states from our leadership.

Autism can choose any child. I recommend an amendment to this bill that is a recommendation from the ND Autism Spectrum Disorder Task Force Initial State Plan of 2010. It recommended that all children to be screened for developmental delay within the first year of life. In the second year, all children will receive a screening by a qualified healthcare professional for ASD.

Conclusion:

In conclusion, you can see how spending more now will save us in the end. ABA is the most effective and most researched treatment for Autism. We have seen the results in our daughter and we cannot keep this to ourselves. We have been given a great opportunity and we want to share it with every other parent that will hear the words "autism" and their child's name. The word Autism is scary. So is Cancer. But when you know there is a potential treatment and it's covered by insurance, that makes a huge difference. I don't want any other parent to feel the way we did when we heard "autism" and "insurance won't cover the most effective treatment" – I don't want another parent to even have the OPTION of waiting until the child goes to school. Every child in North Dakota deserves a future, and children with autism, ABA gives them the best skills possible for a bright future.

[redacted]



AUTISM SPEAKS™
It's time to listen.

North Dakota SB 2268
Public Employees Retirement System
Medical Benefits Coverage for Autism Spectrum Disorders
(Senators Nelson and Wardner)

- Would require health plans to cover medically necessary autism treatments prescribed by a licensed physician or a licensed psychologist.

- Autism is a neurological disorder that affects 1:110 children. Access to medically necessary treatments endorsed by the American Academy of Pediatrics and the U.S. Surgeon General can dramatically affect the quality of life for people diagnosed with autism.

- Research indicates that 90% of children with autism improve when they receive evidence-based intensive interventions like applied behavior analysis (ABA). Almost half of these children enter public school indistinguishable from their peers. Children come to school ready to learn, needing fewer supports.

- The long term cost of caring for a person with autism is $3.2 million over their lifetime according to a 2007 study by the Harvard School of Public Health.

- Experience rates from states that have passed similar legislation indicate a minimum cost impact:

    - BCBS of Minnesota reported their coverage costs in 2007 at 83¢ per member per month. This included coverage of more than 2,100 individuals with ASD with no age or dollar caps.

    - Actual South Carolina cost for similar coverage in 2009 was $856,000, or approximately 20¢ per member per month. SC has a population of 4.5M, an enrollment in the state employee health plan of 350,000, and a dollar cap on ABA only of $50,000.

    - Actual South Carolina cost for similar coverage in 2009 was $2,042,392, or approximately 44¢ per member per month.

- Independent actuarial analysis prepared by Oliver Wyman (a leading, global actuarial firm) for multiple states considering similar legislation has indicated premium impact of less than 1%, generally falling within a range of $1.00-$2.50 per member per month.

- Similar legislation that was passed in Montana was projected to have a premium impact of a mere $1.00 per member per month. Fiscal impact per the state fiscal note was projected to be $766,465 in FY10 and $835,323 in FY11 for 9,600 dependent children.

- Provider growth has been experienced in the states that have passed similar legislation:

    - South Carolina and Louisiana have more than doubled the number of BCBA's providing treatment.

    - University Programs in Texas educating BCBA's have tripled in the past three years.

- Twenty-three states have passed similar legislation and many are currently considering it.

For additional information, please contact:

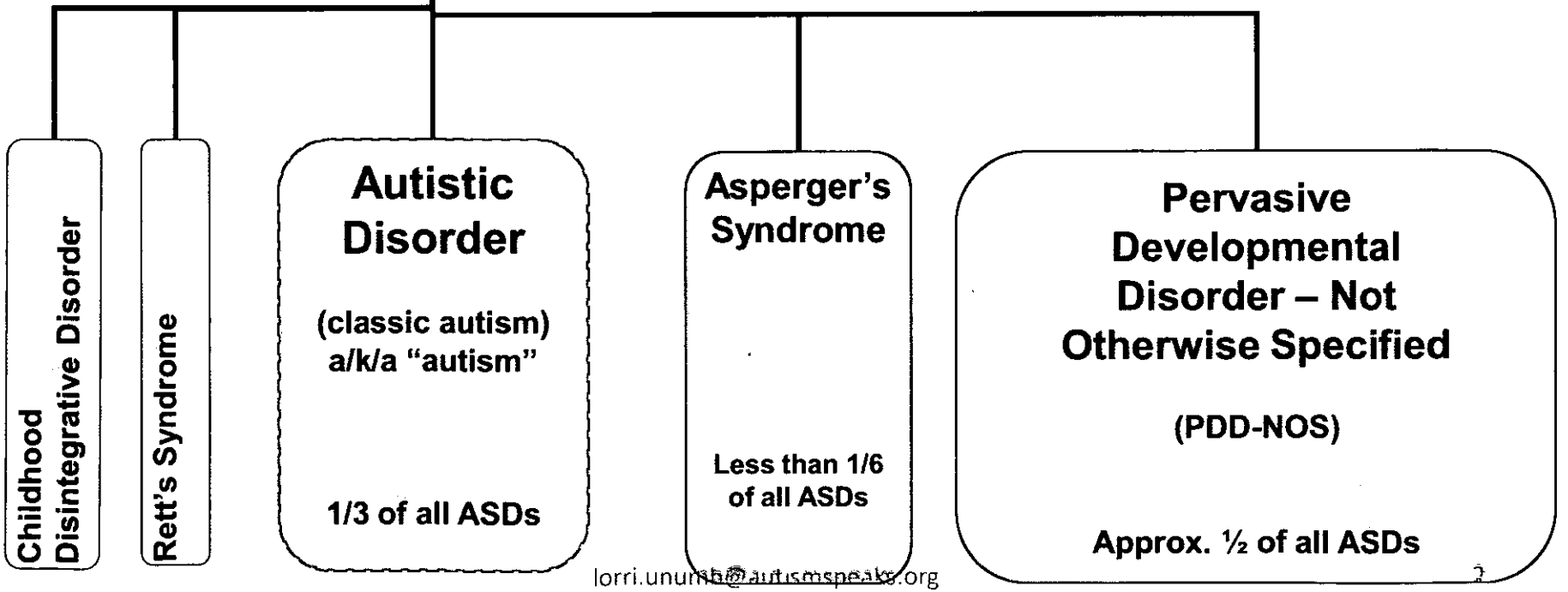
Judith Ursitti, CPA,
Regional Director State Advocacy Relations
Autism Speaks
judith.ursitti@autismspeaks.org
(508) 785-4074

Pervasive Developmental Disorders

(the umbrella category in the DSM-IV)

There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below.



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Autism Spectrum Disorder

- Curable? No
- Treatable? Yes

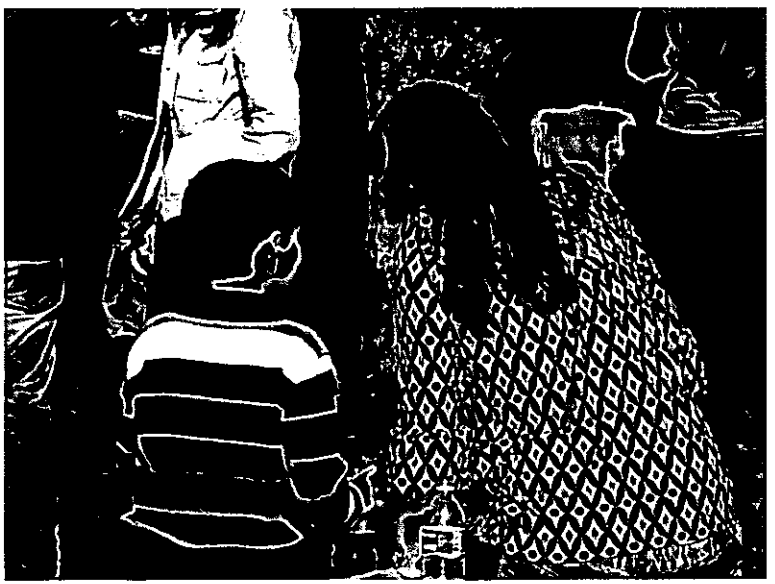
- Impaired Communication
- Impaired Social Interaction
- Repetitive or Stereotyped Patterns of Behavior
- Narrow Range of Interests

- Four times more common in boys than girls
- Average age of diagnosis: 5-1/2

Applied Behavior Analysis (ABA Therapy)

- One-on-one therapy based on principles of repetition, reinforcement, and extinction.

- When an environment supports a set of behaviors, they increase. When an environment does not support behaviors, they tend to extinguish and fade away.



ABA Therapy Is Not Experimental

- "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

  Report of the Surgeon General of the United States, 1999

- "ABA therapy is not experimental or investigational in nature."

  McHenry v. PacificSource Health Plans (D. Oregon, Jan. 5, 2010)

- "The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research . . . . 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."

  American Academy of Pediatrics

Applied Behavior Analysis: Sample Therapy Structure

- Consultant
  - Highly educated and trained
  - Board certified
  - Evaluates, designs, trains
  - 3-6 hours per month

- Mid-level supervisor (lead therapist)
  - Highly educated and trained
  - May be board certified
  - Updates programming; trains; oversees
  - 6 hours per week

- Line therapists
  - Trained & supervised by above
  - Provide 40 hours per week of direct therapy, usually in 3-hour shifts

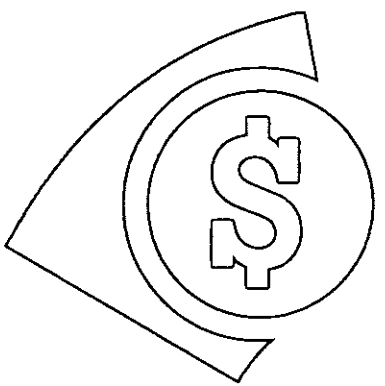
Applied Behavior Analysis: Cost of a Sample Therapy Program

- Consultant
  - 3-6 hours per month
  - $100-$150/hour
  - 6 hours x $150 = $900/month
  - $900 x 12 months = **$10,800**

- Mid-level supervisor (lead therapist)
  - 6 hours per week
  - $30-$60/hour
  - 6 hours x $60 = $360/week
  - $360/week x 52 weeks = **$18,720**

- Line therapists
  - 40 hours per week
  - $10 - $30/hour
  - 40 hours x $20 = $800/week
  - $800/week x 52 weeks = **$41,600**

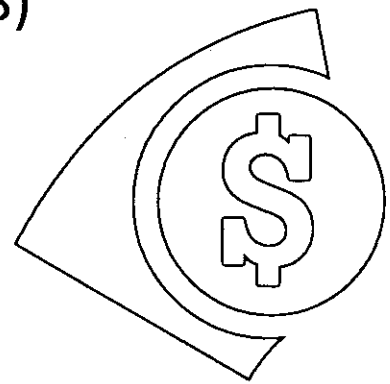
- $10,800 + $18,720 + $41,600 = **$71,120**



Societal Costs of Autism

- Harvard School of Public Health (Ganz, 2006)
- $3.2 million per person over lifetime
  - Includes direct and indirect costs, such as lost productivity

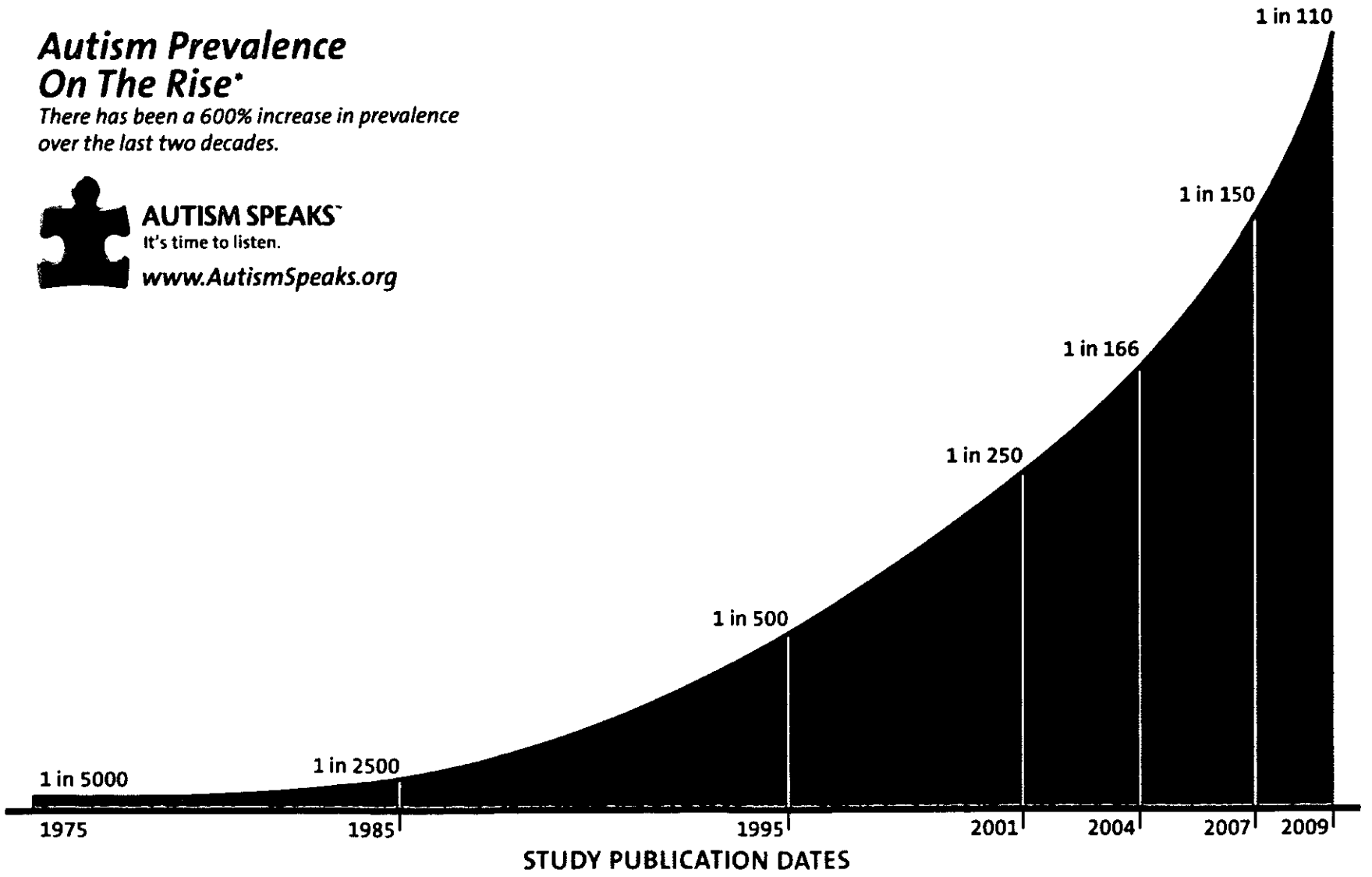
- Pennsylvania (Green, Jacobson & Mulick, 1998)
- Over $1 million per person



Autism Prevalence On The Rise*

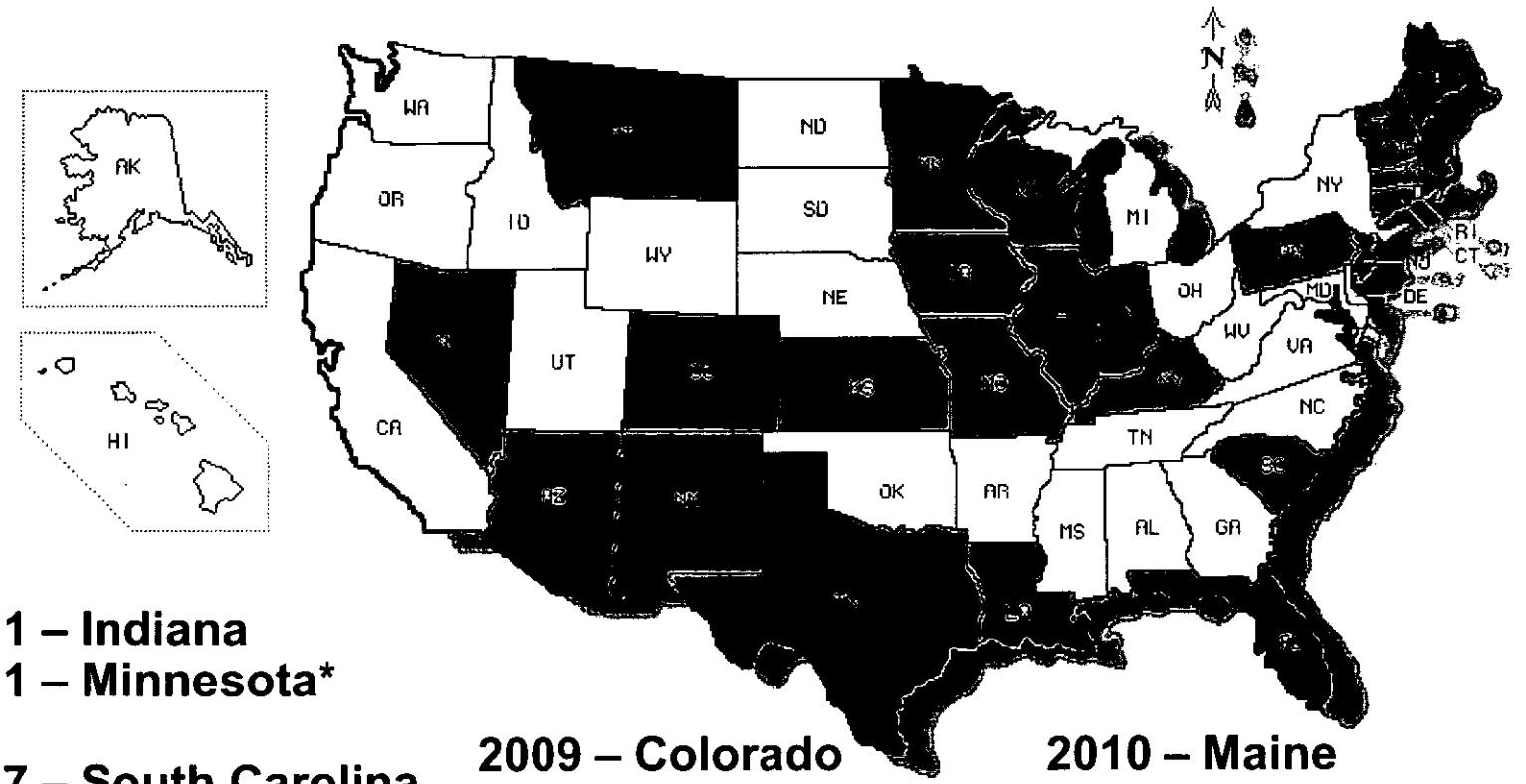
There has been a 600% increase in prevalence over the last two decades.

AUTISM SPEAKS™
It's time to listen.
www.AutismSpeaks.org



*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.

States with Autism Insurance Reform



2001 – Indiana
2001 – Minnesota*

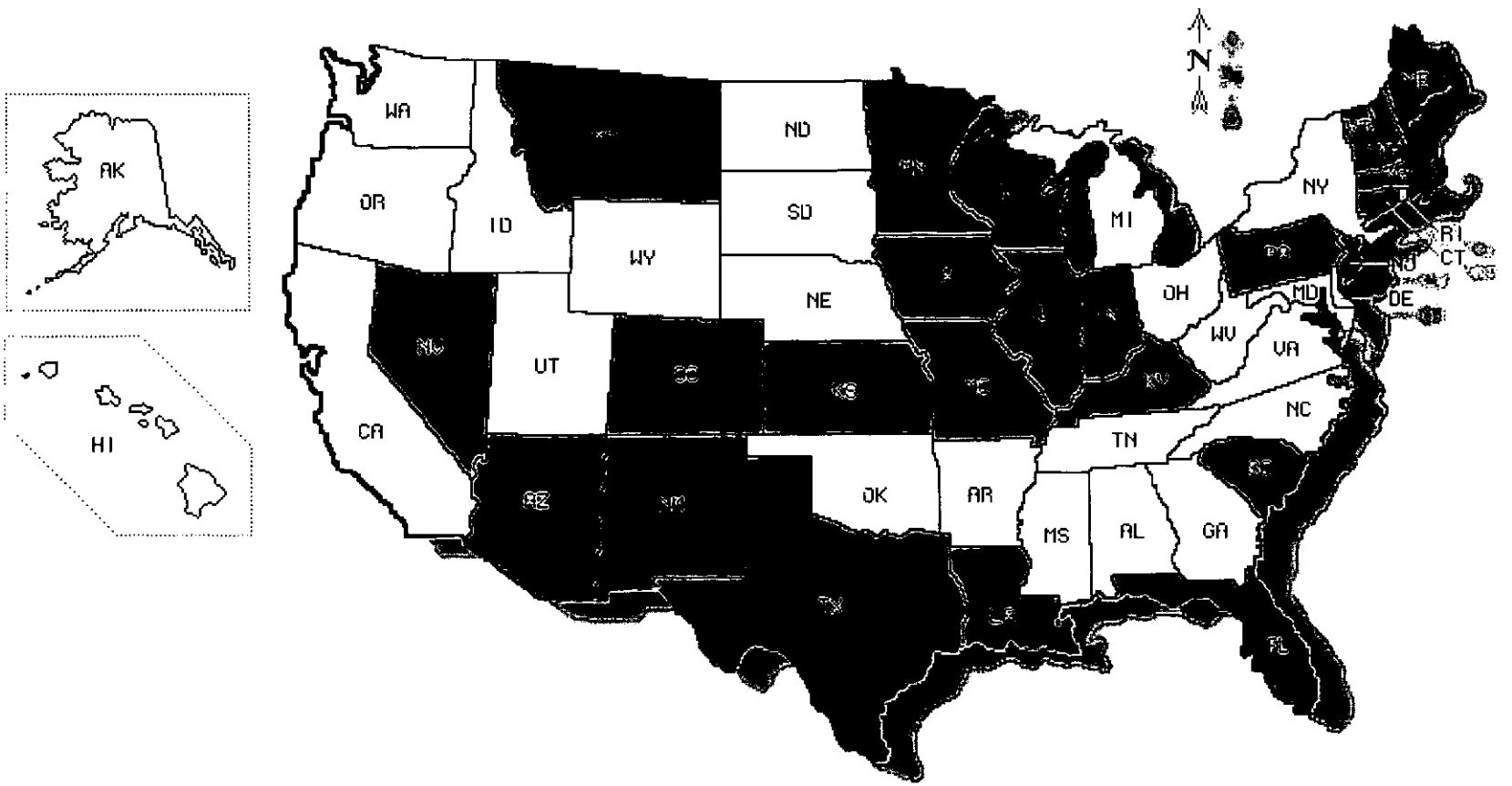
2007 – South Carolina
2007 – Texas

2008 – Arizona
2008 – Florida
2008 – Louisiana
2008 – Pennsylvania
2008 -- Illinois

2009 – Colorado
2009 – Nevada
2009 – Connecticut 19-11
2009 – Wisconsin
2009 – Montana
2009 – New Jersey
2009 – New Mexico

2010 – Maine
2010 – Kentucky
2010 -- Kansas
2010 -- Iowa
2010 -- Vermont
2010 – Missouri
2010 – New Hampshire
2010 -- Massachusetts

+ States with Bills Pending



1-19-11

lorri.unumb@autismspeaks.org

Comparison of Autism Benefits

State	Annual Cap	Age Cap
Indiana	None	None
Minnesota**	None	None
South Carolina	$50,000 - ABA	16
Texas	None	11
Pennsylvania	$36,000	21
Montana	$50,000/$20,000 at 10	18
Arizona	$50,000/$25,000 at 9	17
Missouri	$40,000	18
New Hampshire	$36,000/$27,000 at 13	21
Kansas*	$36,000/$27.000 at 7	19
Massachusetts	None	None
Vermont	None	6, or 1st grade***
Iowa*	$36,000	21

Behavioral Therapy Benefits for Autism

Major Group

Student Guide

South Carolina

APS HEALTHCARE
Healthy Together

State of South Carolina
State Health Plan Autism Spectrum Disorder Benefit

Effective with the 2009 Plan Year, the State Health Plan began covering Applied Behavior Analysis (ABA) for children diagnosed with an Autism Spectrum Disorder. The Employee Insurance Program (EIP) asked APS Healthcare to develop guidelines for administering the new benefit. Just like other services covered by APS for behavioral health diagnoses, the new Autism Spectrum Disorder (ASD) benefit services must be pre-authorized as medically necessary by APS, and providers must be contracted with APS as in-network providers. Only ABA providers fully certified by the Behavior Analyst Certification Board will be part of the network and be able to file claims for ABA services. All reimbursements for ABA services will be made by APS directly to ABA providers.

Board Certified Behavior Analysts (BCBA's) contracted with APS must provide direct supervision to their staff, including Board Certified Associate Behavior Analysts and/or any non-certified ABA therapists. Direct supervision includes the observation and oversight of the delivery of "hands on" ABA therapy by behavioral therapy staff.

The new benefit became effective on **January 1, 2009.** Following is a summary of requirements for coverage under the new benefit.

Eligibility Requirements:

1) Member must be covered by the State Health Plan and under sixteen (16) years of age with no pre-existing condition exclusions.

2) Member must be diagnosed by age eight (8) with Autistic Disorder, Asperger's Disorder or Pervasive Developmental Disorder Not Otherwise Specified by a Physician or Certified Registered Nurse Practitioner.

3) Diagnosis by age 8 must be confirmed by the following diagnosis-specific tests/screening tools:

   a. Autism Disorder using one of the following:
      1. Checklist for Autism in Toddlers (CHAT); or
      2. Modified Checklist for Autism in Toddlers (M-CHAT); or
      3. Screening Tool for Autism in Two-Year Olds (STAT), or
      4. Social Communication Questionnaire (SCQ) (recommended for children four-years of age or older)

   b. Asperger's Syndrome using one of the following (recommended for school-age children):
      1. Autism Spectrum Screening Questionnaire (ASSQ); or
      2. Childhood Asperger Syndrome Test (CAST), or
      3. Krug Asperger's Disorder Index (KADI)

   c. Pervasive Development Disorder, NOS using the following:
      1. One of the previously mentioned tools to rule out Autism and Asperger's; and
      2. DSM-IV Diagnostic Criteria/Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

4) Member must be evaluated by an appropriate diagnostician to rule out the following as a sole explanation for symptoms of Autism Spectrum Disorder:

   a. Neurological Disorder (must be by an MD).
   b. Lead Poisoning (must be by an MD).
   c. Primary Speech Disorder, and
   d. Primary Hearing Disorder.

5) Member must be evaluated by a licensed Psychologist within the last 6 months for current validation of the ASD Diagnosis, using:

   a. Autism Diagnostic Observation Schedule (ADOS); or
   b. Autism Diagnostic Interview (ADI-R), or
   c. Childhood Autism Rating Scale (CARS); or
   d. A DSM-IV Diagnostic Criteria which validates one of the three ASD diagnoses.

Excerpt from 2009 Report of Council of Affordable Health Insurance: "Health Insurance Mandates in the States"

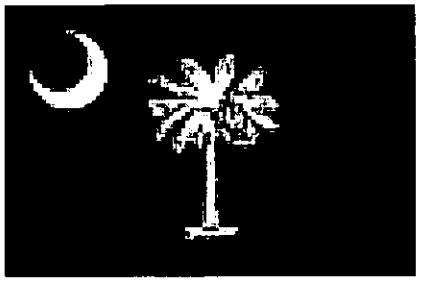
BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	23
Contraceptives	1-3%	29
In Vitro Fert.	3-5%	15
Prescriptions	5-10%	3

Actual Claims Data
BCBS of Minnesota (2007)

- Dates
  - In effect 2001
- Population
  - State has population of 5.3M
  - BCBS has 2100 members with ASD
- Terms
  - No dollar cap
  - No age cap

- Cost
  - Total claims = $12M
  - 315 of the 2100 members accounted for $9.7M of the $12M cost
- Premium impact PMPM (per member per month)
  - $0.83 commercial mrkt
  - $0.79 public programs
- Average annual cost for behavioral health treatment = $30,000

South Carolina State Employee Plan



APS HEALTHCARE
Healthy Together

- Dates
  - Statute passed in 2007
  - Applicable to state health plan as of 1-1-09
- Population
  - State has 4.5 M
  - State health plan has 350-390,000 members
- Terms
  - $50,000 cap on ABA
  - To age 16

- Projected Cost

  Original: $18.9 million

  Revised: $9 million
- Actual cost

  2009: $856,371

  PMPM - 20 cents

  2010: $2,042,392

  PMPM - 44 cents

  PEPM – 75 cents

(228,048 employees/subscribers;
79 kids accessing coverage)

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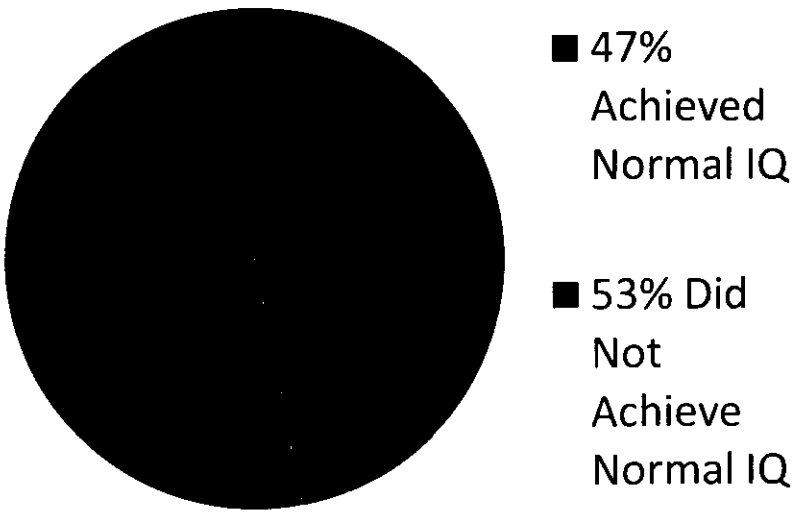
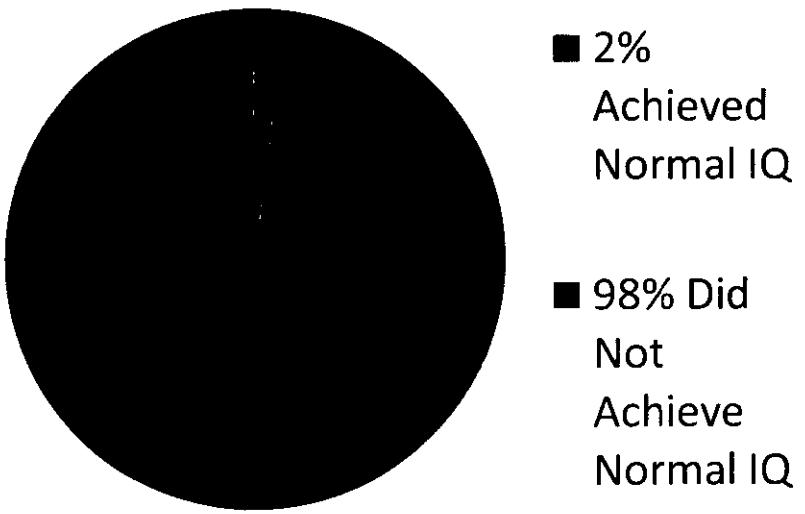
Savings to the State: Special Education

Outcome of 1987 UCLA Study on Efficacy of ABA

ABA Group

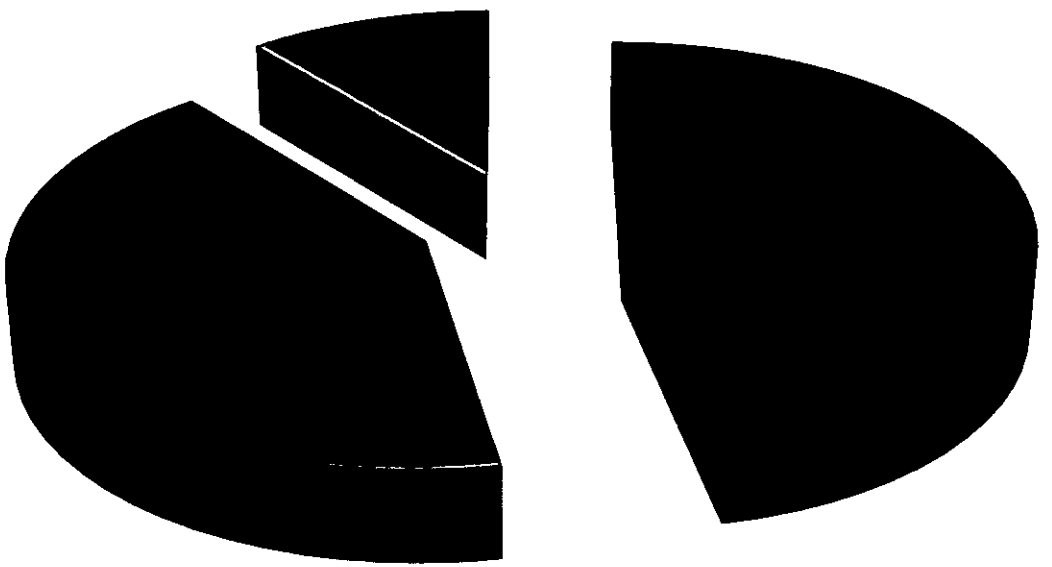


Other Intervention (Control) Group



Outcome of 1987 UCLA Study

Educational Placements for Group That Received ABA



- 47% = Mainstreamed with No Support
- 42% = Low-Intensity Special Education Placement (for language delay)
- 11% = High-Intensity Special Education Placement (for autism or intellectual disability)

Savings to the State: Special Education

"A study published in a national journal found that Pennsylvania could save an average of $187,000 to $203,000 on each child who received three years of EIBI relative to one who received special education services until age 22. The Pennsylvania study also suggested that cost savings would likely continue to accrue after children exit the school system. The study found that the state could save from $656,000 to $1.1 million per child if expenditures up to age 55 are included.

Another study published in a national journal found that Texas could save an average of $208,500 in education costs for each student who received three years of EIBI relative to a student who received 18 years of special education from ages four to 22. Applied to the estimated 10,000 children with ASDs in Texas, it was estimated that the state could save almost $2.1 billion by implementing intensive treatment programs."

Source: 2009 Report of the Joint Legislative Audit and Review Commission to the Governor and General Assembly of Virginia (JLARC Report)

"Educational in Nature"?

- False choice
- What does "educational in nature" mean?
- *Schools provide?*
- *Schools would provide if adequate resources?*
  - No obligation under IDEA or state law to <u>treat</u> medical condition
    - Schools are required to accommodate the disabling condition, not remedy it.
- Is speech therapy "educational in nature"? AAP report.
- *Provided by school personnel?*
- Academic goals
- ASD is diagnosed by a doctor, not a principal
- Argument du jour
  - Rejected in 23 states
  - Rejected in federal court

"Educational in Nature"?

- *McHenry v. PacificSource Health Plans (D. Oregon, Jan. 5, 2010)*
- "While ABA therapy may have beneficial effects on an autistic child's social and academic skills, its defining characteristic is application of techniques to modify behavior in every area of an autistic child's life. In this regard, a sports analogy is instructive. While participation in sports can benefit a student's academic and social skills, no one would classify sports as academic or social skills training.
- Similarly, the incidental benefits in these areas resulting from ABA therapy, while real, do not dictate that it be classified as either academic or social skills training.
- . . . While aimed at improving social and academic functioning, it does this by specifically addressing behavioral deficits possessed by autistic children that interfere with every area of their life, not by educating kids on social norms or teaching study skills or other tools specific to academic success."

Impact of Federal Health Care Reform

- 2009 Amendments by Rep. Doyle (Pa.) & Sen. Menendez (NJ)
- Changed "**Mental health and substance use disorder services**", one of ten required benefits, to "**Mental health and substance use disorder services, *including behavioral health treatments***".
- Applies to plans issued through Exchanges as well as small group and individual plans.
- N/A to existing coverage, large groups, self-funded
- Starts in 2014.
- http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=7522291

The Essential Benefits Package

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care

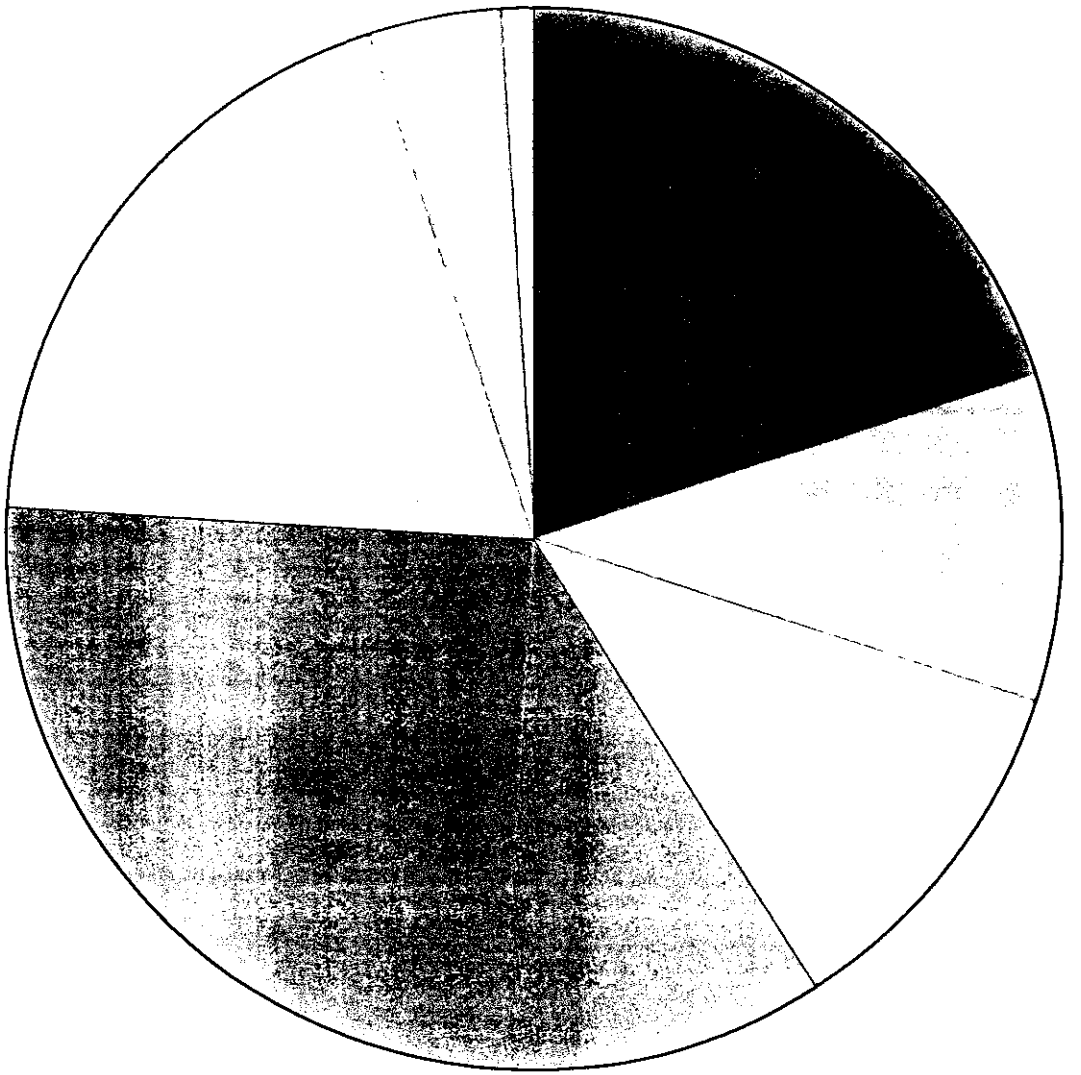
Impact of Federal Mental Health Parity Law

2008 Wellstone-Domenici Act prohibits:

- Quantitative Treatment Limitations
- Non-Quantitative Treatment Limitations

- Applies to large group fully-funded and self-funded policies.

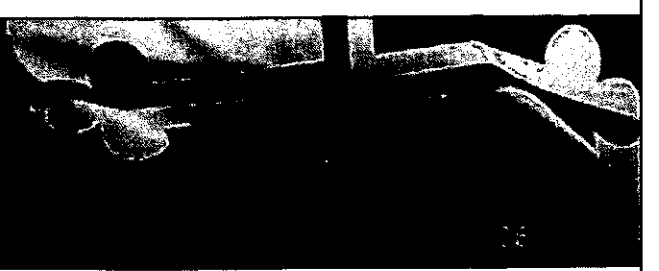
Sources of Health Care Coverage



- Medicaid - 20%
- Medicare - 10%
- Uninsured - 11%
- State Health Plan - 10%
- ERISA - ASO - 25%
- Federal Tricare - 2%
- Federal Civilian - 2%
- Other Insured - Large Group - 15%
- Other Insured - Small Group - 4%
- Other Insured - Individual - 1%

Self-Funded ERISA Plans

- "Overall, self-funded plans voluntarily cover 86% of the cost of mandated services."
- 2008 Report of Maryland Health Care Commission



Self-Funded ERISA Plans That Cover Autism Treatments

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- Time Warner
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Wells Fargo
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Symantec
- DTE Energy
- Cerner
- State Street Financial
- Children's Mercy
- EMC
- Yahoo
- Sisters of Mercy
- Princeton University
- And many more . . .

Provider Credentials

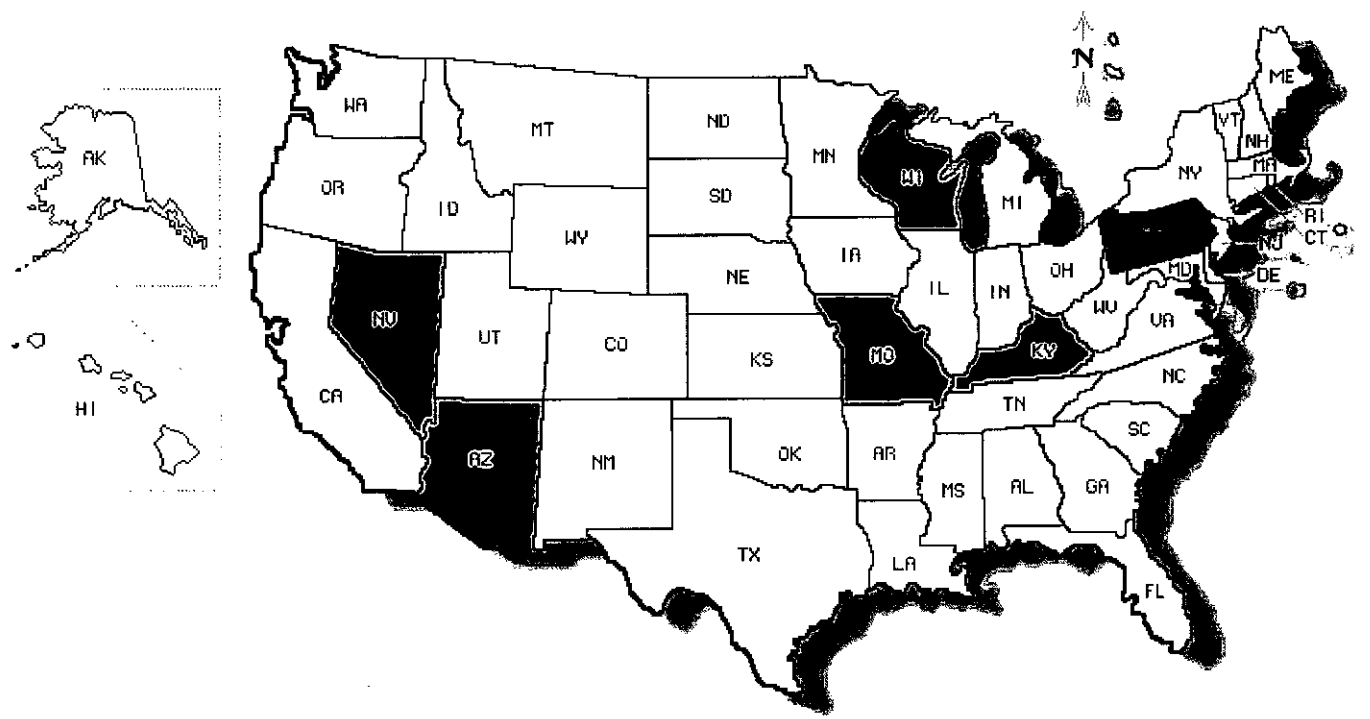
www.BACB.com

The Behavior Analyst Certification Board, Inc.® (BACB®) is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services.

The BACB's mission is to develop, promote, and implement a voluntary international certification program for behavior analyst practitioners. The BACB credentials Board Certified Behavior Analyst® BCBA®) and Board Certified Assistant Behavior Analyst® (BCaBA®).

Insurance States that License Behavior Analysts

- License
- "Behavior specialist
- License/no insurance



5-29-10

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Neurology

January 2007 Issue

Table 3 Summary of evidence: Incidence and prevalence of 12 neurologic disorders

Disorder	Class of evidence	Range of ages included (y)	Median estimates: Annual incidence Rate/ 100,000	Annual incidence No.*	Prevalence Rate/ 1,000	Prevalence No.*	Rate ratio, M/F†	Age(s), y, of peak incidence
Autism spectrum disorders	I, II	2–15	—	—	6.8	500,000‡	4.2	—
Cerebral palsy	I, II	3–13	—	—	2.4	207,000‡	1.3	—
Tourette syndrome	II	7–17	—	—	3.5§	301,000	4.8	—
Migraine	I, II	12–65	—	—	121	35,461,000	0.4	—
Epilepsy	I, II	All	48	142,000	7.1	2,098,000	1	<1, ≥80
Multiple sclerosis	I	All	4.2	12,000	0.9	266,000	0.5	30
Traumatic brain injury	I	All	101	298,000	—	—	2.1	20, ≥80
Spinal cord injury	I,II	All	4.5	13,000	—	—	4.2	20
ALS	I, II	All	1.6	5,000	0.04	12,000	1.3	≥60
Stroke	I, II	All	183	541,000	10	2,956,000	1.1	≥80
		≥65	1,093	401,000	—	—	—	
Alzheimer disease	I,II	≥65	1,275	468,000	67	2,459,000	0.5	≥80
Parkinson disease	I,II	≥65	160	59,000	9.5	349,000	1.8	≥70

* Estimated number of cases in United States in 2005, rounded to nearest 1,000.
† Ratio of rates among males to rates among females.
‡ Estimated number of cases among children younger than 21 years of age only.
§ Data inadequate for firm estimate.

Why Our Job Is Not Done

- May 27, 2010 at 5:08pm
- Subject: thanks
- I just wanted to say thank you for accomplishing what many people would not have attempted. I live in Charleston, SC. My husbands insurance is self funded so we are having to give up custody of our autistic 2 year old to my parents because their insurance is better. ABA is really helping and there is nothing I wouldn't do for him. You are inspirational to me and a hero. God bless you.

"[N]o disability claims more parental time and energy than autism."

New York Times, 12/20/04

Autism Spectrum Disorder Task Force 2010

Initial State Plan

NORTH DAKOTA
AUTISM SPECTRUM DISORDER TASK FORCE
INITIAL STATE PLAN-2010

I. EXECUTIVE SUMMARY

Senate Bill 2174 established the autism spectrum disorder (ASD) task force during the 2009, 61st Legislative Assembly. During the first year of its existence, the task force met eight (8) times; reviewed legislation, other state's ASD information, plans, and funding mechanisms; formed five workgroups focused on comprehensive analysis, evidence-based services, training and education, infrastructure, and funding structures; developed, disseminated, and summarized a statewide ASD Needs Assessment Survey; and wrote an initial state plan. A resource book developed by the Department of Health accompanies this report and provides a baseline of available services in North Dakota.

The State Needs Assessment Survey indicates that current ASD services are inadequate, information is scarce, and training is needed for parents and professionals. Families are distressed and children are losing once-in-a-lifetime opportunities. Professionals recognize this problem and want progress. Both groups understand the situation is critical.

North Dakota does not have a funding mechanism that is accessible and seamless. Data collected in the State Needs Assessment Survey support the notion that funding is a serious issue at every level. Sixteen percent of the written responses to an open-ended State Needs Assessment Survey question indicated funding problems. Furthermore, survey responses indicate that North Dakota needs more qualified individuals to deliver evidence-based services. Second, as ASD services increase, people need to know how to access those services.

II. ABOUT NORTH DAKOTA's ASD EFFORTS

The work of this group was preceded by the work of a Minot State University-led work group formed in 2008. This workgroup sent a team to the Act Early Summit in 2009 and developed a state logic model plan. This plan focused on the dissemination of 'Learn the Signs' materials, coordinating training, and assisted in applying for technical assistance from the National Professional Development Center on ASD. The group gathered North Dakota information on individuals with ASD served in the Developmental Disabilities, Mental Health, and Public Education systems. A survey was sent out by Family Voices, an advocacy group, to assist in group direction. The group provided recommendations to the Governor's office to consider potential members to this Governor- appointed ASD Task Force.

Their work and the ongoing efforts of parents in the state serve as an important part of the progress made to date.

III. ABOUT ASD

Autism Spectrum Disorders (ASD) are developmental disorders that cause significant impairments in the areas of socialization, learning, communication, behavior, and play skills. These deficits can lead to serious behaviors and interfere with daily living. Characteristics do not usually manifest until between one and three years of age. The spectrum includes Autism, Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Rett's Syndrome, and Childhood Disintegrative Disorder. Symptoms and levels of impairments vary widely. It is important to note that, "if you have seen one child with ASD, you have seen one child with ASD." (Temple Grandin)

IV. FACTS AND PRINCIPLES GUIDING THIS INITIAL ASD PLAN

Facts and guiding principles:

The North Dakota State Plan for Individuals with Autism Spectrum Disorders is founded on the following facts and guiding principles:

- ASD are spectrum disorders with tremendous variability within the population.
- ASD occur in all geographic, ethnic, racial and socioeconomic groups.
- Every child in North Dakota with an ASD deserves an accurate and timely diagnosis.
- North Dakota children with an ASD diagnosis deserve appropriate, timely treatment and appropriate education in the least restrictive environment according to their individual needs.
- People with ASD benefit from an individualized approach based on their unique needs. This can range from minimal or no formal support to intensive coordinated personal care and behavioral supports.
- Families and caregivers of people with an ASD deserve and benefit from quality information and supportive services.
- Health, transportation, education, and law enforcement personnel provide services more effectively when appropriately educated about ASD.
- Adults with ASD benefit from employment, inclusive community living options and supports of their choosing.

V. EXISTING RESOURCES IN NORTH DAKOTA

The ASD Needs Assessment Survey was developed to gain more information about available ASD resources and gather feedback on suggested ASD services direction.

It is important to note that this survey was completed as a snap shot in time event, without a rigorous sampling design. While this may limit the generalizability of the results, it does provide a reasonable view of ND's current environment and support for individuals with ASD from the view of the respondents.

The survey produced 187 useable responses with 29.9% from parents/family members, 15.5% from teachers/educators, 8% from administrators, 6.4% from private providers, and 20.3% from public providers (duplication possible).

The majority of responses came from the Grand Forks, Fargo, and Bismarck regions (73.8%).

The replies to several questions provided rich access to the responder's opinions, experiences, and suggestions.

The top responses to the open-ended questions are listed below.

Question31: **"What would you like us to know about services in your area?"**

1. Services are lacking
2. Information is lacking
3. Training is needed for professionals

Question 46: **"What research would be most helpful?"**

1. Comprehensive therapy options
2. No research – we need services
3. Help with managing behaviors

Question 49: **"Suggestions and recommendations"**

1. Training for educators
2. Resource list
3. School mistrust issues

Question 50: **"What would you like included in our state plan for addressing autism?"**

1. Increase funding in education for these needs
2. Train all teachers – not just special education teachers

3. Early identification and earlier intervention

VI. RECOMMENDATIONS

A. EARLY IDENTIFICATION & SCREENING

Vision: All children in North Dakota will receive screening for a developmental delay within the first year of life by a qualified healthcare professional. In the second year of life, all North Dakota children will receive a screening by a qualified healthcare professional for ASD as recommended by the Centers for Disease Control and Prevention (CDC) and the American Academy of Pediatrics.

All North Dakota children with a positive ASD screen will be referred by the healthcare professional for evidence-based early intervention. Early intervention should focus on the child's needs and should begin even before a child has a definitive diagnosis. For those children who are identified with possible ASD, a diagnostic consultation by a trained professional will be available within two months, and a thorough diagnostic assessment within six months.

Current Barriers:

- Lack of awareness of the importance for early identification and screening.
- Lack of specific training for healthcare professionals to identify potential autism spectrum disorders (ASDs) in children.
- Long wait times for diagnostic consultations and thorough diagnostic assessments by properly certified professionals for children with a suspected ASD.
- Lack of standardized training for screening methods.
- Lack of standardized screening instruments for certain age groups.
- Lack of referral network.
- Inconsistent referral options across the state.
- The rural nature of North Dakota presents challenges for referral options and access.
- Lack of accurate and localized information for parents.

Recommendations:

- Promote awareness of CDC screening tools and resources.
- Training in and the subsequent use of autism screening tools for healthcare professionals, including Indian Health Services, should be made available to allow all children to be screened for an ASD in the second year of life.
- Awareness materials and early identification and screening information on the characteristics of ASDs should be made available to ensure

timely referrals for young children even before a definitive diagnosis. For those children who are identified with possible ASD, a diagnostic consultation and appropriate evaluation should occur within state and federal timelines by trained professionals.
- Ensure children with a suspected ASD wait no longer than two months for a diagnostic consultation by a trained professional and receive a thorough diagnostic assessment within six months.
- Increase the use of telemedicine in diagnostic assessments of children in rural areas of North Dakota.

B. APPROPRIATE AND EFFECTIVE PRACTICES

Vision: Evidence-based intervention services will be readily and consistently available for all North Dakotans diagnosed with an ASD regardless of age, culture, socio-economic level, or geographic location. The key to designing an effective program/treatment lies in assessing the person's present level of performance and developing appropriate goals and outcomes with family and individual input and participation. Much more important than the name of the program/treatment utilized is how the environment and program strategies allow implementation of the person's goals. Thus, effective services will and should vary considerably across individual people depending on age, cognitive and language levels, behavioral needs, educational/vocational needs, and family priorities.

Current Barriers:

- Current lack of understanding and agreement about appropriate and effective practices (including program structure and intensity) leads to a lack of access to services.
- Lack of communication among service systems leads to ineffective and inappropriate service decisions.
- No easy or reliable route(s) for identification of evidence-based interventions and lack of consensus as to which interventions are evidence-based.
- Lack of funding for evidence-based interventions.
- Limited service options for individuals who do not qualify for developmental disabilities Medicaid waivers or the current Autism Spectrum Disorder waiver.
- Too few qualified personnel (*e.g.* behavior analysts, direct service providers) to implement evidence-based interventions.
- Lack of training for existing personnel (*e.g. educators*, para-professionals, childcare providers, and allied health providers) and families to implement evidence-based interventions.

Recommendations:

- Provide a comprehensive and uninterrupted system of services to individuals across the lifespan.
- Adopt standards for ASD practices in North Dakota that identify appropriate and effective practices for individuals with an ASD.
- Maximize funding available to local communities for the provision of intensive supports to individuals with ASD.
- Ensure training programs for service providers and families are developed by professionals knowledgeable in the latest evidence-based interventions and delivery techniques.
- Ensure that trained professionals are available to provide appropriate and effective services to all North Dakotans with an ASD.
- ASD waiver expansion for coverage across the lifespan.

C. QUALITY PROVIDERS

Vision: Qualified personnel sufficient to meet the need of North Dakotans with ASD will be available throughout the state.

Current Barriers:

- Too few qualified personnel (*e.g.* behavior analysts) to implement evidence-based interventions.
- Lack of training for existing personnel (*e.g.* teachers, para-professionals, allied health providers) to implement evidence-based interventions.
- Lack of incentive (outside school systems or DD providers) for individuals to choose behavioral intervention-type for professions/certifications due to limited reimbursement and absence of recognized certification in North Dakota.
- Lack of funding for attracting, training and retaining qualified personnel.
- Lack of agreement on the level of qualifications required in order for personnel working with individuals with ASD to be identified as "highly trained" (*e.g.* "Autism Specialists" within the school districts & DD providers).

Recommendations:

- Provide financial incentives for students pursuing an advanced degree/certificate with an emphasis in ASD.
- Provide incentives for current and future professionals to further their knowledge and expertise in ASD (*e.g.* scholarships, pay commensurate with training) and to provide services to individuals with ASD.
- Ensure adequate continuing education opportunities and requirements are in place to guarantee that providers maintain current knowledge in ASD.
- Work with Children and Family Services – Childcare licensing administrator – to increase childcare options in North Dakota for children and youth with ASD.
- Develop a process to recognize expertise in evidence-based interventions and supports for children and adults with ASD.

D. FUNDING ISSUES

Vision: Funding shall be available for early identification and definitive diagnosis of ASDs in North Dakota. For every North Dakotan with an ASD diagnosis, adequate funding shall provide access to appropriate early evidence-based intervention and ongoing support. Families, public schools, state and federal programs, and private insurance companies will play a responsible, proactive role in assuring the accomplishment of this goal.

Current Barriers:

- Limited access to intensive services (i.e. 25+ hours of intervention per week is often recommended as a minimum across environments) due to insufficient funding.
- Current available funding for the ASD Waiver limits services to 30 children, age's birth to five.
- Inconsistent health insurance coverage for both the diagnosis and treatment of individuals with ASDs.
- Limited availability of state, federal, and local funds to support the high cost of the intensive needs of individuals with ASD.
- Absence of specific funding mechanisms across systems to identify and provide high cost intensive support services to individuals with ASD.

Recommendations:

- Create specific funding mechanisms across service systems to support providers of high-cost intensive services to individuals with ASD.
- Expand the number and age range of individuals and scope of services in Autism Spectrum Disorder Waivers in Fiscal Year 2011.
- Expand healthcare coverage for individuals with ASD.

E. INFORMATION ACCESS

Vision: All North Dakotans will have ready access to a centralized, comprehensive, dynamic source of information regarding ASDs, including appropriate and effective practices, and the availability of state and local resources including funding options.

Current Barriers:

- Geographic and socioeconomic considerations limit statewide access to internet technology.
- Limitations in existing infrastructure and the expense of regular updates do not support the use of a centralized information outlet as the sole means of information dissemination.
- Lack of public awareness of 211 information line.
- Frequent scientific advances and changes in availability of service providers limit the value of printed media.
- Information is often not written in 'family-friendly' language.
- Information is inconsistent, fragmented, ever-changing, confusing and unverifiable. Often people do not know how to access information.
- Information is not available in alternate languages.
- Limited information exchange among providers.

Recommendations:

- Partner with North Dakota Center for Persons with Disabilities (NDCPD) to develop and maintain a comprehensive ASD website which serves as the first stop for ASD information.
- Raise awareness and identify importance of maintaining of 211 information line.
- Identify and explore internet access options for individuals with ASD.
- Provide incentives for family support provider agencies to assist families in locating and understanding service and support options.
- Provide culturally diverse and accessible resources.
- Pursue a routine ASD state conference representing support networks, state agencies, private providers, healthcare providers, family support; all stakeholders in ASD represented to present comprehensive information on the state of ASD in North Dakota.

F. FAMILY SUPPORT

Vision: All North Dakotan families affected by ASD will have access to supportive services. These services will enable them to effectively care for and nurture each other while maintaining their family continuity. Each family member's needs will be acknowledged and addressed. People will better understand ASD so that families thrive and are accepted by their communities. Individuals with ASD will have a bright future.

Current Barriers:

- Insufficient information on ASD and common misperceptions exist about ASD.
- Lack of recognition of the impact of an individual's ASD on siblings.
- Lack of awareness of the impact of ASD on the family structure and the marital relationship.
- DD services are not available to individuals with ASD unless they have an intellectual disability.
- Respite care is minimally available and insufficient to meet needs.
- Extracurricular/recreational activities and general socialization options are limited and/or inappropriate for individuals with ASD.
- Support groups are limited or nonexistent in the rural areas.
- Safety equipment/environmental modifications (e.g. car seats, wandering) are unavailable or inaccessible.
- Employment supports are lacking for individuals with ASD.
- Independent living skills lack which presents challenges for adult living situations.
- Individuals with ASD are vulnerable to exploitation.
- Crisis situations create challenges for emergency responders who lack training on appropriate intervention to individuals with ASD.

Recommendations/training:

- Create public awareness regarding ASD.
- Increase training opportunities for community clubs, parks & recreation, and other organizations on ASD.
- Pursue incentives for training for emergency responders on appropriate techniques for crisis intervention with individuals with ASD.
- Research the benefits and challenges regarding the establishment of an ASD registry to better distribute information to individuals with ASD and to better identify incidence of ASD leading to better resource allocation.
- Identify the need and clarify the benefits of increased respite.
- Increase awareness of impact on families.
- Increase awareness of increased safety risks for individuals with ASD.
- Increase training, education, and funding to better support individuals and their families and communities in the areas of recreation, independent living, and employment.
- Pursue alternative options to support individuals in rural areas through technology connections with support agencies.

G. ACCOUNTABILITY

The task force has concluded that mechanisms may need to be established to assure ongoing accountability for the implementation of its recommendations.

Over the course of the next year, it will consider what mechanisms may best assure this accountability. The Task Force will identify action steps on which they will concentrate over the next year and update the plan as appropriate. The Task Force welcomes opportunities to discuss this plan and future activity with the Governor's Office and the Legislative Council.

VII. ABOUT THE TASK FORCE

The ASD Task Force members were appointed by the Governor.

The ASD Task Force members are:
JoAnne Hoesel, Chairperson, Department of Human Services
Darren Dobrinski, Psychologist
Carolyn Fogarty, parent
Cathy Haarstad, parent, Pathfinder Center Inc.
Senator Joan Heckaman, Legislative Assembly

Carol Johnson, College Faculty Member/ Speech Language Pathologist
Tori Johnson, Special Education Director
Teresa Larsen, Protection & Advocacy
Robert Rutten, Department of Public Instruction
Nancy Crotty-Ulrich, Development Homes, Residential Care Facility
Thomas Gaffaney, Behavior Analyst, Anne Carlsen Center
George O'Neill, Ph.D., Blue Cross/Blue Shield of ND
Tricia Kiefer, Department of Health, designee for Dr. Dwelle
Linda Getz-Kleiman, M.D., Pediatrician

Prepared by the Legislative Council staff for
Senator Wardner
February 2, 2011

PROPOSED AMENDMENTS TO SENATE BILL NO. 2268

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

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EXCELLENCE PILOT PROGRAM - DEPARTMENT OF HUMAN SERVICES STUDY - REPORT TO THE LEGISLATIVE MANAGEMENT.

1. During the 2011-13 biennium, the department of human services shall establish and operate a regional autism spectrum disorder centers of excellence pilot program.

   a. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for the mentally retarded which is licensed by the department of human services.

   b. A qualified applicant shall establish the availability of one dollar of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds may not be a gift or grant, but must be funds of the applicant.

   c. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of excellence in a city with a population of more than ten thousand.

   d. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

2. During the 2011-13 biennium, the department of human services shall work with public and private stakeholders to study the feasibility of establishing a network of regional autism spectrum disorder centers of excellence. The study must include:

   a. Consideration of funding needs and sources for startup as well as ongoing financial sustainability of a network of regional autism spectrum disorder centers of excellence;

   b. Evaluation of the unmet needs in the state related to the regional delivery of skilled services to individuals with autism spectrum disorder, consideration of the most effective and efficient delivery system for these skilled services, and evaluation of whether the skilled

services provided by the qualified applicant under subsection 1 is part of a viable plan to increase availability of these services; and

c. Evaluation of the funding, development, and delivery of the skilled services provided by a qualified applicant under subsection 1, including recommendations regarding the feasibility and desirability of implementing the pilot program on a broader scale.

3. Before September 1, 2012, the department of human services shall report to the legislative management on the preliminary findings and recommendations of the regional autism spectrum disorder centers of excellence pilot program and study. During the 2013 legislative session, the department of human services shall introduce any legislation that may be necessary to implement the study recommendations.

SECTION 2. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $600,000, or so much of the sum as may be necessary, to the department of human services for the purpose of implementing the regional autism spectrum disorder centers of excellence pilot program and study provided for under section 1 of this Act, for the biennium beginning July 1, 2011, and ending June 30, 2013."

Renumber accordingly

#1

TESTIMONY TO
HOUSE HUMAN SERVICES COMMITTEE
2011 LEGISLATIVE SESSION
REGARDING
SENATE BILL NO. 2268

March 8, 2011

Chairman Weisz, Committee members, my name is Cal Rolfson, I represent the Anne Carlsen Center for Children. I am pleased to appear before you in support of SB 2268 in its Engrossed version.

The Anne Carlsen Center is an ICF/MR facility licensed as such by the Department of Human Services. They care for some of the State's most medically fragile and behaviorally challenged children and young adults. They are like a step-down ICU unit and have facilities in Jamestown, Fargo, Grand Forks, and will soon have facilities in Bismarck and other regional cities providing day-support and community services care to those vulnerable clients we are all called upon to serve.

The Anne Carlsen Center had a representative at the table for the Governor's Task Force on Autism. The Center is respected State-wide as providing care for those families that have children on the autism spectrum. The Center teaches and conducts leading workshops around the state on autism issues and is seen as a state leader in that area. That is why the Center supports this need.

I do not need to add to testimony that will discuss the devastating impact that families face with children on the autism spectrum. That impact is medical, social, financial and familial. Again, it goes without saying that the Governor's Task Force has identified the need and you, as policy makers for our State, are aware of that need. This Bill helps respond to the concerns identified by the Task Force.

The idea behind the Engrossed version of the Bill is two-fold. First, the Bill in its original form may have had tough sledding and may have had trouble passing with an insurance mandate at the center of the Bill. Second, in the original version, the Bill had a fiscal note that called for State general funding of $2.7 Million and total funding at $5.8 Million. That became a major hurdle also.

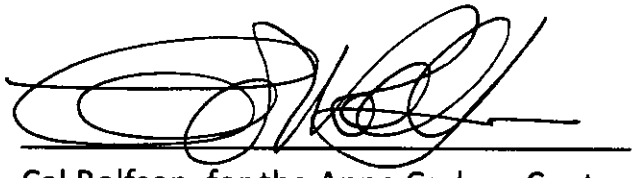
Regardless, there is a vital need to still fulfill the urgings by the Governor's Task Force and begin with something to support families that suffer due to this issue. That was the function of the amendments in the Senate that created the Engrossed Bill. The amendments in the Senate cut the general fund fiscal note by over four times. This Engrossed Bill provides for a pilot project for regional centers that, if successful and able to properly fulfill this need, can be studied and expanded in future Sessions if policy makers agree with that. The concept in the amendments is to take the successes that have been documented in the Education Title of the Century Code (Title 15) and transplant that idea into a public/private partnership in this human service area.

With a 50/50 public/private partnership match, the private non-profit entity has a real investment into the success of the project. At the same time, the State and the tax payers that fund our government, have an investment as well and an equal need to track and follow up with any documented success. It seems to be a wonderful team approach that has proven business success, and uses non-public dollars to help spread the risk, spotlight and promote good business models and help create a conservative approach to meeting a clear need.

SB 2268 seems like a wonderful idea that helps meet devastating family needs, responds to the urgings of experts perhaps wiser than many of us in this room – certainly wiser than I am – and conservatively responds to the compassionate purposes of government to serve those that need that support.

On behalf of the Anne Carlsen Center and CEO Eric Monson, I urge this Committee to give the Engrossed Bill a "Do Pass".

Thank you for the privilege of appearing before this Committee. Even though I have a grandchild in Tennessee with autism and advocate for the Anne Carlsen Center, I am no expert in this area, but I will offer to respond to questions.



Cal Rolfson, for the Anne Carlsen Center
(Lobbyist #38)

TESTIMONY

Engrossed Senate Bill 2268—House Human Services Committee

Representative Weisz, Chairperson

March 8, 2011

Chairperson Weisz, members of the House Human Services Committee, I am Dr Kenneth Fischer, a physician who specializes in Pediatric Psychiatry. I have had the privilege of working with Autistic Spectrum Disorders (ASD) afflicted children and their families for over a decade now, in multiple settings (inpatient, outpatient, community, schools, etc). I am also the newly appointed Medical Director for Behavioral Health, at Blue Cross Blue Shield of North Dakota.

I am familiar with the findings of the North Dakota Autism Spectrum Disorder Task Force Initial State Plan-2010 and the published North Dakota *Guidelines: Identifying, Serving and Educating Children and Youth with Autism.*

I support the Engrossed SB2268 in its currently amended form. A regionally based ASD centers of excellence model would be an essential component in the mission of everyone (at all levels public, private, school, family, etc) who work to support children afflicted with Autism Spectrum Disorders and their families. An evaluation of the unmet needs in the state related to the regional delivery of skilled services to individuals on the spectrum is definitely needed.

ASD's are associated with a tremendous range in syndrome expression; that is, symptoms change over the course of development and in relation to the degree of any associated developmental disability. An ongoing awareness of the range of syndrome expression and an appreciation of the complexities of developmental change are important, even for the most seasoned of clinicians.

Though individuals with ASD's may present for evaluation and treatment at any point during their development, most children with ASD unfortunately will remain within the spectrum as adults, and, regardless of their intellectual functioning, continue to experience problems with independent living, employment, social relationships and mental health. That is what we know from the current state of the science, and from the clinical experience of those of us clinicians who have followed these families along their Autism Journey over time.

North Dakota needs a comprehensive study of the current system for the diagnosis of, treatment of, care for, and education of individuals with ASD. While there are pockets of excellence, the system as whole can be improved with the much needed input of all relevant stakeholders at the local, regional and state levels. The Engrossed SB2268 would do just that.

Chairperson Weisz , members of the committee, thank you for your time and consideration.

Kenneth J. Fischer, MD

Bill 2268 - Autism Human Services

Testimony for people of North Dakota
Reference to 7½ yrs. experience with
Autism - Father single parent

My grandson Kevin Karch - Son Thomas Karch.
~~Att~~ Mother left when Thomas was at age 2
diagnosed with Autism Kevin was in
college at NDSU. Finished the year & lost
BSC & University of Mary before Tommy was born
Moved back to Bismarck single ~~pa~~ parent could
not finish college as Tommy could not speak
We have been his only ~~Baby~~ people as we could
not have Baby sitting. I worked selling Real estate
& took the financial responsibility as Kevin came to
me at age 15 finished Bismarck High with all A's
Help for Tommy in Bismarck was Bell.. &
Speech Therapist from BSC & MedCenter. Kevin
searched & found great help for Tommy in Minneapolis
So they moved there got a address & in a few months
Tommy started getting help 2 specialist in that field
came to the house 6 hrs. a day 5 days a week 2 hrs each
for 2+ yrs. Kevin had to be at the home. He was
Tommy's only person & myself when I could go to Minn.
New school was built, Tommy got to start only 6 kids
& he was the 6 teacher - now 21 & 21 specialists at the
school. Tommy is doing wonderful. Kevin got to go back
& finish college with Tommy in school. Kevin is graduating
with A's Deans list. 11 scholastic collegial
[illegible]

UCLA & U of Southern California flew him
to Chicago for interview. He took graduate
test & scored perfect score so we wanted
UCLA. is flying him into California for final
interview March 14th. He will be working
women. Like Diana Spalding. Sign on Bonnie
& Freddy will be able to financially be able to
be independent from me. Mom spends
35 billion per yr on detention home &
school help - I am very interested in
seeing N.D. step up & help & give these
wonderful people that have degrees &
are helping these children every day in their
homes some have 18 they need more people
educated to help them & they need larger
places outside of their home to teach one
on one as much as they can. They need
you

#4

TESTIMONY ON SB 2268
HOUSE HUMAN SERVICES COMMITTEE
March 8, 2011
Department of Public Instruction

Mr. Chairman and members of the committee:

My name is Alison Dollar and I am an Assistant Director of Special Education for the Department of Public Instruction. I am here to speak on behalf of the Department in support of SB2268.

The recommendation of SB2268 is that the Department of Human Services establishes and operates a regional Autism Spectrum Disorder Center of Achievement pilot project. The conditions described in this Bill include that the applicant is a nonprofit intermediate care facility for individuals identified with Intellectual Disabilities (Mental Retardation (MR)). This Bill also states that the recipient must be capable of matching the funds up to $600,000. And finally, the Bill states that the recipient of this pilot project is located in a city with a population of 10,000 or greater.

Based on the recommendations of the Special Education State Advisory Committee, the Department would like to suggest three revisions. We offer these recommendations because the Federal Individuals with Disabilities Education Act (IDEA, 2004) requires that all children with disabilities are educated in the least restrictive educational environment, beginning with the regular classroom. We are recommending the removal or revision to three conditions stated in the Bill to allow schools, agencies, or centers the opportunity of applying for and conducting this pilot project; thus allowing the pilot project to be conducted in schools or communities where children could continue being educated in their least restrictive education environment.

The first recommendation is that the applicants are not required to be a nonprofit intermediate care facility for individuals identified with Intellectual Disabilities. I have included with this testimony a table describing the current data on the 586 children and students three (3) years old to twenty-one (21) identified with Autism. Of those, only 21 students, 3.58%, were identified with Intellectual Disabilities as a secondary disability. Further investigation of the data showed that of the 10 students with Autism served in a residential center, only 2 students had Intellectual Disabilities as a secondary disability. Three children under the age of five were received services at the location of the service provider. The remaining 573 students were served in schools, with 314 being served in either a regular classroom or regular early childhood program at least 80% of the day. We ask that this pilot project be conducted in settings other than a residential facility, but rather in or near settings where children are currently attending school.

The second recommendation is to remove the requirement that the applicant match funds. North Dakota has several schools, agencies, and centers currently serving children and students identified with Autism. This requirement removes the possibility for these educators or service providers to apply for this pilot project. Together with this is the third recommendation; removing the requirement that the city of the applicant has a minimum population of 10,000. This further reduces the number of qualified applicants and could move children farther from their homes.

It is the recommendation of the Department of Public Instruction that these three conditions be revised to allow schools, agencies, or centers the opportunity of applying for and conducting this pilot project; thus allowing the pilot project to be conducted in schools or communities where children could continue being educated in their least restrictive education environment.

Chairman and members of the Committee, this concludes my testimony. I would be happy to answer any questions the committee may have.

March 8, 2011

Data: Autism including Reported Secondary Disabilities and Educational Settings.

December 1, 2010 Child Count Data; Department of Public Instruction, Special Education Unit

December 2010 Data	Actual Count	Percent		
Primary Disability				
Autism	586			
Secondary Disability (261)				
Emotional Disturbance	10	1.71%		
Hearing Impaired	1	0.17%		
Intellectual Disability (MR)	21	3.58%		
Other Health Impaired	29	4.95%		
Speech/Language	189	32.25%		
Specific Learning Disability	11	1.88%		
Early Childhood Programs: 36 Children		**% Total Population**	**% Preschool Only**	**Autism and ID (MR)**
Regular Early Childhood Program 80% or more of Time	13	2.22%	36.11%	
Regular Early Childhood Program 40% to 79% of Time	9	1.54%	25.00%	
Regular Early Childhood Program less than 40% of Time	2	0.34%	5.56%	
Early Childhood Special Education Prg - Separate Class	8	1.37%	22.22%	1 = 2.78%
Early Childhood Special Education Prg - Separate School	1	0.17%	2.78%	
Early Childhood Special Education Prg - Residential Facility	0	0.00%	0.00%	
Not Attending Spec Ed Prg – Home	0	0.00%	0.00%	
Not Attending Spec Ed Prg -Service Provider Location	3	0.51%	8.33%	
6yrs to 21 yrs Programs: 550 Students		**% Total Population**	**% 6 - 21 yrs**	**Autism and ID (MR)**
Regular Classroom 80% or more	301	51.37%	54.73%	1 = 0.18%
Regular Classroom 40-70%	130	22.18%	23.64%	6 = 1.09%
Regular Classroom less than 40%	97	16.55%	17.64%	9 = 1.64%
Separate School	6	1.02%	1.09%	2 = 0.36%
Residential	10	1.71%	1.82%	2 = 0.36%
Homebound/Hospital	0	0.00%	0.00%	
Parentally Placed in Private School	6	1.02%	1.09%	

PROPOSED AMENDMENTS TO FIRST ENGROSSMENT with House Amendments of ENGROSSED DENATE BILL NO, 2268

Page 1, line 3, after "study" insert "to provide for an appropriation;"

Page 1, line 7, replace "may" with "shall"

Page 1, line 8, replace "$200,000" with "$400,000" and remove "from its legislative appropriation"

Page 1, line 15, remove "may not be a gift or grant, but"

Page 2, after line 14, insert:

"**SECTION 3. APPROPRIATION.** There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $200,000, or so much as may be necessary, and from special funds, the sum of $200,000, or so much of the sum as may be necessary, to the department of human services for the purpose of establishing and operating the autism spectrum disorder centers pilot program required in section 1 of this Act."

Page 2, line 15, replace "**SECTION 3**" with "**SECTION 4**"

Renumber accordingly

SB 2268

ROUGH ESTIMATE OF EXPENSES FOR 1 YEAR OF AUTISM SPECTRUM DISORDER REGIONAL PILOT PROJECT. DOES NOT INCLUDE ANY REVENUE OR ANY STATE MATCHING GRANT FUNDS. [Anne Carlsen Center]

Assumption

30 hours per week per client at 95% [illegible]pancy

charge per hour $35 plus $120/month curricular fee.

Admin salaries do not include physican coverage.

Need capital start-up costs:

Transportation not included

Depreciaion not included

Benefits at 30% of salary

Expenses		Jan	Feb	March	April	May	June	July	August	September	October	November	December	Projected
01-60	Salaries	$ 11,904	$ 13,888	$ 13,888	$ 17,360	$ 20,832	$ 24,304	$ 27,776	$ 27,776	$ 27,776	$ 27,776	$ 27,776	$ 27,776	$ 268,832
01-60	Accrued Vacation													$ -
01-61	FICA	$ 911	$ 1,062	$ 1,062	$ 1,328	$ 1,594	$ 1,859	$ 2,125	$ 2,125	$ 2,125	$ 2,125	$ 2,125	$ 2,125	$ 20,566
01-61	Group Health	$ 3,571	$ 4,166	$ 4,166	$ 5,208	$ 6,250	$ 7,291	$ 8,333	$ 8,333	$ 8,333	$ 8,333	$ 8,333	$ 8,333	$ 80,650
01-61	Dental													$ -
01-61	Vision													$ -
01-61	STD/LTD Disability													$ -
01-61	Group Life/AD&A													$ -
01-61	Pension													$ -
01-61	Pre Employment	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-61	Professional Fees													$ -
01-62	Ed/Continuing Ed													$ -
01-63	Groceries													$ -
01-64	Office/Other Nor	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-64	Computer Suppli	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-64	Program Supplies	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 350	$ 4,200
01-64	CARD Curriculu	$ 480	$ 480	$ 480	$ 600	$ 720	$ 840	$ 960	$ 960	$ 960	$ 960	$ 960	$ 960	$ 9,360
01-64	Postage	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-64	Copier Expense	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-64	Minor Equipment Purchas													$ -
01-64	Building Rental/Lease													$ -
01-64	Minor Equipment Rent/Le													$ -
01-65	Travel & Meeting	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-65	Travel - Client	$ 9,129	$ 8,670	$ 9,173	$ 9,173	$ 9,814	$ 11,722	$ 10,876	$ 12,506	$ 11,420	$ 11,420	$ 10,538	$ 11,650	$ 126,091
01-65	Travel - Education&Trai													$ -
01-60	Telephone	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -	$ -
01-60	Vehicle Maint & Repair													$ -
01-67	Maint&Repair													$ -
01-68	Vehicle Depreciation													$ -
01-68	Auto Insurance													$ -
01-69	Dues, Books and Subscri													$ -
	Total Direct Clie	$ 26,345	$ 28,617	$ 29,120	$ 34,019	$ 39,559	$ 46,366	$ 50,420	$ 52,050	$ 50,964	$ 50,964	$ 50,082	$ 51,194	$ 509,698

Prepared by the Legislative Council staff for
Senator Berry
April 15, 2011

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2268

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a regional autism spectrum disorder centers of early intervention and achievement pilot program; to provide for a report to the legislative management; and to provide for a legislative management study.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. REGIONAL AUTISM SPECTRUM DISORDER CENTERS OF EARLY INTERVENTION AND ACHIEVEMENT PILOT PROGRAM - REPORT TO THE LEGISLATIVE MANAGEMENT. During the 2011-13 biennium, the department of human services may use up to $600,000 of funding from its legislative appropriation to establish and operate a regional autism spectrum disorder centers of early intervention and achievement pilot program.

1. The pilot program must provide a matching grant to a qualified applicant that is a nonprofit intermediate care facility for individuals with intellectual disabilities which is licensed by the department of human services.

2. A qualified applicant shall establish the availability of $1 of nonstate, cash matching funds for each grant dollar awarded under this section. The source of the matching funds must be funds of the applicant.

3. A qualified applicant shall submit a plan for the funding, development, and delivery of skilled services to individuals with autism spectrum disorder who reside within the applicant's service region. The plan must provide for the establishment of a regional autism spectrum disorder center of early intervention and achievement in a city with a population of more than ten thousand.

4. As a condition of award of a grant under this program, a qualified applicant shall agree to collaborate with the department of human services in developing and implementing the plan as well as postaward monitoring by the department of human services.

5. The department of human services shall report to the legislative management before September 1, 2012, on the preliminary findings and recommendations of the pilot program.

SECTION 2. AUTISM STUDY - LEGISLATIVE MANAGEMENT STUDY. During the 2011-12 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 include a review of a sliding fee scale for payment of services and the value of services provided. The study must consider the recommendations of the autism spectrum disorder task force and must seek input from stakeholders in the private and public sectors, including families impacted by autism spectrum disorder, insurers, educators, treatment providers, early childhood

service providers, caretakers, and nonprofit intermediate care facilities for individuals with intellectual disabilities. The legislative management shall report its findings and recommendations, together with any legislation required to implement the recommendations, to the sixty-third legislative assembly."

Renumber accordingly

Prepared by the Legislative Council staff for
Senator Berry
April 15, 2011

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