#### **2023 HOUSE HUMAN SERVICES**

HB 1035

### Human Services Committee

Pioneer Room, State Capitol

HB 1035 1/4/2023

Relating to the cross-disability advisory council, and to the autism spectrum disorder task force; to provide for a report; to provide an appropriation; and to provide an effective date.

Chairman Weisz called the meeting to order at 10:45 AM

Chairman Robin Weisz, Vice Chairman Matthew Ruby, Reps. Karen A. Anderson, Mike Beltz, Clayton Fegley, Kathy Frelich, Dawson Holle, Dwight Kiefert, Carrie McLeod, Todd Porter, Brandon Prichard, Karen M. Rohr, Jayme Davis, and Gretchen Dobervich. All present.

### **Discussion Topics:**

- Down syndrome
- Eligibility criteria
- Limitations of services for children
- Application and selection process
- Developmental disability equipment
- Cross-disability waiver for children
- Income and expenses
- Waiver amendments

Vice Chairman Ruby introduced HB 1035.

Roxane Romanick, Executive Director of Designer Jeans of ND, Inc., offered testimony in support of HB 1035 (No. 12307).

Vicky Peterson, Family Consultant for Family Voices of ND, testimony in support of HB 1035 (No. 12356).

Nikki Madock, parent of a child with disabilities, oral testimony in support of HB 1035.

Kirsten Dvorak, with the Arc of North Dakota, oral testimony in support of HB 1035.

Krista Fremming, Interim Director of Medical Services in the Department of Health and Human Services testimony in support of HB 1035 (No. 12323).

Chairman Weisz closed the hearing at 11:11 AM.

Chairman Weisz adjourned the meeting at 11:19 AM.

Phillip Jacobs, Committee Clerk

### **Human Services Committee**

Pioneer Room, State Capitol

HB 1035 2/6/2023

Relating to the cross-disability advisory council, and to the autism spectrum disorder task force; to provide for a report; to provide an appropriation; and to provide an effective date.

Chairman Weisz called the meeting to order at 3:03 PM.

Chairman Robin Weisz, Vice Chairman Matthew Ruby, Reps. Karen A. Anderson, Mike Beltz, Clayton Fegley, Kathy Frelich, Dawson Holle, Dwight Kiefert, Carrie McLeod, Todd Porter, Brandon Prichard, Karen M. Rohr, Jayme Davis, and Gretchen Dobervich. All present.

#### **Discussion Topics:**

- Committee work
- Support services
- Full-time equivalent consultant positions
- Similar programs in other states

Chairman Weisz called for a discussion on HB 1035.

Krista Fremming, Director of Medical Services Division of the Department of Health and Human Services, answered questions from the committee.

Rep. Porter moved to amend HB 1035 as follows: in Section 4 on page 2 and 3 remove line 8, on line 10 insert \$350,000, remove line 11, and on line 12 Insert \$350,000 and remove line 13.

Seconded by Vice Chairman Ruby.

Voice Vote: Motion carries by voice vote.

Representative Porter moved a Do Pass as amended and rereferred to Appropriations on HB 1035.

Representative Frelich seconded the motion.

Roll Call Vote:

Representatives	Vote
Representative Robin Weisz	Y
Representative Matthew Ruby	Y
Representative Karen A. Anderson	Y
Representative Mike Beltz	Y
Representative Jayme Davis	Y
Representative Gretchen Dobervich	Y

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Representative Clayton Fegley	N
Representative Kathy Frelich	Y
Representative Dawson Holle	Y
Representative Dwight Kiefert	Y
Representative Carrie McLeod	Y
Representative Todd Porter	Y
Representative Brandon Prichard	Y
Representative Karen M. Rohr	Y

Motion carried 13-1-0.

Representative Beltz carrier.

Chairman Weisz adjourned the meeting at 3:31 PM

Phillip Jacobs, Committee Clerk

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February 6, 2023

#### PROPOSED AMENDMENTS TO HOUSE BILL NO. 1035

Page 3, replace lines 8 through 13 with:

Operating expenses Total all funds Less estimated income Total general fund appropriation \$700,000 \$700,000 350,000 \$350,000

Renumber accordingly

#### **REPORT OF STANDING COMMITTEE**

HB 1035: Human Services Committee (Rep. Weisz, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS and BE REREFERRED to the Appropriations Committee (13 YEAS, 1 NAY, 0 ABSENT AND NOT VOTING). HB 1035 was placed on the Sixth order on the calendar.

Page 3, replace lines 8 through 13 with:

Operating expenses Total all funds Less estimated income Total general fund appropriation \$700,000 \$700,000 <u>350,000</u> \$350,000

Renumber accordingly

#### **2023 HOUSE APPROPRIATIONS**

HB 1035

### **Appropriations Committee**

Brynhild Haugland Room, State Capitol

HB 1035 2/15/2023

Relating to the autism spectrum disorder task force

8:58 AM Chairman Vigesaa- Meeting was called to order and roll call was taken:

**Members present;** Chairman Vigesaa, Representative Kempenich, Representative B. Anderson, Representative Brandenburg, Representative Hanson, Representative Kreidt, Representative Martinson, Representative Mitskog, Representative Meier, Representative Mock, Representative Monson, Representative Nathe, Representative J. Nelson, Representative O'Brien, Representative Pyle, Representative Richter, Representative Sanford, Representative Schatz, Representative Schobinger, Representative Strinden, Representative G. Stemen and Representative Swiontek.

Members not Present- Representative Bellew

### **Discussion Topics:**

- Study Disparity in Disability Ranges
- Hire a Consultant
- Make it Equitable
- FTEs

Representative Weisz- Introduces the bill.

9:06 AM Chairman Vigesaa Closed the meeting for HB 1035

Risa Berube, Committee Clerk

### **Appropriations Committee**

Brynhild Haugland Room, State Capitol

HB 1035 2/16/2023

Relating to the autism spectrum disorder task force

10:18 AM Chairman Vigesaa- Meeting was called to order and roll call was taken:

**Members Present;** Chairman Vigesaa, Representative Kempenich, Representative B. Anderson, Representative Bellew, Representative Hanson, Representative Kreidt, Representative Martinson, Representative Mitskog, Representative Meier, Representative Mock, Representative Monson, Representative Nathe, Representative J. Nelson, Representative O'Brien, Representative Pyle, Representative Richter, Representative Sanford, Representative Schatz, Representative Schobinger, Representative Strinden, Representative G. Stemen and Representative Swiontek.

Members not Present- Representative Brandenburg

#### **Discussion Topics:**

- Study for Differentials of Disabilities
- Additional FTEs
- Add to Human Service Budget

Chairman Vigesaa- Reviews the bill.

Representative J. Nelson Move for a Do Not Pass

Representative J. Stemen Seconds the motion.

Committee discussion Roll call vote

Representatives	Vote
Representative Don Vigesaa	Y
Representative Keith Kempenich	Y
Representative Bert Anderson	Y
Representative Larry Bellew	Y
Representative Mike Brandenburg	А
Representative Karla Rose Hanson	Y
Representative Gary Kreidt	Y
Representative Bob Martinson	Y
Representative Lisa Meier	Y
Representative Alisa Mitskog	Y
Representative Corey Mock	Y
Representative David Monson	Y

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Representative Mike Nathe	Y
Representative Jon O. Nelson	Y
Representative Emily O'Brien	Y
Representative Brandy Pyle	Y
Representative David Richter	Y
Representative Mark Sanford	Y
Representative Mike Schatz	Y
Representative Randy A. Schobinger	Y
Representative Greg Stemen	Y
Representative Michelle Strinden	Y
Representative Steve Swiontek	Y

### Motion Carries 22-0-1 Representative J. Nelson will carry the bill.

**10:21 AM Chairman Vigesaa** Closed the meeting for 1035.

Risa Berube, Committee Clerk

#### **REPORT OF STANDING COMMITTEE**

HB 1035, as engrossed: Appropriations Committee (Rep. Vigesaa, Chairman) recommends DO NOT PASS (22 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). Engrossed HB 1035 was placed on the Eleventh order on the calendar. TESTIMONY

HB 1035



HB 1035 House Human Services Wednesday, January 4, 2023 Representative Robin Weisz, Chair

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm writing as the representative for Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 230 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

Designer Genes is in support of HB 1035 and asks for your consideration of a "yes" vote. The content of HB 1035 was put forth following Human Services Interim work stemming from the passage of SB 2256 during the 67<sup>th</sup> session.

Our organization was involved in the passage of SB 2256 during the 67<sup>th</sup> session and have closely followed the work of the Human Services Interim committee, including the work of a study conducted by Alvarez and Marsal. This is a link to their summary presentation during the interim: <u>North Dakota Developmental Disabilities Study (ndlegis.gov)</u>, We have been interested in seeing a better alignment between North Dakota's Century Code language and the eligibility determination practice in the field for individuals with developmental disabilities. We have supported previous attempts to assure that children with Down syndrome have a more seamless transition without onerous eligibility requirements when they turn three, resulting in the addition of Down syndrome into the ND Century Code in the definition of someone with a developmental disability (North Dakota Century Code t25c01.2 (nd.gov)).

The SB 2256 study was pursued to make the path smoother for families that find themselves caring for a loved one with a special health care needs or a disability like Down syndrome. We have some solid public services in ND but there are cracks that children and adults fall through because they don't meet the eligibility criteria that our state has designed. I see these cracks through my family support work when I'm assisting families to navigate our system of supports.

Section 3 and Section 4 of HB 1035 provides the necessary permissions for the Department of Health and Human Services to move forward to address these system gaps. The Alvarez and Marsal study recommended a three-phase implementation to streamline our current 1915c Medicaid waivers and creating a cross-disability 1915c Medicaid waiver to serve a wider population of eligible children. This work would re-evaluate the eligibility criteria used for children, create more appropriate assessment of need, and assure a more seamless and less confusing transition for children and their families.

In the past, you, the Legislature, have heard from parents who have children with Down syndrome, cerebral palsy, and other special health care needs that had a robust system of wrap-around services until age 3. Annually, North Dakota serves roughly 3000 children and their families in our Part C Early Intervention program for infants and toddlers with delays and disabilities. We have maximized the use of the federal Medicaid match for this program, so close to 100% of the children can be eligible for Medicaid as well as being screened to our Individuals with Intellectual state plan Disabilities/Developmental Disabilities (IID/DD) 1915(c) Medicaid waiver. Children with conditions like Down syndrome are essentially automatically eligible for this program based on their diagnosis. At age 3 however, all of the children face more stringent eligibility criteria both for school-based special education services as well as continued support under the IID/DD waiver. The Alvarez and Marsal study found that only 9% of the children exiting ND Early Intervention services continued to receive services under a 1915c Medicaid Waiver:



While it is very appropriate for many of these children to find their delays mitigated, we have children whose special health care conditions continue and their needs don't stop. As eligibility criteria changes, they face no longer being eligible for Developmental Disabilities Program Management, descreened from the IID/DD waiver and then have no way to access Medicaid, In-home supports, additional therapies, equipment or supplies, or behavioral health support.

We acknowledge that addressing this gap will mean serving additional individuals. But they are individuals that we should be serving. They are individuals with developmental disabilities and our state definition is clear on our responsibility to them.

We would also like to offer some possible language for amendments to Section 1. In lines 14 - 17, we suggest that the contracted facilitator work with the department to establish an application and selection process to establish the initial council and that thereafter the council manage membership recruitment and maintenance with assistance from the contracted facilitator. In lines 17 - 18, we believe that the presiding officer should be selected by the seated advisory council. We also suggest that an additional responsibility in Section 1.5 would be to provide feedback to the department on support and service provision to individuals with disabilities.

I'm available for any questions.

Roxane Romanick Executive Director Designer Genes of ND, Inc. 701-391-7421 info@designergenesnd.com



Health & Human Services

## Testimony House Bill No. 1035 House Human Services Committee Representative Weisz, Chairman January 4, 2023

Chairman Weisz and members of the House Human Services Committee, I am Krista Fremming, Interim Director of Medical Services with the Department of Health and Human Services (Department).

Reforming the Medicaid developmental disabilities and children's waivers is no small task and should be thought of as a marathon, not a sprint. Full implementation will take several years to achieve. The Department believes a cross-disability advisory council as it is proposed in House Bill 1035 can work effectively with the Department and subject matter expert consultants to plan and design for a system that can continue to meet the needs of people with disabilities in North Dakota.

Section 4 of the bill is the appropriation and authorization of full-time equivalent positions to support the effort. The Department provided a recommendation to the interim Human Services committee to address the resources needed to move the waiver reforms forward in a timely manner. House Bill 1035 reduced the Department's recommendation made to the interim committee by half.

The Department believes that additional resources are needed to move this work at the pace desired by the broader stakeholder community and the legislature. If the resources remain at the levels proposed in House Bill 1035, we will likely need to adjust the proposed implementation by adopting a phased approach, with the children's cross-disability waiver being addressed first and the developmental disabilities level of care redesign sequenced to occur later. It is the Department's opinion that it is important to have the cross-disability waiver in place first because this can help assure that those who may be affected by any level of care changes in the developmental disabilities waiver will not be left without service during a transition period.

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

### HB 1035 Testimony

#### **House Human Services**

#### 01/04/2023

Representative Chairman Weiz, Vice Chairman Representative Ruby and Members of the House Human Services Committee.

My name is Vicki Peterson and I am a Family Consultant for Family Voices of ND, the Family-to-Family Health Information Network in ND, a non-profit that works with families whom have children and youth with special health care needs, chronic health conditions and disabilities. We also work with self-advocates and professionals. I am also a parent of a young adult with Autism and Intellectual Disability along with chronic health conditions and a former parent representative of the ND Autism Task Force.

I am here today to provide testimony in favor of the creation of a crossdisability advisory council and to repeal the ND Autism Spectrum Disorder Task Force.

The study conducted by Alverez and Marsal, action taken on SB 2256, proposed a recommendation to create a cross-disability advisory council. A cross-disability advisory council would lead to more participation that would represent the needs and challenges of many and not a specific disability. For all those whom have disabilities and challenges to bring their unique perspectives and join as one advisory council would lead to a greater voice that is needed to identify and prioritize policy issues as it relates to accessibility, inclusive and equity for persons with disabilities. A cross-disability advisory council would better address gaps in services and programs and to educate the Department of Health and Human Services and the community.

As a parent who sat on a very specific task force and as a professional working with families who have children with many different disabilities, the needs do cross-over and are not very specific to the name given to the disability. Implementation of a neutral facilitator will enhance a councils' meeting process so that everyone has the ability to contribute without influence from any one certain agency and increase the productivity of accomplishments to be achieved.

Thank you for your time and consideration.

Vicki L Peterson

Family Voices of ND

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