2013 HOUSE HUMAN SERVICES

HB 1039

2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1039
January 15, 2013
Job #17218

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Explanation or reason for introduction of bill/resolution:
Establish a voucher system for autism spectrum disorder services and support and provide an appropriation.

Minutes: Testimony #1-4 Attached

Chairman Weisz: Opened the hearing on HB 1039.

Rep. Alon Weiland: From District 13 introduced and supported the bill. HB 1039 is a voucher system for spectrum disorder services and support. This would be through the DHS and it is asking that they develop the voucher system. In Section 2 we are asking for an appropriation of $4.5 million or as may be necessary to the department for administering the voucher system. The numbers came from $30,000 per year for each person enrolled. I hope you will favorably favor this bill. I'll answer any questions.

5:08 Dr. Barbara Stanton: Outpatient therapist specializing in autism spectrum disorders testified in support of bill. (See Testimony #1)

10:08 Chairman Weisz: Your caseload of patients, how many are Medicaid, private pay, and no insurance? Please expand on what is covered by insurances and what is not.

Dr. Stanton: I can get you those figures for you. The majority were Medicaid when I worked for the DHS. Now they run around 50 and 50 between private insurance and Medicaid payments. Because of the facility I am working in I can see Medicaid eligible patients. If I were in private practice that would not be the case based upon my licensure. I could see Blue Cross Blue Shield. Licensed professional clinical counselors and licensed marriage and family therapists are not Medicaid eligible providers in the state. The services I provide that are covered by insurance and Medicaid include, diagnostic assessments, evaluations and individual and family therapy. I can provide services at Prairie St. John that are not reimbursed. Those include case management working with daycare providers and juvenile justice people and the school system. Those are not reimbursed.

Rep. Mooney: This is essentially dealing with vocational education, correct?

Dr. Stanton: It is dealing with a number of different services from equipment needs to service needs.

Rep. Mooney: Is there a range of individuals you would be working with as far as their age is concerned?

Dr. Stanton: When we talked to the interim committee we talked about 150 vouchers and 100 would be for individuals 0-26. Then 50 vouchers for 26 to death; a lifetime.

Rep. Mooney: I assume there is a wide range of named disorders that currently fall into that category. This means that you would define clearly the perimeters the people you would be working with?

Dr. Stanton: Absolutely. In the interim committee we did talk about individuals who would be diagnosed by qualified professionals. In May of this year the diagnostic and statistical manual is going to be changing. What is currently under pervasive development disorders is now under going to be under the umbrella of autism spectrum disorders. It will be defined by level of severity and services that are needed; a one to three grid that people will be placed on.

Rep. Mooney: Who would be the case management persons?

Dr. Stanton: I'm not sure. I don't have an expertise on that.

Chairman Weisz: How early can you diagnose someone with autism?

Dr. Stanton: The Center of Disease Control website has information along with a flow chart. Even in infancy pediatricians can recognize some of the early signs of autism. They can do assessments or have a wait and see attitude to see whether there are some developmental issues may resolve themselves as the child grows. We are starting to see children under 12 months being assessed. They are looking primarily at 18 months as the earliest time to really make a more comprehensive assessment. Some that have never been diagnosed or misdiagnosed are being diagnosed correctly now. Early intervention is the best.

Rep. Keifert: Do you see this as a pilot project or (inaudible) addressed whole need for the state?

Dr. Stanton: I know this body is apprehensive of spending the new dollars. We need the opportunity to prove the dollars can be spent wisely. I would like to see it as an ongoing funding source.

Rep. Mooney: The 4.5 million dollars would encompass facilities primarily or training combination staff? Is that an all encompassing number or do you see it being specific to certain aspects of a program?

Dr. Stanton: We used the dollar amount that is currently for DD case management. The average amount of money that they have spent per individual and multiply that by 150 vouchers. It was an estimated amount of dollars being spent now on DD case management. I would hope these dollars would be for direct services that impact families immediately.

Rep. Fehr: If funding for vouchers is 150 and there is a lot more than that, what happens to the rest?

Dr. Stanton: We see this as a starting point. The earlier they are diagnosed the more they will need help as time goes by.

Rep. Mooney: Looking at the Fargo/Moorhead area we have a couple of places that work to help people get back into the workforce. Have you modeled this program after Connections or partner with existing or modeled after other states?

Dr. Stanton: I utilize (inaudible) with vocational rehabilitation. Many states use voucher systems for education. This bill is the first hit I've gotten on Google for voucher systems for individuals on the autism spectrum. ND could pioneer and pave the way for other states to do things.

JoAnne Vieweg: Testified in support of the bill. (See Testimony #2).

28:56 Chairman Weisz: Do you find the services are available if you do have the ability to pay? Can you get the services that you think are necessary?

Vieweg: There are speech and language services available at some schools. Insurance only covers a certain amount. There is occupational therapy that can be done to help him with his sensitivities better. That is a service we can't afford.

Rep. Muscha: I have no idea what the services cost. Do you know?

Vieweg: A $125 a visit. My daughter had to pay a $30 copay plus a percentage.

Rep. Kiefert: I appreciate you helping your family. My wife and I are in the same situation. We have a granddaughter repeating the 1st grade. She has been declared disabled because it is so severe. I'm not impressed with the treatments that they have. In her case they lower her blood pressure at night so she can sleep and then play around with her medicine during the day. They switched medicines a few weeks back and the school called and said she took a marker and colored her arm for cutting her hair off. I just wanted to let you know you have somebody on the board that has firsthand experience with it too.

Vieweg: Thank you. I appreciate that.

Rep. Oversen: Can you speak how important these services are.

Vieweg: One of the things I do is pick up my grandson after school rather than riding the bus. Riding the bus is a nightmare as it is too loud. He is more flexible than a lot of people are. In school his classes have changed because we are in the second semester and he had a good day yesterday. The teacher coach watched out for him and helped him and made sure he knew that this different teacher he was going to have for his social skills development was somebody he already knew. If he doesn't get the consistency at school for help it will throw him off and he will forget and get distressed and whatever he has learned goes by the wayside. He learned in therapy to ask, "Do you mean that literally or is this a figure of speech you are talking about?"

34:54 Eric Munson: CEO of Anne Carlson Center testified in support of the bill. The Anne Carlson Center is a direct service provider. We have made a significant investment in service provision in many parts of the state of ND. We have been serving children on the spectrum disorder since the mid 1980's. In partnership with Minot State three years ago we began to staff diagnostic evaluation clinics around the state. Addressing issues like autism will take many people and organizations. I urge your leadership of the passage of these bills. We appreciate all the work the interim committee did. My board asked the same question on how much we will spend on providing services. We stand ready to work on defining the services on how they might be provided and paid for.

38:04 Rep. Fehr: You said your staff does diagnostic evaluation clinics. I assume you set up a clinic and families will contact you and schedules appointments and get diagnostic workups completed.

Munson: We have pediatricians, speech language pathologists, occupational therapists and physical therapists who staff the clinics. Most of the clinics are provided in Jamestown. We operated some summer camps in Fargo and Dickinson this past year to meet a need that was identified.

Rep. Fehr: What is the cost for an individual getting a complete diagnostic work up.

Munson: We provide most of that through donated dollars that we have raised. The cost would be about $3500-$5000 for a diagnostic per individual.

Chairman Weisz: Would the full cost be covered by insurance?

Munson: Some are covered. It depends on the insurance coverage of the individual.

Rep. Porter: As we look at a bill like this with 4.5 million dollars and the 800 individuals diagnosed with autism, is there a program at the Anne Carlson Center that would be spent that would touch more individuals than what this particular program could touch?

Munson: The last session we introduced a bill that offered a match with state funding dollar for dollar. We are interested in that concept. If we can figure out a way to combine public and private dollars to that, yes.

43:05 Chris McCwen: From the River Valley Asperger Network testified in support of the bill. (See testimony #3)

Chairman Weisz: What services would you look at to help you with your career?

McCwen: How I made it through college was just basic psychiatric services and the right diagnosis and medications. I had no family support and was on my own to pay my medical bills. Just the basic services of $130 with no co-pay racked up a bill. I work with ARVAN and work with adults who are homeless need more services. The state doesn't have these adequate services. The voucher could go a long way to help find these services.

Rep. Reporter: Did you access any services from Southeast Human Services?

McCwen: I did. I got basic medications and got the psychiatric part worked out. I had to deal with coping everyday college problems and with the autism spectrum. I did require some kind of outgoing services which helped with that process. Even though based on lower income it was a longer wait and I was fortunate to get access to a specialized counselor who was familiar with the autism spectrum. There was $120 and copay. I had to do a lot of paperwork and I was in no condition to do all that paperwork without assistance. When I got a job I was able to get more help outside of the Southeastern Human Services. The voucher allows the options and can be beneficial.

Dr. Barbara Stanton: I want to address something Chris said. Regarding the Southeastern Service Center; providing services on the autism disorder spectrum is not a core service. What I was told in my time there, if someone had a primary or singular diagnosis I was to refer them elsewhere.

Rep. Mooney: If someone isn't high functioning like Chris, what do they do?

Dr. Stanton: I'm sorry to say I know of a couple of individuals who have committed suicide because they couldn't access services. We have people on social security disability who are capable and would like to work, but can't access the support or training that would allow them to do this. The people I work with do not want to be on public assistance.

Vice-Chair Hofstad: Talk to me about services that are available out there?

Dr. Stanton: There are not enough services anywhere. There is nothing in rural parts of the state. Very limited supply around the state of qualified people on autism. The need is so great that we need to work together. Not enough services out there.

Rep. Kiefert: I have a question for Chris. I'm interested in treatment. Are you on medication too. Give us an insight of the last ten years of different pills and dosages you have been on.

Chris McCewn: I'm not on long standing everyday medication. I do have emergency medications for stress. I've been on various anti-depressants over the years and it did helped. I started with Prozac and SSRI which is the basic entry level medication. I was misdiagnosed in high school with bipolar disorder and with that you are either way up or way down. They put me on some of those medications which are very intense. The voucher system could open up more options.

59:10 Tina Bay: Director of Developmental Disabilities Division for the DHS testified in support of the bill. (See testimony # 4)

1:2:59 Rep. Fehr: I'm wondering if the voucher program is funded at this level and the time period is ended; is it reasonable to expect that the DHS would also collect some data on use of this voucher and what we learned from doing this?

Bay: I don't believe that was the intent of voucher system or the bill.

Chairman Weisz: If we pass it, what would be the timeframe?

Bay: I believe 12 months would be accurate. Administrative Rule could take 6-9 months to develop.

Rep. Oversen: What is your role do you and the department have in working with the interim committee in coming up with this bill?

Bay: The department is part of the autism taskforce that was started by the governor. JoAnne Hoesel who is the program lead for the DHS is the chairperson of that taskforce. I'm not part of that taskforce. The taskforce brought information to the interim committee. This voucher bill was something different than what was provided to the interim committee from the taskforce.

Chris Wellman: On Board of Education in Fargo and President of the Autism Society of ND and I'm a parent of a son who has autism. Two years ago the Human Services Committee gave $800,000 for an autism Medicaid waiver and about $130,000 was spent. It was for kids from zero to five, up to thirty-three slots. It hovered around only 15-17 kids. I don't think the most was made of that money before. I would encourage you to consider those important questions Tina asked. I would hate to have the money appropriated without looking at those questions.

Chairman Weisz asked for further support and then for opposition. No response so he closed the hearing on HB 1039.

2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1039
1/30/2013
JOB # 17945

☐ Conference Committee

Committee Clerk Signature	Vicky Crabtree

Rep. Hofstad called the meeting to order for the sub-committee on HB 1037, HB 1038 and HB 1039 on January 30, 2013 at 8:05 a.m.

Roll call was taken and Rep. Hofstad, Rep. Looysen and Rep. Oversen and Dr. Stanton were present.

Rep. Hofstad: The focus of the committee is to gather information. The chairman wanted us to get more information on the registry and educational component for autism and see how effective it could be and if we can make it more effective and working with early diagnosis.

Rep. Hofstad: The autism society ranked the registry as number 1. Give us some insight as to why that is important and can be effective in the overall issue of how we treat autism.

Dr. Stanton: The registration can be valuable because you need to know the numbers. There are different functions from state to state. Most registries are just to gather the data to help direct and funding within each state. New Jersey's registry also links families to services. I think the whole epidemiological aspect to autism is important. There are some issues and questions about causal factors. Some causal factors they are looking at are environmental pollutants that may contribute to the development of autism. In our state we could understand the risk factors. We can contribute to the national body of research.

Rep. Hofstad: The diagnosis of part autism and the registry seem to go hand in hand. To what extent does that need to be part of this program and what can we do as move this bill forward?

Dr. Stanton: Need in the bill the qualification of individuals who would have access to use the registry. Those people need to be licensed and trained to use the diagnostic and statistical manual and the one coming up would be the DSM5. Also in the bill it should be a mandated service.

Rep. Hofstad: How do you make the qualifiers component work?

Dr. Stanton: To make it work, are people who are able to make diagnose with the DSM5 who would be medical doctors, nurse practitioners, licensed psychologists, licensed independent clinical social workers, licensed professional clinical counselors and licensed marriage and family therapists.

Hofstad: Do they have the qualifications, knowledge and expertise to do that?

Dr. Stanton: We need to train more professionals in the state. The educational field has done a lot more education and has more research and materials open to their professionals than we do in the mental and medical health field.

Rep. Looysen: I've been hearing from parents that they don't want their child's name on the registry or their social security number. The way this bill reads to me is the department can add any information deemed relevant and appropriate. If we could clear that up in the bill or if you have any suggestions that might make it favorable to the public.

Dr. Stanton: Parents post all this information about their children on the social media. That is more public than what this does. Our registry does need to fall under HIPPA compliance. We can encrypt the information or they can have a number. You need to find a way not to duplicate numbers.

Looysen: I noticed New Hampshire doesn't use the name. How do they avoid duplication?

Dr. Stanton: I don't know, but know someone you can contact.

Rep. Looysen: I can do that.

Dr. Stanton: We looked at a number of states to compare programs.

Rep. Muscha: It depends upon the parent. Some will want the registry and some won't. I have been e-mailing public health people from my district and area concerning the vaccination registry and a Ransom County public health person told me they have been doing this for a long time. Do people even know that?

Dr. Stanton: Most parents I have talked to do not have a problem with this.

Hofstad: Can you give us some insight as to why the taskforce as they rated these things, the registry was way down the list and the people who deal with this, was way up on their priority list?

Dr. Stanton: I'm afraid I can't. Those decisions were made by the committee.

Levi Andrust: A lobbyist representing the Anne Carlson Center. I attended most of the interim meetings. It took a few meetings for the taskforce to come to the table with recommendations and I felt recommendations were done rather hastily. JoAnn Hoesel the head of the taskforce said they had an accumulative voting system where the taskforce members prioritized then they did the math and it came out as such.

Rep. Hofstad: One of the things in the registry component would be to qualify those with the diagnosis part?

Dr. Stanton: Correct.

Rep. Hofstad: Should we amend the bill so we have that component is in there?

Dr. Stanton: Yes.

Rep. Hofstad: Will you help us with that?

Dr. Stanton: Yes.

Rep. Muscha: Would you recommend that the wording be changed too? The line that Alex mentioned?

Dr. Stanton: I like details and know what people are talking about. The more detail the less anxious parents will be.

Rep. Hofstad: We will work on that with Dr. Stanton.

Dr. Stanton: I want to emphasize again, "mandated".

Hofstad: The educational component of this, it seems to me that all the children end up in that setting. We teach them how to be interactive with that component. Is there something we can do in these bills that strengthens that? We have two different issues; a medical and educational component. Where should our emphasis be?

Dr. Stanton: The kids are struggling in the educational system. Having the core training of everyone employed in the school. Everybody plays a role in the success of the child. We need consistency in the home and school. The kids on the higher level end of the spectrum have the hardest time.

Rep. Looysen: You talked about educating bus drivers, maintenance and cafeteria personnel who may not stay in that job very long. If the state funds this program and teaches these people, would it be better if the teacher teaches them.

Dr. Stanton: You'd be surprised how long people stay. We do training in Fargo for the bus drivers. We have done that for 8 years now. Not everyone goes through the same level or type of training.

Rep. Muscha and Rep. Looysen discussed with each other this topic.

Rep. Hostad: We will work on the amendments and bring back to the committee. We will have one more meeting at the beginning of next week.

Rep. Muscha shared a letter she got.

Meeting adjourned.

2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1039
February 5, 2013
Job #18258

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Explanation or reason for introduction of bill/resolution:

Relating to austim.

Minutes:

See Attachment #1

Rep. Hofstad called the subcommittee meeting to order at 7:59 a.m.

Roll call was taken. Present: Rep. Hofstad, Rep. Looysen and Rep. Muscha and Dr. Fisher.

Rep. Hofstad: Let's look at the document from New Hampshire. We would like to find out who makes that diagnosis. (Read from the document. See attachment #1) There was concern from parents about the child's name being out there. Let's see what we can do so we can move this forward. How can we fit that child into educational component and under the voucher and medical insurance?

Rep. Hofstad: How can we treat those patients under the educational environment and how would we pay for them under the insurance component and the things that would be covered under the voucher component?

Dr. Kenneth Fisher: A medical director of behavioral health of Blue Cross and an adult and pediatric psychiatrist. The first answer; it starts out with screening and then diagnosis and the moment the child is identified for being at risk for autism should be referred to an early prevention program. That is for ages 0 - 3 and then when you get to kindergarten it becomes part of IDEA. School age children primarily receive rehabilitative therapies. That would be occupational therapy on both the rehabilitative and disabilitative side. They might receive social skills training and group work in a school setting by a speech and language pathologist. They would receive evaluation in public and private sector. Components might be done by the school psychologist and other components might be done by people in the private sector if the school doesn't have access to the team required to make a sophisticated diagnosis.

Rep. Hofstad: Would the private component be part of the voucher system?

Dr. Fisher: No. Most public and private payers be it Medicaid or BC of ND pay for aspects of evaluation, medical and psychological evaluations and core treatments for autism. The voucher by definition is taking what is under medical necessity and services that would benefit kids with autism and don't fall under the tradition Medicaid or private payer definitions of medical necessity; things such as afterschool programs, transportation and wrap around services. BC and Medicaid currently pay for wrap around and PATH. A voucher and waiver would cover what doesn't fall under the traditional scope of utilization management criteria of a Medicaid and private payer. Everything has to be tied to evidence based outcomes driven care. On the private side the services would be occurring in school as well, but not all schools have access like they do under IDEA. A waiver would come in to pay for services that we know work like speech and O.T, P.T., etc. Other aspect is non-evidence based like case management and wrap around. The voucher could augment the funding that is supposed to be received by the schools under the federal Individuals with Disabilities Act. The services have to be clearly defined under regulatory framework. You have to prioritize the non-evidence services. The voucher could augment what the schools are supposed to be doing. I suggest to very carefully and narrowly define what the voucher should cover and a fiscal note on what they would cost and then how to prioritize the priorities.

Rep. Hofstad: Let's get back to the registry. Under item number 2, I would like to offer an amendment and have that drafted up.

Rep. Looysen: I agree.

Rep. Hofstad: We want to define who can make the diagnosis and make sure child's name is not part of the registry and not have child submit to a medical examination.

Rep. Looysen: Are we going to have a mandate component where all physicians, etc. must report their cases?

Rep. Hofstad: It will say shall.

Rep. Hofstad: JoAnn with the voucher system and that component in education; is that something that is workable or do?

JoAnn Hoesel: From DHS. Those partnerships are in place now. The model is there. The partnering will make the dollars go further. The consistency between school and home will help with the outcome of the child.

Dr. Fisher: The most critical piece is the training component for all the employees of the schools. One of the bills was for money for training in the schools.

Rep. Hostad: We will look at those issues and close the meeting.

2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1039
February 11, 2013
Job #18650

☐ Conference Committee

Committee Clerk Signature Vicky Crabtree

Explanation or reason for introduction of bill/resolution:

"Click here to type reason for introduction of bill/resolution"

Minutes:

You may make reference to "attached testimony."

Chairman Weisz: Called the meeting to order on HB 1039.

Rep. Hofstad: SB 2193 coming over from the Senate has all of these components in it. I think it would be prudent if we killed this voucher system and work with the Senate to meld these two bills together and make a bill we can all live with.

Rep. Hofstad: I move a Do Not Pass on HB 1039.

Rep. Looysen: Second.

Chairman Weisz: Rep. Hofstad please give an update at what the Senate is looking at in theirs.

Rep. Hofstad: 2193 does the same thing. It has the appropriation to get a registry and has an educational component and defines some perimeters in which they would use the voucher system. They have more money in the educational component of $500,000.

Rep. Oversen: I'm not willing to wait and see if they pass that bill. We need to pass this bill now.

Chairman Weisz: Part of the issue is with Appropriation. Even though they are doing the same thing the dollars double. There was somewhere $4 million in their bill and $4.5 in this one. I visited with Senator Lee today and it appears they are a little further along than we are. I liked what they were doing on the education component. It will be an easier sell if we wait for the Senate bill to come over.

Rep. Silbernagel: I think there are some passionate people on the Senate side that want to see this bill go through. I recommend we kill ours and move forward with theirs.

Rep. Oversen: Would that as well cancel out 1038?

Chairman Weisz: It will and in the end we may tell them to kill that one on their side.

ROLL CALL VOTE: 12 y 1 n 0 absent

Bill Carrier: Rep. Hofstad

Date: 2-11-13
Roll Call Vote #: 1

2013 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1039

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. Hofstad Seconded By Rep. Looysen

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

Total (Yes) No

Absent

Floor Assignment Rep. Hofstad

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

REPORT OF STANDING COMMITTEE

HB 1039: Human Services Committee (Rep. Weisz, Chairman) recommends **DO NOT PASS** (12 YEAS, 1 NAYS, 0 ABSENT AND NOT VOTING). HB 1039 was placed on the Eleventh order on the calendar.

2013 TESTIMONY

HB 1039

#1

Chairman Weisz and Members of the Human Services Committee:

I am Dr. Barbara Stanton. I am employed at Prairie at St. John's as an outpatient therapist specializing in autism spectrum disorders. I conduct diagnostic assessments, do individual and family therapy and provide consultation, collaboration and case management services. I also conduct trainings and workshops about autism for educators, law enforcement,

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families. I average 14 intakes per month. I work with children, adolescents and adults who have an autism spectrum disorder or want an assessment to determine if their current diagnosis is accurate. I also work closely with families and collateral contacts such as schools, daycare providers, afterschool programs, juvenile justice systems, county social services, etc.

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

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

I would like to speak in favor of **House Bill 1039** which provides appropriations for the establishment of a voucher system for autism spectrum disorder services and support.

The North Dakota 63rd Legislative Assembly has the opportunity to pass legislation that will be the first of its kind in any state. Your pioneer spirit can better the lives of individuals on the autism spectrum by establishing a voucher system for services.

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

> "Moving to a voucher-based system will significantly improve the quality of services and care, eliminate fraud and abuse, and improve access to the ever-shrinking pool of healthcare providers willing to accept Medicaid reimbursement rates. A voucher-based system would allow

> people to receive care on the private market, decreasing the financial burden on federal and state governments."

The passage of legislation to establish a voucher system will open opportunities for people, wherever they live, wherever they are on the spectrum and whatever their needs are, to receive services.

There are many essential services for children and adults with autism spectrum disorders that are not covered by insurance. There are many adults, and some children, who do not have insurance to access critical medical and mental health care. Many need equipment such as educational materials, sensory equipment, visual aids, safety equipment, assistive technology, and speech generating devices. This equipment must be purchased by the family.

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

It is my belief that a voucher system will encourage providers across the state to receive appropriate training and offer services to individuals with autism. These providers include occupational therapists, speech and language therapists, and behavior interventionists. Many of my colleagues in North Dakota, who are licensed mental health practitioners, do not have the training to work with autism nor are they Medicaid eligible providers. Many children and adults with an autism spectrum disorder have co-morbid mental health issues so access to care is essential. Last Thursday I had a 13 year boy, who is intelligent and talented, tell me that he'd rather be dead than have autism. I wish I could tell you that this is an isolated situation. It is not. Every day is a struggle for individuals on the spectrum as they try to fit into a world that does not understand them. Services provided by family therapists are critical for family stability. There is an 80-90% divorce rate for parents of children with special needs. Many families do not get services because they can't afford the transportation. Specially trained childcare and respite services are scarce and those that exist are expensive.

In a study by the Harvard Department of Public Health it was found that the direct medical and non-medical costs of autism ranged from $38,000 – 100,000 for each autistic individual per year. This does not include costs to the school system which can be around $40,000 per student per year. The indirect costs which include lost productivity/wages can range from $40,000 – 130,000 per family per year. The total cost of autism can be $3.2 million over their lifetime.

It will be cost effective to be pro-active in providing access to services. Without appropriate interventions that are provided in a timely and efficient manner these individuals are more likely to become a part of the legal, mental health or disability system thereby adding to the cost of these programs. For children the costs include additional educational services and out of home placements at the expense of the state. Citizens of North Dakota with an autism spectrum disorder deserve choices in quality services provided by competent professionals offered in their home communities. I believe that the best way to improve access and build a full range of services is through the private public partnership of a voucher system.

I want to thank Chairman Weisz and the members of this committee for the privilege to talk about this important issue. I urge you to vote yes on House Bill 1039. I am open to answer your questions.

#2

Mr. Chairman, members of the committee, thank you for the opportunity to speak with you today. My name is JoAnne Vieweg. I am the grandmother of Colin, a 13 year old boy with Asperger Syndrome, a form of high functioning autism. He and I both had the privilege of testifying before the Interim Human Services Committee about living with autism. We were moved by the interest our legislators have taken in studying this important issue. I wish to speak to you today regarding HB 1039 which will provide a voucher system for provision of services to individuals with autism spectrum disorders.

Autism takes a toll on the entire family. Although my daughter is employed and can care for many of Colin's needs, his grandfather and I help with medicine expenses, after school care, transportation and purchasing learning materials for him to use at home. His mother fears that if she did not have this much support she might not be able to work because of the demands of caring for her child. My husband and I are spending our retirement money to insure his well being. Colin is not eligible for respite care or other services outside of the school day because of the way the regulations are currently written. He cannot benefit from the Developmental Disability waiver for help with services because he does not have an intellectual disability even though he does have a developmental disability—autism spectrum disorder.

We are not alone in our struggles. As president of the Red River Valley Asperger-Autism Network I am in contact with over 90 families who look for support. Our organization is able to provide support groups, community education, and help with advocacy, but families still cannot afford services for their children, and adults with autism need support as well.

Currently Colin needs help with social interaction skills and regulating his emotional responses to situations. He gets some instruction at school, but we constantly monitor his interactions at home and in the neighborhood. We have bought video modeling software that helps him learn how to appropriately interpret good interaction skills because he needs practice beyond the school day. Continued attention to language processing and understanding what people mean and how he can express himself accurately are also on-going concerns. As he gets older he will need help with transitioning to high school, college and beyond, as well as help learning to live independently. Vocational assistance will be needed. He will most likely need job coaching and training of his employer so that he can find a compatible work environment. These types of services are not yet widely available. If qualified professionals were able to be reimbursed for providing such services, more would be available to individuals and families.

There is a great deal of evidence that early intervention is critical to the success of children with autism spectrum disorders. Older children and adults also need support as they navigate the larger world beyond school. Many can live independently, hold a job, travel within the community, pay taxes and contribute to the community and society as a whole when they have been appropriately supported.

Families and individuals need help in finding and paying for services that develop these skills. Investing now in helping children and adults with autism spectrum disorders to receive services pays off in the long run with higher levels of living independently, finding and maintaining a job, paying taxes and contributing to society.

HB 1039 will provide a means for individuals and families to find the services they determine are most useful and necessary. Professionals will be encouraged to gain skills in providing services for people with autism, which will make more services available across the state. Investment in a voucher system will end up being a cost-effective means of developing full potential and independence for people on the autism spectrum.

Thank you for the opportunity to address you today. I appreciate your taking a close look at the needs of those on the autism spectrum and ask you to vote yes on HB 1039.

#3

FOR HB1039 By Chris McEwen

As mentioned in my testimony for HB1038, I cannot necessarily speak for all folks on the autism spectrum as we're all unique, but a very large number of us struggle with paying for basic services needed to cope with a very difficult environment. Due to the nature of autistic spectrum disorders, a lot of us need, at least at some point in our lives, access to mental health care and psychiatric medications to function well in educational and workplace situations.

However, accessing this care can be very difficult without insurance. Even monthly psychiatric bills and generic monthly medications can be extremely hard for adults on the spectrum, or families of those caring for children on the spectrum, to regularly afford. Unless they qualify for disability or Medicaid funding, they are largely limited to state-ran resources that may not be as well equipped to meet the unique needs of those on the spectrum as professionals working for non-profit or private entities, and wait lists for those capable of prescribing psychiatric medications can be long.

The voucher system proposed by HB1039 has a lot of potential to really improve the lives of many of those on the spectrum by increasing their options and allowing potentially more efficient care. This could allow families to better care for their children and also help their children to better adapt to traditional K-12 education. This could help adults on the spectrum better function in a difficult world for them, which could help them hold down jobs and help them be active in their communities.

The voucher program holds a lot of great potential to make a real difference in the lives of those on the autism spectrum, as well as the families and community members that care for them. This could also be an excellent investment by the state of North Dakota as well due to the benefits specific care can provide.

On those grounds, I hope you support HB1039.

#4

Testimony
House Bill 1039 – Department of Human Services
House Human Services Committee
Representative Weisz, Chairman
January 15, 2013

Chairman Weisz, members of the House Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Division, for the Department of Human Services (Department). I am here today to discuss House Bill 1039.

House Bill 1039 instructs the Department to implement a voucher system for up to 100 individuals up to age 26 and up to 50 individuals aged 26 and older with autism spectrum disorders.

If this bill is adopted, the Department will need clarification on a number of items in order to ensure that we honor legislative intent and implement a successful program.

A voucher program is a program where, once eligible for the program, a person receives "vouchers" to "purchase" services.

The Department would need staff resources to run a voucher program, which would include establishing the mechanisms of the voucher program, developing prior authorization criteria, and monitoring the services received and payments made. The program would need management and monitoring of the infrastructure, service agreements, and utilization. We would expect that the legislature would want the Department to reconcile vouchers issued with vouchers used and attend to the issues that arise in the development and implementation of the program and services.

Some questions for which answers would be helpful so the Department understands legislative intent include:

Who decides that the services a family requests are approved?

Who would determine which services are allowable and unallowable?

Who are the appropriately trained individuals to make these decisions?

Is the voucher funding intended to be used last if an eligible person had other resources or assistance available such as eligibility for Medicaid or other insurance?

Who would be qualified to provide the services?

Who decides if a requested service is tied to the autism diagnosis or another medical condition?

As some of the services mentioned do not exist, is it the intent that the Department establish the parameters of the provider qualifications and reimbursement levels?

Is the intent that the Department makes the final decision on these items?

Would providers be required to enter a vendor agreement in order to become an approved vendor?

In Section 1, Number 4, House Bill 1039 lists a wide variety of services ranging from medical care to housing, to transportation. The Department requests clear criteria on what the vouchers would cover to avoid the Department being more lenient or more prescriptive than intended. Due to the potential magnitude of the program, the development of administrative rules would likely be necessary.

In Section 2, the appropriation states that up to $30,000 per year per person is available for a total of $4,500,000 for the biennium. The Department would like clarification on the appropriation. According to the information proposed in the bill: $30,000 per person X 2 (years) X 150 individuals = $9,000,000. The $4,500,000 would be appropriate if the intent is that it would take 12 months to develop a voucher program; therefore only one year of vouchers would be issued. If this is the case, the Department recommends a delayed effective date be added to the bill.

We pose these questions so you may consider them in your discussions on this bill because the Department wants to follow the intent and be able to fulfill the scope of intended outcomes of this program.

I am available to answer any questions.

#1

TITLE XII
PUBLIC SAFETY AND WELFARE

CHAPTER 171-A
SERVICES FOR THE DEVELOPMENTALLY DISABLED

Autism Registry

Section 171-A:30

171-A:30 Autism Registry. –

I. There shall be established a state registry in the department which shall include a record of all reported cases of autism spectrum disorder (ASD) that occur in New Hampshire and other information relevant and appropriate to conduct thorough and complete epidemiologic surveys of ASD, to enable analysis of this problem, and to facilitate planning for services to children with ASD and their families. The department may enter into an agreement with an appropriate entity for the management of the registry; provided, that any records and data submitted to the department pursuant to this subdivision shall be the property of the department.

II. Physicians, psychologists, and any other licensed ~~or certified health care~~ provider who is qualified by licensure; by training to make the diagnosis and who then makes the diagnosis that a child is affected with ASD shall report all new cases of this diagnosis to the department in a form and manner prescribed by the commissioner. The report shall be in writing and shall include the name and address of the person submitting the report and the child's date of birth, gender, and zip code at birth residence, and the specific diagnosis of the child diagnosed as having ASD. The department shall assign a unique identification code to identify the child diagnosed as having ASD. The code shall not include the name or address of the child.

III. All information required to be reported under this subdivision shall be confidential. A physician, psychologist, or health care provider providing information to the department in accordance with this section shall not be deemed to be, or held liable for, divulging confidential information.

IV. Nothing in this section shall be construed to compel a child who has been reported as affected with ASD to submit to medical or health examination or supervision by the department.

Source. 2006, 106:2, eff. Aug. 7, 2006.