

**FISCAL NOTE**  
**Requested by Legislative Council**  
**02/05/2015**

Amendment to: SB 2234

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

	2013-2015 Biennium		2015-2017 Biennium		2017-2019 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

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

	2013-2015 Biennium	2015-2017 Biennium	2017-2019 Biennium
Counties			
Cities			
School Districts			
Townships			

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

Engrossed SB 2234 provides for the Department of Human Services to study eligibility for developmental disability waivers and to report to Legislative Management by January 1, 2016.

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

Engrossed SB 2234 has no fiscal impact. The information that would need to be gathered for this study would be assigned to current department staff.

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

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*
- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*
- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.*

**Name:** Debra A McDermott

**Agency:** Human Services

**Telephone:** 328-3695

**Date Prepared:** 02/06/2015

**FISCAL NOTE**  
**Requested by Legislative Council**  
**01/16/2015**

Bill/Resolution No.: SB 2234

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

	2013-2015 Biennium		2015-2017 Biennium		2017-2019 Biennium	
	General Fund	Other Funds	General Fund	Other Funds	General Fund	Other Funds
Revenues						
Expenditures						
Appropriations						

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

	2013-2015 Biennium	2015-2017 Biennium	2017-2019 Biennium
Counties			
Cities			
School Districts			
Townships			

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

SB 2234 allows an individual diagnosed with Down syndrome to automatically meet the criteria for developmental disability without regard to intellectual disability or impairment of general intellectual functioning and to be eligible for medical assistance.

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

The Department cannot calculate the fiscal impact until we understand the details from the bill sponsors and advocacy organizations about the scope of change and its impact on DD and Medicaid expenditures.

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

- A. **Revenues:** *Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.*
- B. **Expenditures:** *Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.*
- C. **Appropriations:** *Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation or a part of the appropriation is included in the executive budget or relates to a continuing appropriation.*

**Name:** Debra A McDermott

**Agency:** Human Services

**Telephone:** 328-3695

**Date Prepared:** 01/27/2015

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**2015 SENATE HUMAN SERVICES**

**SB 2234**

# 2015 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

SB 2234  
1/28/2015  
22694

☐ Subcommittee  
☐ Conference Committee

Committee Clerk Signature



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

A bill relating to Down Syndrome and eligibility for medical assistance

## Minutes:

Attach #1: Testimony by Roxane Romanick  
Attach #2: Testimony by Beth Nodland  
Attach #3: Testimony by Stacey Castleman  
Attach #4: Testimony by David Boeck  
Attach #5: Designer Genes Brochure  
Attach #6: Written testimony by Michelle Ragan  
Attach #7: Written testimony by Dionne Spooner  
Attach #8: Written testimony by Katie Rizzo

**Senator Dever** introduced SB 2234 to the committee. When dealing with children with special needs, special children lines up with special parents. When a child turns 3 years old and their eligibility for continued services under developmental disabilities. At age 3, they are evaluated to consider if eligibility continues. If a child is diagnosed with down syndrome, they are able to continue their eligibility. There is not a consistent method across the state.

**Senator Terry Wanzek** testified IN FAVOR of SB 2234. He provided testimony about his personal story, his sister who has Down Syndrome who came to his childhood home through foster care. Objective is to try to help those parents who has a child with down syndrome. (end 5:54)

**Senator Howard Anderson, Jr.** why the down syndrome individual who could otherwise pay for themselves - why should we treat them differently than other disabled individuals, such as someone with genetic issues such as missing leg.

**Senator Wanzek** answered he wasn't sure he could answer. His sister needs oversight, still needs cognitive support.

**Roxane Romanick**, representing Designer Genes of ND, Inc., testified IN FAVOR of SB 2234 (attach #1) (7:41-20:00). Ms. Romanick also provided a Designer Genes brochure. (attach #5).

**Senator Warner** asked are there other conditions where diagnosis would indicate a certainty of development disabilities. Are there metabolic diseases which would show up the inability to process a protein which would be genetic which would cause diminishment in mental facility by the age of three, and the simple diagnosis would be a determining factor.

**Ms. Romanick** deferred to a solid medical professional. They can't be tested if they have an intellectual disability and our current ability to assess is limited. They are out there, but she doesn't want to be the one to name them.

**Chairman Judy Lee** indicated PKU and proper syrup that they will end up with intellectual disabilities.

**Beth Nodland** testified IN FAVOR of SB 2234 (attach #2) (22:45-30:05). Ms. Nodland provided personal testimony in regards to her child.

Recess

**Chairman Judy Lee** indicated fiscal note.

**Stacey Castleman** testified IN FAVOR of SB 2234 (attach #3) (31:04-42:00). Ms. Castleman provided personal testimony of her child.

**Mr. David Boeck**, Protection and Advocacy Project, spoke IN FAVOR of SB 2234 (attach #4) (43:11-44:32)

**Chairman Judy Lee** asked how many other diagnosis will be under this umbrella. If we pass this with down syndrome, what about the other people with other issues?

**Mr. Boeck** indicated he doesn't know the answer to that. Look at down syndrome as a sample group to see how the system works for providing services, learn from that. Goal last session was to come up with a way to serve children with continuing and substantial needs for services and support. We did not come up with a program, so this is one effort.

No testimony In Favor.

#### Neutral Testimony

**Chairman Judy Lee** asked about HB 1378, what has transpired?

**Maggie Anderson**, Executive Director for the Department of Human Services, stated last session HB 1378 to study over the interim when children fall off at age 3. Eligibility criteria, etc, should we amend the existing development disability waiver or create a new one. So we convened work group, "build a waiver document", defined the gap, eligibility criteria defined. Through that conversation, the advocacy organization including parents. Maggie Anderson (DHS) can't quantify how people we are talking about. **Chairman Judy Lee** indicated we have no registry. **Maggie Anderson** (DHS) continued that we have drafted a level of need tool, using Oregon rating schedule tool, we looked at waiver and the developmental disability waiver. These are the needs that my children have, and they are

not going to score on the developmental disability test. Drafted a level of need, all waivers have to have a level of care. That tool is drafted. If legislature wants us to modify the fragile waiver, you adjust. If legislature says they don't want to expand, Department of Human Services will still move forward to use the level of need tool. The tool is not final at this point. We provided work group and appropriations committee, for every additional 15 children that we would serve; it would cost \$770,000 of which \$385,000 would be general fund for 18 months. That is the outcome of HB 1378. Maggie Anderson (DHS) indicated she can provide the supporting documents.

**Senator Howard Anderson, Jr.** stated that he thought what he heard from families that they did not qualify even if they are below three years of age based on criteria. Is that correct?

**Tina Bay**, Developmental disabilities division of Department of Human Services, they were eligible for services under early intervention program under 3. We do test for adults for children over 3. Our criteria are intellectual disability. If a person does not have a diagnosis of intellectual disability, we then have to look for a related condition, and we have to use functional limitations for eligibility.

**Senator Axness** the population he looks at that the developmental disabilities waiver is the best thing. State Department of Health agrees with this. But why are we creating new waivers with new eligibility requirements, where people fall in gaps. Why not build on the developmental disabilities waiver. Waiver process since that works, consistent, simplify, one universal waiver with a menu of services.

**Maggie Anderson** (DHS) we talk about that all the time. In work group, if legislature wants to expand the waiver, our preference would be to expand an existing waiver. We can't model after Developmental Disabilities because some are very specific for aged population, technology waiver that is very specific, so may limit services if we went under one waiver.

**Senator Axness** recommended a menu of services for a universal waiver. You don't get everything, but just what they need. The fiscal note wouldn't be for paying for all services for everybody.

**Maggie Anderson** (DHS) the requirement of CMS is not that straightforward.

**Senator Howard Anderson, Jr.** asked if we expanded the current waiver, will the criteria be the same if we moved the age to 5.

**Maggie Anderson** (DHS) stated that if we were to change the redetermination period to age 5 instead of 3, that will have implications to Part C dollars because that's what we use for infant development. There are a lot of other funding streams in the developmental disability waiver. Maggie Anderson (DHS) doesn't want to say it's not a possibility, but we would have to look at all the funding streams to early intervention services and Medicaid state plan.



**Senator Howard Anderson, Jr.** how does the Department of Human Services view the addition of a particular genetic criteria as far as setting aside the other criteria. What problems does that cause?

**Maggie Anderson** (DHS) referred to Ms. Romanick testimony. We wanted to hear the dialog. We need discussion with CMS, because it is based on intellectual disability. It is based on level of care. It's based on the criteria we set up in the waiver. We have not set up the waiver to say, with this diagnosis or that diagnosis. There may be other individuals who have other diagnosis who will then request.

**Senator Howard Anderson, Jr.** do you see the language that's in this bill now making people eligible who weren't eligible before, I'm not in favor of telling a particular family that they don't have to spend their own money because they have a particular genetic predisposition. Some of what he heard this morning was that. Their deductibles are too high, while other people who have other abnormalities bear the same situation. Do you see that what's in this bill setting that aside and making them eligible for service regardless of their own ability to pay?

**Maggie Anderson** (DHS) indicated that would be the effect. Department of Human Services takes a neutral position on this. It would make the individuals eligible for Medicaid without looking at income and assets.

**Chairman Judy Lee** can you do that now under the waiver?

**Maggie Anderson** (DHS) answered for children who are eligible, it is based on the child's income and we don't look at the assets.

**Chairman Judy Lee** there is an overlap at that three year age between services Department of Human Services provides and the school.

**Amanda Carlson**, Department of Human Services, Children and Family Services administration for development disabilities, spoke about early intervention (Part C). We coordinate with children who are ages 3 to 5 services, which Part B is coordinated by the Department of public instruction, in regards to Section 619 of the Individuals with Disabilities Education Act. Families that were in early intervention we assist transition to Part B if parents are seeking both services, and determining if eligibility is available for them on the Part B side. If developmental disability waiver services may no longer available, they may be potentially eligible for Part B. However the delivery method is different, as Part B is focused around the education component. Part C is a family model.

**Chairman Judy Lee** asked for cheat sheet for part B and part C.

**Ms. Carlson** discussed early intervention, which are a home based service. So we are providing therapists, speech pathologists, social workers, nurses, etc., so we can help meet any need. In pre-school, they also have therapists and services, but focus is on educational aspect. Part C or early intervention will often include family in the plans. The IEP would rarely contain information on family situations.



No more neutral testimony

OPPOSITON TO SB 2234

No opposing testimony

Closed Public Hearing

Written testimony was electronically received from the following people:

- **Michelle Ragan** (attach #6)
- **Dionne Spooner** (attach #7)
- **Katie Rizzo** (attach #8)

# 2015 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

SB 2234  
2/2/2015  
22994

☐ Subcommittee  
☐ Conference Committee

Committee Clerk Signature

*Donald Mueller*

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

A bill relating to Down Syndrome and eligibility for medical assistance

## Minutes:

Attach #1: 2013 HB 1378 Information

**Chairman Judy Lee** noted that who can't say that we support the idea of children having all appropriate services. She indicated that she struggles with one particular diagnosis move forward when there are other needs for other persons that don't move forward. She also recognized the differences between high function and high need, and she also recognizes the difficulty in testing a 2 year old.

**Senator Dever** provided explanation of why the bill came forward. It appears there are different standards in district 7 then other areas of state. There have been 8 children who have been denied services because of the difference in the way they evaluate. Perhaps there is a different way of working through, protection advocacy indicated possible lawsuit. Perhaps more to this bill. Not about expanding services, but equal access to services that are available.

**Chairman Judy Lee** how do we assure there is consistent assessment throughout the state for these services.

**Senator Dever** indicated the Department of Human Services may not be aware of this.

**Senator Howard Anderson, Jr.** if that's the problem, rather than saying all Down Syndrome children are eligible, then maybe we have an appeal process where they could have a different evaluator.

**Senator Dever** not sure if he's the best person to carry discussion, there is a psychological review that takes place in district 7 that doesn't take place elsewhere.

**Maggie Anderson** (DHS) after the hearing, she did talk with other parents. Indicated that there could be some inconsistencies, and that more training is needed. It is possible the other seven regions are doing it incorrectly. The final decision is done by professionals, and professional discretion is there for that clinician. The committee previously asked what

it will cost, and that data is still being researched. If we have big differences, no matter what program in the state, between regions, we want to look at that and train. Maggie Anderson (DHS) also provided SB 1378 information from last session. (attach #1)

**Chairman Judy Lee** stated the other 7 could end up like the 8. Some kind of assessment is critical to see if it is consistent. I'm sure it isn't just Down Syndrome issue.

**Maggie Anderson** (DHS) stated that when Tina Bay comes tomorrow, they will discuss the importance of with a Medicaid waiver, you have to meet a level of care. Within the waiver, you have to pick which institutional level those children would otherwise be served in, if not for the waiver, so our choices are nursing home, hospital, or intermediary care facilities. Children also need to meet that level of care requirement. Tina plans to bring back summary information.

# 2015 SENATE STANDING COMMITTEE MINUTES

Human Services Committee  
Red River Room, State Capitol

SB 2234  
2/3/2015  
23145

☐ Subcommittee  
☐ Conference Committee

Committee Clerk Signature

*Donald Mueller*

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

A bill relating to Down Syndrome and eligibility for medical assistance

## Minutes:

No Attachments

**Roxanne Romanick** indicated that she testified last week and provided an afterthought. Assuring that there are already a number of people who have down syndrome that receive developmental disabilities services, this is not new, and said she wishes she knew how many there are. From the time we started to de-institutionalize, they were among the folks who were eligible for developmental disabilities. Knowing that we supported these before both in our institutions and with our home and community based waiver, is to try to streamline the process so that these families aren't having to do psychological testing to determine that their child has a developmental disability when we know that the diagnosis carries that. It is rare that down syndrome doesn't have developmental disabilities.

**Chairman Judy Lee** the flip side, is that there are other maladies that also end up with developmental disability, and we aren't naming any other condition. It means you zip through the fast line on this one. We care about the kids, but struggle that we would fast track one set of children. Is there some other way that we can have an appeals process or look at the evaluation. It is causing trouble for us.

**Senator Howard Anderson, Jr.** along the lines just mentioned, not opposed to raising the age limit or review process, but hesitates if there is one specific genetic disorder. Realize that is tough for the evaluations. We all go through evaluation to get services.

**Chairman Judy Lee** what would the situation be if age was raised to 5?

**Ms. Romanick** stated that in her testimony, we are generally broadly concerned about eligibility determination for children. Children with Down syndrome end up being part of the fall out. She thinks that it warrants some look at how we are making determination under developmental disabilities for the children. She cannot identify the best age for the test, but worthy to look at it. We've had a problem who are clearly developmental disabilities falling through the cracks in the waivers. There is room to continue to look at the situation.

**Chairman Judy Lee** if we extended the age two years, to age 5, and included a study to look at eligibility deamination, that would give us 2 years for these children to see if there is a need for these children. That may provide an opportunity.

**Senator Howard Anderson, Jr.** asked if Maggie Anderson (DHS) if that was a possibility to just increase the age. Didn't just hear that these children weren't over three, but objected to the way the evaluations were done even if under the age 3.

**Ms. Romanick** indicated it is the practice in helping children transition out of the early intervention program, to transition try to do the eligibility testing for developmental disabilities and special education, which are two separate eligibility processes around the ages of 2 years, 9 months. It is rare that they don't developmental disabilities. On Medicaid waiver up to age 3 even though testing happens before that. The practices differ around how eligibility or what criteria and what tools need to be in place to do that eligibility. That is when we see folks falling off of the waiver.

**Tina Bay**, Department of Human Services, we did ask Centers for Medicare and Medicaid Services (CMS) if we could have a diagnosis with specific waiver, so down syndrome automatic eligibility into the waiver and CMS said no. You need to have that functional limitation as well as the diagnosis, and right now the waiver is for intellectual disabilities. As far as looking at increasing age for early intervention from 3 to 5, several funding mechanisms, we could extend that eligibility, several options, but to get to the details of which funding, there would be an impact. We serve 800-900 kids in the infant development for age 0 to 3. If we were only going to access Part C money, it does not come with the Medicaid match. As a department, we have recognized that that criteria at age 3, adult criteria, has some gaps for children, so we have group of psychologists are working with division looking at criteria and eligibility and see if we need to change the criteria. Maybe they should change the tool, and look at several different levels. Maybe align more with education purposes, at age 12 they look at different IQ test.

**Senator Howard Anderson, Jr.** stated that he likes the approach that we are taking. Is there anything in this bill that we can do to help?

**Maggie Anderson** (DHS) talked about this in the department. They would be fine if there was an amendment for a study in Department of Human Services and report back to interim committee by 01/01/2016.

**Senator Howard Anderson, Jr.** made a motion to ADOPT AMENDMENT, to direct the Department of Human Services to study the issue of eligibility for developmental disabilities waivers and report back to the interim by January 1, 2016, and hog house the bill. The motion was seconded by **V. Chairman Oley Larsen**. No discussion.

Roll Call Vote to ADOPT AMENDMENT for SB 2234

6 Yes, 0 No, 0 Absent. Motion passed.

**Senator Dever** made motion to DO PASS SB 2234 as Amended. The motion was seconded by **V. Chairman Oley Larsen**. No discussion.



Senate Human Services Committee

SB 2234

02/03/2015

Page 3

Roll Call Vote to DO PASS SB 2234 As Amended

6 Yes, 0 No, 0 Absent. Motion passed.

**V. Chairman Oley Larsen** will carry SB 2234 to the floor.

On 02/04/2015, Senator Warner voted YES for the amendment and voted YES on SB 2234 as amended.

February 4, 2015

TD  
2/4/15

PROPOSED AMENDMENTS TO SENATE BILL NO. 2234

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a department of human services study.

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

**SECTION 1. LEGISLATIVE MANAGEMENT STUDY.** The department of human services shall study eligibility for developmental disability waivers and report to the legislative management by January 1, 2016."

Renumber accordingly

Date: 02/03 2015  
Roll Call Vote #: 1

2015 SENATE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. SB2234

Senate Human Services Committee

☐ Subcommittee

Amendment LC# or Description: Study, Log House

Recommendation: ☒ Adopt Amendment  
☐ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation  
☐ As Amended ☐ Rerefer to Appropriations  
☐ Place on Consent Calendar

Other Actions: ☐ Reconsider ☐ \_\_\_\_\_

Motion Made By Anderson Seconded By Larsen

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	✓		Senator Tyler Axness	✓	
Senator Oley Larson (V-Chair)	✓		Senator John M. Warner	✓	
Senator Howard C. Anderson, Jr.	✓				
Senator Dick Dever	✓				

Total (Yes) 6 No 0

Absent 0

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

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

Date: 02/03 2015  
Roll Call Vote #: 2

**2015 SENATE STANDING COMMITTEE**  
**ROLL CALL VOTES**  
BILL/RESOLUTION NO. SB 2234

Senate Human Services Committee

☐ Subcommittee

Amendment LC# or Description: 15.0546.01001 Title. 02000

Recommendation: ☐ Adopt Amendment  
☒ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation  
☒ As Amended ☐ Rerefer to Appropriations  
☐ Place on Consent Calendar

Other Actions: ☐ Reconsider ☐ \_\_\_\_\_

Motion Made By Dever Seconded By Larsen

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	✓		Senator Tyler Axness	✓	
Senator Oley Larson (V-Chair)	✓		Senator John M. Warner	✓	
Senator Howard C. Anderson, Jr.	✓				
Senator Dick Dever	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment Larsen

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

**REPORT OF STANDING COMMITTEE**

**SB 2234: Human Services Committee (Sen. J. Lee, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2234 was placed on the Sixth order on the calendar.

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to provide for a department of human services study.

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

**SECTION 1. LEGISLATIVE MANAGEMENT STUDY.** The department of human services shall study eligibility for developmental disability waivers and report to the legislative management by January 1, 2016."

Renumber accordingly



**2015 HOUSE HUMAN SERVICES**

**SB 2234**

# 2015 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Fort Union Room, State Capitol

SB 2234  
3/17/2015  
Job #24940

- ☐ Subcommittee  
☐ Conference Committee

Committee Clerk Signature

*Beckie Struge*

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

Provide for a Department of Human Services study on eligibility for disability waivers.

### Minutes:

Testimony #1, #2

Chairman Weisz opened the hearing on SB 2234.

**Roxane Romanick:** Executive Director of Designer Genes of ND, Inc. testified in support of the bill. (See Testimony #1)

8:42

**Chairman Weisz:** You stated individuals were rejected for services. Can you explain why?

**Romanick:** They all went through the testing. The eligibility is very complex. They were found to either not have an intellectual disability, or they were found to not have the amount of functional limitations needed to meet the eligibility test.

10:07

**Stacey Castleman:** I am one of the families not getting the services. My daughter was 2 when she went for testing to determine the eligibility as a child who was already diagnosed with Down syndrome. She was frightened as she didn't know the lady and it was a strange place, and as a result she did not test to her ability. We were rescheduled a number of times over the next two months. We got the test results that she failed. The recommendations were that my daughter continue her occupational, physical and speech therapy to address her multiple areas of need. All the services that were recommended were discontinued - they said her IQ was too high. My daughter was not disabled enough. My daughter needs these services. It would be nice to have the services she needs without fighting for them. I'm asking you to please support this bill.

**Rep. Fehr:** Do you mean the original bill or the study bill?

**Castleman:** It bothers me that you want to study this another two years - because that's another two years wasted.

**Chairman Weisz:** In your daughter's case, it was recommended to have all the services that she didn't qualify for, because the IQ test was too high?

**Castleman:** Correct.

**Chairman Weisz:** They recommended all the services, but she was kicked out strictly because of the IQ?

**Castleman:** Correct. I was told that they suggested that she come back because that score would probably be about where we're at that time. They set them up for failure.

**Sen. Dick Dever:** I am a Senator from District 32. This bill, as introduced would have provided a child with Down syndrome would automatically qualify for a DD waiver. The reason for the bill is one region evaluated them on different standards than the other seven regions. It is important we have equity across the state. Maggie Anderson, from Human Services, didn't know there was a problem and suggested a study. This would be a Human Services study, and they can look at their procedures and how that happens. I don't have any problems if you support the original bill.

**Chairman Weisz:** Was there any indication on the Senate side that there would be a potential issue if you were to pass the original bill, any unintended consequences?

**Sen. Dever:** I don't think there was a downside to passing the original bill. The concern is there may be other children with other circumstances that might be affected by the same thing.

**Rep. Mooney:** In that same context, wouldn't it make sense to consider reverting back to the original bill and then amending it asking DHS to do the study?

**Sen. Dever:** I would appreciate that, but will leave it to this committee.

**Rep. Porter:** The one component on the fiscal impact section...

**Sen. Dever:** I think the fiscal note indicates as they did in the hearing that they weren't sure what the intent of the bill was, and didn't initially see the problem.

25:00

**David Boeck:** Lawyer for the Protection & Advocacy Project testified in support of the bill. (See Testimony #2)

**NO OPPOSITION**

Hearing closed on SB 2234.

# 2015 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee  
Fort Union Room, State Capitol

HB 2234  
3/17/2015  
Job #25016

☐ Subcommittee  
☐ Conference Committee

Committee Clerk Signature

*Beckie Struge*

## Minutes:

Chairman Weisz opened the meeting on SB 2234.

**Chairman Weisz:** With the engrossed bill this becomes a study.

**Rep. Porter:** In the fiscal note, it appears they really don't know what they aren't doing correctly. I think leaving it as a study for the interim gives them a chance to figure it out. If the original bill passed as it is, they won't be able to change anything that fast without first studying it.

**Rep. Mooney:** Why couldn't you revert back to the original bill as it was brought to the Senate, then include that study piece as a last section within the bill itself? Then we could insure the children with Down syndrome who would qualify for assistance would then get the needed assistance while the department is doing their due diligence.

**Chairman Weisz:** Sen. Lee, my question is from your committee's respective what did you see if you had turned it into a study?

**Sen. J. Lee:** Our concern was individuals who make use of these services also who are not diagnosed with Down syndrome who would also make use of these waivers. Testimony from the department was the level of need and services required that are more appropriate to consider when discussing the waivers, rather than the diagnosis that lead to the level of need and the services required. We are back to knowing whom we have to serve and whether they are high function or high need.

Also, the department learned there was a problem with the evaluations in one region that was different from all the others. The bill was to fix that problem and provide consistent eligibility determination so that the services could be made available appropriately everywhere.

**Rep. Oversen:** Was there any conversation in your committee about the study from last session? They were directed to study providing services for ages between 3 and 21 on a Medicaid waiver.

**Sen. J. Lee:** I can't recall. If you need more information please do inquire about that - they would be eager to answer any questions.

**Rep Porter:** I move a do pass on SB 2234.

**Rep Fehr:** Seconded the motion

**A roll call vote was taken for a DO PASS. Yes: 12 No: 0 Absent: 1**

Representative Bert Anderson will carry the bill.



Date: 3-17-15  
Roll Call Vote #: 1

2015 HOUSE STANDING COMMITTEE  
ROLL CALL VOTES  
BILL/RESOLUTION NO. 2234

House Human Services Committee

☐ Subcommittee

Amendment LC# or Description: \_\_\_\_\_

Recommendation: ☐ Adopt Amendment  
☒ Do Pass ☐ Do Not Pass ☐ Without Committee Recommendation  
☐ As Amended ☐ Rerefer to Appropriations  
☐ Place on Consent Calendar  
Other Actions: ☐ Reconsider ☐ \_\_\_\_\_

Motion Made By Rep. Porter Seconded By Rep. Fehr

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Rep. Mooney	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Vice-Chair Hofstad	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Rep. Muscha	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Rep. Bert Anderson	<input checked="" type="checkbox"/>	<input type="checkbox"/>	Rep. Oversen	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Rep. Dick Anderson	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Rich S. Becker	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Damschen	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Fehr	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Kiefert	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Porter	<input checked="" type="checkbox"/>	<input type="checkbox"/>			
Rep. Seibel	<input checked="" type="checkbox"/>	<input type="checkbox"/>			

Total (Yes) 12 No 0

Absent 1

Floor Assignment Rep. B. Anderson

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

**REPORT OF STANDING COMMITTEE**

**SB 2234, as engrossed: Human Services Committee (Rep. Weisz, Chairman)**  
recommends **DO PASS** (12 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING).  
Engrossed SB 2234 was placed on the Fourteenth order on the calendar.

**2015 TESTIMONY**

**SB 2234**

**SB 2234**

**Down Syndrome and Developmental Disabilities Eligibility**

**Senate Human Services**

**Wednesday, January 28, 2015**

Madam Chair Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes represents 140 individuals with Down syndrome and their families across the state of North Dakota, about a quarter of the state's 600 residents with Down syndrome. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong. My passion and interest in Designer Genes is primarily driven by my opportunity to be Elizabeth Romanick's mom, who I'd also like to see earn, learn, and belong.

I am here to ask your support for SB 2234 which would establish that persons with a diagnosis of Down syndrome be automatically eligible for Developmental Disabilities (DD) services without the undue burden of additional cognitive and functional testing, after the age of 3 and through their lifetime. It is the intent of this language to assure that the individuals are both eligible and are able to be screened for the Intellectual Disabilities/Developmental Disabilities (ID/DD) Home and Community Based Waiver. Presently, Designer Genes is aware of eight individuals with Down syndrome that were not found eligible for DD services. We are also concerned about the onerous, and what we feel to be, unnecessary testing that individuals with Down syndrome must endure in order to determine that they have a developmental disability which is already established through their diagnosis. We feel like this is not a good use of our resources as families, as a community, or as a state.

In order to streamline the efficiency of determining eligibility for the federal Supplementary Security Income (SSI) Program, the Social Security Administration uses Down syndrome (non-mosaic type) as a presumptive disability category. The presentation of the lab report or a doctor's statement confirming the diagnosis is the only documentation needed to determine medical eligibility for SSI. We would like the same consideration in North Dakota for purposes of determining eligibility for Developmental Disabilities and access to the Medicaid waiver that they manage.

I'm going to make an assumption today that I don't have to give you much of a tutorial on Down syndrome. I'll save that for Appropriations if you allow this bill to move forward with a "Do Pass". This is a difficult piece of legislation for me to talk about because I spend most of my time focused on portraying positive messages about the potential of individuals with Down syndrome. I also spend most of my personal time helping my 15 year old daughter, Elizabeth, to live up to her potential. But today, I have to talk to you about some of the more harsh realities of having Down syndrome, one of which is living with intellectual disabilities. Intellectual and developmental disabilities inherently comes with extra chromosome material.

Every medical reference that exists regarding Down syndrome associates the diagnosis with intellectual and developmental disabilities. Down syndrome is present before birth and is life-long. This has not

changed no matter how advanced we've become in medicine, psychology, and or education. If you need the references, I'll produce them, but I think the community at large knows this fact.

If you don't mind, I'd like to use a family story of sorts to help you better stand in the shoes of our families:

*You are relieved to hear that the state DD system has been willing to reach out to families who have found out that their babies are going to be born with Down syndrome. While they are unable to make your baby eligible for any formal services, they do use their resources to meet with you and get you information about ND Early Intervention, DD services, and other formal supports in the state. This is extremely valuable for you because you are scared stiff about the future with their new little one. It is good to hear that babies with Down syndrome are considered "high-risk" in our state, and so automatic eligibility for DD services can happen at birth.*

*You come to discover that little ones under 3 years of age experience amazing services in our state. You have access to Infant Development (ID) services which bring an array of professional staff (PT, OT, Speech, etc.) to your home through a home visitation model. You have access to a DD Program Manager. Your little one is screened for the ID/DD Medicaid Waiver, so has a family income and asset disregard in order to access State Plan Medicaid. Medicaid then acts as a secondary insurance because you are lucky enough to have a primary insurance. This is critical because Down syndrome is associated with a high number of medical conditions and you worry about being underinsured with only your primary insurance. The ID/DD Medicaid waiver also assists you with in-home supports (respite), equipment and supplies, travel expenses, and home modifications if you need these services.*

*When your child gets to be about 2.5, your team starts talking to you about what happens when your child turns 3. They start to explain that the supports as you currently know them may not continue because new eligibilities for both special education and DD services must be determined. While it would be extremely rare to find a child with Down syndrome who was not eligible for special education in our state, the greater challenge is the eligibility for DD. Even though you vaguely remember this, you are told the loss of DD means that you will lose access to your program manager, in-home supports, assistance with travel expenses, etc. In addition, the loss of the ID/DD Medicaid waiver means that your child loses additional state plan Medicaid coverage. Understanding what must happen in order to maintain the current services you have for your child is very difficult to understand. It is explained to you that your child must be eligible because their disability is due to an intellectual disability or a related condition that is similar and then on top of that you must justify your need for a waiver service, such as in-home supports, and then, just when you think you've understood, you find out that your child must also meet the criteria for the Level of Need screening into the Medicaid Waiver.*

*You are told that in order to determine DD eligibility your child's diagnosis of Down syndrome is not enough and at the age of 2.5 – 3 years old, it must be additionally determined that they have a diagnosis of an intellectual disability. Mind you, that this just so happens when you are starting to see the more striking differences in development from your child and their peers. You were hoping that you had somehow dodged the ID bullet – call it denial, call it hope, but the age of 3 just seems to bring some of these new thoughts on.*

*You take your child for the testing because the supports have been critically important to your family. Your child is uncooperative appreciating the dank, coolness underneath the psychologist's desk versus the bright, shiny testing objects that they are attempting to get your child to manipulate. Every parent sits there and thinks "You are not seeing what my child can*



*really do – why are we here? Don't they understand that my child has Down syndrome – isn't that enough?" In the mean time, you have now sat through around 5-8 meetings of different sorts because your child is turning 3.*

*Because having additional therapies becomes very critical at this stage, you wonder what you'll do if you lose Medicaid. You are just starting to think that you need additional care giving because it's more difficult to supervise and manage your child when you go out or need to get something done at home. If you're not eligible, there is no other support for this in ND until your child turns 18 or you enter into the child welfare system.*

**It is our belief that this complicated process for determining DD eligibility, including the additional cognitive and functional testing is unnecessary, inefficient, and inappropriate when Down syndrome itself is known to be married to a diagnosis of intellectual and developmental disability. We are asking that you help the Department to streamline and ease this process for individuals and their families.**

Last week, I testified in front of Senate Appropriations about the legislation that was passed in the 63<sup>rd</sup> Legislative Assembly – HB 1378. This legislation read: "shall identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but whom, at the age of three years, no longer qualify for services under the developmental disabilities waiver." This concern that I'm rising about children with Down syndrome not being found eligible is related to the larger issue of assuring that all children with developmental disabilities have the needed services and supports in our state. Addressing this issue of finding individuals with Down syndrome eligible based on diagnosis is like putting a band-aid on a wound that needs stitches. Don't get me wrong...I still want the band-aid. However in the same vein (no pun intended), I'm attaching my testimony regarding the Department's study which includes additional recommendations that I would like this committee to consider. These call for a dedicated FTE as well as funding to pay for a consultant to assist the Department in assuring appropriate services and supports to our ND children with developmental disabilities.

When I held Elizabeth in my arms moments after her birth, I remember thinking that we were so lucky as a family that she was born in a time when no one was going to come into our hospital room to tell us that the best place for her was in the state institution at Grafton. Many families before us had that experience and worked hard to make a change for those of us that came after. The truth is that Grafton was full of persons with Down syndrome – it was their only option. It is possible that they were housed there based on their mere physical features. The roots of our DD system were built on serving people with Down syndrome. Let's continue to honor the promises made in the Arc lawsuit to assure that community based services are available to those that would otherwise be institutionalized.

Thank you for your time. I'd be willing to answer any questions.

Roxane Romanick  
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A • DOWN • SYNDROME • SUPPORT • NETWORK

## Down syndrome and Developmental Disabilities Eligibility Determination Fact Sheet

***Designer Genes asks your support of SB 2243 to streamline the determination of eligibility for persons with Down syndrome and assure services.***

- ✓ According to the Centers for Disease Control, Down syndrome occurs 1 in every 691 births. It is estimated that 1 in every 1200 persons has Down syndrome. Based on this estimate, approximately 600 individuals living with Down syndrome reside among us in ND.  
<http://www.cdc.gov/ncbddd/birthdefects/features/key-findings-down-syndrome-prevalence.html>
- ✓ Designer Genes' membership represents 140 individuals with Down syndrome population in ND.
- ✓ The primary outcome for the legislation is to remove undue burden from individuals with Down syndrome and their families, who must demonstrate that a developmental disability is present. This occurs even though it is widely known in the professional community and the community, at large, that this population of individuals has a diagnosis that is known to cause a permanent intellectual disability and functional concerns.
- ✓ While individuals with Down syndrome show immense capacities for growth and independence in functioning, the extra copy of the 21<sup>st</sup> chromosome is still associated with delays in cognitive development, ranging anywhere from mild to severe.
- ✓ State Developmental Disabilities services and state plan Medicaid are necessary for individuals with Down syndrome and their families to continue to live independently in their communities.
- ✓ The Social Security Administration recognizes the medical diagnosis of Down syndrome as a presumptive disability, meaning that no further disability information is required to meet the disability determination criteria. (Non-mosaic Down syndrome)
- ✓ Presently, psychological testing (including cognitive and adaptive behavior domains) is being required for eligibility determination for Developmental Disability Program Management services over the age of 3. It is our belief that this testing is unnecessary, inefficient, and inappropriate when Down syndrome itself is known to be closely associated with a diagnosis of intellectual and developmental disability.
- ✓ Designer Genes is familiar with eight ND families that have individuals with Down syndrome that were found not eligible for Developmental Disabilities services at the time they were exiting ND Early Intervention services.





**SB 2012**

**Department of Human Services Budget  
Long-Term Care and Medical Services: Relating to HB 1378 (63<sup>rd</sup> Legislative Assembly)  
Tuesday, January 20, 2015**

Chairman Holmberg and Members of the Senate Appropriations Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc. Designer Genes represents 140 individuals with Down syndrome and their families across the state of North Dakota. This represents approximately 25% of the Down syndrome population in ND. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

I would like to thank the Department for following through on the study bill (HB 1378) that passed last legislative session. However I do not feel like we're done studying this issue about access for services for children with disabilities in our state.

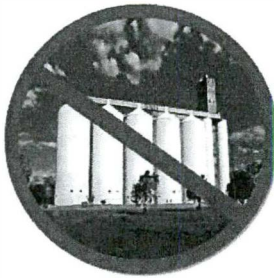
Here are some of the issues as I currently see them:

- The HB 1378 Stakeholders group worked on a new assessment tool for the Level of Need within the Medically Fragile waiver in order to make it more accessible for children with significant health care needs. At this time, it is unknown whether this tool will actually do what everyone hopes which is to assure that children will not realize a gap in services.
  - I would like to commend the Department of continuing to attempt to fix the access issue; however today children who you would assume should access the waiver cannot due to the assessment tool and the scoring instrument.
- Maggie Anderson testified yesterday that the Division for Developmental Disabilities discovered that the Supports Intensity Scale, which is the new assessment tool the DD Division is rolling out in working on a new payment system with the DD providers, does not work for children. This means that they are currently working on a new assessment tool and potentially a new approach to eligibility and determining Level of Need for the ID/DD waiver for children.
  - The current eligibility and assessment process for the ID/DD waiver can be onerous and in my opinion, inappropriate for young children and their families. Again, children who you would assume should access the waiver cannot. Presently, I know of children with Down syndrome that were found not eligible for the ID/DD waiver. SB 2234 has been introduced to attempt to address this concern and to make Down syndrome an automatic qualifier for DD.
- The current Children's with Disabilities Medicaid Buy-in program is underutilized as a possible resource.
- We continue to build the Autism services program which is good for our children with Autism; however adds to the complexity of our service delivery system for families.
- We know from the Schulte report that services for children with behavioral and mental health issues are scattered, scarce, and difficult to access.

- 1.6
- Currently, the Autism waiver, the Medically Fragile waiver, and the ID/DD Waiver (including Birth to 3 Early Intervention services) are all administered in different programs within the Department of Human Services. And while we haven't talked about it, the Children with Special Health Care Needs is in a totally different department, being under the Department of Health. While I don't mean in any way to downgrade the Department's administration of these programs, this does add to the complexity for families as they are trying to find the right answers.

I believe that we can do better. Every time that I've come to this Legislative Assembly to ask for help for children with special health care needs, you've responded in a way that shows you care. Perhaps I'm part of the problem, because I've certainly advocated for many of the pieces that I've just talked about. Maybe that's the beauty of getting older is that you can see the full picture in a way that you couldn't when you were young.

I'm hoping that those of you that are farming, don't take my visual personally, but I think that we may need to adopt this symbol for the benefit of our families in the state that are working hard to make the best life for their child with disabilities and/or special health care needs. We need to break down the silos of service delivery for our children. If we can't break them down, then we definitely need to figure out how to build a connecting ladder or tunnel system to make them easier to move around in.



I am requesting that this committee consider an amendment to SB 2012:

- To appropriate adequate funding to conduct a comprehensive legislative study of ND's delivery system for children with special health care needs and/or disabilities.
  - I would suggest that this study include the Department of Health.
  - The funding for the study should be adequate enough to hire a consultant with a national perspective on state and Medicaid funded programs for children as well as adequate funding for stakeholder involvement, which would include families.
  - It would be important to assure that the findings are published and available for public consumption.
- To appropriate funding for at least a part-time FTE in the Department to serve as a cross-department and inter-departmental liaison which can assist Legislative Management and the Department in conducting the study and other duties as assigned.
  - My suggestion is that this liaison answer directly to Maggie Anderson in DHS and Dr. Dwelle in the Department of Health and not be designated to a particular department or division.
- To appropriate additional funding to the Department to assist with the resolution of the issue regarding assessment tools.

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J# 22694

Attach#2

SB2234

01/28/2015

**Testimony of Beth Nodland Regarding SB2234** Eligibility Determination Process for Developmental Disability Program Management in ND



John G. Morrison and I have a son, Lochlan Morrison, who is now 6 years old. Loch was diagnosed with Down syndrome at birth. Our family participated in intensive Early Intervention services since day two of his life, including OT, PT, Speech, case management, home visits, hearing testing, etc. We know how important EI is to help people achieve the most they can.

**Eligibility Testing**

- At age 2.75, we began eligibility continuation testing for Loch at WCHS
- Met with other parents at a Designer Genes family event, talked:
  - A teacher said it was first time he didn't want his kid to do well
  - Should we keep him up all night? Give him caffeine?
  - First time your kid officially gets the dreaded label: "mentally retarded."
- During the testing, as it got more difficult, Loch signed for "help" "more" "please"
- When refused help, he refused to continue
- Went back 2 times = he was deemed "untestable" but still given a number
- Bell curve = ours just above "mental retardation," therefore ineligible
- Other parent said their kid's assessment was same, until later, tested substantially lower
- Sat in Dr.'s office for discussion: "you have a checkers not chess kid"
- "He'll have a good job bagging groceries at Walmart one day"
- Had just come from a Family Voices conference where we met Joe Steffe's a young man who has Down Syndrome and Autism, who also owned his own kettle corn business. We were thinking entrepreneurial, about the possibilities.

**Eligibility Meeting at WCHS**

- a. Loch in hospital, had been four times that winter, upper respiratory issues, RSV, pneumonia,
- b. Held in a darkened room, nine people, knee to knee, most of whom had never met Loch
- c. Worked through the checklist
- d. "Will he be able to ride the bus to his job at Walmart someday?"
- e. Someone said "This is crystal ball time"
- f. What about other families in Bismarck who didn't know they could attend the hearings?
- g. How many 3 year olds in Bismarck lose their services? What happens to those families?

Thank you for your time. Please support SB2234, so the diagnosis of Down syndrome is used as an automatic qualifier. **Beth Nodland, 1111 W. Highland Acres Rd., Bismarck, ND 58501 (701) 527-7022**

J# 22694 Attach#3  
SB2234  
01/28/15

Madam Chair Lee and Members of the Senate Human Services Committee:

My name is Stacey Castleman. I come here this morning with my 3 year old daughter, Ari. In addition to Ari, I have three boys ages 15, 11, and 10. And can't forget a wonderful husband.

To be honest with all of you, I'm still in shock that I even need to be here. I guess this is just another mountain my family needs to climb. I'm here to tell you about the life of a princess. The very princess standing here in front of all of you being as brave as she continues to be through the battles we continue to face.

#### Princess Ari

In 2010, I found myself waiting in my doctor's office for what seemed like forever. I was prepared to hear the big C word. Why else, after an ultrasound, would I need to wait forever! To make this part short, basically, we were done having children. Oops! Guess not! We were blessed with a less than 1/2% chance baby! The surprises kept coming. We later found out we were expecting a GIRL! At almost 29 weeks, the princess made a surprise appearance via C-section due to lack of nutrition in the womb. Arriving at 2 1/2 pounds she was whisked away. All I wanted was to hear her cry. I never got to hear that first cry. It was several hours later before I was able to meet the Princess. I looked down at this tiny angel and emotions came flooding out. She was beautiful, but so tiny. Was she going to live? How could she be strong enough? What would we do if we lost her? She could fit in the palm of my husband's hand. (Pictures and candy)

We were finally able to meet with the doctor. Princess Ari was a micro preemie. Because she was so little, we were not able to hold her. We could touch her through the holes on the isolet. However, we weren't even allowed to do that very much because it would overstimulate her creating a loss of weight. Princess was just like all her other roomies, hooked up to whatever machine they could attach. They were very concerned about her lung development since most of us know the lungs are one of the last things to develop. After 3 days, the princess showed us what a fighter she was going to be. She was weaned of oxygen within the first week. A miracle in and of itself as that is not the norm with micro preemies, some of them being on oxygen for months and months.

After a few days, we met with the doctor wherein he informed us that Ari had Trisomy 21. I love my daughter so much! But I will not lie to you. I had the same feeling as one would have losing a loved one. I felt I had lost everything! The dancing little girl, painting our nails, eating gallons of ice cream watching movies, her first sleep over, going to school, her first boyfriend, shopping, first kiss, the big dance, driving a car, college, a new job, getting married, and kids of her own. I was lost. You see, these are the things society has us believing when it comes to trisomy 21.

I had no idea what to do from there. You would think after three kids I would be able to say "I got this!"

But it was like being a first time mother. It was, at this time, I met Roxane from Designer Genes. Finally, someone who was able to pick me up and carry me through the doors of my new life. Roxane will probably tell you I didn't go through that door very willingly. I was scared to death.

Roxane has already testified about the wonderful services that are provided in the first three years. But I would like for you to know what they have done for princess Ari. Many of the obstacles that doctors told us Ari would never overcome, she has. Many of the milestones that would never be met, have been met.



Because of all the hard work through her therapy sessions and the work that our whole family has done at home with Ari, she is thriving. She is a three year old, although small, with a mind of her own willing and able to do what she wants when she wants. She may be delayed in some things, but there is no doubt in my mind that those delays will be overcome.

The testing that Roxane mentioned in her testimony is something I am far too familiar with. The days of those testing are hard to forget, as a parent....

It all started the end of May, 2014, Ari and I attended an appointment where they started the testing to determine her eligibility as a child who had been diagnosed with down syndrome. The first day of testing was a struggle. Ari is quite strong willed and she didn't exactly partake in the testing like they wanted her to. Mind you, she was a 2 year old, going into a strange office, with strange people wanting her to do things that she didn't want any part of. As her mother, I knew what she was capable of doing and knew the results of the test were not going to show her abilities adequately. In my head, I thought, who are these strangers to tell me how my daughter can't do certain things, when really she just didn't want to do them.

The rest of the testing had to be rescheduled a number of times due to illnesses on either Ari's part, the family's, or the examiners. By the time the testing was over, it was two months later, the end of July. The examiner went over the results of the test in person with me. I listened...I left...I cried. No parent wants to hear about how their child is failing...in anything. No parent wants to hear that their child will have difficulties to overcome. No parent wants to label their own child as being different than other children.

And that is exactly what I, my family, has never done. We don't talk about any syndrome at home. We don't think of Ari as any different than any other child. She is our princess. She is MY life!

That report, the findings from the testing, to be honest with you, I never actually sat down to read it until two days ago. I couldn't. I never wanted anyone to see it. Until last night, when I let a friend of mine read it to help me to write up this testimony. To help me get through the struggle I was having in trying to not label my child and to continue to be positive.

The recommendations were: (list recommendations)

- 1) It is recommended that Ari continue with her occupational, physical, and speech therapy and early intervention services to address her multiple areas of need. It is also recommended that her family continue to support Ari in Maintaining and gaining her adaptive and cognitive skills.
- 2) It is recommended that Ari be seriously considered for ongoing services due to significant delays and some adaptive delays.
- 3) It is recommended that in a few years Ari again receives cognitive and adaptive testing to determine how she is progressing.

Although this is what had been recommended, all services were discontinued. For years now, Ari had been getting therapy of all kinds. Along with all the attention and work we did at home. It was making a difference. And now, all those services are gone. All because she turned 3 years old.

I hope that my personal story about the Princess you see here with me today will help to encourage you all to move this bill forward with a "Do Pass."



Thank you for your time,

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Stacey and Ari Castleman

Senate Human Services Committee  
Sixty-Fourth Legislative Assembly of North Dakota  
Senate Bill No. 2234  
January 28, 2015

Attach #4  
SB 2234  
11/28/15  
J# 22694

Good morning, Chairman Lee and Members of the Senate 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.

Ms. Romanick knows far more about Down syndrome than I do. I cannot knowledgeably discuss characteristics or incidence of Down syndrome.

But I am aware of how the bill began and why it is important. Last session HB 1378 passed optimistically aiming for the launch of a Medicaid waiver program "to provide coverage for children who have continued and substantial medical and support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver." The Legislature had hoped to learn the estimated number of children that would be eligible, criteria for the provision of services under the waiver, identification of services to be offered, and a timeline for implementation of the waiver.

This ambitious goal could not be accomplished. The proposal for children with Down syndrome could provide a smaller test run for a program that would provide services to needy children who would otherwise go unserved.

SB 2234 could establish a program to serve some children who are not being served through a Medicaid waiver. This would not provide an estimate of the number of other unserved children. It would not create a new eligibility instrument. But it might demonstrate whether children currently left out of the system could be served effectively and appropriately under the package of services and supports presently available through an existing Medicaid waiver program.

I strongly support the passage of SB 2234. This might provide some evidence for further expansion to unserved, needy children.

Please let me know if you have questions. Thank you.



## OUR MISSION

**To strengthen opportunities for individuals with Down syndrome and those who support them to learn, earn and belong**

## CIRCLES OF SUPPORT

Three circles of support shape the work of Designer Genes: Learning, Earning and Belonging. These circles represent the triplicate copy of the 21st chromosome, as well as wholeness, completeness and protection. Designer Genes embraces people as they are, aiming to create supportive and protective communities.

### LEARNING

Designer Genes believes learning is a powerful tool and works to empower and educate professionals, parents and the community.

### EARNING

Designer Genes strives to find earning opportunities for members and the organization through education, employment, independence and support.

### BELONGING

Designer Genes believes everyone has the right to belong and works to create connections, opportunities and outcomes.

## ABOUT DOWN SYNDROME

Down syndrome isn't a disease. It is a chromosomal abnormality that affects about one out of every 700 babies.

- Down syndrome affects people of all races and income levels.
- Down syndrome is a trait – not a condition or affliction.
- People with Down syndrome have 47 chromosomes instead of the usual 46. Most people have two copies of chromosome 21; Down syndrome occurs among people who have a third copy.
- People with Down syndrome may have mild to moderate intellectual disabilities, low muscle tone and higher chances of some health conditions.
- People with Down syndrome lead fulfilling lives. They attend school, hold jobs, participate in decisions that affect them, get involved in community activities and contribute to society.
- High-quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to develop to their full potential.



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Attach #5  
01/28/2015  
22694  
SB2234



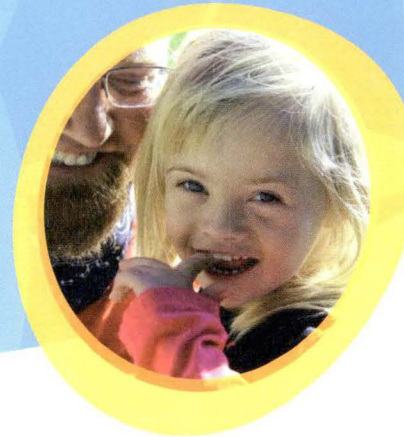


## WITH A LITTLE HELP FROM OUR FRIENDS

Designer Genes enjoys the generous support of individuals, businesses and organizations in the Bismarck-Mandan area and beyond. The non-profit organization receives donations at the annual Buddy Walk, as well as grants and charitable contributions. For a complete list of funding sources, go to [DesignerGenesND.com](http://DesignerGenesND.com).

## DESIGNER GENES FAMILIES KNOW HOW TO HAVE FUN!

- **BUDDY WALK**
- **FAMILY PICNIC**
- **BOWLING PARTY**
- **ICAN SHINE - BIKE CAMP**
- **SUPPER WITH SANTA**
- **BOOK FAIR & STORY TIME**



## OUTREACH

**To North Dakota families:** Designer Genes helps fill gaps in information and services available to families who receive a Down syndrome diagnosis.

**To schools and communities:** We are more alike than different – Designer Genes works to build understanding of this important message among educators and the public.

## GROWING THROUGH A SHARED JOURNEY

Now more than 300 members strong, Designer Genes serves families across the state, working to strengthen opportunities for people with Down syndrome and those who support them. Designer Genes provides encouragement and information to help families, whether it's dealing with a pre-natal or at-birth Down syndrome diagnosis or assisting them throughout the lifespan.

Designer Genes took root in the early 1980s when a group of Bismarck-Mandan parents shared the challenges and rewards of raising children with Down syndrome. Over the years, this network of families broadened their support system by reaching out to others with the same diagnosis.

**To healthcare professionals:** With considerable expertise in supporting people with Down syndrome, Designer Genes is a valuable asset and partner to the medical community.

**To government officials:** Designer Genes advocates for the value, acceptance and inclusion of people of all abilities, not only Down syndrome.

## IMPACTING EXCEPTIONAL PEOPLE *Page 2*

Designer Genes' outreach efforts improve the quality of life for people with Down syndrome and their families. The organization touches families throughout North Dakota by:

- Providing early visits and informational packets to families of babies with Down syndrome
- Organizing and hosting family activities and networking events
- Sponsoring an annual Buddy Walk, one of 250 Down syndrome advocacy and awareness walks in the nation
- Partnering with educators for improved awareness of the abilities and challenges of students with Down syndrome
- Providing information to healthcare professionals
- Advocating for state and federal policies and legislation to support the provision of services for people with Down syndrome





**From:** Michelle Ragan [mailto:m.ragan.445@gmail.com]  
**Sent:** Monday, January 26, 2015 9:59 AM  
**To:** Lee, Judy E.  
**Subject:** SB2234

Attach #6  
SB2234  
01/28/15  
UH 22694

Dear Senator Lee,

I am writing in support of SB2234. I work as an occupational therapist in the early intervention program. Early intervention is a state and federally funded program for families of children with special needs. We work together with the parents and their child, in the home from birth to age 3.

Passage of this bill would alleviate much anxiety and fear for parents as their child turns 3. It would provide uniformity across the state (as often some children qualify and others do not) and one less hoop and meeting and appointment, as they enter preschool and school-age years of IEP meetings and navigating a confusing system. Continuous eligibility would provide them with their same DD program manager to help with IEP meetings and any other special health care issues that arise. Having a child with special needs is difficult. It takes advocacy, determination and having people "on your side." I have a 5th grader with a reading learning disability and having an advocate is so important to me and, yet, I have very few issues that call for an advocate or more people "on my side."

Be "on the side" of children with Down syndrome and vote "yes" on SB2234.

Thank you for your time  
Michelle Ragan



SB 2234  
01/28/15  
J# 22694  
attach#7

**From:** Dionne Spooner [mailto:dionne.l.spooner@minotstateu.edu]

**Sent:** Monday, January 26, 2015 9:43 AM

**To:** Lee, Judy E.; Dever, Dick D.; Axness, Tyler; Anderson, Jr., Howard C.; Larsen, Oley L.; Warner, John M.

**Subject:** SB2234

Dear Senators,

I am writing to you not only as a Licensed Independent Clinical Social Worker who has worked with those with Down syndrome but also as a mother of a 5 year old son who has Down syndrome. I am a North Dakota native who has been educated, lived and worked in North Dakota my entire life. I have been a practicing social worker for over 20 years and have taught at Minot State for the past 4 years. I have had the opportunity to not only work as an advocate for Developmental Disability services for clients but also for my own son after he was born. Due to my work experience, I was able to understand the process and ask the questions that many other parents simply are not aware of. I also was fortunate to have workers whom I personally knew who could help me when I felt lost. This is simply not the case with most families. I truly felt like our DD program was good until I had to experience it personally. The paperwork and hoops that are required for services are extremely daunting and even though I understand the necessity of such elements, it does not alleviate the stress that parents/caregivers experience in completing all of those steps. With that being said, DD services are essential to our son and our family and I would not want to even imagine what it would be like if we did not have them. We also are recipients of Medicaid for our son as a secondary insurance source and without such services I am certain that we would be filing for bankruptcy by now. Our son requires specialized eye care which has required regular trips to Minneapolis as well as surgery. In addition, he requires so many additional providers due to his diagnosis including; podiatry, cardiology, physical therapy, occupational therapy, speech, audiology, endocrinology. My son has 4 doctors simply to care for his eyes and without each and every one of them he would most likely not be reading today. I would never want to imagine that we would have to make a choice that would harm my son or his development because we could not afford it. Our son is a rather healthy young boy who does not have any significant major medical issues yet he still requires all of these providers and the cost of just the co-pays with our own private insurance would be staggering. I thank GOD every day that we have Medicaid. With that being said, the stigma that exists with Medicaid is still very prominent and I have had many unpleasant experiences utilizing Medicaid including them denying our out of state care once because I saw a physician at his private office at the hospital instead of at the children's clinic because the scheduler made a mistake when I made the appointment. On another occasion, our pediatrician submitted prior authorization several months before our trip to the cities and we never received formal approval only to receive a denial after we returned. The denial was unfounded but it took me several hours, several phone calls and my own investigation to find out that the denial was made without sufficient information. I don't want to sound negative because as I have said, we truly are thankful for the services and I am not sure where we would be without them but I also think that many times there is this assumption that it is all so seamless and beneficial for recipients and that is simply not the case. I want you all to understand what it is like for a parent of a little one who was brought into this world just like any other baby to navigate the world of disabilities and to understand that I simply want the best for my child just as anyone else does for their own children. I have two older children who are "normal" so to speak and I advocate for them but it seems that when advocating for those whom have a DD we have to advocate just a bit louder. Please feel free to contact me at my office number or my cell phone 701-721-8978 any time if you want me to share or answer any of your questions and THANK YOU for addressing this important issue.

Dionne L. Spooner, MSW, LICSW  
Social Work Instructor  
Minot State University  
500 University Ave W.  
Minot, ND 58707  
(701) 858-3142 phone

**From:** Katie Rizzo [mailto:katie-rizzo@hotmail.com]

**Sent:** Saturday, January 24, 2015 9:06 PM

**To:** Lee, Judy E.; Larsen, Oley L.; Anderson, Jr., Howard C.; Axness, Tyler; Dever, Dick D.; Warner, John M.

**Subject:** SB 2234

Attach#8  
01/28/2015  
SB 2234  
J# 22694

Dear Senators:

I am writing to you in support of SB 2234 (Medical Assistance for Individuals with Down Syndrome). This bill is set for a hearing before the Human Services Committee on Wednesday, January 28.

My son has Down Syndrome. He will be three years-old in May.

He has gross motor, fine motor, cognitive, and speech delays, but we are oh so very proud of how far he has come.

He attends a regular daycare center with "typical" children. He started walking a few months ago, does sign language, and uses silverware. He loves music, books, and cuddles. He has a tendency to pull his sister's hair.

He would not be where he is today without therapy.

He receives occupational therapy, physical therapy, and speech therapy for a combined total of eight times per week. This therapy is prescribed by his physician.

My husband and I are employed full-time and have health insurance through my employer. Our insurance does not cover all of his therapy bills. Without having Medicaid as a secondary insurer, we could not afford to continue therapy for our son after our insurance benefits are exhausted.

Some might say we should just cut back on his therapy sessions. However, our son needs regular, consistent, intensive therapy, because it takes him longer to learn. Some might say we should discontinue his therapy altogether if we can't afford it on our own. However, as parents, we want him to be as successful as he can be and see therapy as a key component of that. The more successful and independent he is able to be over the long term, the more beneficial it is for him, our family, our community, and our State.

I ask your support for SB 2234 to provide Medicaid benefits for all individuals with Down Syndrome.

Thank you.

Katie Rizzo

429 Prescott Place

West Fargo, ND 58078



02/02/15  
Attach#1  
SB 2234

# 2013 House Bill 1378 — Estimated Cost

	TOTAL	General Fund	Federal Funds
For Every 15 children added to Waiver*	\$ 770,436.00	\$ 385,218.00	\$ 385,218.00

\* 18 months - January 1, 2016 Implementation

## Assumptions:

15 new children would use \$1,580.50 per month in waiver services

15 new children would also incur an average of \$1,191.20 of other Medicaid costs per month

Average of \$50 per month per child for fiscal agent costs

Medical costs were inflated by 4% in July 2016

Attach#1  
SB 2234  
02/02/15  
J#22994

## Department of Human Services

### Report on 2013 HB 1378 – Provided to Senate Human Services

Excerpt from Maggie Anderson – DHS Overview testimony on 2015 SB 2012

#### 2013 House Bill 1378

- *The department of human services, during the 2013-14 interim, shall identify the estimated cost to implement a medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver. In preparing the estimate, the department shall secure input from stakeholders, including families, providers, and advocates. The department of human services shall report its findings to the sixty-fourth legislative assembly. The report shall include the estimated number of children eligible, criteria for the provision of services under the waiver, the services to be offered, and a timeline for implementation of the waiver.*

The Department coordinated a workgroup that included parents, advocates, Legislative representation and Department staff. The workgroup met regularly throughout the interim with the final meeting held in July 2014.

As of result of the collective work of the group, the Department is providing this report as required in 2013 HB 1378.

**Number of Children Eligible:** This was an area that was a struggle when this study was first contemplated, and we are no closer to being able to quantify the number of children who would be eligible.

**Criteria for the Provision of Services:** The group worked from a “build a waiver” worksheet (Attachment A) which identifies the criteria that the group would propose for a new or amended waiver.

**Services to be Included:** Attachment A also contains the proposed services.

**Timeline for Implementation of the Waiver:** If there is direction and an appropriation to amend the existing Children’s Medically Fragile Needs Waiver, the Department expects a January 1, 2016 implementation. If there

1.3

is direction and an appropriation to initiate a new waiver, specifically for this population, the Department would expect a July 1, 2016 implementation.

**Estimated Cost:**

	TOTAL	General Fund	Federal Funds
For Every 15 children added to Waiver*	\$ 770,436	\$ 385,218	\$ 385,218

\* 18 months - January 1, 2016 Implementation

**Assumptions:**

15 new children would use \$1,580.50 per month in waiver services

15 new children would also incur an average of \$1,191.20 of other Medicaid costs per month

Average of \$50 per month per child for fiscal agent costs

Medical costs were inflated by 4% in July 2016

Funding for a new waiver or an expansion of an existing waiver is not included in the Executive Budget recommendation.

**SB 2234**  
**Down Syndrome and Developmental Disabilities Eligibility**  
**House Human Services**  
**Tuesday, March 17, 2015**

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes represents 140 individuals with Down syndrome and their families across the state of North Dakota, about a quarter of the state's 600 residents with Down syndrome. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong. My passion and interest in Designer Genes is primarily driven by my opportunity to be Elizabeth's mom, who I'd also like to see earn, learn, and belong.

I am here to ask your support for SB 2234. This bill was originally written to address two problems in ND. We have children who have Down syndrome in our state that are not being found eligible for Developmental Disabilities Program Management and thus the Home and Community Based Services (HCBS) waiver. In addition, the state is requiring IQ testing that is a waste of resources as a family, community, and state. Presently, Designer Genes is aware of eight individuals with Down syndrome that were not found eligible.

Down syndrome is typically diagnosed prenatally or at birth by a blood test that reveals a panel with three copies of the 21<sup>st</sup> chromosome. You and I have 2 copies. The extra genetic material creates the physical, medical, and cognitive patterns that you usually associate with Down syndrome. While advances in medicine, education, and family support have enhanced the quality of life for persons with Down syndrome, the challenges associated with an intellectual disability and medical issues continue to need to be addressed through services and supports that are available through our public system.

In order to streamline the efficiency of determining eligibility for the federal Supplementary Security Income (SSI) Program, the Social Security Administration uses Down syndrome (non-mosaic type) as a presumptive disability category. The presentation of the lab report or a doctor's statement confirming the diagnosis is the only documentation needed to determine medical eligibility for SSI. We would like the same consideration in North Dakota for purposes of determining eligibility for Developmental Disabilities and access to the Medicaid waiver that they manage.

Presently, the state has carved out a waiver for children with autism. You need to be diagnosed with autism, show functional limitations and you are eligible for the Autism waiver. Down syndrome is a diagnosed medical condition with practically a 100% guarantee that you will have an intellectual disability and functional impact, so why is that not enough? On average parents endure around 6 – 8 appointments/meetings at the time their child's turning 3 and transitioning out of Early Intervention in order for their child to qualify for special education and continued DD services. This is a waste of their time and our time.



The services under DD and the waiver are important services for all of our individuals with Down syndrome. Access to all of the waiver supports depending on someone's age is critically important to keeping folks active and productive in their homes and communities. In addition, the safety net that ND Medicaid can provide for needed therapies and medical care is also needed.

Major changes were made to the bill in the Senate; in fact all of the original language to change the statute around the definition of developmental disability was removed. What's before you today is a study by the DHS. Last session, legislation was enacted to direct the Department of Human Services to study the issue of eligibility for children with disabilities (HB 1378). This legislation read: "shall identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but whom, at the age of three years, no longer qualify for services under the developmental disabilities waiver." Today, no practices or administrative code have been adjusted because of the study enacted by HB 1378. What assurances need to be in place for change to occur by 2017?

Presently, SB 2012 contains language for a similar study by Legislative Management as well as funding to assist with the study. This concern that I'm rising about children with Down syndrome not being found eligible is related to the larger issue of assuring that all children with developmental disabilities have the needed services and supports in our state. But we will be four years out since we started studying the issue and will the studies, whether Department or Legislative, make a difference?

I would like to see stakeholder involvement that includes families added to the bill language as well as ongoing public reporting that is accessible on the Department's website. I would like to see language included that would assure that this issue specifically addresses this issue for our individuals with Down syndrome as well as others.

When I held Elizabeth in my arms moments after her birth, I remember thinking that we were so lucky as a family that she was born in a time when no one was going to come into our hospital room to tell us that the best place for her was in the state institution at Grafton. Many families before us had that experience and worked hard to make a change for those of us that came after. The truth is that Grafton was full of persons with Down syndrome – it was their only option. It is possible that they were housed there based on their mere physical features. The roots of our DD system were built on serving people with Down syndrome. What I really wish is that somehow we could talk about supporting our ND children and families without talking about our children's weaknesses, without feeling like we are not contributing because we are asking for help, and without having to say our family will fall apart without the services. The very essence of asking for help can be more emotionally terrifying and devastating than having a child with a disability. I wonder if it needs to be.

Thank you for your time. I'd be willing to answer any questions.

Roxane Romanick  
Executive Director  
Designer Genes of ND, Inc.  
701-391-7421  
romanick@bis.midco.net



## **Down syndrome and Developmental Disabilities Eligibility Determination Fact Sheet**

***Designer Genes asks your support of SB 2243 to streamline the determination of eligibility for persons with Down syndrome and assure services.***

- ✓ According to the Centers for Disease Control, Down syndrome occurs 1 in every 691 births. It is estimated that 1 in every 1200 persons has Down syndrome. Based on this estimate, approximately 600 individuals living with Down syndrome reside among us in ND.  
<http://www.cdc.gov/ncbddd/birthdefects/features/key-findings-down-syndrome-prevalence.html>
- ✓ Designer Genes' membership represents 140 individuals with Down syndrome population in ND.
- ✓ The primary outcome for the legislation is to remove undue burden from individuals with Down syndrome and their families, who must demonstrate that a developmental disability is present. This occurs even though it is widely known in the professional community and the community, at large, that this population of individuals has a diagnosis that is known to cause a permanent intellectual disability and functional concerns.
- ✓ While individuals with Down syndrome show immense capacities for growth and independence in functioning, the extra copy of the 21<sup>st</sup> chromosome is still associated with delays in cognitive development, ranging anywhere from mild to severe.
- ✓ State Developmental Disabilities services and state plan Medicaid are necessary for individuals with Down syndrome and their families to continue to live independently in their communities.
- ✓ The Social Security Administration recognizes the medical diagnosis of Down syndrome as a presumptive disability, meaning that no further disability information is required to meet the disability determination criteria. (Non-mosaic Down syndrome)
- ✓ Presently, psychological testing (including cognitive and adaptive behavior domains) is being required for eligibility determination for Developmental Disability Program Management services over the age of 3. It is our belief that this testing is unnecessary, inefficient, and inappropriate when Down syndrome itself is known to be closely associated with a diagnosis of intellectual and developmental disability.
- ✓ Designer Genes is familiar with eight ND families that have individuals with Down syndrome that were found not eligible for Developmental Disabilities services at the time they were exiting ND Early Intervention services.



## OUR MISSION

**To strengthen opportunities for individuals with Down syndrome and those who support them to learn, earn and belong**

## CIRCLES OF SUPPORT

Three circles of support shape the work of Designer Genes: Learning, Earning and Belonging. These circles represent the triplicate copy of the 21st chromosome, as well as wholeness, completeness and protection. Designer Genes embraces people as they are, aiming to create supportive and protective communities.



### LEARNING

Designer Genes believes learning is a powerful tool and works to empower and educate professionals, parents and the community.

### EARNING

Designer Genes strives to find earning opportunities for members and the organization through education, employment, independence and support.



### BELONGING

Designer Genes believes everyone has the right to belong and works to create connections, opportunities and outcomes.



## ABOUT DOWN SYNDROME

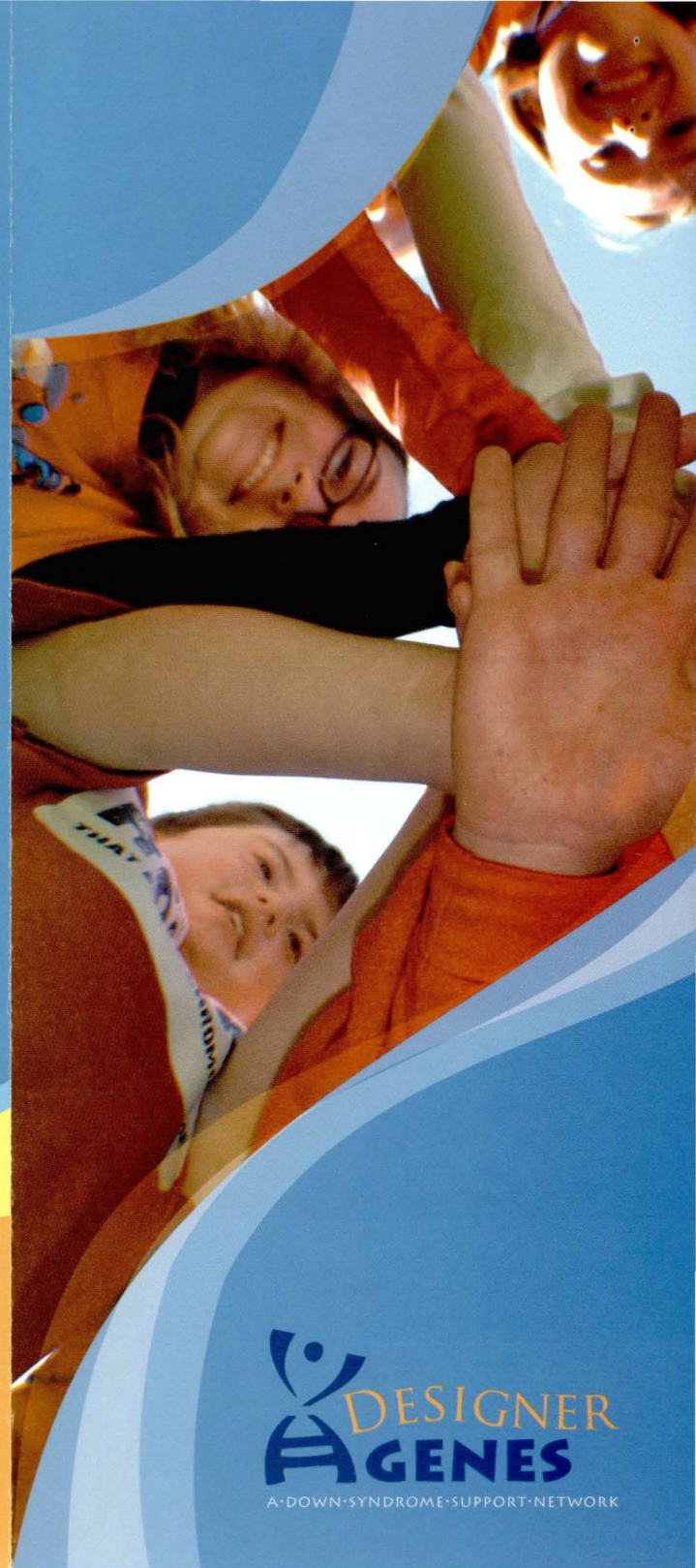
Down syndrome isn't a disease. It is a chromosomal abnormality that affects about one out of every 700 babies.

- Down syndrome affects people of all races and income levels.
- Down syndrome is a trait – not a condition or affliction.
- People with Down syndrome have 47 chromosomes instead of the usual 46. Most people have two copies of chromosome 21; Down syndrome occurs among people who have a third copy.
- People with Down syndrome may have mild to moderate intellectual disabilities, low muscle tone and higher chances of some health conditions.
- People with Down syndrome lead fulfilling lives. They attend school, hold jobs, participate in decisions that affect them, get involved in community activities and contribute to society.
- High-quality educational programs, a stimulating home environment, good health care and positive support from family, friends and the community enable people with Down syndrome to develop to their full potential.



PO Box 515  
Bismarck, ND 58502-0515  
info@designergenesnd.com  
701.258.7421

**DesignerGenesND.com**





## WITH A LITTLE HELP FROM OUR FRIENDS

Designer Genes enjoys the generous support of individuals, businesses and organizations in the Bismarck-Mandan area and beyond. The non-profit organization receives donations at the annual Buddy Walk, as well as grants and charitable contributions. For a complete list of funding sources, go to [DesignerGenesND.com](http://DesignerGenesND.com).

## DESIGNER GENES FAMILIES KNOW HOW TO HAVE FUN!

- **BUDDY WALK**
- **FAMILY PICNIC**
- **BOWLING PARTY**
- **ICAN SHINE - BIKE CAMP**
- **SUPPER WITH SANTA**
- **BOOK FAIR & STORY TIME**



## OUTREACH

**To North Dakota families:** Designer Genes helps fill gaps in information and services available to families who receive a Down syndrome diagnosis.

**To schools and communities:** We are more alike than different – Designer Genes works to build understanding of this important message among educators and the public.

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- Advocating for state and federal policies and legislation to support the provision of services for people with Down syndrome





World Down Syndrome Day (WDS D) is an annual global awareness day advocating for the rights, inclusion and well-being of individuals with Down syndrome.

You have been chosen as the recipient of this Random Act of Kindness in honor of all people with Down syndrome.

**#WDS D15**



[www.designergenesnd.com](http://www.designergenesnd.com)

Designer Genes of North Dakota is aiming for 321 Random Acts of Kindness (RAK) in honor of World Down Syndrome Day on 3/21/15.

3/21 symbolizes Trisomy 21, Down syndrome's medical term, for a third copy of chromosome 21 (instead of the usual 2).

We are collecting our RAKs on facebook at <http://bit.ly/321RAK> Check them out, and maybe help us reach our goal of 321!



Promote acts of kindness. Pay it forward.



#2

House Human Services Committee  
Sixty-Fourth Legislative Assembly of North Dakota  
Senate Bill No. 2234  
March 17, 2015

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.

This bill arises from last session's HB 1378. HB 1378 passed optimistically aiming for improvements to a Medicaid waiver program "to provide coverage for children who have continued and substantial medical and support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver." The Legislature had hoped to learn the estimated number of children that would be eligible, criteria for the provision of services under the waiver, identification of services to be offered, and a timeline for implementation of the waiver.

This ambitious goal could not be accomplished. SB 2234, as introduced, proposed a smaller test run of a program that would cover children with Down syndrome who would be needy children who might otherwise go unserved. That proposal was changed in the Senate.

As amended, SB 2234 might identify children currently left out of the system who could be served effectively and appropriately under the package of services and supports presently available through an existing Medicaid waiver program.

I strongly support the passage of SB 2234.

Please let me know if you have questions. Thank you.