

2017 SENATE HUMAN SERVICES

SB 2041

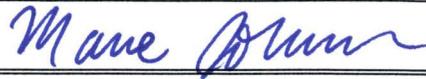
2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2041
1/10/2017
Job Number 26733

- 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:

5 attachments

Chair J. Lee brought the meeting to order.

All members are present.

Michael Johnson, Legislative Counsel introduced the bill.

Roxane Romanick, Executive Director of Designer Genes of ND: Testimony provided, please see attachment #1 (2:00-11:05)

Senator Anderson how is Down syndrome originally determined?

Ms. Romanick: A blood test, prenatally to check for genetic markers.

Senator Anderson: Would you agree that Down syndrome manifests itself in a lot of different forms and some children might be quite competent, and some might have significant disabilities?

Ms. Romanick - yes, wide continuum of abilities and health concerns, related to having extra genetic material. In reality even children who are at the top of the spectrum for cognitive function continue to have intellectual disabilities. It's a very rare case where it doesn't have an effect on their adaptive, executive functioning, and ability to make decisions. Unless they are diagnosed with a form of mosaicism, which is not in all of their cells.

Senator Anderson: The descriptions seem to paint several categories of disabilities; they don't single out the long list of things that could cause those disabilities. This bill looks to focus Down syndrome as one of those automatic choices. Now do we make automatic choices for all of the other people who might fall into a similar category? What's your opinion about that?

Ms. Romanick: I can't speak to those other populations. We have potentially 600 individuals in the state with Down syndrome, which is a lot more than 5 with a particular disorder. I know that the services in Developmental Disabilities and the Intellectual and Developmentally Disabled waivers seem to fit best for our individuals with Down syndrome. It's very difficult for me to understand why we have individuals who fall through outside of that.

Senator Kreun: You're indicating that people fall through the cracks, that there are good programs available by there are gaps, how many of the six hundred individuals with Down syndrome fall into the gaps?

Ms. Romanick: There's no registry for Down syndrome in the state, we don't have an exact count, there is no data pool to draw information from. In the Bismarck Mandan area 1-2 children in the last 9 years that were not found eligible. And primarily this happens when they move from services for birth to 2 year olds into adult criteria service, there is a change in eligibility at that point.

Tina Bay, Director of the Developmental Disability Division, DHS: Testimony provided, please see attachment #2 (17:30-20:15). In regards to the two different eligibilities, we have a waiver that serves birth to death, then we have different eligibility criteria at age 3. That's where there's different criteria; birth to 3 just looking for developmental delays, it's a bit broader, in terms of eligibility, and when they turn 3 we're looking at eligibility for the adult criteria, which then is looking at different functional limitations and abilities, and all of our services within the waiver have to have that functional assessment. As I testified during the interim committees, there are no automatically eligible individuals. You have the flexibility to choose which tools they use to determine that function ability, which have to be approved by the Center for Medicaid Services (CMS).

Our waiver focuses on intellectual or developmental disability. We are working on our eligibility testing to unify it across the state. We are reaching out to national sources to look at our eligibility across all of our waivers that we manage to look at those gaps.

Senator Lee: I do struggle with naming any one condition, in other bills that dealt with one condition it's awkward there's going to be in some other condition that may result in an intellectual disability that we may find to be just as necessary for those services to be available, but we're not automatically putting them into the system. CMS won't let us automatically include a diagnosis.

Ms. Bay: That is correct, after the last session, I talked to CMS directly to see if there were any automatic eligibles, it is not allowable because it is tied to that institutional level of care. There are different levels of care, there's nursing, then there's different levels of hospital care within the waiver that you have to select. For our IDD waiver we select that Intermediate Care Facility (ICF) level of care. So there are no automatics. A diagnosis of an intellectual disability will not automatically screen you for the waiver, you still have go through that functional criteria.

Chair J. Lee: Any suggestions for how we address this?

Ms. Bay: There been several bills to study with the technical assistance that we're reaching out for, and this is technical assistance that is provided through the CMS. They have to approve our plan and request. But I hope that that will help us dig down into we don't have the expertise to say with all of our waivers to ok where is the gap and what would be the best approach, maybe it's a change to another one of the other waivers that are available, the medically fragile or maybe it might be a recommendation to make changes to those waivers maybe it might be a recommendation to make changes to our waiver. Those changes may affect our budget and our capacity. We hope to know back from CMS by the end of the month.

Senator Piepkorn: Is Down syndrome automatically excluded?

Chair J. Lee: No, it's note excluded, but they have to do functional testing, to show that they're not capable, and as result qualify for the waiver. This would put them as an automatic in, rather than a functional testing.

David Boeck, Director of Legal Services for the Protection and Advocacy Project: Testimony provided (29:20-34:05), please see attachment #3.

Senator Anderson: It seems to me that whether including Down syndrome on line 9, or not, the assessment still needs to be done, to see if the other criteria are met, so it doesn't really exempt them from this assessment anyway.

Mr. Boeck: No, it doesn't exempt them from the test, but it would get them through without requiring them to have an intellectual disability. That's a requirement that North Dakota has had, that there be an intellectual disability, and that isn't really essential either for the waiver or for identifying individuals that need help.

Senator Anderson: Do we need to change this bill or change the waiver, in order for CMS to approve it with this inclusion?

Chair J. Lee: Defer to Tina Bay

Mr. Boeck: We could with legislation require that the waiver include individuals with developmental disabilities and not be restricted to individuals with intellectual disabilities.

Ms. Bay: The current waiver does check intellectual and developmental disability. The tool focuses on cognitive ability. So when we're talking about the Vineland for autism, we have progress assessment review for our waiver, we're looking at defining those folks who may have a developmental disability but those would mirror someone with an intellectual disability.

Chair J. Lee: Please clarify the definitions of developmental, intellectual, and cognitive disability?

Ms. Bay: Defer to Dr. Cramer.

Dr. Dan Cramer, Regional Director of South Central Human Service center, DHS: Provided testimony (37:50-40:10) please see attachment #4. Mosaic Down Syndrome typically have an IQ that is 1-30 points higher than other forms of Down syndrome. Be careful about generalizing disability across all people with a given condition, and instead look at each individual uniquely, and assessing based on standard set of procedures.

Chair J. Lee: How do you assess a child?

Dr. Cramer: Assessing a child, especially a child that may have a disability at age 3 is challenging, there are some tools out there, but people will argue about using those tools on children so young. I defer to Ms. Bay and the recommendation she had, that technical assistance and rather than us trying to come up with something, deferring to people who have looked at this issue and have recommendations that have been tried and used and make sense. I will email the definitions requested above.

Senator Anderson: I have a question when we look at page 2 of the proposed bill, lines 26-28; what does this do other than the definition earlier?

Mr. Boeck: Lines 26-28 make the difference in terms of Medicaid eligibility, and this law doesn't require that some who meets these criteria get funds, it exempts them and moves them past intellectual disability requirement, wouldn't have to have them. Allows the department to extend Medicaid benefits to this group.

Attachment number 5 provided for the committee's review.

Chair J. Lee: Hearing closed

2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2041
1/10/2017
Job Number 26757

- Subcommittee
 Conference Committee

Mame Blum

Explanation or reason for introduction of bill/resolution:

A bill relating to Down syndrome and eligibility for medical assistance.

Minutes:

0 Attachments

Chair J. Lee: Called the meeting to order.

Chair J. Lee: (8:00) This morning got a little more complicated than I was expecting.

Senator Heckaman: I had an email from Donene Feist, from Family Voices, she is concerned the assessment tools that are used to determine the criteria to be on the DD waiver are not appropriate. I visited with Roxane Romanick, who testified yesterday, the most important part to put in this is not the name, but on her page 3 of testimony she said the second part is in administrative code. That DD eligibility for age 3-12 has to use age appropriate practices. I think we need to look at that issue, versus maybe even putting the word Down syndrome in here that we make sure that there is somewhere in administrative code we write it to address something, because yes, it did get deeper and more involved this morning from what I think it started out as.

Senator Anderson: The bottom line for most people is the assessment tool that we use, it's not so much whether Down syndrome is involved or not. They are concerned with assessment, that it is inadequate or intrusive or doesn't do a good job. Here they talk about an adult tool basis, juvenile tool and so forth. That isn't something that the legislation specifically speaks to. We heard from the Department that they tool they use assesses mostly intellectual capability, but yet the statute in the availability of the services includes both development and intellectual. We need to encourage someone look at the tool and the assessment, not the statute.

Chair J. Lee: We need Tina Bay to assist us. I'm not comfortable having the name Down syndrome in there as it is, because as Dr. Cramer said, the functionality of an individual can be very varied depending on what type of Down syndrome they have. It isn't fair to stereotype anyone for any reason, really. We all know it's pretty hard to easily evaluate the functionality of a 2 year 10-month old child. So we'll chat with Tina tomorrow, have her help us out.

Senator Larsen: When someone give birth and the child receives a diagnosis of Down syndrome, the family automatically gets access to the services. Then when they turn 3, that's when the testing comes, so these parents are educating their children, but if they make them too smart, they lose the coverage, and they still need the coverage. So there is a gap from ages 3-5, because then they go to school, they get reassessed, and get the coverage back.

They want to get rid of the gap, that's where they're going with this. They are born, and then they get reassessed at age 5, and then the school is responsible from age 5 on.

Senator Heckaman: Some school systems do more earlier than 5, too. There's early intervention opportunities too. The school does educational services, they do functional with children with intellectual disabilities, and that category gets misconstrued in school, because of how some schools are able to provide services, and some aren't. In rural areas, the case manager may not be specialized. So you take the case manager closest to that disability to that and provide services, and a lot of times, speech and language pick up these younger children, because if they can't communicate, that seems to be where they go. So many of these disabilities coexist at the same time. Early intervention is so important. The school is responsible for educational services, some of these families need services above and beyond that. Especially the medical end of it is where they get caught in the bind.

Chair J. Lee: They do have programs for medically fragile children, and as they get older there is the Medicaid program where people with disabilities who want to work won't lose their Medicaid benefits just because they're making more money than the benefit usually allows. But it's patchwork, so everybody isn't covered the same way.

Senator Kreun: when they get to school, there are 3 different types of down syndrome, the school can't take care of all three do they? They have to take care of intellectual, which is one part, but do they do physical therapy as well? Is the school responsible for all that?

Chair J. Lee: They get the whole thing.

V-Chair Larsen: That's determined by the Individualized Education Program (IEP), who'll meet with that team of school psychologists.

Senator Kreun: In some cases, they might qualify for two, not every service that's available, is that what the parents are concerned about as well? That they're not getting all the services they need, or is it that gap.

Senator Anderson: The gap.

Chair J. Lee: The schools try hard to be comprehensive, but I know that my school which has really great programs, there is some economies of scale that benefits us. There are quite a few families that move in for those services, for the kids.

Senator Heckaman: (18:00)(talked about difficulties of finding case managers, special education teachers, cross training) But this is about getting on the waiver for other health concerns and other medical needs the family may have.

Senator Kreun: But if those case managers are crossed trained, do we want to keep that term Down syndrome? If we have several people collaboratively taking care of this child, then the child gets labeled, someone might say, you can't be caring for this child, he needs to go to a different category Then they send the child to a different category.

Senator Heckaman: In a school setting it's much different than out in a medical setting. The school has their categories of disability and when the child will usually meet one, sometimes two or three, but then you have a primary disability, the main disability that's affecting this child, and how do the other disabilities affect their acquisition of education. The team works together.

V-Chair Larsen: As Dr. Cramer testified this morning, having the name on there isn't enough, the child still needs two of those criteria. Having the name on there isn't enough.

Senator Piepkorn: It must have something with 3-5-year gap. Because other than that, why is Down syndrome included.

Chair J. Lee: It's the parents of kids with Down syndrome who brought the bill to us.

Senator Piepkorn: It's a physical or mental impairment, a combination, I wonder why the bill is here, it seems automatic that Down syndrome should be included in this greater classification.

Chair J. Lee: We don't include by disease label; we include by function. Some of them are higher functioning than others. Just as other individuals with other circumstances have higher function. Autism for example. So it's supposed to be determined by function, and really that's why we need Tina. These families want the services to be able to continue. The Department has been working with this, see if we can figure out some better language so we can be sure that kids are being evaluated appropriately.

Senator Heckaman: Some of these children aren't qualifying for the DD waiver. So that takes those services for that child and family away. That most usually they should be able to access. By putting this disability in here, it would allow them to automatically go in to DD waiver.

V-Chair Larsen: They get reassess in kindergarten, then they get reassessed in 7th grade, then they get reassess as senior. Some of those might drop off of the service, which is a progression, but what's happening is the cutoff happens, and they get no service, and then they get put back on service, that's what it is. As they're tested as they get older, its different than the 3-year-old, they don't know, basically they keep them on until they can get reassessed at 5 years old.

Chair J. Lee: I think it's the inconsistency of the services available with that 3-5-year gap that is one of the big challenges here.

The committee discussed bills and scheduling.

Chair J. Lee: closed the meeting.

2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2041
1/11/2017
Job Number 26813

- Subcommittee
 Conference Committee

Committee Clerk Signature

Maria Johnson

Explanation or reason for introduction of bill/resolution:

A bill relating to Down syndrome and eligibility for medical assistance.

Minutes:

3 Attachments

Senator Piepkorn provided test Attachment #1(1:20-4:05)

Chair J. Lee: Ms. Bay, please refresh our memories about how one qualifies for the DD waiver, and whether or not an adult functional test is needed.

Tina Bay: We have the part c program, which was put into the DHS. Part of that was because we have the service delivery system for people who had developmental delays. Part is managed by us. We only receive \$2.6 million every year from Office of Special Education to manage the part C program. The part c is above and beyond what Medicaid program pays. In the past we had people who wanted Part C coverage and access infant development programs, apply to Medicaid, and be eligible for waiver services. We found out that we could not require people to apply for Medicaid. We are now responsible to provide an array of early intervention services through the Part C funding. The \$2.6 million that we have, we have to use for direct services for developmental disabilities, OSEP says we have to provide, if we are accepting that federal money. A difference that \$2.6 is all we get, which is different from other Medicaid programs. The state has to provide those services even when the money runs out. We tried in the past to tie it into Medicaid, to try to make the federal resources last longer. Some people in recent years aren't getting Medicaid, whether they choose not to or are not eligible. We have seen a significant increase in cost for direct services. The infant development program, which is part of the waiver, we spend \$20 million, it is a significant cost for services. There would be a huge gap if we weren't able to tie into the Medicaid waiver. Unfortunately, there are levels of complexities attached to those programs. Early intervention covers birth through the age of 2. When they turn 3 there is a new eligibility requirement. We look at if they continue to qualify for our waiver. We do not have any other funding through OSE that would cover that population. Department of Public Instruction manages the Part B Program, which then covers the 3 to 5 year olds. They could still qualify for services, through our Medicaid waiver, and then they would still receive residential services, equipment and supplies, environmental modifications, things like that through our waiver, and then receive educational component from DPI.

Senator Piepkorn: Is there any way we can provide better services at lower cost.

Ms. Bay: I know that many states who have the Part C, anytime you have Medicaid adds a level of complexity, however people want or need that for additional services.

Chair J. Lee: We can't pay this out of state funds. We rely on federal funds. They are sure everybody's cheating, and create a bunch of hoops.

Ms. Bay: We have two federal entities that we are accepting funds for, specifically for this early intervention, it complicates things, we have to try to please both entities. Certainly it would be easier to take it out of DHS, however that would create a huge general fund liability.

Senator Kreun: Have we looked at some programs, to see if we'd be ahead if we didn't use fed funds? Doing roads, we did analysis, and we lose money using federal funds for some of the smaller projects them.

Chair J. Lee: There aren't any small programs, they all have lots of zeros. We are always looking for ways to be more efficient, but federal funds are the best recourse.

Ms. Bay: (provided test attachment walked through flow chart (16:20-18:10) Attachment #2). Any disability diagnosis has to walk through these criteria. I don't understand why we might need this new language in the bill.

V-Chair Larsen: The parents want it in here so they don't lose coverage from 3 to 5 years. If we add this, who else will want to be added?

Ms. Bay: The eligibility group tried to address that in the work that we presented to the interim committee, they supported the work, that why you have this bill. The technical assistance that we have requested will hopefully make some recommendations. You still have to have that level of care. The autism group we have our waiver; we recognize that some people with the diagnosis of autism might not meet that level of care, and are then able to access services through the voucher program, which his state funded. No matter what we choose, we have to look at that level of care.

Senator Kreun: Looking at test (attach #4 1/10), Dr. Dan Cramer. If we do what they're asking we're going to label that child all the way through, unfair and inaccurate to label as developmentally disabled just because they have Down syndrome.

V-Chair Larsen: There's no fiscal note, but if it does pass, then there are a handful of people who will be able to access the funding. Do you know how many that will be? 5 people?

Ms. Bay: We don't know how many people haven't applied for services and don't feel that they qualify. It's been a fairly difficult fiscal note.

V-Chair Larsen: Those that aren't reporting now, probably won't jump on the band wagon. It's just a 2-year deal, that's not that long.

Senator Kreun: What are the costs, to get private services? Is it huge? There are other funding mechanisms out there.

Senator Clemens: My sister had a Down syndrome child, he passes away at 2 years old. But those are not high maintenance kids. They are so loving, smiley. I don't see the hardship other than realizing that your child has a disability. I don't see the big issue.

Chair J. Lee: They would have a better chance with continued service, develop skills more quickly.

Ms. Bay: They are receiving our services if they are eligible for early intervention, we have list of diagnosis for the 0-3 years that we say is high risk, Down syndrome is on that list. When they turn 3 our services stop, then at 5 the schools pick it up with Part B.

Senator Clemens: I wasn't asking to get the Down syndrome off. Leave it off and let the criteria determine the need.

Chair J. Lee: Ms. Romanick's testimony, it isn't just putting down syndrome in, on page 3, she wanted to create and fund additional waiver. I'd like to see the results of this technical assistance, please keep us informed.

Ms. Bay: We did ask CMS for states that have a specific waiver for Down Syndrome. Region 8 doesn't have any other states that have waiver for Down syndrome.

Chair J. Lee: (Spoke on the forthcoming health information hub. Hoping to organize all the data, for access by legislators, and the public; a couple of pilot project on the ground.)

Ms. Bay: I'll get those definitions from Dr. Cramer (Attachment #3 provided after the hearing ended).

Senator Anderson: I'd like to see us wait to do the technical assistance review. Maybe include developmental stuff with the mental health stuff. I'm reluctant to add Down Syndrome to the group. I don't like labelling kids as disabled if they're not.

Senator Anderson: I'll move Do Not Pass

Senator Kreun: Seconded.

Senator Clemens: The Do Not Pass is based on the Down syndrome addition.

Chair J. Lee: Yes, and based on the fact that all of them don't have the same functional impairment levels. They have requested federal technical help and assistance.

A roll call vote was taken for SB 2041.

Motion Do Not Pass accepted (5-2).

Carried by Sen Anderson.

Chair J. Lee: Closed the hearing on SB 2041.

Date: 1/11 2017
 Roll Call Vote #: 1

**2017 SENATE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. 2041**

Senate 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 Sen. Anderson Seconded By sen. Kreun

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee (Chairman)	X		Senator Joan Heckaman		X
Senator Oley Larsen (Vice-Chair)		X	Senator Merrill Piepkorn	X	
Senator Howard C. Anderson, Jr.	X				
Senator David A. Clemens	X				
Senator Curt Kreun	X				

Total (Yes) 5 No 2

Absent 0

Floor Assignment Sen. Anderson

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

REPORT OF STANDING COMMITTEE

SB 2041: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO NOT PASS** (5 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING). SB 2041 was placed on the Eleventh order on the calendar.

2017 HOUSE HUMAN SERVICES

SB 2041

2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2041
3/8/2017
28876

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

Relating to Down Syndrome and eligibility for medical assistance.

Minutes:

1, 2, 3, 4, 5, 6, 7,

Chairman Weisz: Called the committee to order.

Opened the hearing on SB 2041.

Is there any testimony in support of SB 2041?

Rep Hogan
(Attachment 1)

Chairman Weisz: Are there any questions from the committee?
Further testimony in support of SB 2014?

Roxane Romanick, Designer Genes of ND, Inc.
(Attachment 2)

Chairman Weisz: Are there any questions from the committee?

Chairman Weisz: Is there further testimony in support of SB 2041?
14:00

Dr. Steve McDonough
(Attachment 3)

Chairman Weisz: Are there any questions from the committee?

Chairman Weisz: Further testimony in support of SB 2041?
17:45

Brian William Mueller, Father of a Down syndrome child
(Attachment 4)

Chairman Weisz: Are there any questions from the committee?

Representative Skroch: Does your current insurance cover the cost after the age of 3 and has that been helpful, or are there many shortcomings in that coverage?

B. Mueller: Before age 3 Medicaid covered whatever my insurance didn't cover. After the age of 3 everything that is not covered by insurance is out of pocket. At first we have BC/BS and it was good health insurance, so we were responsible for copays and deductibles. We still ended up paying thousands of dollars out of pocket each year. Now we have a high deductible insurance plan and the \$7500 deductible is met every year.

Representative Schneider: Was SSI a possibility for you? Did you appeal?

B. Mueller: We did not appeal. We pursued with other folks that had children with downs syndrome that were getting services up to the age of three. It was hard for us to understand why we were denied access to the waiver. We thought he would qualify based on the difficulties that he had. At first we were told that he was progressing rapidly. He didn't walk until he was 2 years, 2 months and 2 days old. Between 2 and 3 years old he made a lot of progression, but the gap continued to widen after age three. I think it is very difficult to test at age 3, because it is very difficult to see what a child's outcome is going to be when they are so young. The services really help to get him to a higher point when he had them. We struggled trying to find other services for him.

26:39

Chairman Weisz: Further testimony in support of SB 2041?

Dr. Mark Doerner, Child Psychologist
(Attachment 5)

Chairman Weisz: Are there questions from the committee?
What method of testing would you recommend?

Dr. Doerner: Basically it is a deeper issue. There is not transparency around the formula that is used to make this decision. Various pieces of data are fed into a computer program and then a result is produced, but no one is certain how that formula is constructed.

Representative Porter: When Mr. Mueller was testifying he talked of the test being performed while the additional services were being offered and kind of at the plateau of his child's development and abilities. After that it was determined he did not qualify for services, it was a very rapid downturn when the services stopped. Is that something that is noted inside of these tests and adapted for or is that often the way it works?

Dr. Doerner: It is very difficult to capture or predict how that child is going to do as he goes forward. The best predictions it can make are performance at school and academic tasks.

Representative Porter: Inside of how the system works and you're working in the clinical setting and dealing with the kids and doing the testing. Is there repeat or ability to test back in at say age 5 if we see that they are heading the other direction or is it just one time before the age 3 that determines their future inside of the programming for these services?

Dr. Doerner: It is my understanding that it is just one and done. You are either in or you are out as I understand the process. I am not familiar with an appeals process to determine reentry.

Vice Chairman Rohr: When you administer these tests do you send them out to be read or do you do it yourself?

Dr. Doerner: I do the test and send it to the case manager and they integrate it with whatever other findings they possess and I don't know what happens after that.

Chairman Weisz: Is there further testimony in support of SB 2041?

38:45

David Boeck, Dir. Of Legal Services for Protection and Advocacy Project
(Attachment 6)

Chairman Weisz: Are there questions from the committee?

Representative Schneider: Do you know if other states include presumptive disability for downs syndrome in their criteria?

D. Boeck: I don't know about other states, but when the senate debated this it was stated that no other states in this region had this kind of eligibility.

Representative Schneider: Have you been able to review the amendments? It appears to me that it would be a set back because it means another study that would make it longer before they could get it done.

D. Boeck: I have not seen the proposed amendments, but I know the department began studying this from 2 sessions ago.

Representative Schneider: So you don't think there needs to be another study?

D. Boeck: I think that what is happening between CMS and the department will lead us to solid information that would suggest that maybe there doesn't need to be a study, but they need to pursue this process with CMS.

Representative Schneider: Including this language, down syndrome as a presumptive but not a required category, that actually is making our law more consistent with what the federal social security disability or SSI laws, does it not?

D. Boeck: Yes, I think it is, but it doesn't really make for a presumptive eligibility. I think it puts you in the ballpark as being possible, but the individual would still have to meet the criteria established in the rest of this statute.

Representative P. Anderson: We have earlier testimony from Dr. McDonough that he felt the Dept. of Human Services spends more time and effort to deny children services instead of trying to figure out how to get them the services they need. Do you agree with that?

D. Boeck: I am not sure what he means by that. Certainly if there is an appeal it goes to a hearing and then it could go to court. That is very time consuming, of course. The department putting together the waiver is very lengthy and has different parts and certainly that is very time consuming, but I would say that I believe that the department of human services and the people employed there have spent a lot of time trying to figure out how to fit these individuals in. Simply the way it is written now it is very difficult to get them to qualify for Medicaid services.

Chairman Weisz: Further questions from the committee?

Chairman Weisz: Is there further testimony in support of SB 2041?

Chairman Weisz: Is there any opposition to SB 2041? Seeing none, Tina I think we have some questions.

Tina Bay, Director of the DD Division for the Dept. of Human Services
(Attachment 7)

50:00

Chairman Weisz: Are there questions from the committee?

If they are denied, can they be tested again? What would be the process?

T. Bay: They can appeal and if their condition changes like Representative Porter asked, they can reapply at any time. They would just go to the local human services center to do that.

Chairman Weisz: There is no timeline?

T. Bay: There is no time line.

Representative Schneider: Is this an area where there might be a possible waiver opportunity. Are there other states that have allowed a presumption based on downs syndrome?

T. Bay: We did ask our CMS representative in the regional office if there was any state that had a specific waiver for downs syndrome and they do not know of any. No matter what the diagnosis, you still have to meet that functional criteria, that level of care.

Representative Schneider: Do you know of any state that has been turned down and has actually made the request to have a presumptive category based on downs syndrome?

T. Bay: I am not aware that there has been any state.

Representative McWilliams: Are there people that are diagnosed with downs syndrome and are not receiving services because they fall into that gap and if so, how many?

T. Bay: Yes, there are people with the diagnosis of downs syndrome that are not receiving services. I do not have the numbers.

Representative P. Anderson: How can the child that was described earlier require a one on one aide and still not qualify. How can that be?

T. Bay: There are different criteria for what we use for Medicaid that need to be met.

Representative Skroch: Currently there is a structure in place to identify those children that qualify and there are people falling through the cracks. What I am curious about is if there could be any kind of prejudice in particular that would require us to specifically name downs syndrome diagnosis into the century code? Is there some reason now why we are trying to specifically identify downs syndrome as being different from other diagnosis that might have similar qualifications of needing services and the waiver?

T. Bay: Last session it was determined that there were people with downs syndrome that were being denied eligibility. That was the focus of this legislation.

Representative Porter: Inside of the bill the way we received it without any amendments, do you see that it expands into eligibility individuals that are not currently eligible?

T. Bay: With the amendment, even with section one that includes downs syndrome you still have to go through each one of those criteria. All of those have to be met to have that definition of developmental disability. Adding the language is not going to make it an automatic for developmental disability diagnosis.

Chairman Weisz: What about number three of the bill in section 2. Does that change anything?

T. Bay: We still need the functional criteria to be met for them to be on the waiver. What it could do is that someone that might be eligible for DD management which is general fund services and if they don't need that institution they cannot follow onto a Medicaid waiver. That would leave them with program management and that is about it.

Representative Porter: Inside of this you don't see any change in the way the department is determining eligibility and you don't see any increase in individuals becoming eligible for the waiver because of this bill?

T. Bay: It might open up so that more people might have access to DD program management, but no, it would not change the criteria for the waiver. The state does have the option to determine which tools you use to measure that eligibility criteria,

Representative Porter: Is that why the department feels there is no fiscal effect to this bill?

T. Bay: Yes, that is correct.

Representative Porter: I don't see in the bill where it explains the reevaluation process, appeals process, or to bring in a second opinion. Is there somewhere specific in there that explains that?

T. Bay: I don't think the bill addresses that, but it is included in our policies.

Representative Porter: I would like to get a copy of that too, please.

Representative Schneider: I can assume that this bill has a purpose, but you can tell me if I am wrong. It looks like in section 3 on page 2 of the bill at lines 26 and following that that would eliminate the need to show that there was an intellectual disability or impairment of general intellectual functioning if there is a diagnosis of downs syndrome. I assume that is in there so that they can meet developmentally disability criteria. Are you saying there aren't other service possibilities if they meet that criteria or would that result in expanded services and if it does, what might those services be?

T. Bay: Currently within our budget funds we do not have general fund services for direct services. We have a program management program where if the person is eligible for Medicaid we can draw down federal fund as well as general fund. If we were to look at people that do not meet that institution level of care, we would look at something like what we did for the autism voucher program where folks were not meeting the definition of the level of care needed for the Medicaid waiver and we would have to look at what services families feel are necessary to develop a fiscal note.

Representative Schneider: So to expand services for these people that are not meeting this criteria, what would the department have to do and then what would be available. Would the department have to take other action then to get additional waivers or expand the waiver that you do have and what are the possibilities if you do that?

T. Bay: As far as expanding the waiver. Even if we created a separate waiver for folks with downs syndrome, they still have to meet that level of care. There are 3 different levels of care we can pick from, hospital, nursing or ICF level of care. The intent for the level of care is that except for that waiver, that person would need that level of care that you have selected. For our level of care we have selected intermediate care facility. If that person did not have the waiver, that is the level of care they would need. It doesn't mean they have to go into a facility, but they would meet that criteria. That is what our federal requirements are for CMS.

Representative Schneider: Is there a lower level of care to select?

T. Bay: No, we are at the lowest level.

Representative Schneider: What else could be done to allow people who have a 3 year old child that needs to continue to need the services.

T. Bay: It would have to be from the general fund, like the autism voucher program.

Representative Kiefert: Do you know how many people with downs have been denied.

House Human Services Committee

SB 2041

3/8/17

Page 7

T. Bay: I could get that information for you.

Representative Kiefert: I would appreciate that.

Chairman Weisz: Are there any more questions from the committee?

Hearing on SB 2041 closed.

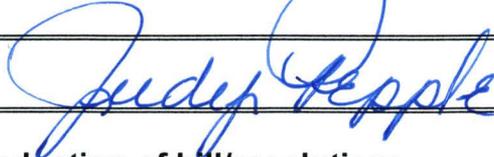
2017 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Union Room, State Capitol

SB 2041
3/20/2017
29476

- Subcommittee
 Conference Committee

Committee Clerk Signature



Explanation or reason for introduction of bill/resolution:

Relating to Down syndrome and eligibility for medical assistance.

Minutes:

1

Chairman Weisz: Called committee to order.

Chairman Weisz: Ok we have an amendment presented by Rep. Hogan.

Representative Porter: I move the amendments.

Chairman Weisz: Ok we have a motion. Do I have a second?

Representative Seibel: Second

Voice vote to adopt the amendment
Motion carried

Chairman Weisz: further amendments on SB 2041?

Representative D. Anderson: Motion for a do pass as amended

Representative P. Anderson: I second it.

Chairman Weisz: Discussion? Seeing none, the clerk will call the roll for a do pass as amended.

Roll call vote taken Yes 14 No 0 Absent 0
Motion carried.

Do I have a volunteer to carry this one?

Representative P. Anderson: I will carry it.

3/20/17 DA

PROPOSED AMENDMENTS TO SENATE BILL NO. 2041

Page 1, line 1, remove "and section"

Page 1, line 2, remove "50-24.1-02"

Page 1, line 2 remove "Down syndrome and eligibility for"

Page 1, line 3, replace "medical assistance" with "the definition of developmental disability; and to provide for a report"

Page 2, replace lines 1 through 30 with:

"SECTION 2. DEPARTMENT OF HUMAN SERVICES MEDICAID WAIVER STUDY - REPORT TO LEGISLATIVE MANAGEMENT.

- 1 During the 2017-18 interim, as part of the ongoing review of existing and potential Medicaid waivers performed by the department of human services, the department shall conduct a study of the current eligibility requirements for the developmental disability Medicaid waiver.
2. The study must include an analysis of whether the current developmental disability Medicaid waiver eligibility determination protocol uses age-appropriate assessment methods, uses assessment tools reliable and valid in nature for level of need determinations, and utilizes assessment information that may already be available in an individual's record.
3. The study must include an evaluation of the feasibility and desirability of including in the eligibility determination under the developmental disability Medicaid waiver, consideration of related conditions and the possible use of certain medical conditions, such as Down syndrome.
4. Before April 1, 2018, the department shall make a report to the legislative management on the outcome of this study, including any recommendations, together with any legislation required to implement the recommendations."

Renumber accordingly

Date: 3/30/17
 Roll Call Vote #: 1

**2017 HOUSE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. SB 2041**

House Human Services Committee

Subcommittee

Amendment LC# or Description: 17.0049.01001

- 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. Seibel

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz			Rep. P. Anderson		
Vice Chairman Rohr			Rep. Schneider		
Rep. B. Anderson					
Rep. D. Anderson					
Rep. Damschen					
Rep. Devlin					
Rep. Kiefert					
Rep. McWilliams					
Rep. Porter					
Rep. Seibel					
Rep. Skroch					
Rep. Westlind					

*voice to adopt
 vote the amend-
 ment. motion carried*

Total (Yes) _____ No _____

Absent _____

Floor Assignment _____

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

Date: 3/20/17
 Roll Call/Vote #: 2

**2017 HOUSE STANDING COMMITTEE
 ROLL CALL VOTES
 BILL/RESOLUTION NO. S. B2041**

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. S. Anderson Seconded By Rep. P. Anderson

Representatives	Yes	No	Representatives	Yes	No
Chairman Weisz	✓		Rep. P. Anderson	✓	
Vice Chairman Rohr	✓		Rep. Schneider	✓	
Rep. B. Anderson	✓				
Rep. D. Anderson	✓				
Rep. Damschen	✓				
Rep. Devlin	✓				
Rep. Kiefert	✓				
Rep. McWilliams	✓				
Rep. Porter	✓				
Rep. Seibel	✓				
Rep. Skroch	✓				
Rep. Westlind	✓				

Total (Yes) 14 No 0

Absent _____

Floor Assignment Rep. P. Anderson

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

REPORT OF STANDING COMMITTEE

SB 2041: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2041 was placed on the Sixth order on the calendar.

Page 1, line 1, remove "and section"

Page 1, line 2, remove "50-24.1-02"

Page 1, line 2 remove "Down syndrome and eligibility for"

Page 1, line 3, replace "medical assistance" with "the definition of developmental disability; and to provide for a report"

Page 2, replace lines 1 through 30 with:

"SECTION 2. DEPARTMENT OF HUMAN SERVICES MEDICAID WAIVER STUDY - REPORT TO LEGISLATIVE MANAGEMENT.

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3. The study must include an evaluation of the feasibility and desirability of including in the eligibility determination under the developmental disability Medicaid waiver, consideration of related conditions and the possible use of certain medical conditions, such as Down syndrome.
4. Before April 1, 2018, the department shall make a report to the legislative management on the outcome of this study, including any recommendations, together with any legislation required to implement the recommendations."

Renumber accordingly

2017 CONFERENCE COMMITTEE

SB 2041

2017 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Red River Room, State Capitol

SB 2041
4/7/2017
Job Number 29995

- Subcommittee
 Conference Committee

Committee Clerk Signature

Maame Johnson

Explanation or reason for introduction of bill/resolution:

Down syndrome and eligibility for medical assistance revision.

Minutes:

No attachments

Chairman Anderson: Opened the conference committee hearing on SB 2041, all members were present: Senator Anderson, Senator Clemens, Senator Heckaman; Representative Damschen, Representative McWilliams, and Representative Pam Anderson.

Representative Damschen: We heard a lot of testimony, we left section 1 alone, on section 2 we heard that it really wasn't accomplishing what they wanted it to. The Department said that the bill was written to create automatic eligibility for individuals with down syndrome by changing the definition, but CMS doesn't allow that. The Department testified that they were doing some work to provide technical assistance to study the eligibility. Since section 2 wasn't accomplishing what we wanted it to, we converted section 2 to a study. The Department would report back to legislative management, hoping to clarify the inconsistencies.

Senator Heckaman: My understanding why we have section 2 sub 3 in there, it would be a carve out. Individuals with down syndrome don't qualify for other services, don't always qualify for medical assistance, I think that's important to have that. If the Department can't do it, there's a difference between can't and don't want to. We know that there are individuals with down syndrome that don't qualify, that's why we put this in here.

Representative McWilliams: We did get testimony from Tina Bay, they've already begun working with a vendor to provide technical assistance to study the eligibility criteria for all Medicaid waivers to identify potential gaps in services. What we heard was this didn't achieve the purpose for which it was intended; this wouldn't give a Medicaid waiver as intended, the Department can change the testing requirements, that's what we wanted to look at in the study, then apply to a Medicaid waiver in the future.

Tina Bay, DHS: We are working with a technical assistance, we have sent them everything that we use to determine eligibility; they are looking at that, we've asked them to focus on age 3-12, looking at is what we're doing appropriate, is there a better way to do it that would address clients needs instead of using the criteria. We've had six meetings with our technical

assistance vendor, within the next month we hope to have some initial recommendations to explore with them.

Senator Heckaman: Are you specifically addressing down syndrome or is it general?

Tina Bay: We sent them legislation that we have had from previous sessions, there was 1378 that was looking at more physical conditions and this one as well, looking at all the gaps identified in previous legislative sessions.

Roxane Romanick, Executive Director Designer Genes: We're in agreement with the House changes, we worked with the Department between the Senate and the House when we knew that the technical assistance was accepted by the CMS. We know there's no easy answer to this, in a perfect world a carve out waiver could potentially be an answer, the services are in the developmental disability waiver are exactly the services that our individuals need, it would be senseless to add an additional waiver to be managed. We feel like it's way too cumbersome for our young children the amount of testing required. When they come with a file full of information already, they come with a diagnosis that is married to intellectual disabilities we are wasting a lot of time, we want to streamline. The intent of what Ms. Bay said will get us closer. We're glad it will be reported to legislative management; we feel like what's in the bill will work.

Chairman Anderson: Do I understand the Department got notice they had received a grant that you had been working on between the time the Senate considered this and now?

Tina Bay: We did not know initially if we were approved for technical assistance, it was late January or early February.

Senator Heckaman: I move Senate accede to House amendments.

Representative McWilliams: Second.

Senator Heckaman: I think I spoke against the motion on the floor, but if all the stakeholders are comfortable with it right now, I'm comfortable with it.

Roll call vote was taken.

Motion passes 6-0-0.

Chairman Anderson: Closed the hearing.

Date: 4/7
 Roll Call Vote #: 1

**2017 SENATE CONFERENCE COMMITTEE
 ROLL CALL VOTES**

BILL/RESOLUTION NO. SB 2041 as (re) engrossed

Senate Human Services Conference Committee

- Action Taken** **SENATE accede to House Amendments**
 SENATE accede to House Amendments and further amend
 HOUSE recede from House amendments
 HOUSE recede from House amendments and amend as follows
- Unable to agree**, recommends that the committee be discharged and a new committee be appointed

Motion Made by: Sen. Heckaman Seconded by: Rep. McWilliams

Senators	<u>4/7</u>			Yes	No	Representatives	<u>4/7</u>			Yes	No
Senator Anderson	<u>X</u>			<u>X</u>		Rep. Damschen	<u>X</u>			<u>X</u>	
Senator Clemens	<u>X</u>			<u>X</u>		Rep. McWilliams	<u>X</u>			<u>X</u>	
Senator Heckaman	<u>X</u>			<u>X</u>		Rep. P. Anderson	<u>X</u>			<u>X</u>	
Total Senate Vote						Total Rep. Vote					

Vote Count Yes: 6 No: 0 Absent: 0

Senate Carrier Sen. Anderson House Carrier Rep. Damschen

LC Number _____ of amendment

LC Number _____ of engrossment

Emergency clause added or deleted
 Statement of purpose of amendment

REPORT OF CONFERENCE COMMITTEE

SB 2041: Your conference committee (Sens. Anderson, Clemens, Heckaman and Reps. Damschen, McWilliams, P. Anderson) recommends that the **SENATE ACCEDE** to the House amendments as printed on SJ page 951 and place SB 2041 on the Seventh order.

SB 2041 was placed on the Seventh order of business on the calendar.

2017 TESTIMONY

SB 2041

SB 2041
Attach #1
4/10/17



SB 2041

Down Syndrome and Developmental Disabilities Eligibility Senate Human Services Tuesday, January 10, 2017

Chairman 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 187 individuals with Down syndrome and their families across the state of North Dakota which is roughly about 30% of the estimated number of individuals with Down syndrome who reside in our state. 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 mom to my daughter Elizabeth, who happens to have Down syndrome and who I'd also like to see earn, learn, and belong.

Down syndrome is a genetically, diagnosed medical condition with a highly-correlated diagnosis of intellectual disability and substantial functional limitations. Even the federal Supplementary Security Income (SSI) Program, 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 primary documentation needed to determine medical eligibility for SSI. For your review, I've included a fact sheet on Down syndrome from the National Down Syndrome Society.

First of all, I'd like to thank the Interim Human Services Committee for sponsoring this bill and helping us to continue to discussion about children with special health care needs like Down syndrome that continue to fall through the cracks of our service delivery system. Please allow me to provide some historical perspective on the bill in front of us. During the 2015 session, a

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number of senators assisted our organization to bring forward SB 2234 to address two concerns that we were facing: 1) children with Down syndrome who were not being found eligible for Developmental Disabilities (DD) Program Management nor screened for the Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) Medicaid Waiver and 2) our concern over inconsistencies throughout the state in eligibility and waiver screening processes, often times including what we believe to be, excessive and unnecessary testing requirements for young children. In the end, the content of SB 2234 was essentially exchanged for a Department of Human Services study of the problem. In November, 2015, the Division of Developmental Disabilities Director, Tina Bay, reported back to the Interim Human Services about the results of the Department's study. Ms. Bay's report is attached to my testimony. Because of the discussion in the Interim Human Services, SB 2041 was recreated with exact wording from the original language of SB 2234.

Going even further back, during the 2013 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: "The department of human services 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." The issue of children with Down syndrome not qualifying was discussed in that study as well as the Department's study under SB 2234. Today, to my knowledge, neither study have led to an adjustment in administrative code, policies, or procedures within the Department that would improve this situation for children with special health care needs and/or developmental disabilities that do not qualify for DD services.

Sadly, the language that is contained in this bill does not fix, mend, nor even bridge the issue of finding children diagnosed with Down syndrome over the age of 3 eligible for DD Program Management and the Medicaid Waiver. This legislation, as it's currently written, does not fix the problem because disconnect exists between the definition of developmental disability

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under Century Code 25-01.2-01 and the eligibility practices for DD Program Management and then ultimately, screening criteria for the IID/DD Waiver. We agree that the language in SB 2041 should be maintained in Century Code, but based on work over the past years with SB 2234 and previously with HB 1378 in the 63rd session, we feel further language is needed in this bill. Therefore, we recommend that for children with Down syndrome to receive the benefits meant to allow them to be productive citizens of our state, the solution is that a waiver specific to this group will need to be instated or legislative directive is issued to amend administrative code for eligibility. A new carve-out waiver is in line with the precedence set by the autism and traumatic brain injury waivers. In these circumstances, which the ND Legislature funded, it was determined that the needs of children with autism and traumatic brain injuries were not being met because of system gaps and therefore specific waivers needed to be carved out for them. This is where we are at with children with Down syndrome as well and believe that it is relatively no different than the precedence that exists.

To summarize, we are recommending an amendment to SB 2041 directing the Department to either:

1. Create and fund a new Medicaid waiver for children and youth with Down syndrome, where a Down syndrome diagnosis and related functional delays are adequate for eligibility, and so that a diagnosis of Down syndrome can be used as a substitute for an intellectual disability or
2. Amend the administrative code (75-04-06) relating to DD eligibility for children ages 3 – 12, that demands age-appropriate eligibility practices, amend the current IID/DD Medicaid waiver to align with the eligibility change, include Down syndrome as a “related condition”, and fund any additional waiver slots that are needed.

The services provided through DD and the IID/DD waiver are important services for our children with Down syndrome and their families. Access to the waiver supports keeps children active and productive in their homes, schools, and communities. It also assists families to be productive citizens, maintaining their employment, mental health, and capacity to parent. The

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safety net that ND Medicaid can provide for needed therapies and medical care is also needed and can be very critical to maximize brain development and full potential. These services keep our children with special health care needs in their own homes, keeps families intact, and assures that a disability like Down syndrome is mitigated. Ironically, individuals with Down syndrome emulate who DD services were developed for, yet because of the inconsistencies and gaps in service, children with Down syndrome who were not found eligible and their families are left with less than optimal situations.

When I held my daughter, 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 North Dakota's state institution was full of persons with Down syndrome. In many cases, 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. If someone asked me today what I really want, it would be that we could talk about supporting our ND children and families without talking about our children's weaknesses, that as families, we would not have to feel like we are not contributing because we are asking for help, and that we would not have to say our family will fall apart without the services. The very essence of asking for help and determining need 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

info@designergenesnd.com

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Down Syndrome Fact Sheet



- Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- There are three types of Down syndrome: trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4%, and mosaicism accounts for about 1%.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 691 babies in the United States is born with Down syndrome – about 6,000 each year.
- There are approximately 400,000 people living with Down syndrome in the United States.
- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.
- A few of the common physical traits of Down syndrome are: low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- 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 lead fulfilling and productive lives.

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

For more information on Down syndrome and NDSS, visit www.ndss.org or call 800-221-4602.



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**Department of Human Services
Interim Human Services Committee
Representative Kathy Hogan, Chairman
November 3, 2015**

Chairman Hogan, and members of the Interim Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Division of the Department of Human Services (Department). I am here today to provide an update on the study of eligibility for the developmental disability waiver pursuant to Section 1 of 2015 Senate Bill 2234.

In October 2014, the Department created an internal eligibility workgroup to review the new Diagnostic and Statistical Manual of Mental Disorders (DSM) V and its impact on Developmental Disability (DD) Eligibility. The group also began a review of the current practice of eligibility redetermination for the DD waiver at the age of three. The workgroup consists of four psychologists, two behavioral analysts, eight regional and state developmental disability staff, and the state autism coordinator. The group has discussed the appropriateness of Intellectual Quotient (IQ) testing for applicants under the age of 12; who should conduct the IQ test; and if IQ testing were removed as a requirement what assessments would be required to determine eligibility. The DD waiver eligibility criteria for adults was also reviewed and felt to be applicable for anyone applying at age 12 and over. The workgroup formed a smaller group to look specifically at the eligibility criteria for children ages 3 to 12. The internal workgroup consulted with a psychologist at a human service center that conducts IQ testing for those at the redetermination age of three.

The smaller group's initial recommendations include:

- If cognitive testing has previously been completed and it is still valid, it will be considered in eligibility determination; however, it will not hold as much weight in the eligibility formula as it currently does;
- If no cognitive testing has been completed or it is no longer valid, it will not be required; however, a cognitive screening will be required;
- Adaptive functioning testing will be required and will hold more weight in the eligibility formula than intellectual functioning;
- Those with a related condition must have an intellectual disability and/or an adaptive functioning disability.

2015 Senate Bill 2234, as enacted, requires the Department to study eligibility for the DD waiver. A survey was distributed by the Department to a group of stakeholders which included Pathfinders, Family Voices, Designer Genes, The ARC, Protection & Advocacy, and Regional Developmental Disability Administrators. A meeting was held in September to discuss the survey results and the recommendations of the smaller workgroup. There was significant discussion regarding the need for having a cognitive component to eligibility. It was expressed by some stakeholders that cognitive ability should not be a consideration in determining eligibility to access the DD waiver, specifically for the 3 - 12 year old group. One stakeholder expressed this should also be considered for the 12 and up age group. It was also shared by one that the DD waiver should be able to serve those with Autism after they age out of the current Autism waiver.

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The Department will analyze the impact of how the recommendations from the internal workgroup and survey/study results would impact future expenditures. Any enhancements and recommendations will be considered as the Department prepares its 2017 - 2019 budget request.

While the current intent of the DD waiver is to assist those with an intellectual or developmental disability or those with a related condition which requires similar services as someone with an intellectual disability, one of the benefits of a waiver is it allows states to choose a target population (i.e. autism, intellectual disability, physical disability, etc.) and serve those identified that meet the level of care.

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

SB 2041
Attach #2
1/10/17

Testimony
Senate Bill 2041 – Department of Human Services
Senate Human Services Committee
Senator Judy Lee, Chairman
January 10, 2017

Chairman Lee, members of the Senate Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities (DD) Division for the Department of Human Services (Department). I am here today to provide information on Senate Bill 2041 for your consideration as you review this bill.

Before an individual can access long term care services available through the DD system, two eligibility determinations are required. The first is the eligibility per NDAC 75-04-06 that would allow the individual access to state-funded DD services and coordination of services through DD Program Management. NDCC 25-01.2-01 definition of "developmental disability" is referenced in NDAC 75-04-06. To meet the eligibility in NDAC 75-04-06, an individual must have a diagnosis of intellectual disability or have a condition other than mental illness that results in a developmental disability, which results in impairment of general intellectual functioning or adaptive behavior similar to that of an individual with the condition of intellectual disability.

If the individual wishes to access long term care services that are funded through the Centers for Medicaid and Medicare Services (CMS) Home and Community Based Services waiver, they must meet the Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/IID) level of care. States are advised that this level of care is defined in 42 CFR §440.150(a)(2) as serving persons with "intellectual disability or persons

with related conditions." Participants linked to the ICF/IID level of care must meet the "related condition" definition when they are not diagnosed as having an intellectual disability. Persons who qualify as having a "developmental disability" under the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 may not meet ICF/IID level of care. While "developmental disability" and "related conditions" overlap, they are not equivalent. The definition of related conditions is at 42 CFR §435.1009, and is functional rather than tied to a fixed list of conditions.

It appears Senate Bill 2041 is intended to create automatic eligibility for individuals with Down syndrome by changing the definition of developmental disability in NDCC 25-01.2-01 and therefore automatic eligibility via 75-04-06, access to the waiver and then Medicaid. For individuals who do not have a diagnosis of intellectual disability, they must meet the definition of related condition under 42 CFR §435.1009 to qualify for level of care and waiver services. CMS does not allow states the option of automatically eligible diagnoses for the waiver.

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

SB 2041
Attache #3
1/10/17

Senate Human Services Committee
Sixty-Fifth Legislative Assembly of North Dakota
Senate Bill No. 2041
January 10, 2017

Good morning, Chairman Lee and Members of the Senate Human Services Committee. I am David Boeck, a State employee and Director of Legal Services 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.

Senate Bill 2041 offers a sensible approach to extending care to individuals who have a developmental disability arising from Down syndrome. The key to determining an individual's exceptional need for care and services is whether the individual has substantial functional impairments in specified areas of major life activities.

An individual with Down Syndrome might have exceptional needs for care and services even though the individual might not have an intellectual disability. If an individual has Down Syndrome, a developmental disability, and substantial functional impairments in the specified areas of major life activities, the individual has exceptional needs ... regardless of whether the individual has an intellectual disability.

2041
#3
4/10

The laws on availability of Medicaid assistance are premised on the state's determination to help families that have major expenses for care and services for a family member with developmental disabilities. An individual's need is better measured by the individual's substantial functional impairments in specified major life activities than by the presence or absence of an intellectual disability.

Some individuals with Down Syndrome might not have qualifying substantial functional impairments and, under SB 2041, they would not be automatically eligible for Medicaid assistance based on these criteria. Other individuals with Down Syndrome would.

Passage of SB 2041 would benefit individuals with developmental disabilities arising from Down Syndrome. It represents a step forward for the Medicaid program in North Dakota.

Please let me know if you have any questions.

Testimony
Senate Bill 2041 – Department of Human Services
Senate Human Services Committee
Senator Judy Lee, Chairman
January 10, 2017

Chairman Lee, members of the Senate Human Services Committee, I am Dan Cramer, a licensed clinical psychologist in the state of North Dakota and Regional Director of South Central Human Service Center for the Department of Human Services (Department). I am here today to provide information on Senate Bill 2041.

Senate Bill 2041 is a Bill for an Act to amend subsection 1 of section 25-01.2-01 and section 50-24.1-02 of the North Dakota Century Code. The intention of this bill is to identify all individuals diagnosed with Down Syndrome as Developmentally Disabled without regard to the presence of intellectual disability or functional impairment.

It appears Senate Bill 2041 was introduced based, at least in part, on the assumption that the diagnosis of Down Syndrome by its very nature includes a combination of intellectual and functional deficits consistent with Developmental Disability as it is otherwise defined within section 25-01.2-01. While this is generally true, it is critical to recognize that there are three subtypes of Down Syndrome including Trisomy 21, Mosaic Down Syndrome, and Translocation Down Syndrome. Each of these subtypes is identified based on specific genetic conditions associated with chromosome 21. While individuals who are diagnosed with Down Syndrome share many physical and cognitive characteristics, across and within the identified subtypes there is a broad range of intellectual and

developmental functioning. Indeed, functional deficits among individuals diagnosed with Down Syndrome are generally noted to range anywhere from mild to quite severe.

It is unfair and inaccurate to identify an individual diagnosed with Down Syndrome as Developmentally Disabled without consideration to his or her unique set of skills and deficits. Further, for those who may wish to access long term care services, The Center for Medicare and Medicaid Services (CMS) highlights the necessity of identifying functional impairment to substantiate eligibility within their definitions of Intellectual Disability, Persons with a Related Condition, and Developmental Disability (ICF/IID Glossary). For us to neglect consideration of intellectual and adaptive functioning when making a determination regarding eligibility would be to fall short of the Federal expectations as outlined by CMS as well as to run the risk of unfairly and inaccurately presuming disabilities that may in fact not be present.

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

SB 2041
Attache
#5
1/10

Testimony on Senate Bill 2041
2017 Legislative Session
January 9, 2017

Sen. Lee Senate Human Services Committee Chairperson

Senator Lee and Committee Members,

My name is Donene Feist and the state director for Family Voices of North Dakota. Thank you for the opportunity to testify on behalf of SB 20141.

Family Voices of North Dakota is statewide health information and education center who serves families of children with special health care needs in ND. We provide emotional and informational support to many families across North Dakota who have a child who has an ongoing medical diagnosis such as asthma, heart conditions, physical disabilities, and emotional/behavioral issues. Our staff provides assistance and care coordination to families by helping them access and navigate services, understand what these services mean, how systems work, where does the funding come from and by providing emotional, informational and educational support information to assist with their unique and individual needs.

In addition to being the statewide health information and education center, we also offer two additional programs. The North Dakota Parent to Parent program which provides connection with a volunteer parent as a mentor for emotional support. Volunteer parents receive training on listening skills, emotional support and community resources. We utilize family volunteers from across North Dakota.

In partnership with other groups we provide support through Project Carson. Project Carson provides emotional and informational support to families who may receive a **prenatal diagnosis or an at birth diagnosis**. We began this program in 2012 and have assisted many families who have received a prenatal or at birth diagnosis ranging from cleft palate, Down Syndrome, Spina Bifida, congenital anomalies etc.

Family Voices of ND has been a non-profit since 2001, and volunteered from 1996-2001. In those 21 years, we have assisted many families of children with a Down Syndrome diagnosis. Over the past couple of years have seen a sharp increase in the number of children who at the 2.5-2.9 years of age, during a reassessment from early intervention for continued DD waiver and services, an increase in those who were not screened eligible for the DD waiver.

This has caused much concern. For some, at that very moment that the screening occurs, the child may have caught up to their peers in the general population with on target development. Having early intervention services, provided the assistance necessary to meet these targets. That being said, we know and understand that many of those who may not screen eligible at a later date, again screen DD waiver eligible.

FVND has always advocated for early intervention services being extended from age 3 to age five/seven. Additionally, have advocated that **using an adult assessment tool criteria is not appropriate for children**.

From a historical perspective, Family Voices of North Dakota has been a part of several workgroups to identify gaps in services. During the 63rd 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: "The department of human services 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." Then in the 64th session, SB 2234 asked the Department to study

“eligibility for developmental disability waivers and report to the legislative management by January 1, 2016.” Much work went into both of these initiatives.

We support the addition of Down Syndrome, however, in both of the legislative initiatives above, our ongoing concerns continues to be not just in the language and definition but also in assessment of toddlers under the adult criteria of DD.

Children with a developmental disability as you know are screened for the adult DD waiver at 2.5-2.9 years of age. We know many children lose services at the age of three, due to not screening eligible under the adult criteria. There seems to be somewhat of a disconnect between the statute and definition of DD and what is used for eligibility. We firmly believe with an age appropriate assessment that addresses the needs of toddlers-transition of youth, the gaps in service coverage would decrease. Children with a Down Syndrome diagnosis and losing the DD services eligibility being one of several diagnosis.

Services provided under the DD waiver are vital for children and families. It provides vital assistance to families who are often drowning in a sea of unknown's, respite care which is an essential component for families to work, be part of the community of which they reside and be contributing members to North Dakota. Without the waiver, many families would have to forego employment to care for their children. Additionally, it allows access to Medicaid. So many families who have a child with special health care needs face the reality of bankruptcy on a daily basis.

As a mother myself who has been through the bankruptcy process due to astronomical medical expenses, we had no choice. For many families, although they may have private insurance, remain *underinsured* as the child with special health care needs often will need ancillary therapy services that go beyond the limits of private insurance. Medicaid, for these children is crucial. It is imperative to receive habilitative therapy services at these very early ages to maximize development.

Over the years, we have also seen the results when children lose these vital services, often regressing and losing important skills. This seems so unnecessary and in the long run costs the state and consumer's valuable time and dollars.

Family Voices would like the committee to consider the following:

- Identify screening tools that are age appropriate, no longer using the adult DD assessment to address the gaps for those who lose services at 2.5-2.9, and extending the age of early intervention to 5-7 years of age.
- Assist the Department in review of all waiver eligibility and criteria, administrative code changes and amendments that were provided in the November interim report. We feel, with the very stringent adult criteria, many children including those with Down Syndrome fall into a gap area, that we have attempted to address over the course of the last 3-4 legislative sessions.
- Lastly, we feel it important that as work continues to include all stakeholders, especially families who utilize these services. It is vital to include families with lived experience in these processes.

Thank you for your consideration.

Donene Feist
Family Voices of North Dakota
701-493-2634
fvnd@drtel.net

SB 2541
Attach # 1
1/11

Hi Merrill, Hope things went well your first week!

Here are a few points that I tried to make during our conversation - there is so much and issues are so complex that it's hard to make sense sometimes.

Human Services is the Lead Education Agency for services under Part C of the Individuals with Disabilities Act (called Early Intervention services or Infant Development in ND) , providing home-based services to infants and toddlers with disabilities (and developmental delays) and their families.

Early Intervention is administered by the Division of Developmental Disabilities (DD) of DHS. They get millions of dollars every year from the feds for Early Intervention services.

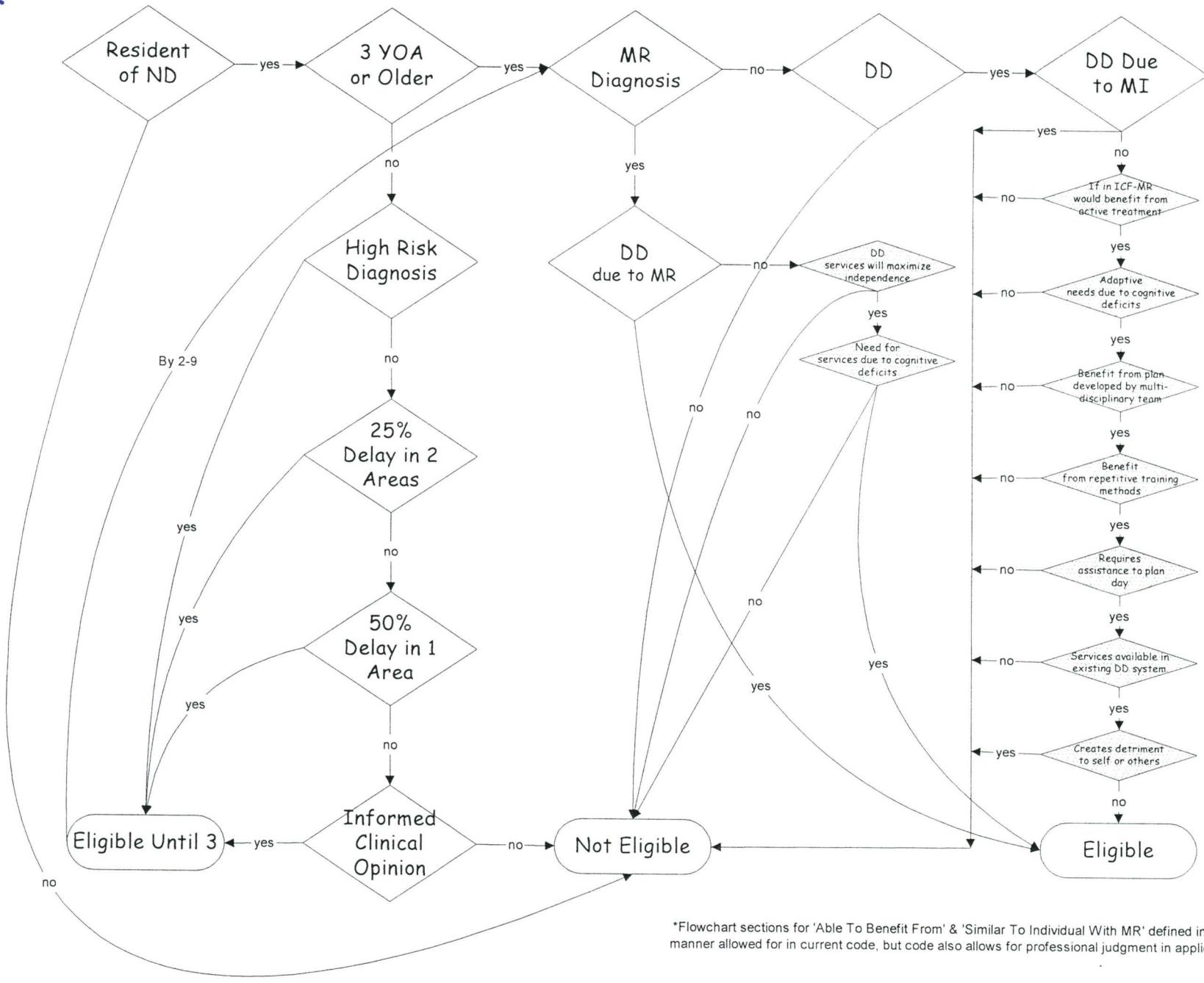
All DD services are coordinated by DD Program Managers (used to be called Case Managers)- a very complicated system set up for the adult system that was established in the 80s as a part of the deinstitutionalization process. That system has grown to be very complicated and I feel much of it unnecessary now although Medicaid does require some coordination. It is certainly unnecessary for a majority of children in Early Intervention who don't have significant delays and need little coordination. The DD system makes it very cumbersome and confusing for parents. Also providers don't get paid until 4-6 people have signed their approval - and maybe only one of them (maybe not even one) would even know anything about early intervention services.

Possible solution - move Early Intervention services to Division of Children and Family Services. Those children and families who need more than early intervention (respite care, family support, etc.) can get DD Program Management for those services which might require more coordination.

Or - at least get a study committee to look at the DD system and see if there are ways to simplify and make it more efficient and effective, especially since the services they coordinate have been in place for over 30 years now and probably don't need such a complicated system.

I could go on, but it is such a complicated system that I think could be streamlined to deliver better services at a lower cost.

SB 2041
 Attach #2
 1/11



*Flowchart sections for 'Able To Benefit From' & 'Similar To Individual With MR' defined in an exclusive manner allowed for in current code, but code also allows for professional judgment in application of code

Chairman Lee, members of the Senate Human Services Committee, please find below the requested definitions regarding Developmental Disability, Intellectual Disability, and Cognitive Disorder. I had presented testimony on Senate Bill 2041, and at the conclusion of that testimony was requested to provide written definitions of Developmental Disability, Intellectual Disability, and Cognitive Disorder. I have included the requested definitions and their sources below. It is hoped that this information is helpful and please feel free to contact me should you have any further questions.

Sincerely,

Dan Cramer, Ph.D., L.P.
Regional Director
South Central Human Service Center

Developmental Disability: per NDCC: **25-01.2-01**

"Developmental disability" means a severe, chronic disability of an individual which:

- a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b. Is manifested before the individual attains age twenty-two;
- c. Is likely to continue indefinitely;
- d. Results in substantial functional limitations in three or more of the following areas of major life activity:
 - (1) Self-care;
 - (2) Receptive and expressive language;
 - (3) Learning;
 - (4) Mobility;
 - (5) Self-direction;
 - (6) Capacity for independent living; and
 - (7) Economic sufficiency; and
- e. Reflects the individual's needs for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Developmental Disability - Per the ICF/IID Glossary per The Center for Medicare and Medicaid Services (CMS):

A severe, chronic disability of a person 5 years of age or older which:

- (a) Is attributable to a mental or physical impairment or is a combination of mental and physical impairments;
- (b) Is manifested

before the person attains age twenty-two; (c) Results in substantial functional limitations in three or more of the following areas of major life activity: (I) self-care;(ii) receptive and expressed language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living; and (vii) economic self-sufficiency; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are lifelong or extended duration and are individually planned and coordinated; except that such term, when applied to infants and young children (meaning individuals from birth to age 5, inclusive),who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Intellectual Disability:

Per The Diagnostic and Statistical Manual of Mental Disorder, Fifth Edition (DSM-5). (This is the primary diagnostic tool utilized for behavioral health in the U.S. and is published by the American Psychiatric Association (APA).

Is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains. The following three criteria must be met:

- A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
- B. Deficits in adaptive functioning that result in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
- C. Onset of intellectual and adaptive deficits during the developmental period.

Intellectual Disability per: American Association on Intellectual and Developmental Disabilities (AAID)

An individual is determined to have an intellectual disability based on the following three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in adaptive skill areas; and the condition is present from childhood (defined as age 18 or less).

**Cognitive Disability:**

Current called "Neurocognitive Disorder" per DSM-5:

These references a range of cognitive issues including Delirium, Amnestic, and Other Cognitive Disorders. Common diagnoses that fall in this category include Alzheimer's disease, Parkinson's disease, and Traumatic Brain Injury. This is likely less relevant for discussion regarding SB 2041

Att. 1
SB 2041
3-8-17

TESTIMONY

SB 2041

House Human Service Committee

March 8, 2017

Representative Kathy Hogan

Chairman Weisz and Members of the House Human Service Committee, my name is Representative Kathy Hogan, and I chaired the interim human service committee. This bill was an interim bill.

SB 2041 is a bill that attempts to address an issue that has been discussed for several sessions. Since this bill passed the Senate there has been a collaborative effort to amend this bill in a way to address the eligibility issue and to assure that the current Century Code is implemented consistently.

I urge you to seriously study the proposed amendment and address this issue.

Thank you.

PROPOSED AMENDMENTS TO SENATE BILL NO. 2041

Page 1, line 1, remove "and section"

Page 1, line 2, remove "50-24.1-02"

Page 1, line 2 remove "Down syndrome and eligibility for"

Page 1, line 3, replace "medical assistance" with "the definition of developmental disability; and to provide for a report"

Page 2, replace lines 1 through 30 with:

"SECTION 2. DEPARTMENT OF HUMAN SERVICES MEDICAID WAIVER STUDY - REPORT TO LEGISLATIVE MANAGEMENT.

1. During the 2017-18 interim, as part of the ongoing review of existing and potential Medicaid waivers performed by the department of human services, the department shall conduct a study of the current eligibility requirements for the developmental disability Medicaid waiver.
2. The study must include an analysis of whether the current developmental disability Medicaid waiver eligibility determination protocol uses age-appropriate assessment methods, uses assessment tools reliable and valid in nature for level of need determinations, and utilizes assessment information that may already be available in an individual's record.
3. The study must include an evaluation of the feasibility and desirability of including in the eligibility determination under the developmental disability Medicaid waiver, consideration of related conditions and the possible use of certain medical conditions, such as Down syndrome.
4. Before April 1, 2018, the department shall make a report to the legislative management on the outcome of this study, including any recommendations, together with any legislation required to implement the recommendations."

Renumber accordingly

Att. 2 SB 2041
3-8-17



SB 2041
Down Syndrome and Developmental Disabilities Eligibility
House Human Services
Wednesday, March 8, 2017

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 187 individuals with Down syndrome and their families across the state of North Dakota which is roughly about 30% of the estimated number of individuals with Down syndrome who reside in our state. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

SB 2041 was put forward by the Interim Human Services Committee. Please allow me to provide some further historical perspective. During the 2015 session, a number of senators assisted our organization to bring forward SB 2234 to address two concerns that we were facing: 1) children with Down syndrome who were not being found eligible for Developmental Disabilities (DD) Program Management nor screened for the Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) Medicaid Waiver and 2) our concern over inconsistencies throughout the state in eligibility and waiver screening processes, often times including what we believe to be, excessive and unnecessary testing requirements for young children. In the end, the content of SB 2234 was essentially exchanged for a Department of Human Services study of the problem. In November, 2015, the Division of Developmental Disabilities Director, Tina Bay, reported back to the Interim Human Services about the results of the Department's study. Ms. Bay's report is attached to my testimony. Because of the discussion in the Interim Human Services, SB 2041 was put forward.

Today, I am asking that you preserve Section 1 of SB 2041 and replace Section 2 with the amendment language as presented by Rep. Kathy Hogan. I believe that preserving Section 1 honors the conversations about these issues in both the 64th and the 65th sessions, without creating undue burden on the State. In comparison, Section 2 as it comes to you from the Senate, does not add or assist the issues that we are concerned about.

I hate having to advocate for this bill, because I spend all the rest of my time, speaking positively about the potential of individuals with Down syndrome. Sadly, to qualify for any service, families are forced to discuss an individual's weaknesses vs. their strengths. So, to have this discussion, I too must emphasize the strong correlation between Down syndrome and a diagnosis of intellectual disability and substantial functional limitations. The correlation is even recognized by the federal Social Security Administration, as the medical diagnosis of Down syndrome (non-mosaic type) is considered as a presumptive disability category. The presentation of the lab report or a doctor's statement confirming the diagnosis is the primary documentation needed to determine medical eligibility for Supplemental Security Income. For your review, I've included a fact sheet on Down syndrome from the National Down Syndrome Society. Following my testimony, I have also asked Dr. Stephen McDonough, a long-standing pediatrician in the Bismarck-Mandan community to provide you with further information about the types of Down syndrome as well the impact of a Down syndrome diagnosis on functioning.

In the Senate, information was shared about how individuals with Mosaic Down syndrome can have much higher functioning. This information was shared to inform the Senate members that it's possible that an eligibility system that would recognize Down syndrome as a presumptive eligibility condition may be at risk of admitting individuals that don't really need the supports or services. I'd like to make sure that you are clear in the House that it is highly unlikely that ND will erroneously serve a large population of persons with Down syndrome that don't need the services or supports. As Dr. McDonough, will share with you, only about 1 – 2% of all individuals with Down syndrome have Mosaic Down syndrome. Today you will also hear testimony from Brian Mueller, who is the parent of a child with Mosaic Down syndrome, who was not found eligible for Developmental Disabilities. Brian's story exemplifies that even the 6 to 12 individuals* in the state of ND with Mosaic Down syndrome may have significant needs. (*Statistic is based on approximately 600 individuals with Down syndrome in ND and Mosaic Down syndrome occurs in 1 – 2% of the population of people who have Down syndrome.)

It is true that when our organization first turned to you as legislators, we wanted a way to bypass the requirement for psychological testing for Developmental Disabilities services and screening for the IID/DD Medicaid waiver. This was especially true for our young children with Down syndrome. After speaking with the Department and understanding the requirements set by the federal Centers for Medicare and Medicaid (CMS), we understand that Down syndrome cannot replace a diagnosis of Intellectual Disability; however, we continue to disagree with the eligibility methods and processes with

which the Department is using for young children. This is the main reason for the study language presented to you in the amendment regarding age-appropriate assessments, etc. I have asked Dr. Mark Doerner, board-certified psychologist to present information to you about best practice standards around assessing cognition and adaptive behavior in young children. He will present following Dr. McDonough and Brian Mueller.

It was not our intent to end up with more study language as there have been Department studies regarding children with developmental disabilities falling into Medicaid waiver gaps dating back to the 63rd Legislative Session and to date, there have been no major changes. At the time this bill was being heard in the Senate, we knew that the Department had taken the initiative to apply for a technical assistance grant through CMS. Since the time the bill passed in the Senate, the Department has been made aware that the grant has been awarded to them. Therefore, we are willing to consider another study with the provisions that are outlined in the amendment in front of you. **In addition, we'd like the committee to consider language that would direct the Department to include stakeholders that are representative of the consumers and families that may be affected by the Department's study in their efforts to review the various Medicaid waivers.**

One of the arguments that continues to present itself as we have advocated for individuals with Down syndrome has been that the State would be in error if they carve out services for certain disability or diagnosis groups. I would like to remind the committee that the State has done just that for the population of individuals with Autism and Brain Injury, both which are medical diagnosis just as Down syndrome is. While we are not asking for a "carve-out" waiver, the amendment language does talk about the inclusion of a diagnosis of Down syndrome if the state chooses to use "related conditions" criteria in eligibility determination if other medical conditions are listed.

The services provided through DD and the IID/DD waiver are important services for our children with Down syndrome and their families. Access to the waiver supports keeps children active and productive in their homes, schools, and communities. It also assists families to be productive citizens, maintaining their employment, mental health, and capacity to parent. The safety net that ND Medicaid can provide for needed therapies and medical care is also needed and can be very critical to maximize brain development and full potential. These services keep our children with special health care needs in their own homes, keeps families intact, and assures that a disability like Down syndrome is mitigated.

Ironically, individuals with Down syndrome emulate who DD services were developed for, yet because of the inconsistencies and gaps in service, children with Down syndrome who were not found eligible and their families are left with less than optimal situations.

When I held my daughter, 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 North Dakota's state institution was full of persons with Down syndrome. In many cases, 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. If someone asked me today what I really want, it would be that we could talk about supporting our ND children and families without talking about our children's weaknesses, that as families, we would not have to feel like we are not contributing because we are asking for help, and that we would not have to say our family will fall apart without the services. The very essence of asking for help and determining need 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
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Down Syndrome Fact Sheet



- Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- There are three types of Down syndrome: trisomy 21 (nondisjunction) accounts for 95% of cases, translocation accounts for about 4%, and mosaicism accounts for about 1%.
- Down syndrome is the most commonly occurring chromosomal condition. Approximately one in every 700 babies in the United States is born with Down syndrome – about 6,000 each year.
- Down syndrome occurs in people of all races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80% of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.
- A few of the common physical traits of Down syndrome are: low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today.
- People with Down syndrome attend school, work, participate in decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- 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 lead fulfilling and productive lives.

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome. The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.

For more information on Down syndrome and NDSS, visit www.ndss.org or call 800-221-4602.



AH 3
SB 2041
3-8-17

Chairman Weisz and Members of the House Human Services Committee:

My name is Dr. Stephen McDonough. I am a board-certified pediatrician who has worked in North Dakota since 1980. At one time, I provided pediatric care to nearly a dozen children with Down syndrome and their families. I am a general pediatrician with a long-standing interest in children with chronic disease. My wife, Dr. Denise McDonough, a family physician, and I have long supported the Buddy Walk for many years and we have also supported efforts to help children with intellectual impairments and adults learn to ride a bicycle.

I made it a practice to refer all babies with Down syndrome to Early Intervention services. They received excellent services in the first three years of life. However, when children with Down syndrome turned 3, some lost intervention services and often did not pass eligibility to get Developmental Disability services. This was despite significant obvious developmental disabilities. Unfortunately, this is not surprising because, in my opinion, the North Dakota Department of Human Services spends more time and effort to deny children of needed services instead of figuring out how to meet the variety of needs that children present.

There are three genetic types of Down syndrome, classic trisomy 21 (95%, translocation (3 to 4%) and mosaic (1 to 2%) Down syndrome. Although children with mosaic Down syndrome tend to have higher functioning than classic Down syndrome, this is highly variable and significant intellectual impairment can still exist. Mosaic Down syndrome is quite rare and there are not a lot of published studies. In ND given the statistics of 600 individuals living with Down syndrome, only 6 – 12 individuals would be diagnosed with mosaic Down syndrome.

Almost all individuals with Down syndrome have cognitive impairment. Most individuals have mild to moderate intellectual disabilities, with an intelligence quotient (IQ) in the 50 to 70 or 35 to 50 range, respectively, although some individuals can have severe impairments with an IQ of 20 to 35. Nearly 20 percent of children and 25 percent of adults with Down syndrome will have a mental health disorder. Seven percent of children with Down syndrome will have autism.

I believe that all children with Down syndrome should be eligible for DD services until the point that more accurate information can be obtained about their cognitive functioning at an older age. One of the many great things about Early Intervention is that if you have Down syndrome, you are eligible for

services. It makes no sense to me why, after investing all those great services in the first three years of like, that many families of children with Down syndrome are left on their own when their child turns three.

I will be happy to respond to any questions that you may have.

Dr. Stephen McDonough

A.H. 4
SB 2041
3-8-17

Testimony for Public Hearing
House Human Services Committee
March 8th, 2017

Brian William Mueller
2625 E Calgary Ave
Bismarck, ND 58503

S.B. No. 2041 – A BILL for an Act to amend and reenact subsection 1 of section 25-01.2-01 and section 50-24.1-02 of the North Dakota Century Code, relating to Down Syndrome and eligibility for medical assistance.

Chairman Weisz and Members of the House Human Services Committee.

Thank you for the opportunity to testify in support of Senate Bill 2041. My name is Brian Mueller. I'm a husband of almost 14 years and a father of 3 wonderful boys. My middle son Ethan is 12 years old. He's blessed us with a journey so amazing, remarkable and rewarding, but that also came with some very trying, frightening and challenging times. Ethan has Mosaic Down syndrome.

We found out there wasn't something quite right with his heart during ultrasounds at 20 and 21 weeks. During week 23 my wife and I were in Minneapolis with ultrasound specialists who immediately diagnosed a severe heart defect. During this appointment, we were given the news that our baby had 4 heart defects and other symptoms that aligned with Down syndrome. We had an amniocentesis test to confirm.

After Ethan was born, our pediatrician ordered a blood test which confirmed his type of Down syndrome was Mosaic. At the time my wife was pregnant the chances of Down syndrome were approximately 1 in 1200 or 0.08%. The chances of Mosaic Down syndrome occur in approximately less than 2% of those diagnoses. Our pediatrician explained some physical features could be less prominent and some learning impairments could be less severe. He also said that while the first few years he would show signs of much higher functioning, that could revert in later years. What he projected was pretty accurate.

Medically related, Ethan has had many difficulties. He had open heart surgery before he was 3 months old. He also went through 4 sets of ear tube surgeries, and had over a hundred doctor appointments from cardiologists, pediatricians, eye specialists and ear, nose and throat doctors by his 3rd birthday. Fortunately, during this time, we were able to receive Medicaid services as a secondary insurance to my family insurance plan. We were also provided early intervention services from West Central Human Services and BECEP. These services provided Ethan additional in-home physical, occupational and speech therapies. Unfortunately, at age 3 we were required to test for re-eligibility and were denied further benefits.

Since age three Ethan's had his tonsils and adenoids removed in addition to another 4 ear tube surgeries. He goes in for annual echocardiograms to monitor his mild-moderate valve leakage. He endures bi-annual blood draws for a thyroid disorder that started at age 6. He's woken at 6am every morning to take his thyroid medicine. While I've always been able to purchase good health care insurance through my employer, we still endure thousands of dollars each year from out of pocket costs for Ethan's medical bills alone.

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Academically speaking, Ethan has largely struggled. We started Ethan very early in BECEP which he attended for 3 years until age 6. We contemplated private schooling, however the services he could be provided in public schools overwhelmingly outweighed private school offerings. Ethan started Kindergarten at Miller Elementary with full-time aide support. We worked very closely with Miller staff to focus on independence. We had dozens of meetings with his support staff working through his educational and behavioral plans with minimal progress. Our pediatrician referred us to a psychologist when Ethan was in 3rd grade, and he was diagnosed with a transitional disorder. To best explain his diagnosis, Ethan had trouble suddenly adjusting from one task to another. He was being pulled in and out of the classroom for different therapies, seeing different people in different rooms. He had a difficult time detaching from the busy outdoor recess times to quiet and calm classroom time. Miller staff worked very hard to minimize his transitions and dedicated one aide to work with him all day instead of switching aides between mornings and afternoons.

Ethan is now a 6th grader at Simile Middle School. Simile staff worked with him at both schools the last two months of 5th grade so he could have a comfortable transition to middle school. We had high hopes he could outgrow dependence on aides. He started going to classroom learning with his peers but within a couple weeks had to be taken out. We consulted again with our pediatrician and were referred to a psychiatrist in November of last year. Ethan was diagnosed with Attention Deficit Hyperactivity Disorder, also crossing into the spectrum of Autism. Unfortunately, this had gone undiagnosed for many years.

Since December, Ethan's been on medication to help with ADHD symptoms and his behavioral problems have improved. He is slowly making progress on his behavioral and educational plans. However, Ethan still has a full-time aide and does not attend any classroom learning except for fitness. Sadly, he spends very little time with his peers. He's recently moved on to 3rd grade math, reads extremely well but comprehends poorly. He is a social butterfly and has hordes of friends, but he socializes at an extremely low level, measured in the 2nd percentile of his peers.

I share this story with you today to show that even with a diagnosis of Mosaic Down syndrome, our son has many challenges. I wish that Ethan and our family could have been supported in much the same way after he turned 3. It was very difficult to lose the supports when we did. It's important that we continue to figure out how to assure that North Dakota is a supportive place for children with disabilities and their families.

This ends my testimony. Thank you, Chairman Weisz, and Members of the Committee.

AH. 5
SB 2041
3-8-17

Chairman Weisz and Members of the House Human Services Committee:

My name is Dr. Mark Doerner. I am a Child Psychologist with over 30 years of experience working with children. I was asked today to provide expert testimony by Designer Genes of ND in relationship to best practices around assessing cognition and adaptive behavior in toddlers and preschool-age children.

Cognitive testing is best done in one setting in one day, with "breaks" for young children when necessary. Cognitive testing is generally a "snapshot" that reflects the child's abilities on that day, at that time of day, under those circumstances, with that examiner, being that tired, hungry, irritable, happy, rested, etc., (and this may apply to both child and examiner!). In short, there is an abundance of potential "error" inherent to the process of assessment, particularly if cognitive testing is conducted "in pieces and days apart." And though most cognitive tests used with young children are standardized and "scripted," with abundant accompanying interpretive and technical manuals, there remains the potential for a test administrator to "deviate from script" because of a child's unique presentation and personality, and changes, however small, may introduce additional "error."

The reliability of a test is a measure of how confident you can be that the same child, given the same test on a different day, will get close to the same result. The most frequently used tests, the Wechsler Preschool and Primary Scales of Intelligence (WPPSI) and the Bayley Scales, have good reliability in this sense. However, consider the following facts:

The WPPSI uses a normative sample of 200 male and female children for the age range of 2:6 – 2:11. But children were EXCLUDED from the WPPSI normative sample if they were or having, for example:

"primarily nonverbal or uncommunicative"

"disruptive behavior or insufficient compliance with testing to ensure a valid assessment"

"uncorrected visual impairment"

"uncorrected hearing loss"

"upper extremity disability that would affect motor performance"

"currently taking medication that might impact cognitive test performance (seizure meds, antipsychotics, some

antidepressants and anxiolytics)"

"period of unconsciousness greater than 20 minutes related to medical condition"

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"previously or currently diagnosed with any physical condition, neurological condition, psychological condition, or illness that might depress performance, such as:

stroke, epilepsy, brain tumor, TBI, brain surgery, encephalitis, meningitis, mood disorder"

Is it fair to use a test to make statements about cognitive functioning in children who would be excluded from the normative sample for that test?! It's NOT apples to apples. Furthermore, many young children with Down syndrome experience one or more of the above conditions.

We should also consider how these tests were developed. The test administrators who collected the normative population data received the same training on how to administer the tests, were provided corrective feedback as they proceeded with testing (and scoring), and inter-scorer reliability was closely monitored to promote maximum fidelity. They were trained to the same standard to test to the same standard. It is unclear if psychologists doing this work throughout the State of North Dakota have been "trained the same," and it is reasonable to also ask if the "fidelity" of cognitive testing and scoring practices is periodically audited. When these testing methods and tools are used to determine if a child will receive critical services, it is imperative that ongoing training and upkeep occur to insure this fidelity.

There are similar concerns about "error" regarding adaptive behavior measures. For example, the Vineland, when administered to children under 3, requires use of the Survey Interview Form, which measures adaptive behavior in four domains; Communication, Daily Living Skills, Socialization, and Motor Skills. Generally, the inter-rater reliability coefficients, or the degree to which different examiners would obtain the same results using the same instrument with the same child, are *lower than preferred* for semi-structured interviews regarding the adaptive behaviors of a child. This limited reliability is often attributed to challenges administrators have in framing the questions and eliciting "score-able responses." The publisher of the Vineland has training tapes available to improve the fidelity of administration.

It is my opinion that given the fragile nature of testing the cognition and adaptive functioning of young children, the State should look for other ways to meet the requirements put forth by their funding sources. Further study of this issue is warranted. If the State cannot find any other way around meeting the eligibility requirements using standardized cognitive testing and assessing adaptive behavior functioning in young children, then at the very least there is an inherent responsibility to administer these assessments with attention to validity issues and assuring the fidelity of the methods whereby they are administered and interpreted.

Att. 6
SB 2041
3-8-17

House Human Services Committee
Sixty-Fifth Legislative Assembly of North Dakota
Senate Bill No. 2041
March 8, 2017

Good morning, Chairman Weisz and Members of the House Human Services Committee. I am David Boeck, a State employee and Director of Legal Services 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.

For several sessions, the Legislature has considered how to address most appropriately the needs of North Dakotans with developmental disabilities. The requirement of an intellectual disability has unnecessarily burdened this process.

The state statute that defines "developmental disability" [N.D.C.C. section 25-01.2-01 (1)] includes a requirement that the individual have substantial functional limitations in at least three specified areas of major life activities. As well, the statutory definition includes a requirement that the individual needs—

a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

These elements are sufficient to identify individuals with extraordinary needs, who deserve attention.

Relying on this definition, Senate Bill 2041 focuses on individuals who have a developmental disability arising from Down syndrome.

An individual with Down syndrome might have exceptional needs for care and services even though the individual might not have an intellectual disability. If an individual has Down syndrome, a developmental disability, and substantial functional impairments in at least three of the specified areas of major life activities, the individual has exceptional needs ... regardless of whether the individual has an intellectual disability.

The laws on availability of Medicaid assistance are premised on the state's determination to help families that have major expenses for care and services for a family member with developmental disabilities. An individual's need is better measured by the individual's substantial functional impairments in specified major life activities than by the presence or absence of an intellectual disability.

Some individuals with Down syndrome might not have qualifying substantial functional impairments and, under SB 2041, they would not be automatically eligible for Medicaid assistance based on these criteria. Other individuals with Down syndrome would.

Passage of SB 2041 would benefit individuals with developmental disabilities arising from Down syndrome. It represents a significant step forward for the Medicaid program in North Dakota.

Please let me know if you have any questions.

att. 7
SB 2041
3-8-17

Testimony
Senate Bill 2041 – Department of Human Services
House Human Services Committee
Representative Robin Weisz, Chairman
March 8, 2017

Chairman Weisz, members of the House Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities (DD) Division for the Department of Human Services (Department). I am here today to provide information on Senate Bill 2041 for your consideration as you review this bill.

Before an individual can access long term care services available through the DD system, two eligibility determinations are required. The first is the eligibility per ND Administrative Code (NDAC) 75-04-06 that would allow the individual access to state-funded DD services and coordination of services through DD Program Management. NDCC 25-01.2-01 definition of "developmental disability" is referenced in NDAC 75-04-06. To meet the eligibility in NDAC 75-04-06, an individual must have a diagnosis of intellectual disability or have a condition other than mental illness that results in a developmental disability, which results in impairment of general intellectual functioning or adaptive behavior similar to that of an individual with the condition of intellectual disability.

If the individual wishes to access long term care services that are funded through the Centers for Medicaid and Medicare Services (CMS) Home and Community Based Services waiver, they must meet the Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/IID) level of care. States are advised that this level of care is defined in 42 CFR §440.150(a)(2) as serving persons with "intellectual disability or persons

with related conditions." Participants linked to the ICF/IID level of care must meet the "related condition" definition when they are not diagnosed as having an intellectual disability. Persons who qualify as having a "developmental disability" under the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 may not meet ICF/IID level of care. While "developmental disability" and "related conditions" overlap, they are not equivalent. The definition of related conditions is at 42 CFR §435.1009, and is functional rather than tied to a fixed list of conditions.

It appears Senate Bill 2041 is intended to create automatic eligibility for individuals with Down syndrome by changing the definition of developmental disability in NDCC 25-01.2-01 and therefore automatic eligibility via NDAC 75-04-06, access to the waiver and then Medicaid. CMS does not allow states the option of automatic eligibility for the waiver based on a specific diagnosis. It is our understanding that this bill is not creating a general fund only program; rather it is only creating a requirement if CMS would allow automatic eligibility, based on a specific diagnosis.

I understand that there is an amendment that is being prepared that will require a study. The Department has begun working with a vendor to provide technical assistance to study the eligibility criteria for all Medicaid waivers and identify potential gaps in services. Concerns expressed by stakeholders have been shared with the technical assistance vendor and will be included in the study.

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

A.H. 1 SB2041
3/20/17

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Title.

Prepared by the Legislative Council staff for
Representative Hogan
March 7, 2017

PROPOSED AMENDMENTS TO SENATE BILL NO. 2041

Page 1, line 1, remove "and section"

Page 1, line 2, remove "50-24.1-02"

Page 1, line 2 remove "Down syndrome and eligibility for"

Page 1, line 3, replace "medical assistance" with "the definition of developmental disability; and to provide for a report"

Page 2, replace lines 1 through 30 with:

"SECTION 2. DEPARTMENT OF HUMAN SERVICES MEDICAID WAIVER STUDY - REPORT TO LEGISLATIVE MANAGEMENT.

1. During the 2017-18 interim, as part of the ongoing review of existing and potential Medicaid waivers performed by the department of human services, the department shall conduct a study of the current eligibility requirements for the developmental disability Medicaid waiver.
2. The study must include an analysis of whether the current developmental disability Medicaid waiver eligibility determination protocol uses age-appropriate assessment methods, uses assessment tools reliable and valid in nature for level of need determinations, and utilizes assessment information that may already be available in an individual's record.
3. The study must include an evaluation of the feasibility and desirability of including in the eligibility determination under the developmental disability Medicaid waiver, consideration of related conditions and the possible use of certain medical conditions, such as Down syndrome.
4. Before April 1, 2018, the department shall make a report to the legislative management on the outcome of this study, including any recommendations, together with any legislation required to implement the recommendations."

Renumber accordingly