

2013 HOUSE HUMAN SERVICES

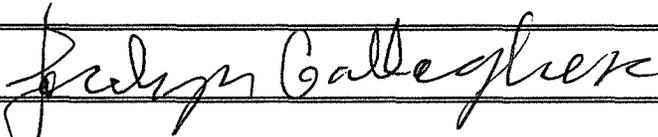
HB 1037

2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1037
January 15, 2013
17216

Conference Committee



Explanation or reason for introduction of bill/resolution:

A legislative management study for autism spectrum disorder.

Minutes:

attached testimony 1, 2

Chairman Weisz: Opened the hearing on HB 1037.

Rep. Weiland: Introduced and supported the bill. We did a study already, but many were not pleased that we didn't have more time with this particular study. The autism spectrum disorder has taken everybody by storm and the numbers are 1 out of 110 children born has this disorder and that is disturbing. We would like to continue this study. There are a lot of organizations and we did not get to hear from all of them to find out what each one of them does and we need to find out what further services are available and needed. This is a continuation of that study and I ask this committee pass bill 1037.

Chairman Weisz: (3:41) Based on the fact that we are hearing two bills that will fund autism. Why are we still studying it? Can you expand on that?

Rep. Weiland: We feel we had not completed it. We had several meetings and a lot of testimony from relatives, children and you may hear from them this morning. They can range from a 12 year old to a man with a PhD.

Rep. Anderson: If HB 1038 is successful we can use data off from that to help with HB 1037?

Rep. Weiland: That is correct.

Rep. Oversen: Are there any certain outcomes or goals you are working towards? Is there anything like with work placement assistance you are hoping to find?

Rep. Weiland: We aren't sure at this time, but it could very well be that we can get into different areas. I had an email that we didn't include families so there are some things that need to be looked at. You will hear about the waiver and in this particular legislation we have not included anything about the waiver. I believe it now covers ages 0- 3 and schools take over at 5 and there is a gap there.

Dr. Barbara Stanton: An outpatient therapist specializing in autism spectrum disorders testified in support of the bill. (See Testimony #1) (8:12)

Chairman Weisz: (11:31) You have numbers that keep increasing, why is the number increasing?

Dr. Stanton: It is a dramatic increase worldwide. Part of the reason is improved assessments and diagnostic tools and better reporting. There is the underlying questions of what the causes are and whether or not we can do something to help prevent further autism.

Chairman Weisz: We don't have an answer to the underlying causes?

Dr. Stanton: We do not.

Rep. Fehr: You talk of about this being a lifelong disorder; we want our young people to grow up to be healthy, productive citizens. Other than just throwing money at a problem if we do a good job, what is the potential of what really could be done to help people become productive citizens?

Dr. Stanton: I agree with you, throwing money at problems is not the answer. We need thoughtful and careful consideration of where important dollars are being spent so they can have their best possibility for an outcome of success is Important. This is why it is important to continue to study this issue. All the time in the research were finding new evidence based interventions and programs, finding to be very effective in terms of school and employment. We need to have interventions everywhere along the life span. Research has started to indicate while early intervention is critical in a child success we also need to watch folks along that developmental track so we see issues all along their life span.

Chairman Weisz: Further questions.

JoAnne Vieweg: Grandmother of a 13 year old Asperger Syndrome child, testified in support of the bill. (See Testimony #2) (16:30)

Chairman Weisz: Any questions? Anyone else in support of HB 1037? Any opposition of 1037, close hearing on HB 1037.

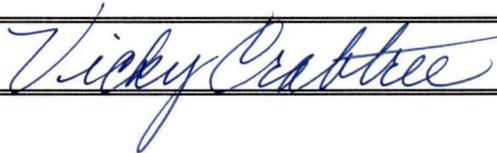
2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1037
1/30/2013
Job # 17945

Conference Committee

Committee Clerk Signature



Minutes:

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. Looyen 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. Looyen: 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.

Looyen: 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. Looyen: 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. Looyen: 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. Looyen 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.

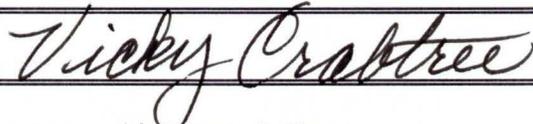
2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1037
February 5, 2013
Job #18258

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

Relating to autism.

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. Looyen 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. Looyen: 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. Looyen: 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 1037
February 11, 2013
Job #18646

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

A legislative management study for autism spectrum disorder.

Minutes:

You may make reference to "attached testimony."

Chairman Weisz called the meeting to order on HB 1037. This is the study.

Rep. Hofstad: I move a Do Pass on HB 1037.

Rep. Looyen: Second.

ROLL CALL VOTE: 13 y 0 n 0 absent

Bill Carrier: Rep. Looyen

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

2013 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1037

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. Hoptstad Seconded By Rep. Looyzen

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) 13 No 0

Absent 0

Floor Assignment Rep. Looyzen

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

REPORT OF STANDING COMMITTEE

HB 1037: Human Services Committee (Rep. Weisz, Chairman) recommends DO PASS
(13 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1037 was placed on the
Eleventh order on the calendar.

2013 SENATE HUMAN SERVICES

HB 1037

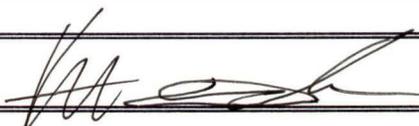
2013 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

HB 1037
3/11/13
19698

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

To provide for a legislative management study of the autism spectrum disorder.

Minutes:

See attached testimony.

Chairwoman J Lee. Opens testimony

(0:00:15) Chairwoman J. Lee makes note that **Rep. Wieland** testified for HB 1038 was chair of the health interim committee, and supports HB 1037.

(0:00:58) Teresa Larsen Executive Director of the Protection & Advocacy Project. Testifies in support of HB 1037 See attachment #1A

(0:02:00) Carlotta McCleary, Executive Director for ND Federation of Families for Children's Mental Health: Supports the language of HB 1037, it would include families.

Closes testimony

Testimony for HB 1037 was also given during HB 1038, job number: 19697

Testimony is as follows:

Chairwoman J Lee opens public hearing for HB 1038

(0:00:41) Rep. Wieland: introduces HB 1038 and is in favor. Provides for autism training and support and autism spectrum registry. The registry will have information provided by a doctor, or any other licensed provider who is qualified by training to make the diagnosis of an autism spectrum disorder, the report will not include the name or address of the child.

(0:04:12) Maarja Krogh from West Fargo: is in favor HB 1038. Training not only in the classroom education, also for childcare providers that are providing services not only in center but also in the home.

There is a discussion about child care and autism.

(0:08:04) Dr. Barbra Stanton - Outpatient therapist specializing in autism spectrum disorder and Prairie St. John's, and is in support of 1038 and 1037. See attachment #1B

A discussion about training education staff, and DPI, and continuing education.

(0:17:21) Dr. Barbra Stanton: the importance of including everyone including library adults on the spectrum, those that have experience in the education systems, so they can provide experiences. In addition to families.

(0:18:05) Colin Vieweg: a 13 yr. old diagnosed with Asperger's Syndrome as in favor in HB 1038. Attachment #2

(0:24:03) JoAnne Vieweg: Grandmother of **Colin Vieweg** is in support of 1038 See attached testimony #3

(0:31:54) Kris Walmen- President of the Autism Society of North Dakota and an elected official for the board of education in Fargo, and has one child on the autism spectrum, is in favor 1038 & 1037. It's difficult to advocate for services and have the correct data. If we can educate educators, and those in the education setting, we can prevent unwanted behaviors.

(0:36:32) Chairwoman J. Lee: the challenge of increasing number of children with behavioral challenges, it's creating challenges for the school districts. The larger communities have become magnets it's deeper and broader, to get the services provided.

(0:39:40) Penny Smith is a parent is in support of HB 1038 and 1037. Gave personal experiences about her 21yr old daughter and an 11yr old son both on the autism spectrum.

(0:41:58)Gerry Teevens- Special education director for the Department of Public Instruction. Is in favor of HB 1038 with an amendment. See attached testimony #4

There is a discussion on SB 2193

(0:51:42) Tamara Gallup-Millner Director of the Division of Child's Special Health services for the North Dakota Department of Health provides information regarding HB 1038. See attachment #5

(0:57:00) Senator Axness: Clarification on money and the funding of the program?

Tamara Gallup-Millner: based on estimate for the interim committee , based on a program that tracks babies with hearing loss at birth, it was proxy measure. The methods are very different for the registry.

Senator Axness: The larger number is more accurate then.

Tamara Gallup-Millner: Yes

Chairwoman J Lee Closes testimony

2013 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

HB 1037
3/20/13
20231

Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

To provide for a legislative management study of the autism spectrum disorder.

Minutes:

You may make reference to "attached testimony."

Committee work

There is a discussion about proposed amendments to HB 1038

There is a discussion about HB 1038 and SB 2193.

There is discussion about the registry and how it would work. In addition, to confidentiality of the registry.

There is a discussion about the HB 1037 and the study being optional, and with HB 1038 being mandatory.

Discussion about a fiscal note and referring to appropriations, if amendment is adopted.

Senator Anderson discusses the registry language of the bill.

Chairwoman J lee discusses about the bill getting services to those that need it, and wraps around the waiver.

There is discussion about FTE's, and staffing the project.

Senator Larsen discusses the voucher.

There is a discussion on the Fiscal Note.

There is discussion about the proposed amendment and collection of data.

Discussion about training and who would be trained.

There is a discussion about if refining the amendment and HB 1038.

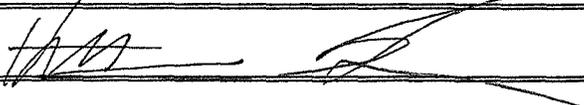
There is a discussion about at what age would be the cut off for the voucher.

2013 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee
Red River Room, State Capitol

HB 1037
3/26/13
20512

Conference Committee

Committee Clerk Signature 

Explanation or reason for introduction of bill/resolution:

To provide for a legislative management study of the autism spectrum disorder.

Minutes:

You may make reference to "attached testimony."

Senator Axness motions for a do not pass

Senator Larsen second

Do Not Pass 5-0-0

Chairman J. Lee will carry

Date: 3-26-13
Roll Call Vote #: 1

2013 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1037

Senate 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 Sen. Axness Seconded By Sen. Larsen

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

Total (Yes) 5 No 0

Absent _____

Floor Assignment Sen. Larsen

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

REPORT OF STANDING COMMITTEE

HB 1037: Human Services Committee (Sen. J. Lee, Chairman) recommends DO NOT PASS (5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1037 was placed on the Fourteenth order on the calendar.

2013 TESTIMONY

HB 1037

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, childcare providers, mental health and medical professionals, and the community at large.

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families. I average 14 intakes per 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, etc.

I am speaking today in support of **House Bill 1037**; a legislative management study of autism spectrum disorders.

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.

Every week new research studies are published. It is important to continually monitor this research and advances in evidence based assessments and interventions. There is a genetic basis to autism but the underlying causes are still being investigated. Research into autism and related issues is being done by the medical, psychological and educational fields.

Autism is a spectrum disorder in which there is great variation in individual differences. Because of this variation different assessments and interventions must be understood so appropriate services can be

rendered.

While there have been advances in research there are gaps in our understanding of autism. This includes public concerns of health and safety including issues of obesity and mental health, efficacy of interventions, transitions to independence, employment and building public private partnerships; just to name a few.

Because the issue is so complex and the research is so new it is important to continue to have a means to inform and educate those involved in state government who can draft and pass meaningful legislation in order to improve the lives of individuals on the autism spectrum and their families.

Allowing stakeholders whose lives are impacted by autism to access the North Dakota Legislature to advocate and educate regarding their needs is critical.

Thank you for listening to my testimony today regarding this important issue. I urge you to vote yes on House Bill 1037. I am open to your questions.

Mr. Chairman, committee members, thank you for the opportunity to speak to 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. As he and I testified before the Interim Human Services Committee, we realized the importance of continued study of autism spectrum disorders. The incidence of autism spectrum disorders is considered to be the fastest growing serious developmental disability in the United States.

While there is no medical cure for autism, there are proven or evidence-based interventions and emerging interventions that are proving to make significant differences in the lives of those with autism spectrum disorders. Since more children will be diagnosed this year with autism than with AIDS, cancer and diabetes combined, there is a strong need to continue to study the needs and appropriate interventions for these children and adults.

Protecting the interests of our children is an important means of preserving the future of our state and country. When we can help people become productive members of society, we are investing in our future.

Further investigation of current needs, and the development of appropriate interventions and services within the state are still needed. I am asking you to support HB 1037 which continues the study of the incidence and impact of autism spectrum disorders in North Dakota.

#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 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.

by
Victor

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.

2A

HB 1037
Senate Human Services
March 11, 2013

Good morning Chairman Lee and members of the Senate Human Services Committee. I am Teresa Larsen, the Executive Director of the Protection & Advocacy Project. I am here to testify in support of HB 1037.

While there is also a study included for ASD in SB 2193, the language in HB 1037 is more descriptive in its inclusion of stakeholders from the private and public sectors. While perhaps not intending to exclude individuals with ASD, their families, service providers, advocates, and the ASD Task Force, SB 2193 in contrast, speaks only to consultation with expert clinicians. HB 1037 is much more inclusive in its intent to gather perspectives from stakeholders.

Thank you. I'm happy to answer questions you might have for me.

Chairman Lee and Members of the Human Services Committee:

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

In the past 13 years I have worked with nearly 1,000 individuals on the autism spectrum and their families.

I am speaking today in support of **House Bill 1037**; a legislative management study of autism spectrum disorders and **House Bill 1038** which provides appropriations to the Department of Health for an autism registry and appropriations to the state Department of Public Instruction for autism spectrum disorder educational training and support.

House Bill 1037 is similar to Section 3 in SB 2193. As you have heard in previous testimony, autism spectrum disorders is a very complex neurodevelopmental disorder.

Legislative Management Study of Autism Spectrum Disorders

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

Currently there is a belief that there are multiple autisms that are due to chromosomal differences, genetics, brain structure changes, and neurochemical differences.

There are many claims of "cures" and interventions that claim to evidence based. In order to provide effective and appropriate diagnostic assessments and interventions we must stay apprised of changes in the research and how to apply it to individuals.

While there have been advances in research there are gaps in our understanding of autism such as causation, public concerns of health and safety including issues of obesity and mental health,

efficacy of interventions, transitions to independence, employment and building public private partnerships; just to name a few.

Allowing stakeholders to access the North Dakota Legislature to advocate and educate regarding their needs is critical.

House Bill 1038 also contains elements similar to Senate Bill 2193 including a registry and training funds.

Autism Registry:

As you heard in testimony for Senate Bill 2193, a registry is a necessary element to better understand the number of individuals diagnosed with an autism spectrum disorder. There is currently no tracking system in the state. Having accurate data is essential to plan future services, access funding, and give us the opportunity for data sharing. It will benefit families and the state.

The language in Senate Bill 2193; utilizing the criteria for diagnosis by the American Academy of Pediatrics is an important element to registry. By having professionals who are qualified to make a medical diagnosis of autism mandated to provide data is an effective means to monitor the numbers of individuals in the state who are impacted by autism. Safeguards to protect the privacy of individuals registered is critical.

Autism Spectrum Disorder Educational Training and Support:

House Bill 1038 addresses training for school personnel specifically. Autism spectrum disorders are present from birth or very early in development. Although the exact neurobiological mechanisms have not yet been established, it is clear that autism spectrum disorders reflect differences in the developing brain. Autism is unique in the pattern of deficits and areas of strengths. It has lifelong effects on how children learn to be independent and to participate in their community. In many cases, autism can occur along with an intellectual disability, language disorders, and mental health issues. Thus, educational planning must address both the needs typically associated with autistic disorders and needs associated with accompanying disabilities.

Educational goals for these students, as part of addressing independence and social responsibility, often need to address language, social, executive skills and adaptive goals that are not part of standard curriculum. The educational setting is currently the primary location of treatment for children with autism spectrum disorders.

One of the biggest challenges facing children on the autism spectrum is attending school. This includes pre-school to high school. I am in schools weekly to attend meetings, provide consultation or meet with students. As I work with school staff, I hear about the struggles they have in understanding and providing services to children with autism spectrum disorders.

Parents are caught in these struggles. They get frequent, sometimes daily, calls from the school as their children show challenging behaviors that impact the learning of their child and other children in the school. Without proper interventions these children can be delayed in their learning and suffer stress that leads to overwhelming anxiety and depression.

Many children with autism are gifted in math, science and the arts. Due to the neurological differences inherent in individuals with autism they often learn differently, struggle with sensory issues, flexibility, cannot navigate the social environment, cannot establish relationships with others, and have trouble communicating their needs. Many problems arise due to delays in emotional development and trouble expressing their emotions. These are children who love to learn but hate school. Students with autism are more likely than other special-need students to receive out-of-district placements. Educating autistic children can be a challenge in the best of circumstances.

I am in schools weekly. At school meetings I regularly hear that these children are rude, lazy, or manipulative. Instead of recognizing the atypical development of children and young people on the autistic spectrum, teachers tend to view them through a "typical lens", comparing their behavior with children who do not have autism. Some believe all they need are behavioral interventions to force autistic children to behave as other pupils do, or that it is a condition that

they will grow out of.

From teachers I hear how much they want to reach these students but often do not have the education or information to best serve them. This bill includes education training and follow up for all school personnel because everyone from the principal to maintenance workers have contact with these children and can contribute to their positive experience at school. Traditional teaching and behavior management methods are not effective for children on the autism spectrum. The teachers I know try hard to do what is best for their students. School systems do not have the resources to bridge the gap between research and practice. The intent of this bill is to provide funding to the North Dakota Department of Public Instruction for nationally known professionals to provide regional training and follow up consultation. There would be tiered training meaning that the support staff would receive training appropriate to their role in the children's lives as would teachers and administrators.

Schools have a legal obligation to provide Free Appropriate Public Education while following the Individuals with Disabilities Education Act. This bill will provide them with the tools they need to meet that obligation. This will also benefit children, their families, and all community members. Senate Bill 2193 had additional dollars appropriated for training of parents which is also very important. Understanding how to best support and intervene with children with an autism spectrum disorder requires consistency between all settings.

While I prefer the more comprehensive Senate Bill 2193 which includes the voucher program; I strongly encourage this committee to pass House Bills 1037 and 1038. Thank you for your attention. I am open to answer any questions you may have.

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Testimony March 11, 2013

Chairman Lee, members of the committee, my name is Colin Vieweg. I am a 13 year old boy. I have Asperger's syndrome, an autism spectrum disorder. I am very smart and plan to be a scientist, astro-physicist, or robotics inventor when I graduate from college. I do pretty well in school, but I need help in figuring out what to do in certain social situations. Dealing with a lot of noise and commotion is also hard for me. And sometimes handling my anger is really hard. It helps a lot when teachers understand me and can help me use my calming strategies. It also helps when I can learn how to calm myself down and how to understand what people are telling me. I need help learning how to do this. I was able to talk about this at the Interim Human Service Committee last year and at the House Human Services Committee in January.

Thank you for learning about living with autism and caring about helping kids like me. My family helps me a lot, but not everyone can do that. Please pass HB1038 so that we can get more help.

Elementary school was terrible because it was nearly impossible for people to understand me. I felt like people were picking on me on purpose. Sometimes I got angry and didn't know how to handle it. I just wanted peace and quiet. Now I have more help from my teachers and the Asperger Coach. They "get me" now. I can go to a safe place at school when it gets to be too much.

One of the pros of having Asperger's is being unique and my memory is quite good. My favorite book genre is science. I love science and Albert Einstein is my hero. He was the world's smartest man, in my opinion.

Sometimes it is very hard for me to focus on one thing, especially if there are other distractions. In fact, while mom is typing this for me, I am playing my Nintendo DS. This is the best way to do it. I don't know why, it is just easier. Strangely, it is really hard for me to focus when I'm just doing one thing. It's like having music on in the background so you can concentrate better. If I'm doing something with my hands, it helps me stay focused on what I'm doing. So I don't always look like I'm listening, but I am—I'm tuning out too many other things.

In January I got to meet Temple Grandin. She is a famous scientist who has autism. I think she helped teachers understand autism better. It helped them to hear from a person who has autism how to help and understand us.

March 11, 2013

Senator Lee, members of the committee, my name is JoAnne Vieweg. I am the grandmother of a 13 year old boy with Asperger Syndrome, a form of high functioning autism. You have just met him. Colin is a smart, charming, caring boy. He is the light of our lives and constantly intrigues us with his interest in the world. He has tested above high school level in achievement, and is only in 8th grade. I do believe he will one day be a great contributor to our society. He will probably invent the next form of robotic machinery or prosthetic limb. (He is currently building a working robot at home.) At the very least, he will make the world a more interesting place. He has some friends, unlimited interests, and an uncanny ability to 'read' the adults in his life. It is much more challenging for him to 'read' his peers and to understand their teasing, goofing around and the general silliness of middle school. He has so much potential, yet he cannot navigate the challenges of school and large groups without trained and compassionate teachers supporting him. As a retired educator I appreciate firsthand the value of appropriate training to help students who are different.

I am here in support of HB 1038 which develops an autism registry and provides training for educational personnel. I would like it to also include training for other community members who play an important part in screening and working with people on the autism spectrum. Since more children will be diagnosed with autism than with AIDS, cancer and diabetes combined, there is a strong need to have accurate diagnoses and a means of tracking the incidence of autism in the state. This will greatly help in developing better services.

My grandson wasn't diagnosed until 3rd grade when his weaker social interaction skills became more obviously different from his peers. He received inconsistent interventions to help him. Most of his teachers were unfamiliar with how to help him. He is exceptionally bright, but when he did not know how to take turns in a conversation or when he would poke a child in order to join the game because he did not know how to approach him and ask, he was told he was rude. He was told, "You are so smart, how come you can't do this?" His mother was accused of not disciplining him well. He was viewed as weird when he covered his ears at recess, on the bus, or in physical education class because the sounds were too loud. Because he has sensory sensitivity to noise and scents, it is painful for him to go to the mall or to physical education class. He describes it as "like being in the jungle surrounded by hundreds of howler monkeys all screaming at the same time." He is learning to recognize when he is stressed and anxious and often can ask for relief, but he needs coaching from understanding adults.

Accommodations need to be made for him at school that allow him to function at his best. He used to hate school in 3rd and 4th grades where he was misunderstood and often lost control. He was, and still is, terrified of losing control and having a meltdown. He became so depressed and distressed that his mother removed him from public school until 7th grade. Earlier, the teachers didn't realize

things such as every time someone used the pencil sharpener it sounded like a chainsaw to him, or that the high-speed flickering of the fluorescent lights gave him a headache by 10a.m. So when he snapped suddenly at a classmate, he wasn't being disruptive. He felt miserable and didn't know why, or how to tell anyone. His behavior was communicating his high levels of anxiety and sensory overload.

Colin is now thriving in the public school system with the addition of an Asperger Teacher coach and in-service training for teachers and support staff. The dedication of his teachers cannot be discounted either. They can help him recognize triggers in the environment and help him cope. They can coach him through a social interaction. He is allowed to get away to a "safe place" in school while he attempts to handle his anxiety. He has a few friends, is less often the target of bullies, and even though he is a little different, kids want him to be on their problem solving team because he always has the right answer. Teacher and staff training has made all the difference.

Colin tells me that now he has people at school he can trust and who "get him". But not all schools have this training, even within the same district.

As a retired educator and family member of a child with autism I've had to become a strong advocate for his needs in school. More awareness on the part of educators should make this easier for families. Also, because navigating the system for finding services is so difficult for parents, I'd like to see additional support for family education and training in advocacy.

We have also felt the need for accurate diagnostic methods. Colin was not correctly diagnosed at an early age. Even as an eight year old, his correct diagnosis was missed by a professional. We were fortunate to find a qualified provider who knew very quickly that Colin had autism. With her help he has been able to find appropriate treatment and we have been able to effectively advocate for his needs. Mandated reporting of the diagnosis of autism spectrum disorder will increase the accuracy of diagnosis and encourage more professionals to gain the training they need to work with 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. There is an economic stress when needs of individuals are not met. With adequate diagnosis and on-going treatment, many people on the autism spectrum are capable of living independently and contributing to the community in significant ways. Some of our most recognized scientists, inventors, artists and business leaders are functioning on the autism spectrum. Investing in training for those educators who are on the front line of working daily with children with autism pays great dividends.

TESTIMONY ON HB 1038
HOUSE HUMAN SERVICES COMMITTEE
March 11, 2013
By: Gerry Teevens, Special Education Director
701-328-2277
Department of Public Instruction



Madam Chairman and Members of the Human Services Committee:

My name is Gerry Teevens. I am the Special Education Director for the Department of Public Instruction. I am here today to provide information and request an amendment related to section 1 of the Reengrossed House Bill 1038.

The Department of Public Instruction/Office of Special Education has the responsibility as set forth in the federal law, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), to assure that a free appropriate public education (FAPE) is available to any individual child with a disability who needs special education and related services. These services must be designed to meet their unique needs and prepare them for further education, employment and independent living. Children with disabilities are to be educated with those who do not have disabilities to the maximum extent appropriate, and should attend and participate in general education classes unless it is inappropriate and otherwise indicated on a student's Individualized Education Program (IEP). An essential consideration in the development of the IEP is the extent to which the child's

instructional needs can be met by general education staff in all environments with or without assistance from special educators.

Over the last several years the number of children identified with autism and needing special education services has increased in North Dakota as well as nationally. Autism is the term used in the IDEA and that is the term that schools use when reporting Child Count data to the Department of Public Instruction. The December 1, 2012 ND child count data, revealed that there were 13,296 children receiving special education and related services in the state. Of this total, 786, (6%) were identified under the disability category of autism. It is important to note that these numbers do not include those children with a secondary disability of autism. Some students with autism may not be identified as having autism, rather they are identified as having a specific learning disability, other health impairment, speech language impairment or a non-categorical delay (a designation for children up to age 10). The December 1, 2012 data shows a steady increase for the previous decade in the number of children with an autism receiving special education services. Included with this document is the historical child count data for ND over the last decade.

It is the responsibility of the ND Office of Special Education to provide technical assistance to local special education units and districts to enhance their services for all children with disabilities. Most recently our office has received an

increased number of requests for funding for professional development training for personnel serving children with autism. During the annual Fall Leadership Conference which our office hosts for local Special Education Unit Directors and Program Coordinators, an emphatic request was voiced by the participants for state sponsored professional development for all school staff working with children with autism. Parents of children with autism have expressed concerns about this need to us as well. This need is reflected in currently proposed legislation. The State Autism Task Force has identified the need for training and support for general education teachers and other school staff as well.

In order to assess more specifically the training needs, the Office of Special Education carried out two activities. Staff in the Special Education Office conducted on-site stakeholder visits throughout the state to develop a statewide perspective on: the types of services currently being provided to children and youth with autism; the school district challenges related to providing those services; and the type(s) of training(s) needed for school staff working with these children. In addition, the Special Education Office disseminated an on-line survey to the 31 special education units in the state. This survey asked special education directors to identify and prioritize the specific types of training needed by the unit staff working with children with autism. Thirty of the thirty one Special Education Units responded. The most frequently requested trainings identified by the directors were

Social Skills Instruction, Communication Systems or skills, and Behavior Supports. Teachers also expressed these needs as well. The rural directors additionally expressed the need for assistance in training and supports to retain trained personnel.

The contracting of national experts to conduct trainings in the area of Autism carries an initial significant cost. Upon research for estimated cost, the Office of Special Education has received an estimate of \$22,000 to bring in national experts to conduct three sets of trainings during a one week period. These trainings use research-based strategies to address problem behavior and communication deficits of this population. This estimated cost does not include travel expenses for the school district staff that will be participating. Although the majority of the local unit directors indicated willingness to cover travel expenses for their staff, their ability to allocate funds for this may be impacted by the federal budget cuts.

Providing ongoing embedded professional development requires a sustained funding stream in order to maintain skills that were developed in these initial trainings. The Office of Special Education intends to work to develop trained regional autism support teams which would be available to provide ongoing support to local districts. These teams would work to build the school staff capacity to provide services and supports using evidence based practices with

individuals having autism. This is a significant need in the more rural districts in the state.

In the reengrossment of this bill, the appropriation to the Department for the training as set forth in Section I was removed. The IDEA, 34 CFR §300.162 - SUPPLEMENTATION OF STATE, LOCAL, AND OTHER FEDERAL FUNDS, forbids the use of IDEA funds to pay for staff, programs, or materials that are required under state law. Supplanting would be presumed to have occurred. There currently is not money in the Department's budget for the trainings as set forth in Section I of this bill.

On behalf of the Department, I request that the committee please consider an amendment to HB 1038 to reinstate the appropriation for the department of public instruction to provide training and support to general education classroom teachers and other school staff regarding the most effective methods of educating and providing services and support to individuals with autism.

Madam Chairman and members of the Committee, this concludes my testimony. I would be happy to answer any questions the committee may have.

Comparison by Disability for Dec. 1999 through Dec. 2012

Disability	Dec 1999	Dec 2000	Dec 2001	Dec 2002	Dec 2003	Dec 2004	Dec 2005	Dec 2006	Dec 2007	Dec 2008	Dec 2009	Dec 2010	Dec 2011	Dec 2012
Autism	112	135	160	197	240	278	320	375	444	514	586	627	718	786
Deaf	43	38	38	35		2								
Deaf/Blind	3	4	4	4	1	2	2	12	8	5	5	5	4	3
Emotional Disturbance	973	1,037	1,096	1,123	1,193	1,278	1,127	1,087	1,054	995	913	836	807	792
Hearing Impairment	111	106	102	102	147	137	139	126	109	120	125	131	125	133
Intellectual Disability	1,241	1,246	1,200	1,169	1,142	1,092	970	975	906	860	801	763	755	767
Non-Categorical Delay 3-5	216	271	305	325	397	423	451	504	567	615	740	803	780	804
Non-Categorical Delay 6-9		49	132	223	260	361	433	517	555	598	671	707	743	789
Other Health Impairment	542	640	781	960	1,086	1,236	1,296	1,388	1,417	1490	1606	1634	1715	1765
Orthopedic Impairment	177	158	159	158	137	182	148	132	124	118	115	110	111	100
Speech Impairment	4,416	4,251	4,204	4,262	4,301	4,619	4,307	4,245	4,032	3644	3439	3298	3237	3087
Specific Learning Disability	5,686	5,620	5,353	5,247	5,043	4,973	4,594	4,387	4,307	4224	4159	4143	4022	4161
Traumatic Brain Injury	31	35	33	35	41	46	51	32	37	43	50	58	57	55
Visual Impairment	61	60	63	61	56	52	45	45	46	52	51	55	49	54
TOTAL	13,612	13,650	13,630	13,901	14,044	14,681	13,883	13,825	13,606	13,278	13,261	13,170	13,123	13,296

**Testimony
House Bill 1038
Senate Human Services Committee
Monday, March 11, 2013
North Dakota Department of Health**

Good morning, Chairman Lee and members of the Senate Human Services Committee. My name is Tamara Gallup-Millner and I am Director of the Division of Children’s Special Health Services for the North Dakota Department of Health. I am here to provide information regarding HB 1038.

Section 2 of the bill instructs the North Dakota Department of Health to establish and administer an autism spectrum disorder (ASD) registry that includes a record of all reported cases of ASD in the state and any other information deemed relevant and appropriate by the department in order to complete epidemiologic surveys of the ASD, enable analysis of the ASD and provide services to individuals with an ASD. Section 2 also mandates reporting of ASD cases by physicians, psychologists, or other licensed providers who are qualified to make the diagnosis and specifies that new cases reported must include the child’s birth date, gender, zip code at birth residence, and specific diagnosis. Name and address of the child are not to be included in the registry and reported children cannot be compelled to submit to medical or health examination or supervision by the department.

If HB 1038 is adopted, the Department of Health requests clarification on a number of items bulleted below in order to ensure we establish and administer a successful registry.

- The department concurs that reporting be mandatory to assure the registry will provide a complete and accurate record of all ASD cases in North Dakota. However, the department has questions and concerns regarding specific reporting requirements included in HB 1038. Clarification is needed on whether the ASD registry is intended to focus on children or if it’s meant to include all reported cases of ASD in the state. It would also be helpful to clarify the usefulness of reporting the zip code at birth residence. Although this may tell you where individuals with ASD were born, you won’t have a good indication of where cases currently are within the state. ASD is not identifiable at birth. Lastly, names and addresses of children diagnosed with an ASD are required to be excluded from the registry. This conflicts with the

requirement that the registry include information in order to provide services to individuals with ASD. The department recommends that names and addresses be included to assure reported cases can be deduplicated for more accurate statistical reporting and that contact can be made if follow-up is needed to link families to educational opportunities or other services. As with other registries maintained in the Department of Health (e.g., HIV), confidentiality would be maintained and the data kept in a secure system.

- Who is expected to establish and administer the registry and complete the epidemiologic surveys conduct analysis and provide services to individuals with ASD? Language in lines 12 through 15 of the bill differs from what was communicated when the Department of Health was initially contacted for information regarding the registry. At that point, it was communicated that only an accurate number of individuals with ASD was needed. To carry out the responsibilities as currently written in the bill, individuals would need to have a thorough understanding of the intricacies and complexities of ASD and have a background in public health informatics. Ongoing FTE would be needed to carry out this level of responsibility.
- Upon request of advocates, the Department of Health provided an initial cost estimate for a simple autism registry. With that option, ASD was to be added to an existing system, the ND Electronic Disease Surveillance System, also known as Maven. With the additional requirements of HB 1038, this system will need to be customized in order to use it for an ASD database. By the time staff is hired, the autism registry is operational, and reporting initiated, it's realistic to anticipate a two-year time frame before the system is fully functional. In addition to the added staff, additional costs include such things as maintenance costs from the system vendor, staff travel, and educational resources to create awareness for registry reporting.
- The fiscal note for HB 1038 is \$589,464 for the 2013-2015 biennium. Of that amount, \$198,000 is for the Department of Public Instruction to provide training and support to teachers and other school staff. Estimated expenditures for the Department of Health total \$391,464. This includes two full-time equivalent positions at \$291,464 and associated operating expenses at \$100,000, which are comprised of \$30,000 in general operating expenses associated with the FTE, \$30,000 for the purchase and license of a new module for the autism registry using our current MAVEN system, and \$40,000 for system maintenance and hosting fees (\$20,000 per year).

SB 2193 contains similar instruction to the Department of Health and a similar fiscal note, but has an appropriation of only \$200,648 and authorizes one full-time equivalent position.

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