

**2013 HOUSE HUMAN SERVICES**

**HB 1378**

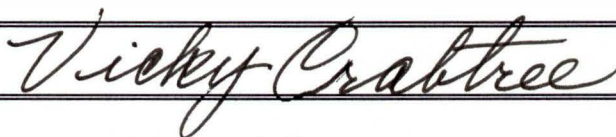
# 2013 HOUSE STANDING COMMITTEE MINUTES

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

HB 1378  
February 4, 2013  
HB 18207

Conference Committee

Committee Clerk Signature



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

DHS conduct a study of cost of services to children and provide a report.

### Minutes:

See Testimonies #1-2

Chairman Weisz opened the hearing on HB 1378.

Rep. George Keiser: Introduced and sponsored the bill. We had several meetings about individuals and dealing with children with disabilities and getting these children into waivers. From age 0-3 they are covered by one of the waivers in our state. At three years old they look at the income of the family and the function of the child and may no longer be covered by any of our programs. There is a young woman who communicates by moving her head back and forth and she communicates through a computer. She fell off at 3 and came back on at 18 and now is going away to attend a University in Florida. The department has worked hard with me to find out why these needs are not being met. Maggie Anderson said if we open their needs to the waivers we have the fiscal note will be beyond comprehension. We are asking for a study to determine if ND should have a third waiver system to address the problems these people have.

7:04 Chairman Weisz: I assume this is an internal study by the department and stakeholders.

Rep. Keiser: I believe that is the way it should be done.

8:17 David Boeck: Attorney for the Protection and Advocacy Project testified in support of the bill See (Testimony #1)

10:44 Rep. Laning: Can you elaborate more on cognitive impairments?

Boeck: Cognitive impairments used to be the key factor in mental retardation. Since they changed that term to intellectual disabilities, it is difficult to get a handle on. Cognitive impairment has to do with IQ.

Rep. Fehr: When you talk about children without cognitive impairments; do the autism folks fit in or not?

Boeck: Some children with autism would fit this definition. And some with autism also have cognitive impairments.

Rep. Fehr: Does the waiver include autism spectrum children?

Boeck: That is not what we are intending to hit. It could if the department was instructed to make that part of their study. The autism group is now being handled under an autism waiver. They have their separate waiver. They wouldn't be included in this group.

Rep. Hofstad: There is a waiver for autism for \$1.8 million of which \$822,000 (recording says million) was from the general fund. We only spent that down to \$165,000. represent Why didn't we utilize that waiver?

Boeck: We do represent children with autism. The problem with having allocated more funds for that waiver than were used is the scope of services was not as wide as many parents of children with autism would like it to have been. The group captured by the waiver was only ages 3-5.

Rep. Anderson: Why did they pick the age of 3?

Boeck: I believe the federal program is set up that way. I don't know the history behind that age.

21:13 Roxane Romanick: Representing Designer Genes of ND testified in support of the bill. (See Testimony #2)

23:49 Rep. Fehr: I got the acronym HCBS. Could I get the rest of that?

Romanick: Intellectual disabilities, developmental disability waiver.

NO OPPOSITION

Chairman Weisz closed the hearing on HB 1378.

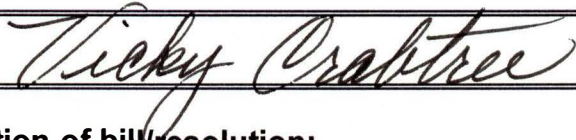
# 2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee  
Fort Union Room, State Capitol

HB 1378  
February 12, 2013  
Job #18807

Conference Committee

Committee Clerk Signature



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

DHS conduct a study of cost of services to children and provide a report.

## Minutes:

Chairman Weisz: Called the Human Services Committee to order. Let's take a look at 1378.

Rep. Fehr: I move a Do Pass on HB 1378.

Rep. Mooney: Second.

Chairman Weisz: This does have the support of the department.

ROLL CALL VOTE: 11 y 0 n 2 absent

Bill Carrier: Oversen

Date: 2-12-13  
Roll Call Vote #: 1

2013 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 1378

House Human Services Committee

Check here for Conference Committee

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

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

Motion Made By Rep. Fehr Seconded By Rep. Mooney

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) 11 No 0

Absent 2

Floor Assignment OVERSEN

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

**REPORT OF STANDING COMMITTEE**

**HB 1378: Human Services Committee (Rep. Weisz, Chairman)** recommends **DO PASS** (11 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). HB 1378 was placed on the Eleventh order on the calendar.

**2013 SENATE HUMAN SERVICES**

**HB 1378**

# 2013 SENATE STANDING COMMITTEE MINUTES

Senate Human Services Committee  
Red River Room, State Capitol

HB 1378  
4/2/13  
20764

Conference Committee

Committee Clerk Signature



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

An Act to require the department of human services to conduct a study of the cost of Services to children

## Minutes:

"attached testimony."

Chairwoman J .Lee opens the Public Hearing for HB 1378

**Roxane Romanick** representing Designer Genes of North Dakota. Testifies in support of HB 1378. **See attached testimony #1**

**Judy Bahae** PT testifies for a Do Pass HB 1378. Shares her experience working with children with disabilities that do not meet Medicaid eligibility. **See attached testimony #4**

**David Boeck** a state employee and Lawyer for the Protection and Advocacy Project. Testifies in favor for HB 1378. **See attached testimony #2. Senator Anderson** asks about another bill that was going to expand the waiver.

**Lynett Wohl** a parent of a 10yr who has a severe medical condition that limits her physically, shares her personal experience, and being denied services because she does not meet the qualifications because she has cognitive ability to make her own decisions and ask for help when needed.. Testifies in favor HB 1378. **See attached testimony #3**

**Maggie Anderson with DHS** is neutral on HB 1378. The department is ready to go forward with the study and quantify all the information. **Senator Dever** asks for clarification about services under Medicaid and services and private insurance.

**Chairwoman J lee** closes the public hearing on HB 1378

**Senator Dever** motions for a Do Pass

**Senator Larson** Seconds

**Do Pass 5-0-0**



Senate Human Services Committee

HB 1378

4/2/13

Page 2

**Senator Dever will carry.**

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

2013 SENATE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 1378

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 Dever Seconded By Lawson

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

Total (Yes) 5 No 0

Absent \_\_\_\_\_

Floor Assignment SEN DEVER

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

**REPORT OF STANDING COMMITTEE**

**HB 1378: Human Services Committee (Sen. J. Lee, Chairman)** recommends **DO PASS** (5 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). HB 1378 was placed on the Fourteenth order on the calendar.

**2013 TESTIMONY**

**HB 1378**

#1

House Human Services Committee  
Sixty-Third Legislative Assembly of North Dakota  
House Bill No. 1378  
February 4, 2013

Good morning, Chairman Weisz and Members of the House Human Services Committee: I am David Boeck, a State employee and lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the disability-related rights of people with disabilities.

Children with developmental disabilities in North Dakota can receive services under a special Medicaid waiver program if they have intellectual disabilities (formerly called mental retardation). Many children with developmental disabilities who do not have cognitive impairments cannot get services through this program.

Since the last legislative Session, several medical professionals, therapists, pediatric physiatrists, educators, parents, and other advocates have been working to get comparable services for children who have developmental disabilities but who do not have cognitive impairments. Representative Keiser has been playing a key role in support and in moving this forward.

As this Session approached, the Department of Human Services was unable to identify the number of children that might benefit from the program and the cost of the program. This bill will put proponents together

with the Department of Human Services to better define the population of children to benefit and the scope of services to be provided. This will enable the Department of Human Services to get a better handle on the goal so it can develop the information the Legislature needs to address the issues. Regrettably, these deserving children will not get coverage during the interim.

Children without cognitive impairments but with developmental disabilities include some children with cerebral palsy, spina bifida, Down syndrome, trisomy 47X, amniotic banding, arthrogyryosis, and others. Over 750 North Dakotans have signed a petition in support of coverage for this group of children.

The Protection & Advocacy Project strongly supports House Bill 1378. Thank you. Please let me know whether you have questions.

# 2

Testimony on HB 1378  
House Human Services Committee  
February 4, 2013

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I am presenting testimony representing Designer Genes of North Dakota. Designer Genes is a Down syndrome support organization consisting of 200 individuals with Down syndrome and families from across the state of North Dakota. I am here in support of HB 1378.

Our organization would like to see this issue studied as we have knowledge of children with Down syndrome that have **not been found eligible** for Developmental Disabilities Program Management and subsequently, the HCBS ID/DD waiver. Presently, the Social Security Administration uses a diagnosis of non-mosaic Down syndrome as an automatic qualifier for Supplemental Security Income thus recognizing that developmental disability is typically inherent with a diagnosis of Trisomy 21. We would like to see this study address the current requirements for eligibility and the strategies used to determine eligibility for young children.

Access to the HCBS ID/DD Medicaid Waiver has many benefits for children and their families. First off, it means that the child is eligible for an income and asset disregard and can qualify for North Dakota Medicaid. In most cases, families are underinsured with their private insurance when they have a child with Down syndrome and special health care needs. ND Medicaid acts as a secondary insurance to cover co-pays and deductibles for much-needed therapies and medical interventions. In addition, the waiver will assist families with in-home supports and/or respite care, travel expenses, equipment and supplies, and behavioral supports. All of these are highly beneficial for our families raising children with Down syndrome and assuring that they are able to maintain their current jobs and family.

I know that you are considering the passage of HB 1305, which is a bill to ban abortions in instances of sex-selection and genetic abnormalities. Down syndrome is specifically noted in this bill. I am hoping that the committee will agree with me that passage of HB 1378 sends a message to North Dakota's families that we are working to improve our system of supports and that families do not have to fear having a baby with Down syndrome. Studying this issue will make North Dakota a better place to raise children with Down syndrome and other disabilities.

We would be very willing to work with the legislature and Department of Human Services on providing further information about our concerns if the study resolution is passed. I would be willing to answer any questions that you may have.

Roxane Romanick  
Designer Genes Board President  
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#1

Testimony on HB 1378  
Senate Human Services Committee  
April 2, 2013

Chairman Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I am presenting testimony representing Designer Genes of North Dakota. Designer Genes is a Down syndrome support organization consisting of 200 individuals with Down syndrome and families from across the state of North Dakota. I am here in support of HB 1378.

Our organization would like to see this issue studied as we have knowledge of children with Down syndrome that have **not been found eligible** for Developmental Disabilities Program Management and subsequently, the HCBS ID/DD waiver after the age of 3. Presently, the Social Security Administration uses a diagnosis of non-mosaic Down syndrome as an automatic qualifier for Supplemental Security Income thus recognizing that developmental disability is typically inherent with a diagnosis of Trisomy 21. We would like to see this study address the current requirements for eligibility and the strategies used to determine eligibility for young children.

Access to the HCBS ID/DD Medicaid Waiver has many benefits for children and their families. First off, it means that the child is eligible for an income and asset disregard and can qualify for North Dakota Medicaid. In most cases, families are underinsured with their private insurance when they have a child with Down syndrome and special health care needs. ND Medicaid acts as a secondary insurance to cover co-pays and deductibles for much-needed therapies and medical interventions. In addition, the waiver will assist families with in-home supports and/or respite care, travel expenses, equipment and supplies, and behavioral supports. All of these are highly beneficial for our families raising children with Down syndrome and assuring that they are able to maintain their current jobs and family.

The children that I discussed earlier will not currently qualify for the current ND Medically Fragile Waiver or the Autism Waiver. They may access the ND Children with Disabilities Medicaid Program depending on their family's income and assets, but with this program, there are no waiver supports such as in-home/respite care, equipment and supplies, behavioral intervention, or environmental modifications. Even as hard as we've worked on this issue, we continue to have a gap that this study can address.

I am hoping that the committee will agree with me that passage of HB 1378 sends a message to North Dakota's families that we are working to improve our system of supports and that families do not have to fear having a baby with Down syndrome. Studying this issue will make North Dakota a better place to raise children with Down syndrome and other disabilities.

We would be very willing to work with the legislature and Department of Human Services on providing further information about our concerns if the study resolution is passed. I would be willing to answer any questions that you may have.

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Senate Human Services Committee  
Sixty-Third Legislative Assembly of North Dakota  
House Bill No. 1378  
April 2, 2013

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As this Session approached, the Department of Human Services was unable to identify the number of children that might benefit from the program and the cost of the program. This bill will put proponents together

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Children without cognitive impairments but with developmental disabilities include some children with cerebral palsy, spina bifida, Down syndrome, trisomy 47X, amniotic banding, arthrogryposis, and others. Over 780 North Dakotans have signed a petition in support of coverage for this group of children.

The Protection & Advocacy Project strongly supports House Bill 1378. Thank you. Please let me know whether you have questions.

Please support house bill 1378 to conduct a study of the cost of providing services to children with a disability & support needs.

I have a 10 year old daughter who has a severe medical condition that limits her physically. She has never been able to sit up on her own, crawl, stand or walk independently.

Her muscles are so weak that she cannot pick up a book with both hands that the rest of us could easily pickup with a few fingers, yet she was denied services under the developmental disability waiver because she has the cognitive ability to make her own decisions and ask for help when needed. She is not able to complete a single simple task from start to finish. She can feed herself however she does not have the strength to open the drawer to get her eating utensils. She can brush her teeth however she does not have the strength to squeeze the toothpaste out onto her toothbrush.

She has therapy weekly, medication and breathing treatments daily and sleeps with a Bi Pap machine nightly. She is required to have 24 hour supervision.

When our daughter turned 3, my husband and I went through a long, frustrating appeal process requesting services to continue beyond age 3, but were denied due to her cognitive ability.

She is very blessed to have the ability to tell people when she can feel her pain or ask someone to lift her head up for her because she has become too fatigued to physically have the strength to lift her head back upright. Such a simple task most of us can do easily.

However having this ability to communicate verbally SHOULD NOT be the reason she or any child be denied from a waiver to help children with a severe disability.

There is a huge gap in the system that needs to be filled for our children between the ages of 3-18, especially for our children who are aware of their physical limitations, who deal with the same issues all children, pre-teens and teenagers deal with, to fit in with peers and just enjoy life as any child and teenager should, yet they understand the struggles they as a family deal with everyday. It may be financially, mentally or physically on all family members as they may be working full time outside the home and/ or is the full time caregiver with no respite care or in home support system due to this gap in the system.

It just isn't right that families who face so many challenges should have to work so hard to go through the numerous applications, make a ton of phone calls, stress out over the appeal process hoping to find a waiver that they MAY be eligible for, that MAY help their child have a decent quality of life.

Thank you for allowing me to share my story and please consider passing this bill.

Lynette Wohl

## Testimony in Support of HB 1378

Good morning Members of the Senate Human Services Committee. My name is Judy Bahe. ~~I am a physical therapist and manager of the children's therapies at Sanford Rehabilitation Center here in Bismarck.~~ I would like to thank you for the opportunity to speak in favor of and to ask for your support of HB 1378.

I am a physical therapist who has worked with children and their families here in the Bismarck-Mandan region for 30 plus years. Throughout that time, there have been several families who have had children with significant functional limitations due to severe developmental disabilities but after the age of 3, they have been determined ineligible to receive any waived services through the Medicaid because the child did not have an IQ score of 70 or below. This greatly impacted these families especially in terms of in-home supports, respite care services and equipment. These services, if available, assist the family in being able to keep the child living in the natural home environment with supports as needed for daily activities, mobility, learning, recreation and respite for the parents. These families have made many concessions and have gone through various appeal processes which they have described as very intimidating and terrifying. I do not feel it is fair to these families to have to fight this hard to keep their child living safely with them in their own home and to be part of the natural family unit.

There seems to me to be a lapse of services available for children between the ages of 3 and 18, who have significant physical limitations but do not have an intellectual deficit. This bill would require the Department of Human Services to conduct a study to determine the extent of this lapse of services.

Please give HB 1378 a "Do Pass" recommendation so this issue will be studied and results reported to the 64<sup>th</sup> legislative assembly.

Thank you.