2023 SENATE HUMAN SERVICES

SB 2276

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
1/24/2023

Relating to legally responsible individuals providing Medicaid waiver services.

9:02 AM **Madam Chair Lee** called the hearing to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** were present.

Discussion Topics:

- Family caregivers
- Primary caregivers
- Eligibility waivers

9:03 AM **Senator Cleary introduced SB 2276** and asked to consider amendments - in favor. #16213

9:07 AM **Tina Bay, Director Developmental Disabilities ND Department of Health and Human Services,** proposed amendments testimony neutral. #15958

9:22 AM **Toby Lunstad, Addilynn's Believers,** testimony in favor #15735

9:31AM **Roxane Romanick, Executive Director Designer Genes,** testimony in favor #16090

9:39 AM **Brittany Zappone, parent,** testimony in favor #16236

9:49 AM **Maran Blair**, **parent,** testimony in favor #16239

9:56 AM **Katynka Morrssette, parent,** testimony in favor #16027

9:58 AM **Jessica Dargis, parent,** testimony in favor #15834

10:02 AM **Sheila Murphy, legal guardian granddaughter,** testimony in favor #16137

10:10 AM **Nicki Maddock, parent,** testimony in favor #16072

10:14 AM **Amy Thom, parent,** testimony in favor #14970

10:18 AM **Brittany Armstrong Hanson, parent**, testimony in favor and **Council Chair, State Council on Developmental Disabilities,** testimony in favor **#16204, #16280, #16427**

10:27 AM **Jodi Keller, parent,** testimony in favor #16257

10:34 AM **Donene Feist, Director Family Voices of North Dakota,** online in favor #15472

Additional written testimony:
Trevor Vannett, in favor #14785
Nathan Leier in favor #14822
Stephen McDonough, Pediatrician, Dakota Reflections in favor #14967
Paula Ennis, in favor #15637
Julie Horntvedt, Executive Director, North Dakota State Council on Developmental Disabilities in favor #15708
Matthew Ferderer in favor #15718
Daniel Gulya, attorney with the ND Protection & Advocacy, in favor #15840
Diedre Hillman in favor #15857
Lisa Kroh, in favor #15896
Tessa Miller in favor #15938
Sommer Jacob in favor #15944
Kali Weinand in favor #16004
Sam Johnson in favor #16038
Carrie Varner, Facilitator, Advocates Leading Their Lives in favor #16262

10:37 AM **Madam Chair Lee** closed the hearing.

Patricia Lahr, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
1/24/2023

Relating to legally responsible individuals providing Medicaid waiver services.

2:20 PM **Madam Chair Lee** called the committee back to order and reopened the hearing. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** were present.

Discussion Topics:
- Lifelong care
- Intellectual and/or developmental disabilities

2:21 PM **Kirsten Dvorak, Executive Director, The Arc of North Dakota,** testified in favor. #15153

2:24 PM **Daniel Gulya, Attorney with the ND Protection & Advocacy Project,** testified in favor. #15840

2:26 PM **Madam Chair Lee** closed the hearing.

Patricia Lahr, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
1/30/2023

Relating to legally responsible individuals providing Medicaid waiver services.

2:52 PM **Madam Chair Lee** called the committee back to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** are present.

Discussion Topics:
- Daily rate
- Waivers

2:53 PM **Jonathon Alm, Attorney, ND Department of Health and Human Services** provided information on amendment verbally.

Senator Hogan moves to **ADOPT AMENDMENT**. (LC 23.0635.02001)
Senator K. Roers seconded.

Roll call vote.

Senators	Vote
Senator Judy Lee	Y
Senator Sean Cleary	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Kristin Roers	Y
Senator Kent Weston	Y

Motion passes 6-0-0

Senator Hogan moves **DO PASS** as **AMENDED** and **REREFER** to **APPROPRIATIONS.**
Senator Cleary seconded.

Roll call vote.

Senators	Vote
Senator Judy Lee	Y
Senator Sean Cleary	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Kristin Roers	Y
Senator Kent Weston	Y

Motion passes 6-0-0
Senator Cleary carries SB 2276

3:01 PM **Madam Chair Lee** closed the meeting.
Patricia Lahr, Committee Clerk

23.0635.02001
Title.03000

Adopted by the Senate Human Services Committee
January 30, 2023

Att
1-30-23
(1-1)

PROPOSED AMENDMENTS TO SENATE BILL NO. 2276

Page 1, line 17, remove "<u>and any subsequent</u>"

Page 1, line 18, remove "<u>Medicaid waivers to be developed</u>"

Page 1, line 19, remove "<u>A waiver under this section which provides for coverage of self-directed in-home</u>"

Page 1, remove lines 20 and 21

Page 1, line 22, remove "<u>4.</u>"

Page 2, replace lines 1 and 2 with:

> "<u>4.</u> <u>This section does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.</u>"

Renumber accordingly

Module ID: s_stcomrep_18_005
Carrier: Cleary
Insert LC: 23.0635.02001 Title: 03000

REPORT OF STANDING COMMITTEE

SB 2276: Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2276 was placed on the Sixth order on the calendar. This bill affects workforce development.

Page 1, line 17, remove "<u>and any subsequent</u>"

Page 1, line 18, remove "<u>Medicaid waivers to be developed</u>"

Page 1, line 19, remove "<u>A waiver under this section which provides for coverage of self-directed in-home</u>"

Page 1, remove lines 20 and 21

Page 1, line 22, remove "<u>4.</u>"

Page 2, replace lines 1 and 2 with:

"<u>4.</u> <u>This section does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.</u>"

Renumber accordingly

2023 SENATE APPROPRIATIONS

SB 2276

2023 SENATE STANDING COMMITTEE MINUTES

Appropriations - Human Resources Division
Rough Rider Room, State Capitol

SB 2276
2/8/2023

A BILL relating to legally responsible individuals providing Medicaid waiver services.

10:55 AM Chairman Dever opened the public hearing on SB 2276.
Senators Dever, Davison, Burckhard, Mathern, Kreun are present.

Discussion topics:

- SB 2276 overview
- Personal care service providers
- Recipient case examples
- ND families need/qualified: 6.1%
- Fiscal note components

10:56 AM Senator Sean Cleary testified. Neutral Testimony #19675

11:05 AM Roxanne Romanick, Executive Director of Designer Genes of ND, Inc., testified in support of SB 2276. Testimony #19739

11:14 AM Toby Lunstad testified affirmatively. Testimony #19664

11:21 AM Donna Feist, Director for Family Voices of ND, testified favorably.
Testimony # 19671

11:30 AM Tina Bay, Director of Developmental Disabilities, NDHHS, testified in support of SB 2276. Testimony #19878

Additional written testimony:
Kellie Hamre, Testimony #19688
Brittany Zappone, Testimony #19695
Deborah Hellman, Testimony #19724
Cari Bousfield, Testimony #19734

11:40 AM Senator Dever closed the meeting.

Carol Thompson for Susan Huntington, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Appropriations - Human Resources Division
Roughrider Room, State Capitol

SB 2276
2/8/2023

A BILL relating to legally responsible individuals providing Medicaid waiver services.

3:46 PM Chairman Dever opened the meeting.
Members present: Chairman Dever, and Senators Davison, Burckhard, Mathern, and Kreun

Discussion Topics:

- Family professional care
- Utilization key
- Foregoing work/homecare
- Reservations

3:46 PM General discussion.

3:53 PM Roxane Romanick, Executive Director, Designer Genes, gave oral testimony.

3:54 PM Senator Davison moved to DO PASS the bill.

3:54 PM Senator Burckhard seconded.

Roll call vote is taken.

Senators	Vote
Senator Dick Dever	Y
Senator Randy A. Burckhard	Y
Senator Kyle Davison	Y
Senator Curt Kreun	Y
Senator Tim Mathern	Y

Motion passed 5-0-0.

This bill does not affect workforce development.

Senator Dever will carry the bill.

3:59 PM Chairman Dever closed the meeting.

Rick Schuchard on behalf of Susan Huntington, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee
Roughrider Room, State Capitol

SB 2276
2/13/2023

Relating to legally responsible individuals providing Medicaid waiver services.

10:17 AM Chairman Bekkedahl opened the meeting.

Members present: **Senators Bekkedahl, Krebsbach, Burckhard, Davison, Dever, Dwyer, Erbele, Kreun, Meyer, Roers, Schaible, Sorvaag, Vedaa, Wanzek, Rust, and Mathern.**

Discussion Topics:

- Committee Action

10:17 AM Senator Dever introduced the bill, verbally.

10:21 AM Senator Mathern moved DO PASS.

10:21 AM Senator Kruen seconded.

10:22 AM Roll call vote.

Senators	Vote
Senator Brad Bekkedahl	Y
Senator Karen K. Krebsbach	Y
Senator Randy A. Burckhard	Y
Senator Kyle Davison	Y
Senator Dick Dever	Y
Senator Michael Dwyer	Y
Senator Robert Erbele	Y
Senator Curt Kreun	Y
Senator Tim Mathern	Y
Senator Scott Meyer	Y
Senator Jim P. Roers	Y
Senator Donald Schaible	Y
Senator Ronald Sorvaag	Y
Senator Shawn Vedaa	Y
Senator Terry M. Wanzek	Y
Senator Rust	Y

Passed 16-0-0
Senator Cleary will carry the bill.

10:22 AM Senator Bekkedahl closed the meeting.
Peter Gualandri on behalf of Kathleen Hall, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2276, as engrossed: Appropriations Committee (Sen. Bekkedahl, Chairman) recommends **DO PASS** (16 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2276 was placed on the Eleventh order on the calendar. This bill affects workforce development.

2023 HOUSE HUMAN SERVICES

SB 2276

2023 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

SB 2276
3/8/2023

Relating to legally responsible individuals providing Medicaid waiver services.

Chairman Weisz called the meeting to order at 3:07 PM.

Chairman Robin Weisz, 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 present. Vice Chairman Matthew Ruby not present.

Discussion Topics:

- In-home services
- Community-based services
- Reimbursement of family caregivers
- Number of qualified caregivers
- Turnover rate
- Costs of services
- Work-life balance
- Work flexibility
- Vulnerability of children
- Routines for children

Sen. Cleary introduced SB 2276 with supportive testimony (#22973).

Toby Lunstad, North Dakota citizen and parent from Mandan, supportive testimony (#22777).

Roxane Romanick, Executive Director of Designer Genes of North Dakota, Inc., supportive testimony (#22993).

Vicki Peterson, spoke in support on behalf of Britanny Supone, North Dakota citizen and parent.

Jody Keller, North Dakota citizen and parent, supportive testimony (#23022).

Tiffany Pederson, North Dakota citizen and parent from Lincoln, supportive testimony (#22874).

Kirsten Dvorak, Executive Director of The ARC of North Dakota, supportive testimony (#22790).

Tina Bay, Director of the Developmental Disabilities Section with the Department of Health and Human Services, supportive testimony (#22926).

Jessica Dargis, North Dakota citizen and parent, supportive testimony (#23003).

Daniel Gulya, Attorney with the North Dakota Protection & Advocacy Project, supportive testimony (#22971).

Sarah Carlson, North Dakota citizen and parent, supportive testimony (#23026).

Additional written testimony:

Donene Feist, Director for Family Voices of North Dakota, supportive testimony (#22015).

Jennifer Zahn, North Dakota citizen and parent, supportive testimony (#22104).

Amy Thom, North Dakota citizen and parent, supportive testimony (#22462).

Quintana Linseth, North Dakota citizen and parent, supportive testimony (#22464).

Brittany Zappone, North Dakota citizen and parent, supportive testimony (#22474).

Matthew Ferderer, North Dakota citizen and parent, supportive testimony (#22638).

Trevor Vannett, North Dakota citizen, supportive testimony (#22765).

Rebecca Busby, North Dakota citizen and grandparent, supportive testimony (#22804).

Lisa Kroh, North Dakota citizen and parent, supportive testimony (#22827).

Katynka Morrissette, North Dakota citizen and parent, supportive testimony (#22948)

Chairman Weisz adjourned the meeting at 4:11 PM.

Phillip Jacobs, Committee Clerk

2023 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

SB 2276
3/29/2023

Relating to legally responsible individuals providing Medicaid waiver services.

Chairman Weisz called the meeting to order at 3:16 PM.

Chairman Robin Weisz, Vice Chairman Matthew Ruby, Reps. Karen A. Anderson, Mike Beltz, Kathy Frelich, Dawson Holle, Dwight Kiefert, Carrie McLeod, Todd Porter, Brandon Prichard, Karen M. Rohr, and Jayme Davis present. Reps. Clayton Fegley and Gretchen Dobervich not present.

Discussion Topics:
- Committee work
- Amendments

Chairman Weisz called for a discussion on SB 2276 and potential amendments.

Vice Chairman Ruby moved to adopt amendment (#23.0635.03001) to SB 2276 (#27025).

Seconded by Rep. Beltz.

Tina Bay, Director of Behavioral Health with the Department of Health and Human Services, answered questions from the committee.

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	AB
Representative Clayton Fegley	AB
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 carries 12-0-2.

Vice Chairman Ruby moved a do pass as amended on SB 2276.

Seconded by Rep. Beltz.

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	AB
Representative Clayton Fegley	AB
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 carries 12-0-2.

Carried by Vice Chairman Ruby.

Chairman Weisz adjourned the meeting at 3:30 PM.

Phillip Jacobs, Committee Clerk

23.0635.03001
Title.04000

Prepared by the Legislative Council staff for
Representative M. Ruby
March 29, 2023

AG
3-28-23
(1-2)

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact a new section to chapter 50-06 of the North Dakota Century Code, relating to a cross-disability advisory council; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

Cross-disability advisory council - Appointment - Duties.

1. The cross-disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers. This subsection does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.

2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.

3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism, traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

Att
3-28-23
(2-2)

5. The cross-disability advisory council shall:
    a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;
    b. Provide for the active participation of stakeholders, including consumers and providers; and
    c. Receive information from the department and its consultants.
6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

SECTION 2. REPEAL. Section 50-06-32 of the North Dakota Century Code is repealed."

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2276, as engrossed: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (12 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2276 was placed on the Sixth order on the calendar.

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact a new section to chapter 50-06 of the North Dakota Century Code, relating to a cross-disability advisory council; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

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2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.

3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism, traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

5. The cross-disability advisory council shall:

    a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;

b. Provide for the active participation of stakeholders, including consumers and providers; and

c. Receive information from the department and its consultants.

6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

SECTION 2. REPEAL. Section 50-06-32 of the North Dakota Century Code is repealed."

Renumber accordingly

2023 SENATE HUMAN SERVICES

SB 2276

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee

Fort Lincoln Room, State Capitol

SB 2276
4/4/2023

Relating to a cross-disability advisory council; and relating to the autism spectrum disorder task force.

10:20 AM **Madam Chair Lee** called the meeting to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** were present**.**

Discussion Topics:

- House amendment concurrence
- Conference committee
- Cost of disability

The committee did not concur.

10:24 AM **Madam Chair Lee** closed the meeting.

Patricia Lahr, Committee Clerk

2023 CONFERENCE COMMITTEE

SB 2276

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
4/12/2023
Conference Committee

Relating to a cross-disability advisory council; and relating to the autism spectrum disorder task force.

3:00 PM **Chair Cleary** opened the conference committee meeting. **Senators Cleary, Hogan, Clemens and Representatives McLeod, M Ruby, Frelich** are present.

Discussion Topics:

- Amendments
- Autism waiver
- Medicaid authorities
- Funds

Senator Cleary calls for discussion.

Representative Ruby provided information on House discussions.

Committee discussion SB 2276.

3:07 PM **Tina Bay Director, Development Disability Section, ND Department of Human Services,** provided information verbally.

3:18 PM **Krista Freming, Interim Medical Services Director, ND Department of Human and Health Services,** provided information verbally.

3:25 PM **Senator Cleary** closed the conference committee meeting.

Patricia Lahr, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
4/17/2023
Conference Committee

Relating to a cross-disability advisory council; and relating to the autism spectrum disorder task force.

9:37 AM **Chair Cleary** opened the conference committee meeting. **Senators Cleary, Hogan, Clemens and Representatives McLeod, Ruby, Frelich** are present.

Discussion Topics:

- Proposed amendment
- Conference committee decision

Chair Cleary calls for discussion.

Chair Cleary provided a proposed amendment from the Department of Health and Human Services. #27602

9:47 AM **Jessica Thommason, Executive Policy Director, Department of Health and Human Services,** provided information verbally.

Senator Hogan moved Senate accede to House Amendments and further amend with the ND Department of Health and Human Services amendment excluding section 5.

Representative Ruby seconded the motion.

Roll call vote-motion carried 6-0-0.

Representative Ruby is the House bill carrier.

Senator Cleary is the Senate bill carrier.

9:55 AM **Chair Cleary** closed the conference committee meeting.

Patricia Lahr, Committee Clerk

NOTE: Committee reconsidered actions on April 19, 2023 at 11:03 AM.

Date: 4/17/2023
Roll Call #: 1

2023 SENATE CONFERENCE COMMITTEE
ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2276 as re-engrossed

Senate Human Services 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: Hogan Seconded by: Ruby

Senators	4/17			Yes	No		Representatives	4/17			Yes	No
Cleary, Chair	X			Y			McLeod, Chair	X			Y	
Hogan	X			Y			M. Ruby	X			Y	
Clemens	X			Y			Frelich	X			Y	
Total Senate Vote				3			Total Rep. Vote				3	

Vote Count Yes: 6 No: 0 Absent: 0

Senate Carrier Cleary House Carrier Ruby

LC Number 23.0635 . 03003 of amendment

LC Number 23.0635.03003 . 05000 of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

2023 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Fort Lincoln Room, State Capitol

SB 2276
4/19/2023
Conference Committee

Relating to a cross-disability advisory council; and relating to the autism spectrum disorder task force.

11:03 AM **Chair Cleary** opened the conference committee meeting. **Senators Cleary, Hogan, and Representatives McLeod, Ruby, Frelich** were present**.** **Senator Clemens** was absent.

Senator Hogan moved to reconsider previous actions of April 17, 2023.
Representative M. Ruby seconded the motion.

Roll call vote-motion passed 5-0-1.

Senator Hogan moved House recede from and further amend by utilizing the prior amendment and then on page 4-line 24 change cap number from 150 to 120 and change the appropriation from 5 million to 2.5 million.
Representative M. Ruby seconded the motion.

Senator Hogan withdrew the motion.
Representative M. Ruby withdrew his second.

Senator Hogan moved House recede from House Amendments and amend as follows by utilizing the prior amendment language and reducing the cap from160 to 120 and change the appropriation from 5 million to 2.5 million with a full time equivalent (FTE) and up to $300,000 for salary and fringe expenses from the 2.5 million. LC 23.0635.03004

Representative Ruby seconded the motion.

Roll call vote-motion carried 5-0-1.

Representative Ruby is the House bill carrier.

Senator Cleary is the Senate bill carrier.

11:18 AM **Chair Cleary** closed the conference committee meeting.

Patricia Lahr, Committee Clerk

2A
4-19-23

23.0635.03004
Title.06000

Adopted by the Conference Committee

April 19, 2023

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

That the House recede from its amendments as printed on pages 1331 and 1332 of the Senate Journal and pages 1446 and 1447 of the House Journal and that Engrossed Senate Bill No. 2276 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact a new section to chapter 50-06 and a new section to chapter 50-24.1 of the North Dakota Century Code, relating to the establishment of a cross-disability advisory council and a family caregiver service pilot project; to provide an appropriation; to provide an effective date; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

Cross-disability advisory council - Appointment - Duties.

1. The cross-disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers. This subsection does not apply to the Medicaid 1915(c) home and community-based services aged and disabled waivers.

2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.

3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

#7
4-19-2

4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism spectrum disorder, traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

5. The cross-disability advisory council shall:

   a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;

   b. Provide for the active participation of stakeholders, including consumers and providers; and

   c. Receive information from the department and its consultants.

6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

SECTION 2. A new section to chapter 50-24.1 of the North Dakota Century Code is created and enacted as follows:

Family caregiver service pilot project - Report.

1. The department shall establish the family caregiver service pilot project to assist in making payments to a legally responsible individual who provides extraordinary care to an eligible individual who is a participant in the Medicaid 1915(c) waivers, excluding the home and community-based services aged and disabled waiver.

2. The family caregiver service pilot project may include funding for extraordinary care, which means care:

   a. Exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical or behavioral needs; and

   b. Is necessary to assure the health and welfare and avoid institutionalization of the individual in need of care.

3. The department may adopt rules addressing management of the family caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall utilize an assessment of an eligible individual to determine the level of care authorized and to determine the best interests of the individual in need of care. The pilot project may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.

4. A decision on an application which is issued by the department under this section may be appealed as provided under chapter 28-32. An individual may not appeal a denial, a revocation, a reduction in payment, or the termination of the family caregiver service pilot project administered by the department due to the unavailability of funding received for the purpose of

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issuing payments as part of the family caregiver service pilot project for the biennium.

5. The department shall provide the legislative management with periodic reports on the impact, usage, and costs associated with the family caregiver service pilot project.

SECTION 3. APPROPRIATION - DEPARTMENT OF HEALTH AND HUMAN SERVICES - ONE-TIME FUNDING - FAMILY CAREGIVER SERVICE PILOT PROJECT - PROJECT COORDINATOR. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $2,500,000, or so much of the sum as may be necessary, to the department of health and human services for the purpose of establishing and issuing payments as part of a family caregiver service pilot project, for the biennium beginning July 1, 2023, and ending June 30, 2025. Of this amount, the sum of $300,000, or so much of the sum as may be necessary, may be used by the department of health and human services for the purpose of hiring up to one full-time equivalent position to serve as the family caregiver service pilot project coordinator, who would be responsible for implementing the pilot project and for establishing a payment portal. Participation in this service pilot project is capped at 120 individuals. The department of health and human services is authorized one full-time equivalent position for this purpose.

SECTION 4. EFFECTIVE DATE. Section 2 of this Act becomes effective January 1, 2024.

SECTION 5. EXPIRATION DATE. Section 1 of this Act is effective through July 31, 2025, and after that date is ineffective; section 2 of this Act is effective until the date the commissioner of the department of health and human services certifies to the legislative council that an approximate or equivalent family caregiver services program is available through a Medicaid and Medicare-approved home and community-based services waiver."

Renumber accordingly

Date: 4/19/2023
Roll Call Vote #:1

2023 SENATE CONFERENCE COMMITTEE
ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2276 as re-engrossed

Senate Human Services 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

*See below:

Motion Made by: Senator Hogan Seconded by: Representative M. Ruby

Senators	4/19			Yes	No		Representatives	4/19			Yes	No
Cleary, Chair	Y			Y			McLeod, Chair	Y			Y	
Hogan	Y			Y			M. Ruby	Y			Y	
Clemens	AB			AB			Frelich	Y			y	
Total Senate Vote				2			Total Rep. Vote				3	

*Note: Senator Hogan moved to reconsider previous action on 4/17/2023.

Vote Count Yes: 5 No: 0 Absent: 1

Senate Carrier Senator Cleary House Carrier Representative M. Ruby

LC Number 23.0635 . 03004 of amendment

LC Number 23.0635 . 06000 of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

Insert LC: 23.0635.03004
Senate Carrier: Cleary
House Carrier: M. Ruby

REPORT OF CONFERENCE COMMITTEE

SB 2276, as engrossed: Your conference committee (Sens. Cleary, Hogan, Clemens and Reps. McLeod, M. Ruby, Frelich) recommends that the **HOUSE RECEDE** from the House amendments as printed on SJ pages 1331-1332, adopt amendments as follows, and place SB 2276 on the Seventh order:

That the House recede from its amendments as printed on pages 1331 and 1332 of the Senate Journal and pages 1446 and 1447 of the House Journal and that Engrossed Senate Bill No. 2276 be amended as follows:

Page 1, line 1, after "A BILL" replace the remainder of the bill with "for an Act to create and enact a new section to chapter 50-06 and a new section to chapter 50-24.1 of the North Dakota Century Code, relating to the establishment of a cross-disability advisory council and a family caregiver service pilot project; to provide an appropriation; to provide an effective date; and to provide an expiration date.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

Cross-disability advisory council - Appointment - Duties.

1. The cross-disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers. This subsection does not apply to the Medicaid 1915(c) home and community-based services aged and disabled waivers.

2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.

3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism spectrum disorder, traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

5. The cross-disability advisory council shall:
   - a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;
   - b. Provide for the active participation of stakeholders, including consumers and providers; and
   - c. Receive information from the department and its consultants.
6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

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2. The family caregiver service pilot project may include funding for extraordinary care, which means care:
   - a. Exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical or behavioral needs; and
   - b. Is necessary to assure the health and welfare and avoid institutionalization of the individual in need of care.
3. The department may adopt rules addressing management of the family caregiver service pilot project and establish the eligibility requirements and exclusions for the family caregiver service pilot project. The department shall utilize an assessment of an eligible individual to determine the level of care authorized and to determine the best interests of the individual in need of care. The pilot project may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid state plan.
4. A decision on an application which is issued by the department under this section may be appealed as provided under chapter 28-32. An individual may not appeal a denial, a revocation, a reduction in payment, or the termination of the family caregiver service pilot project administered by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family caregiver service pilot project for the biennium.
5. The department shall provide the legislative management with periodic reports on the impact, usage, and costs associated with the family caregiver service pilot project.

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Renumber accordingly

Engrossed SB 2276 was placed on the Seventh order of business on the calendar.

TESTIMONY

SB 2276

Senate Testimony SB2276

My name is Trevor Vannett. I am in support of this bill because families should be able to get paid as caregivers when providing up and beyond care of day to day services for their child or loved one. I support the bill as it stands now. Families should not have to worry about finances when they have to stay home with their child with high needs.

Trevor Vannett

420 E Main Ave. Apt. 403, Bismarck, ND 58501

701-955-0000

trevorstwins@icloud.com

Mr. Chairman, and other members of the committee, my name is Nathan Leier and I'm from a family farm near Strasburg. I vote and live in District 8.

I am testifying in support of Bill No. 2276. I live with a rare, progressive, genetic disorder called Friedreich's Ataxia. Currently there is no treatment or cure for this condition. I can only slow its progression by staying active in life. Every day, little strides are being made to find a cure by researchers and God promises that better days are yet to come!

Again, this disease is a rare one and therefore very unique. I have feeling in all of my extremities; I just cannot execute muscle movements. Right now, I live with my parents who help me with daily activities. I have 6 siblings, living close by, who are gracious and willing to fill the gap and help when the others cannot. I start each day by someone helping me to transfer from my bed to my wheelchair and helping me to dress for the day. Someone then follows me to the bathroom to help me transfer to and from the toilet. Daily activities are done independently until nighttime arrives and I need help with transfers again.

Living in such a rural area doesn't allow for many or any caregivers in my surrounding population. Under current Medicaid rules, a company from Bismarck could be hired to drive to me and help me. So that is 3 hours per day of drive time that the company would be getting paid as they drive to me. It just makes sense to pay family to be with me when I need them. All age groups would benefit from this bill being passed. For example, an elderly person who otherwise, would have no choice but to go to a nursing home could instead have family take care of them without compromising the financial future of the caregiver. This would save the State money by not paying the nursing home and would be so much better for the individual's mental health. There is just a special feeling that you get when someone who truly cares about you is there to help, verses someone who is just by your side for the paycheck.

Thank you for your time listening to my testimony today and thank you for serving the GREAT State of North Dakota!

I urge your support and a yes vote on Bill 2276. If we work together and pass this bill, we will produce a positive result for everyone who relies on help from family members!

I would be happy to answer any questions that you have for me.

(701) 321-3060

nathanleier@hotmail.com

Testimony in support of SB 2276

Relating to legally responsible individuals providing Medicaid waiver services.

Senate Human Services January 24, 2023 9:00 AM Fort Lincoln Room

My name is Stephen McDonough. I am a board certified pediatrician who worked in North Dakota for forty years, from 1980 to 2020. I worked at the NDDoH from 1985 to 2000 and for several years was the medical director at what became the Children's Special Health Services at the ND Department of Human Services. I served on the Secretary's Advisory Committee for Heritable Disorders in Newborns and Children at the federal level to the US Department of Health and Human Services from 2011 to 2017.

I was a general pediatrician with a long standing interest in children with chronic disease. Families of children with special health needs experience multiple stresses and among those are: the diagnosis, disability and prognosis for their child's condition; the medical journey that was taken to make the diagnosis; getting their child to appointments with medical providers, therapists and school personnel and paying for the many treatments and interventions not covered by health insurance or the school system.

I tried my best to get as many support services for the children in my practice as possible. For over a decade, I made more referrals to early childhood development than all of physicians in the Bismarck/Mandan area combined.

Access to daycare is especially problematic in our state in both urban but especially rural areas for children with special health care needs. Parents of children with special health care needs find it more difficult to be employed.

Passage of SB 2276 will help alleviate some of the financial stresses that these families experience and I urge you to support this bill.

Stephen McDonough MD

Testimony in Support of SB 2276
2023 Legislative Session
January 24, 2023

Senator Lee and Members of the Human Service Committee,

My name is Amy Thom and our family resides in Bismarck, ND in District 8. I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Our daughter Em was born with Sturge Weber Syndrome in 2013. As a result of this diagnosis she experiences life threatening seizures (which has resulted in numerous hospitalization stays), has global developmental delays, has a port wine stain which needs regular laser treatment, has had countless eye surgeries related to glaucoma, and has undergone proton beam radiation therapy for retinal detachments. She has low muscle tone, which has resulted in recent bilateral hip surgeries. She has also struggled with her immune system which lowers her seizure threshold level. In spite of how hard she has had to fight, she has the gentlest personality and is such a joy in our lives.

Because of her health struggles, and at the recommendation of our doctors not to do daycare, I resigned from my professional job as a Master Level Social Worker 7.5 years ago. I became her full-time caregiver at home. I have been trained and educated on how to best provide her care from Occupational Therapists, Physical Therapists, Speech Therapist, Pharmacists, and Physicians. She is our miracle and has thrived in our home setting.

As time went on and we had more children, I needed more respite services as our daughter continues to need 24 hour care. She needs complete assistance with feeding, drinking, medication administration, dressing, bathing, and incontinence care. She also needs 1:1 assistance with walking, and continuous safety monitoring due to her seizure activity, which also requires overnight monitoring. Her other needs include all the other typical cares; meal prep, laundry, cleaning, playtime, and all the other activities that simply help her to be a kid.

We have always used the self-directed portion of the respite waiver. My husband and I wanted the ability to hire and know exactly who would be coming into our home environment. As time has gone on, it has been more and more difficult to find high quality respite providers that can meet our daughter's level of care. We have been very blessed to have had a family member from out-of-state move back part-time to fill in those respite care gaps for us and provide respite care, as we have been unable to find full-time respite caregivers.

If this bill is passed it would give our family the opportunity to continue to meet our goals of keeping Em in our home. My husband and I would have more flexibility to work together to meet our daughter's needs, instead of relying on an outside individual to do these very personal care needs for her as she ages. It is our deepest wish and prayer that we could be together more as a family unit to continue to make sure Em has the highest quality of life possible as well as meet the needs of our other children.

While I was working in Nebraska during college years, I was able to intern and meet countless families who were on NE Medicaid Aging and Disabled Waiver Programs. The ability for family members to provide and be paid for direct 1:1 care instead of hiring outside facilities or individuals to come into their home was such a beautiful process. Their quality of life, ability to maintain cultural practices, and to honor their family unit was so very evident. It was one of my career highlights because it exemplified my own set of values, which is the importance of the family unit. Little did I know that someday I would be one of those caregivers here in North Dakota. My only wish is that our waiver program could financially support family members who are providing extraordinary care to help keep the cohesiveness of the family unit intact.

That is why I am asking each one of you to please consider a “Do Pass” on Senate Bill 2276, and for it to be implemented July 1, 2023.

Thank you for your time.

Sincerely,
Amy Thom
jonellamy@gmail.com
701-650-8996

The Arc.
North Dakota

Senate Human Services
SB 2276
January 24th, 2023

Senator Lee and committee members. I am Kirsten Dvorak, Executive Director of The Arc of North Dakota; we have six chapters throughout the state of North Dakota that advocate on behalf of individuals with intellectual and/or developmental disabilities (IDD) for full inclusion in their community of choice.

We support SB 2276

Family caregivers of individuals with IDD play an invaluable role in providing the necessary care and support that their loved one needs. Unfortunately, with the changing demographics, such as a lack of workforce, family caregivers often need to meet increasing demands on their time and resources. We must recognize the tremendous dedication of these family caregivers and provide them with the necessary resources and support they need to ensure that individuals with IDD can receive the highest quality of care.

Position:

- Strengthen the caregiving efforts of families, with particular emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction.
- Enable families to make informed choices regarding the nature of community supports for themselves and their members with disabilities.
- Help families with minor members stay intact, preventing out-of-home placements for a minor child, particularly in institutions or congregate settings.
- Ensure aging caregivers can provide care for their loved one as long as necessary and appropriate while honoring self-determination.

At The Arc of North Dakota, we understand the importance of providing lifelong care for individuals with intellectual and/or developmental disabilities. We also recognize that not all families have the resources to provide lifelong care and that paying families as caregivers should not be used as a substitute. We are committed to advocating for policies that support families through financial assistance, home-based services, and respite care so that they can continue to provide quality caregiving for their loved ones. We believe that it is essential for families to be supported to ensure that individuals with disabilities receive the best possible care.

Kirsten Dvorak

701-222-1854

Testimony on SB 2012
2023 Legislative Session
January 20, 2023
Sen Lee Senate Appropriations Human Services Chairperson

Senator Lee and Members of the Committee

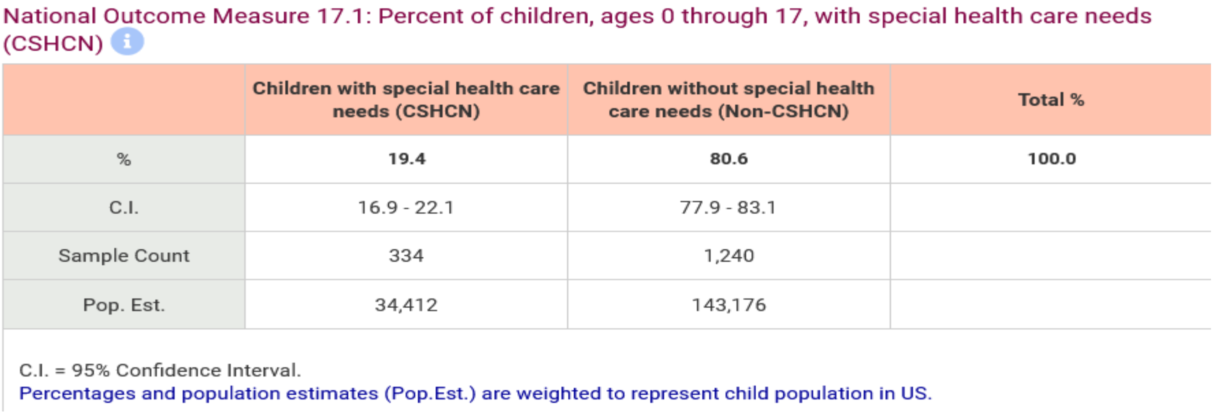
My name is Donene Feist, I am the Director for Family Voices of North Dakota. I come before you today regarding SB 2276, for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Family Voices of North Dakota is statewide family to family health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center by HRSA federally. We are that entity for ND.

According to the 2020-2021 National Survey of Children's Health, there is approximately 34,412 children and youth who have a special health care need. FVND follows the Maternal and Child Health definition of children with special health care needs, which is those children and youth who have a chronic condition of at least one year, a physical disability or mental health/behavior health diagnosis. Additionally, there are many children and youth who may have a physical disability and a chronic health illness but also may have a co-occurring mental health diagnosis. Because of many families have a co-occurring condition, it often leaves families having to understand and navigate many systems and complicated silos. We receive our referrals through agencies, physician offices, out of state hospitals where a child/youth may be receiving services.

The National Data Resource Center for Child and Adolescent Health https://www.childhealthdata.org/ provides clear data on the complexities of children and youth with special health care needs. It also compliments with statistical data, information that has been provided to you all from the Alvarez and Marsal study. The needs for our families are great. We are pleased with the outcome of that study and hope the legislative body, policymakers and families will continue to work to assure we are closing the gaps for families.

Table 1: Number of children and youth with special health care needs in North Dakota

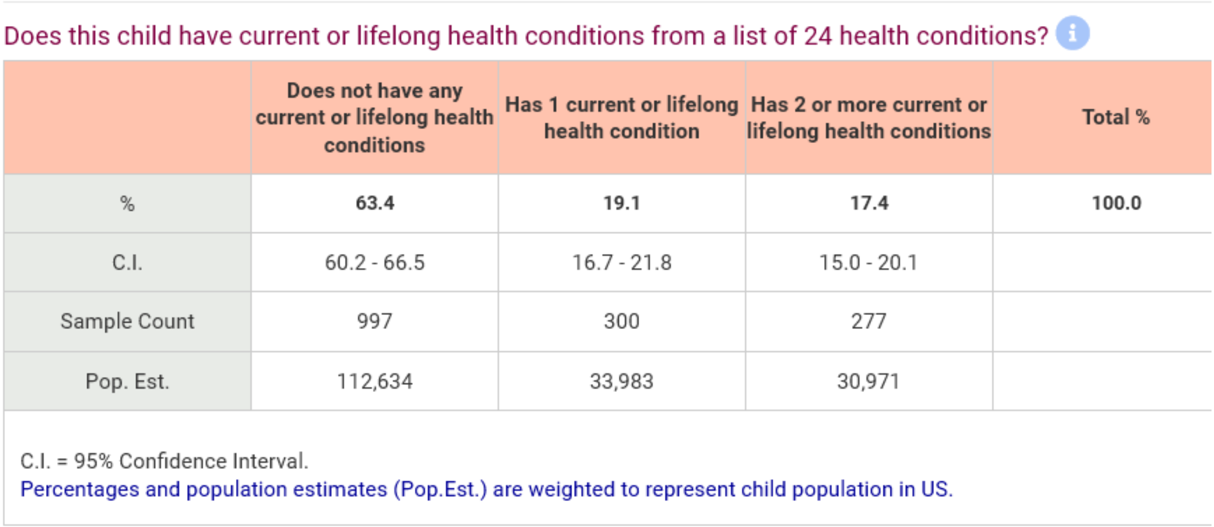


National Outcome Measure 17.1: Percent of children, ages 0 through 17, with special health care needs (CSHCN)

	Children with special health care needs (CSHCN)	Children without special health care needs (Non-CSHCN)	Total %
%	**19.4**	**80.6**	**100.0**
C.I.	16.9 - 22.1	77.9 - 83.1	
Sample Count	334	1,240	
Pop. Est.	34,412	143,176	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

As the diagram indicates the number of children in North Dakota who have one or two life long illness.
Table 2:



Does this child have current or lifelong health conditions from a list of 24 health conditions?

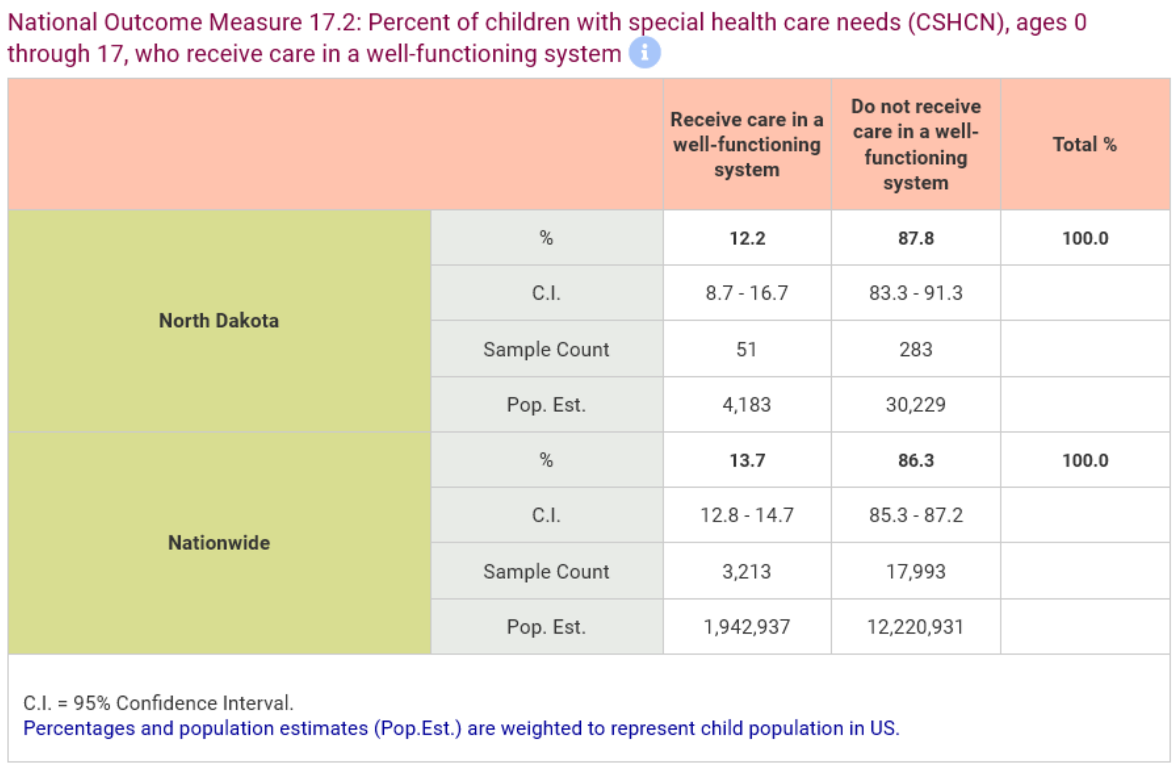
	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Has 2 or more current or lifelong health conditions	Total %
%	**63.4**	**19.1**	**17.4**	**100.0**
C.I.	60.2 - 66.5	16.7 - 21.8	15.0 - 20.1	
Sample Count	997	300	277	
Pop. Est.	112,634	33,983	30,971	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Many advocates and providers have shared over the years the gaps in services in North Dakota. The Alvarez and Marsal study did a tremendous job of aggregating those needs in their study. This illustration identifies how many of these children receive care in a well-functioning system as compared to national data.

My point in sharing this information is more and more states are already supporting a program such as this or are considering this due to the many barriers identified.

The National Academy for State Health Policy (NASHP) developed a brief that was published 1/15/21 ***State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid*** https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/



National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

		Receive care in a well-functioning system	Do not receive care in a well-functioning system	Total %
North Dakota	%	**12.2**	**87.8**	**100.0**
	C.I.	8.7 - 16.7	83.3 - 91.3	
	Sample Count	51	283	
	Pop. Est.	4,183	30,229	
Nationwide	%	**13.7**	**86.3**	**100.0**
	C.I.	12.8 - 14.7	85.3 - 87.2	
	Sample Count	3,213	17,993	
	Pop. Est.	1,942,937	12,220,931	

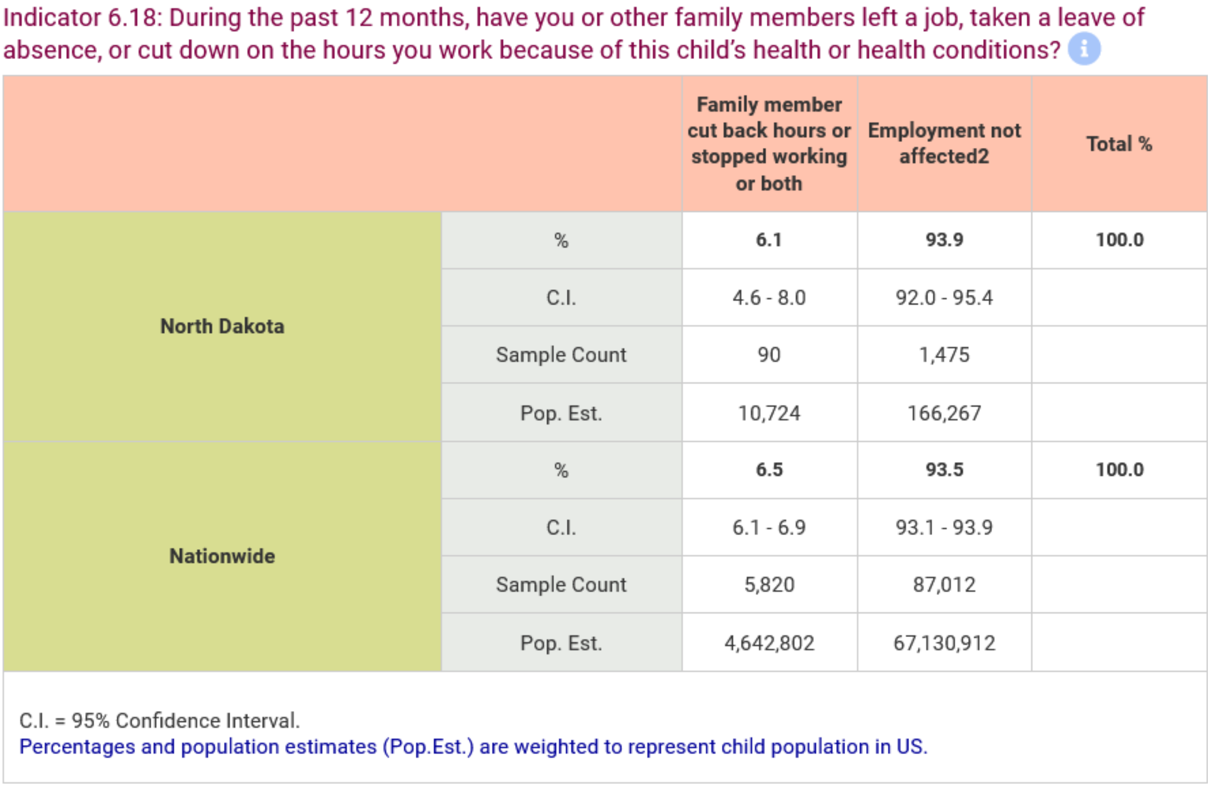
C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

The next illustration is the number of families who have had to leave a job, take a leave of absence or cut down hours because of their child's health condition.

What we know and have heard repeatedly from families for many years are heartbreaking stories of not only families who have left a job but additionally families who have been dismissed due to their child's condition, perhaps needing more time off if their child is sick, for appointments, therapy visits, hospitalizations and care.

Day care is an additional barrier for our families. Centers are full, and despite our best efforts often times providers will also say they are not adequately prepared for many of our children. This is especially true for our families who have high medical needs and care.

As you already know workforce issues impact our families tremendously. Many are struggling to hire and maintain staff. Staff availability has shrunk many times over adding additional barriers to the families we serve with complex medical needs. This diagram identifies the number of families who have left a job, taken a leave or cut hours because of their child's health condition. 6.1% of ND families fit into this category.

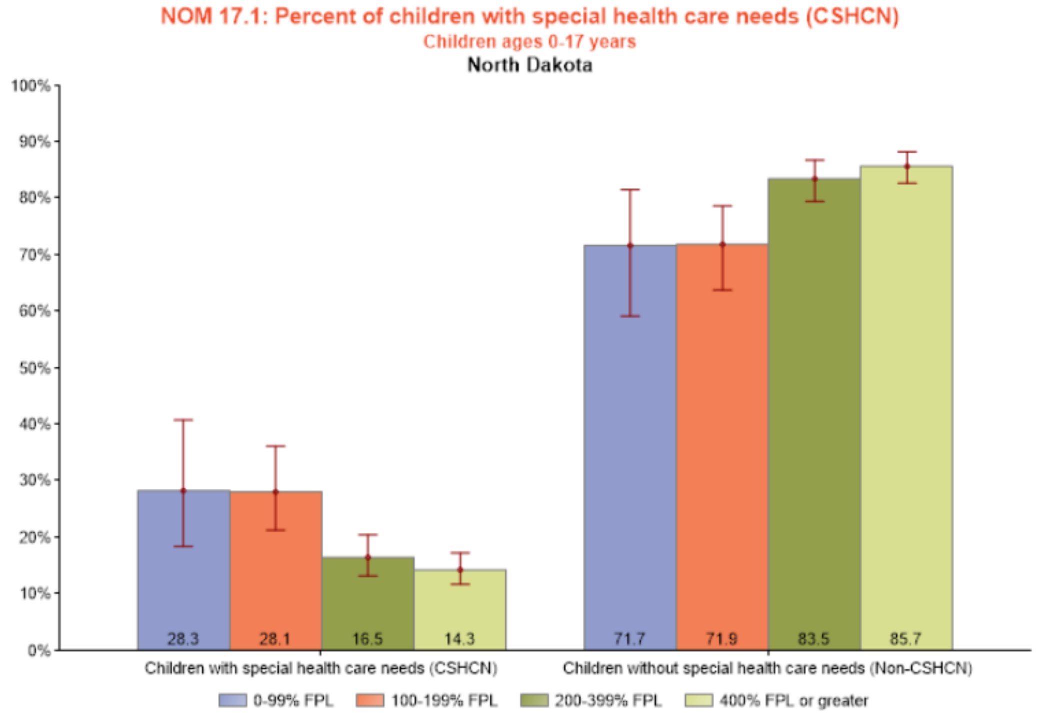


Indicator 6.18: During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child's health or health conditions?

		Family member cut back hours or stopped working or both	Employment not affected2	Total %
North Dakota	%	**6.1**	**93.9**	**100.0**
	C.I.	4.6 - 8.0	92.0 - 95.4	
	Sample Count	90	1,475	
	Pop. Est.	10,724	166,267	
Nationwide	%	**6.5**	**93.5**	**100.0**
	C.I.	6.1 - 6.9	93.1 - 93.9	
	Sample Count	5,820	87,012	
	Pop. Est.	4,642,802	67,130,912	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

I also felt it is important to illustrate the federal poverty level for our families. As you can see from the diagram, families are struggling. These additional barriers for families only adds to the many complexities that families with high medical complexities face.



Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. https://mchb.hrsa.gov/data/national-surveys

Citation: Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [www.childhealthdata.org].

Passage of The Family as Paid Service Providers bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one.

We believe, looking at new approaches to identify and amend gaps in services are necessary. A policy such as this will keep our North Dakota family units intact, close a workforce gap that feels at times that is getting larger than smaller. A policy such as this would also provide a consistent quality of care for our children and youth. Families are in crisis, we hear the dire needs of families who contact us for help. In neighboring states who have this option it has been lifesaving for many. Colorado and Minnesota are an example of this.

Families are not looking for handouts, but they do often need a rope to hang on to, to keep from drowning in an every changing system.

Thank you for your consideration

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

Paula Ennis
Voting district 33

I am testifying in support of bill No. 2276 for an act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing medicaid waiver services.

I am a Grandma to Asher Ennis born on 09/02/2022 and diagnosed with CF on 09/13/2022 who resides in Gwinner, ND
Mother Nicole Ennis.

Becoming a parent for the first time is scary, Nicole faced not only this new scary world but also during a pandemic, and then finding out Asher now has Cystic Fibrosis. This leads to a lot of stress, education, heartbreak, but also a blessing because she still has a beautiful baby boy. We all work every day to ensure one thing: that our children outlive us. Unfortunately, we can never be sure of that, can we? But no parent can. Tragedies happen, and with CF they happen ALOT!

Gwinner is a very small community with limited services, and there is currently one daycare and they do not have the staff to accommodate a baby with CF
One downfall of all the treatments a baby with CF is that your average teenage babysitter is unable to babysit, it takes someone that knows how to do all the treatments necessary for Asher to help prevent early organ damage and help Asher to live a longer, healthier life.
Daycare providers are spending more time with our children than we are.

09/19/2022 Asher was seen at Sanford coordinated treatment center in Fargo. The Doctor explained to Nicole she would need to stay home with Asher for an additional 12 weeks after a short term disability and recommended Asher not to go to daycare until at least one year of age.

Nicole was denied FMLA at her place of employment for 4.5 years due to the fact she had not worked enough hours in 2022
They also explained that she would have to go back to work at 6 weeks with no FMLA for any of Ashers Dr. Visits so unfortunately Nicole had to resign at her place of employment.

I ask you to please consider paying the parents of Cystic Fibrosis especially in ND and vote in favor of bill 2276
Thank you for your time
Paula Ennis

Senate Human Services

SB2276

January 23, 2023

Senator Lee and members of the committee. My name is Julie Horntvedt and I am the Executive Director of the North Dakota State Council on Developmental Disabilities (DD Council). The Council was established through the Developmental Disabilities Act (P.L. 106-402) and is funded by the federal government. Councils are uniquely composed of individuals with developmental disabilities, parents, family members of people with developmental disabilities, and representatives of State agencies that administer funds under Federal laws related to individuals with disabilities, and local and nongovernmental agencies. Members of a Council are appointed by our State's Governor.

One area of our work is to promote system-wide changes that result in long-term positive impact on the capacity of individuals with developmental disabilities to lead meaningful lives in their home communities. We believe this action fits within the goal of this bill and why we are in favor of SB2276. Promoting home-based services, financial assistance, and respite care so families can provide the level of care they need for their loved one at home is essential. We face a workforce shortage crisis, families to be unstable if they cannot work, and are at risk of more institutionalizations of individuals with disabilities if they can't be served at home. This bill is a demonstration of a new approach to service that will benefit the person receiving services as well as their family member.

Thank you for your time and consideration.

Julie Horntvedt

jhorntvedt@nd.gov

701-328-4847

Hello, my name is Matthew Ferderer and this is my wife Kris.
We live in Mandan in voting district 34

We are testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I was raised on a dairy farm just west of Mandan. This upbringing prepared me to handle many life situations with more ease than the average person. As a lot of North Dakotans know, farmers must wear many hats in order to be successful. You must be a veterinarian, an electrician, a mechanic, a welder, an equipment operator, a plumber, an accountant, a businessman, an agronomist and work 100 hours a week. The list goes on and on and you must constantly improve your abilities in this ever-changing world. The same is true for parents of special need children. You have to be a doctor, a nurse, a phlebotomist, an occupational therapist, a physical therapist, a speech pathologist, a nutritionist, a respiratory therapist, a psychologist, a pharmacist. You have to specialize in GI and IR and learn everything there is to know about heart transplants and rejection and worry about sickness and infections constantly. And at the end of the day, the transplant surgeon's voice echoes in our mind. He said to us, "that is a good heart, it will last her 30 years." 30 years! Sometimes we look at each other and say we will bury her someday. We should be enjoying these days but the guilt of not working with her so that she can develop and be the best that she can be and the fear of taking her out in public because she is immunosuppressed and could get sick and have to take another antibiotic and risk heart rejection. Things that most parents don't have to worry about. Raising a child is a feat of its own, but nothing can prepare you for a child with special health needs. A person could never understand unless you have gone through it yourself. We are wearing more hats now than ever and our backs are tired. Most of the time we feel so numb that it is hard to think of the future. We also have another child that we are trying to raise to be the best he can be. The hand we have been dealt has limited us. It has affected our marriage, our bank account, our jobs, our mental and physical health, our relationships with family and friends, opportunities and ultimately our livelihood. I am not standing up here asking for sympathy from anyone in the room but rather empathy. I am just trying to paint a picture so that maybe you can understand. That being said, we wouldn't change it for the world. Our little Elliott brings us many challenges, but also so much joy. We love her in indescribable ways.

My wife and I have worked hard to get to where we are at in life. We planned to have our son and we planned to have our daughter, but we could never have planned for what has happened in the last 2.5 years. We enjoy our jobs. We enjoy what we do with our money that we have rightfully earned. We have had to drain resources we worked hard for due to all the time we have had to take off work unpaid for appointments, therapies, hospital admissions but most of all when we don't have staff to care for her. Changing this legislation would help us and so many other families in similar situations. I am not a political person, but I do stand up for what I believe in and for others that need help. This bill just makes sense.

We decided to not bring Elliott here today because her PT, OT, speech therapy, G feeds and nap is more important to her development than meeting you all. You all are missing out though because she is an angel.

We were told that she had a heart condition at her 20 week ultrasound. At 36 weeks, my wife relocated to Minneapolis as she would have to deliver there. Our daughter, Elliott, was born with an extremely rare heart defect. She was diagnosed with pulmonary atresia and intact ventricular septum with severe hypoplastic right ventricle complete RV-dependent coronary circulation with bilateral atresia of coronary ostia. Shortly after her birth she underwent surgery that involved atrial septectomy, BT shunt and aorto-tricuspid RV shunting. These are medical terms that moms and dads shouldn't need to know, unless you're a pediatric cardiac doctor. Elliott has traveled a very long road in her short life already. The first two open heart surgeries allowed her to survive until transplant. She received a heart transplant at the age of 2 months old. It is very difficult to put the emotions into words, but that day came with several complications. Elliott spent the first 8 months of her life in the hospital. Because of how long Elliott was inpatient, sedated with medications, intubated and immobile along with the complications from surgeries (mainly right after the heart transplant) she suffered seizures and two strokes. The second stroke was more substantial, and the left side of her brain was hit hard. She has right sided hemiparesis as a result, which means she can't move her right arm or leg as effectively as her left. She has also been diagnosed with Cerebral Palsy because of the stroke. Another complication from the day of her transplant was that she lost blood flow to her right foot. Her toes and her heal on her right foot turned black and eventually self-amputated. She does not eat or drink enough orally, so she gets her nutrition via a GJ tube. She has PT, OT and speech therapy that come to our home daily and often several therapists each day. She takes meds twice a day to suppress her immune system in order to prevent rejection of the heart. We could write a book on our journey so far. My wife and I have fought until we are numb so that Elliott has a fighting chance at life and so that she has the best possible outcome.

Now imagine struggling to balance work, other children at home, finances, meds, therapy schedules, medical supplies, sports schedules, marriage, a social life; while constantly worrying if your son or daughter is getting the care she needs. We have gone through several caregivers. Some just don't show up, some show up but obviously don't care, most can only work very limited hours, one we even had to let go because she was intoxicated while caring for our daughter. It is very difficult to find quality caregivers that care about Elliott and impossible to find someone that cares about her as much as her parents. Elliott has special needs. A simple illness can severely threaten her life. Completing PT exercises, OT exercises, range of motion, speech, feeding therapy, g tube feedings; these are just a few of the things in Elliott’s daily schedule. Her daily care takes specialized training and medical knowledge/experience. Because Elliott is immunosuppressed and has these special needs, we cannot take her to a daycare. There are countless days, weeks, and months where my wife or I need to stay home from work because there is simply no staff. We have no PTO. We don't get paid. We cannot afford to have one parent stay home as we both have essential roles in the workforce and need paychecks and benefits to provide for both of our children. Allowing us as parents to be paid when we must stay home from work due to not having staff would alleviate so much stress. It would also give us the option to stay home more often and possibly full-time if we ever chose that. Most importantly it would give Elliott the best care possible. We are her parents, and we are already providing all of these cares. We are the experts and best people for the job. A stranger can get paid to take care of our daughter, but we can't. The funds are already approved and allocated to Elliott and her care.

Having a child with a disability is hard. We shouldn't have to choose between leaving her at home in someone else's care verses going to work to pay the bills. The right solution is to let Moms and Dads have the option to stay home and care for their child and be paid. That solution has the best outcome for everyone involved.

Kris is a program coordinator at HIT Incorporated. She has been there for 12 years. Her extensive knowledge has helped us navigate this process with our daughter. She overseas plans for individuals with developmental disabilities. She lives it day in and day out; caring for her clients and their families. She not only does it for employment, but she lives it.

I am the Service Manager for Titan Machinery in Bismarck. My company has been more than helpful in our situation. I manage 7 people and take care of a statewide community of customers. My customers include farmers, ranchers, and construction contractors.

We both excel in our careers. We enjoy our careers. We, as everyone, strive to live the American dream. Help others, live a meaningful life and enjoy life. If this bill passes it would make that possible for the minority of people now struggling with unforeseen and unchangeable circumstances.

Thank you for your time serving our state and for listening to our testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Testimony in Support of SB 2276

2023 Legislative Session

January 24, 2023

Madam Chair Lee and Members of the Human Services Committee,

My name is Toby Lunstad, this is my husband Shawn and our youngest daughter Addilynn who is 8 years old. Our family lives in Mandan in District 31.

We are here to testify in support of Senate Bill 2276 for an Act to create and enact a new section to chapter 50 – 24.1 of the North Dakota Century Code relating to legally responsible individuals providing Medicaid waiver services.

Passage of this bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one. This is an option in North Dakota's HCBS Aging and Disabled Waiver, it is not possible in our children's waivers nor the Individuals with Intellectual Disabilities/Developmental Disability Waiver.

Addilynn has a rare disease, meaning only 1 in 2,000 individuals are affected. She has variant on a gene called CACNA1A, which controls communication between brain cells. Her variant is ultra-rare because she is the only one in the world with it.

Addilynn has several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, being high risk for hemiplegic migraines, and global developmental delay. At 8 years of age, Addilynn has been hospitalized more days than we can count and receives care above and beyond what is expected for a typically developing 8 year old. She receives this care insure her health and welfare needs are met and to avoid institutionalization.

The list of care Addilynn receives is long. As her rare disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, different medical specialists, pharmacists, and dieticians. The care Addilynn receives includes:

- Medication preparation to insure accurate dosage and frequency, administration of medications via her feeding tube, and monitoring for side effects
- Completion of skilled home programming prescribed by her physical therapist, occupational therapist, and speech therapist
- Repositioning and incontinence management to maintain skin integrity
- Wound care for her feeding tube site as well as miscellaneous incisions after surgeries
- Adaptation of leisure activities to allow her to "just be a kid"
- Weighing and preparation of meals to insure her calorie needs are being met daily. Addilynn eats orally and via her feeding tube, so each meal is calculated to insure her calorie needs are met, as well as facilitating oral motor skills to maximize her safety during eating.
- Calculating fluid intake at regular intervals through the day based on her oral intake and what needs to be given via her feeding tube to insure her hydration goals are met.
- Complete assistance with bathing, dressing, eating, transfers, mobility, and toileting needs.
- Emergency medical interventions including application of oxygen mask, administration of emergency medications during a seizure or hemiplegic migraine, and monitoring of vital signs during an emergency
- Constant 1:1 monitoring for seizures

- Overnight monitoring and checks when alarms sound due to Addilynn's risk of SUDEP (sudden unexplained death of epilepsy)

Due to her disability, Addilynn is eligible for the Individuals with Intellectual Disabilities/Developmental Disabilities Home and Community Based Medicaid Waiver (known from this point forward as the DD Waiver). Addilynn receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications from the DD Waiver.

I worked full-time until 2020, when Addilynn's health took a turn for the worse and we realized that her developmental and medical needs were not being met by in-home support staff despite repeated efforts of training and education of staff and agency management. We experienced staff sleeping during their shifts, being more engaged in their phones or a book than Addilynn, improper set up of feeding tube equipment, unsafe transfer techniques, and staff taking pictures and being on social media in our home. We attempted to hire in-home support staff using self-directed services, but were unable to recruit staff that were willing to provide all of the cares listed above…everyone was intimidated by Addilynn's medical, physical, and developmental needs. We lost my employer paid health, dental, and vision benefits and now pay nearly double for a private health insurance plan, my husband has to work longer hours, and it is difficult to be a one-income family given the state of our economy.

In the 3 years since I have been home with Addilynn full-time, we have seen tremendous gains in Addilynn's function in the midst of setbacks. She is clearly thriving from continuity of care from someone who has the knowledge and skills to care for her. She has had two unexpected surgeries and recovered well. We were able to postpone a complex surgery on her hips for 2 years because I was able to consistently complete her home exercise program…a program that was not being completed when we had in-home support staff caring for Addilynn. Family, friends, and her medical care team have noticed that Addilynn is blossoming with the consistent, quality care that she has been receiving since I left my full-time job.

What Does it Cost To Serve People with Developmental Disabilities in Different Settings?

In both North Dakota and across the country, it costs less per person to serve someone with I/DD on a DD waiver than in an Intermediate Care Facility (ICF)

Waiver Cost Per Person (2018): $39,693

ICF Cost Per Person (2018): $175,049

5,157 North Dakotans receiving LTSS from the State IDD Agency (2018)

Waiver Cost Per Person (2018): $47,835

ICF Cost Per Person (2018): $137,560

1,308,659 Americans receiving LTSS from State IDD Agencies (2018)

State	ICF Spend as % of Total IDD $	Waiver Spend as % of Total IDD $
North Dakota	29%	71%
United States	19%	81%

*North Dakota's share of DD spending in institutions is significantly higher than national figures, indicating there is an opportunity to invest in the home and community-based settings supported by the DD Waiver.

See Appendix, Peer State Benchmarking, for more detailed analysis of ICF and waiver spending.

*Citation: Residential Information Systems Project. (2021). Living Arrangements of LTSS Recipients by Fiscal Year Over Time. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/living-arrangements-of-ltss-recipients-by-fiscal-year-over-time

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ALVAREZ & MARSAL
LEADERSHIP. ACTION. RESULTS.

As I stated before, Addilynn is on the DD Waiver. She also qualifies for an institutional level of care. According to slide 77 in the North Dakota Developmental Disabilities Study completed by Alvarez & Marsal, North Dakota's share of DD waiver spending for individuals to live in institutions is 29%. This is significantly higher than national figures of 19%. Given our experience with trying to find qualified caregivers for Addilynn and the changes our family has made in order for me to be home full-time with her, I was not surprised to learn that North Dakota spending is higher than the nation in this area. Some families have to turn to institutionalization because they have no other options to care for their loved one. I believe SB 2276 has the potential to reduce spending in this area of the DD wavier because paying families to provide care is much less expensive than paying for institutional care. Paying families as service providers would reduce the need for institutionalization and would keep the family unit intact.

I am Addilynn's mom. I am also her service provider because I consistently provide services that a non-legally responsible adult would be paid to do. This is why our family respectfully requests a "Do Pass" from each of you on Senate Bill 2276 and for it to be implemented July 1, 2023. Please give families in North Dakota the option to be paid as service providers for the extraordinary cares they provide on a daily basis. Thank you for your time and I will answer any questions you may have.

Sincerely,

Shawn, Toby, and Addilynn Lunstad

tobylunstad@gmail.com

701-595-4386

Testimony
SB2276
Senate Human Service Committee
01/24/2023

Madam Chairwoman Lee and members of the Senate Human Services Committee.

I thank you for all being here today to listen to me on why you should support Bill 2276.

My Name is Jessica Neigum Dargis, and I reside in District 30. I am here on behalf of my daughter Belle who is 4 years old and is developmentally delayed due to being born with an occipital meningocele.

I also work for a developmental disability provider and I'm a local business owner so I can understand the staffing shortage that faces the North Dakota workforce. While all organizations will remain nameless during my testimony, please know that I sit on the executive team at the organization I serve so I know firsthand the staffing struggles that many DD providers are facing and the difficult decisions that are made daily; Many DD providers are having staffing crisis with a turnover ratio of 40-50% which can be proved through Alvarez and Marsal case, please see page 105.

https://ndlegis.gov/files/committees/67-2021/23_5168_02000presentation1230.pdf

Unfortunately, most of the agencies that provide in home supports provide other services such as day programing, residential support, or intermediate care facilities, so when the organization is short staffed and need someone to cover at a location they manage, they often cut family support care first as there is a "back-up" also known as the parent, which doesn't exist in other care settings. Leaving parents caught in the middle of being at work or caring for their child, which in all cases the parent picks their child. Once a parent misses enough work because they don't have adequate care for their child, the parents' employer starts to consider the parent an unreliable employee.

I can respect agencies being short staffed or having sick staff as I hear about it at the agency daily, however as a parent it can be frustrating to find out 20 minutes before work that you will not have care for their child that day.

At some point parents give up their jobs, to ensure their child has continuity of care. While some may suggest daycare, there are very few daycares that will provide care to medically complex children. My daughter Belle attends Bismarck Early Childhood Education Program and receives a 1 to 1 aid while there, most daycares will not provide a 1 to 1 as that is not cost effective to their programs when in most other situations for a 4-year-old they can have 6-8 children or more to 1 teacher or aid. If daycares are willing to provide care, they want to charge the family for that 1 to 1 staff which in most cases negates the point of the parent working as their hourly wages goes to pay for the hourly wage of the staff taking care of their child as public daycares are not certified to bill the state for Medicaid. Which then pushes parents back to using a certified agency that can charge Medicaid yet is short staffed and always cutting care hours.

The state has really left a hole for parents of children with disabilities or special health care needs and forced many to quit their jobs. I am lucky enough that my mother retired after 39 years with the state of ND several of which were served in the Department of Public Instruction and is caring for my daughter. I don’t have to worry about my staff not showing up, because my mother is always there for her and me. However, if something was to happen to my mother, I would likely be without care.

Thank you for your time and consideration in voting in favor of bill 2276

I would like to close with a final thought.

Children are a vulnerable population. **Individuals with disabilities** are a vulnerable population.

Children strive on routine as they understand what is expected of them. **Individuals with disabilities** strive on routine as they are familiar with the process.

So why not provide **Children with disabilities** the stability of a familiar caregiver such as their parent so they can successfully navigate life?

Jessica Neigum Dargis
Parent of a child with a disability
612.695.8150
jess.neigum@gmail.com

Senate Human Services Committee

Senate Bill 2276 – January 24, 2023

Testimony of Daniel Gulya, Attorney, Protection and Advocacy

Chair Lee and members of the Senate Human Services Committee:

My name is Dan Gulya; I am an attorney with the North Dakota Protection & Advocacy Project (P&A). P&A protects the human, civil and legal rights of people with disabilities. The agency's programs and services seek to make positive changes for people with disabilities where we live, learn, work and play.

P&A supports this effort to create a path for household members- parents, siblings, children - to be paid service providers to meet the extraordinary care needs of their family members. This bill supports person-centered home- and community-based services, so that families can ensure the essential level of care their loved one needs without making more painful sacrifices. We risk destabilizing families if they must choose between their career or supporting their family members, and this service gap increases the risk of institutionalization for individuals if they can't be served at home.

These families come to you with the issue of needing, and being authorized for, more hours of service than providers can supply. They are not asking for funding beyond what they have been told that they can have- if they can find other people to do the work. We hope you will all see the value in supporting families who find themselves in extraordinary circumstances, stretched thin ensuring that their loved ones receive necessary cares amidst our ongoing caregiver shortage.

In support of our agency's priorities, P&A has provided technical assistance to the constituents bringing this bill before you. I respectfully request support for SB 2276. Thank you for your time and I would be glad to answer any questions.

Daniel Gulya, Protection & Advocacy
danigulya@nd.gov
328-3946

Dear Madam Chairwoman Lee and members of the Senate Human Services Committee.

I am Deidre Hillman residing in District 32. I am providing my written testimony in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

My perspective comes to you today likely differently than many others. I have a healthy active 6-year-old girl. Although recently she's been diagnosed with learning challenges including dyslexia and dysgraphia, she comes from a home with two fulltime working adults. I operate my own business and my husband is employed by a private company. We are grateful we can flex our work schedules to take her to appointments which are minor compared to the families I have served over my 8 years as a volunteer at a few organizations.

One organization I volunteer with gifts ill or developmentally/intellectually disabled children a large gift either in the form of an experience, a trip or it can be an enhancement to their lives of some sort. Sometimes I work with the families of the child for months and years while we try to determine the best gift for their minor child. I get to learn so much from these families and I'd like to share my summary of what I've experienced.

I know more about our medical care and the lack of it in our surrounding communities. Often times the parents must take time off of work, to plan the travel and then to travel to Fargo, Sioux Falls, Minneapolis and Denver. In between those major appointments they must juggle local doctoring appointments for routine checkups, scans, physical therapy, occupational therapy, speech therapy and more. And these are all scheduled appointments when the health of their child is WELL. Now add on an infection, an allergic reaction, influenza or any other medical illness that can compromise these children with complex and extraordinary needs. Their whole planned appointment schedule goes out the door. Spiraling sometimes and pushing appointments out sometimes months. One appointment at a time must be moved.

On top of providing medical accommodations for the needs their child may have, they are trying to provide education to their child. I don't know how many of you are raising a child in school but this brings on a whole other list of coping, managing schedules, participating in the arts, sports or rehearsals for choir or dance. Helping with school fundraisers and PTO. It's maddening, rewarding and can become a parttime job for a working parent. But we all do it, because we want to be involved and we want the best for our children.

And then, they must go to work. Weekly and sometimes daily they must pass along the current medial needs or schedules from one staff member and specialist to the other. Sometimes a minor sibling is depended upon to help with this.

These parents truly are my heroes.

I believe in many instances when I ask the parents how they do it all, they have become numb to the lack of support, they believe there is no other option yet they remain hopeful that staffing of suitable support will get better “one day”.

The parents know their children best and could possibly expedite development and advancement in the children. We know there is a shortage of skilled caregivers and has high turnover. Each time a child meets a new caregiver, they have to get to know each other, causing gaps in their development. If the parent could be paid to stay with the child, the child would have consistency and trust would be high.

Thank you for this opportunity to have my opinion heard through my written testimony. I am sorry that I cannot be there today.

I urge you to vote yes on Senate Bill No 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need to help them now.

Sincerely,

Deidre Hillman

828 San Angelo Dr, Bismarck, ND 58504

District 32

deidrehillman@gmail.com

701-400-2598

My name is Lisa Kroh.

Our address is rural New Salem. We live 17 miles west of New Salem on a farm. We are in the Glen Ullin voting district.

[redacted]

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Our Story

In our family we have 6 children, 5 boys and 1 girl. Ages 15, 13, 11, 7, The last 2 are twin boys 5 years old. 2 of our children have disabilities, only one receives services. His name is Benat. I stay home and my husband works full-time and is also a full-time student.

Back – Lisa, DeLainis, Wes, August
Front – Benat, Henry, Fritz, Gordon

Benat was born premature at 33 weeks and is a twin. 7/13/2017

Within minutes after birth, we were told he had a heart defect and was flown to Mayo Clinic in Rochester, MN within 24 hours after birth. We were told he has a bicuspid aortic valve with severe stenosis of his aorta. At 10 days old he had open heart surgery. Luckily, he got to come home after only 4 weeks in the hospital. We were told that the fix was only temporary and by age 2 will more than likely have to have another surgery.

Wes with Benat at Mayo.
9 days before surgery.

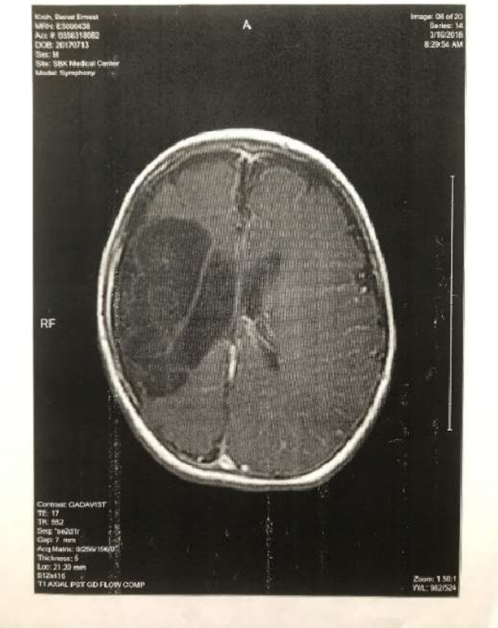
10 days olds.
2 hours after surgery.

Dr. Said, the one who
saved his life.

At 6 months old he was having issues and ended up back at Mayo for a balloonioplasi to open aorta. Which helped his situation and will allow him to grow and get stronger.

Mayo allowed Henry to go as moral support.

Shortly after the procedure, me, a mom of 6, noticed his left hand smelled bad and was clenched all the time. Asking BECEP why this might be, prompted me to further investigate. He had a head ultrasound done which showed there was damage. Then the MRI. He at some point in his short life had a stroke and is missing 80% of the right side of his brain. Meaning cerebral palsy. This affects him mentally and his left side physically.

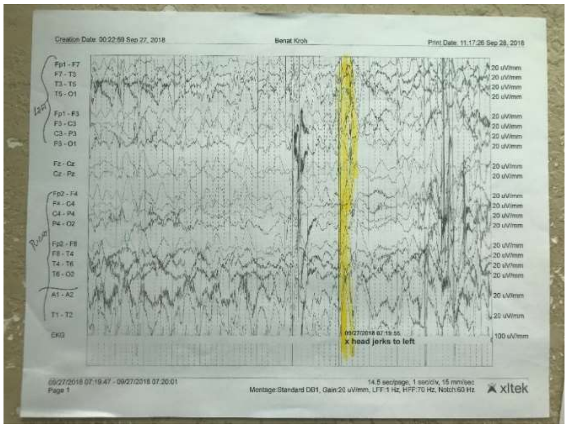


MRI 3/16/2018

Shortly after finding this out, I noticed his eyes roll to back of head and he would twitch. Again, back to a doctor. 2 neurologists in ND then I asked to be sent to an epilepsy specialist in MN. After spending 10 days in the hospital, we found he was having 7-12 seizures and day and they were lasting 2-15 minutes. Partial and focal seizures. Basically, what I found out is his brain is so lit up they can't tell between brain activity and seizures. We now have it under control and have been seizure free for 4 years.

MN Epilespy Group

It was like he was buring up!



Snap shot of EEG. WHAT?!?
How can someone function like this?

We were attached to the wall the entire time we were there. Continual EEG. I feel it was hot at times he got so flush. After removing all the electrods from his head he was left with burn marks.

He has also been diagnosed with visual issues (CVI), autism, speech delay, eating issues (a lack of wanting to eat or drink without being continually prompted to eat) and physical/mental processing delay. However, when tasks are learned it is evident that he is capable of things that are unimaginable to doctors given certain medical conditions and diagnosis that he has.

From the beginning of birth all I heard from doctors was “I’m sorry.” With no answers.

So, I set out to make him the best he could be. He wouldn’t eat and they were talking feeding tubes. He was losing weight. They said he had rib flare and wanted to put him in an abdominal binder. I said the kid is starving. I did not listen to them and started to get him to eat. I fixed the problem. That was year 1. 2018

Benat can hold his own bottle Feb 2019

They said he would probably be in a wheelchair for the rest of his life. Having 6 kids and one possibly in a wheelchair and multiply trips to MN for appointments we bought an actual bus with wheelchair access. Although where were preparing for a future with a wheelchair, I could not give up. New Salem school is not really handicap accessible therefore he has no choice he has to learn to walk. He had therapy at Sandford PT 30-minute sessions once a week. Sanford did allow me to attend his sessions. So, I got to see what to work on and how they did weight shifting. I felt weight shifting sessions a waste of time. I live on a farm 45 minutes from Bismarck. That is 1.5 hours round trip for a 30-minute weight shifting session. So, we quit. We were blessed to have got amazing advice from Cathy PT at BECEP as we got access to a stander, and eventually were able to use a gate trainer then a walker. I was on my hands and knees at home every day moving those little legs because a wheelchair wasn’t going to be an option in New Salem school. He is now walking without a walker or assistance. I programed his brain though words and movements and I TAUGHT HIM TO WALK. That was year 2. 2019

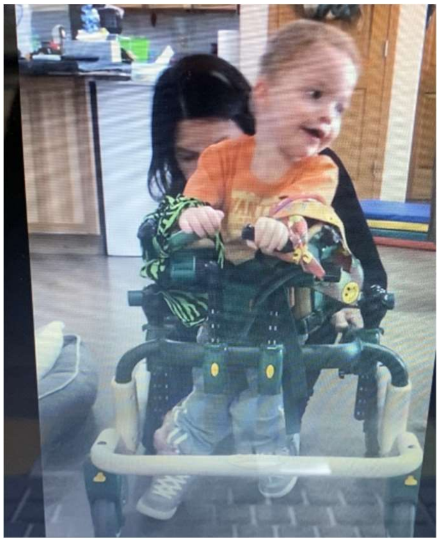
We call this “Benat’s Bus”.

Awesome Zippie adaptive stroller.

Old school stander

Learning to sit

Brand new stander, thanks to BCBS and tons of appointments and referrals.



Gate trainer

BECEP walker

1st time outside with walker not stroller

Through people giving us guidance and our hard work, he now walks. Benat and I did that!

Benat was considered nonverbal. No one can understand him or figure out what he wants except me and some respite workers. He screams, hits, throws things and cries. Or I should say no one has patience to pay attention to what he is trying to communicate. So, year 3 we work on sign language and the use of an iPad as a talker with an app used for communication, which we purchased out of pocket. We started at Sanford therapy however our awesome SLP quit. So again, on my own. That was year 3. 2020

This brings us to education. This is my new challenge. IEP and the school system. I was hoping that they could give me guidance on how to educate my son. We spent 1 year traveling 2 times a week for 1-hour sessions. So, 2 hours weekly for IEP therapy only. Not enrolled in school. I was not allowed to go into session. I have no idea what is going on. I have no ideas what to work on with him. I called an IEP meeting and explained that they have him for 2 hours a week and I have him for 166 hours a week. We need things to work on. Also, when we leave school, he is crying and is crabby for a least 5 hours, possibly the rest of the day. Again, I have no idea what they did to upset him he was nonverbal. The year of regression. That was year 4. 2021

I don't even want to cover my struggles with putting him in head start and the New Salem school system after all the work I have done and the past year that just happened with them. I will make 2 comments though. This is the year my personal health took a turn for the worse due to the stress they caused and the severe regression we experienced. I literally started losing my hair and is a year I wish to forget. That is year 5. 2022

IEP in corner instead of being taught to work with peers.

Sitting with aide on lap instead of floor with peers.

In corner with aide instead of with peers.

Twin brother Henry in same class.

My hair loss due to stress.

This year 2023 is focus on speech and homeschooling education. No one wants to use the talker! I have to teach him to talk! I found Amazing Erin at Little Light Therapy in Bismarck and with her help (2 – 1 hour session weekly) we have been accomplishing unimaginable things. She just told me the other day that he was only saying more and all done by sign language in July 2021.

Benat is not going to school this year with his twin Henry to kindergarten due to past issues with the school system. He is currently however attending IEP therapies that I have determined very important. Such as vision and PT. However, I do anticipate serious problems in the very near future. Meaning today at 11am at my IEP meeting in New Salem.

My Daily Life:

Mondays, Thursdays, Fridays

5:45am – wake up kids, Potty training Benat, Benat seizure meds and applesauce cocktail (sweetened applesause, miralax, muscle milk, cinnamon, graham crackers) help kids get ready for school.

6:45am – Bus picks up kids for school. Start laundry, vacuum, pick up house, work on morning dishes. Benat assists me with all these tasks. Some days we take the time for him to do them by himself with assistance. Takes forever!

8:00am – We go to learning room. I have set up a room in my house designated to Benat's learning and therapies only. I have purchased mats, swings, wedges, therapy items, and school supplies out of pocket to help me with my son over the years.

9:30am – snack time/breakfast – takes him roughly 45 minutes with the use of tablet playing Blippi or Jack Hartmann to eat a bowl of cereal and drink a glass a milk through a straw with continual reminding to eat and drink. If he does not have a tablet he will not eat.

10:15am – learning room

11:30am – free time

12:15am – Lunch (peanut butter and jelly with chips and cheese, glass of milk with straw)

1pm – Benat's Nap time. I take dogs outside and tend to rabbits and chickens.

2pm – Finish house chores I didn't get done in the morning.

3pm – wake up Benat. He is usually very crabby, lots of screaming, very mean for 45 minutes no matter what I try.

3:45-4pm – kids come home from school.

4pm – unpack backpacks, remind kids to get chores done, schoolwork all while Benat is at my side.

5pm – start to make dinner. We have a family dinner every night. All while Benat is at my side.

5:45pm – family dinner. I feed Benat and make sure that he eats. Again, can take 45 minutes+ for him to finish a meal. Often, I end up not eating.

6:30pm – family playtime

7pm – Bath time

7:30pm – Meds and TV time

8pm – Bedtime. Benat usually falls asleep around 8:45-9pm.

3rd Monday of the month is IEP PT at Prairie View Elementary 10:30-11:15am

Tuesdays and Wednesdays

Mornings are the same but no learning time at 8:00am, instead we leave to go to town for therapies and shopping.

Tuesday 9:30am-10:30am Sanford PT in Bismarck then 11:00am chiropractor, lunch (McD or DQ), shopping (Walmart or TSC) then home by 1pm for naptime. This is the only day I get to go to Bismarck/Mandan.

1st Tuesday of the month IEP PT at Brave center 8:30am-9:15am

Wednesday 8-8:45am OT and 8:45-9:15am SLP with Little Lights Therapy from Bismarck but services are at PVE in New Salem, (they travel) then we have to waste 45 minutes which is not easy in New Salem unless you can go to the park. 10am - Vision IEP for 30 minutes. Home by 11am.

Weekends my husband does schoolwork for the past 3 years. So, between tending to Benat and trying to spend time with other kids I am just existing.

Benat does receive Respite. He has received respite care starting with 10 hours weekly 7 months after birth to currently max hours weekly. I was going through agencies here in Bismack for these services. Poppy's Promise, Easter Seals and was going to attempt trying a 3rd before going self-directed. My issue with the agency's is no one wanted to travel. And when someone did accept the position, they only worked 1 time or she was 70 years old and only came for 8 hours a week. She had a hard time getting up off the floor, where we spend 80% of our time. She came for only 8 hours a week when there was a possibility of 75 hours a week. Then someone was clocking in under wrong client and they sent me a bill. They pay an employee $13 per hour but charge me $33.80 per hour. WHAT!?! That is the day I went self-directed.

I find my help through Care.com, posting flyers in New Salem / Glen Ullin and word of mouth. The problems I mainly have is no one wants to travel. The weather prevents people from wanting to travel. Benat can be very challenging and loud. If one kid gets sick in our family, they don't want to work and get sick themselves. I totally understand but that sometimes can take 8-16 weeks to run through a household of 8.

If an employee quits it takes 30+ email to individuals through Care.com and over 3 months to get a response. When I do get a response it's an additional 2 weeks before interview, another 6-8 weeks for paperwork and background checks. I had gals come to interview, fill out paperwork and never hear from them again. I've had gals only work 1 day some 1 week. Most 3 months. I had an employee give me her 2 weeks in July this past year. I was unable to find help until October only for the new hire to work a week or two then have a family emergency and need to take a leave of absence until January. Currently I have 3 respite workers employed, but still can't seem to fulfill hours or have consistency.

I never had to put my kids in daycare because I was fortunate enough to stay home.

Benat should have been in kindergarten this year with his twin brother but due to severe issues with the school system in rural town the past 2 years and the fact that he has certain needs that they can't address, he is not attending school this year and might not be attending in the future. There is nothing but problems in that school for kids with disabilities and if I want Benat to be educated and become productive at all then I am forced to homeschool, which has been mention as an option multiple times during meetings.

Everyone is feeling the financial burdens recently with what is going on in the world. Everyone seems to be affected. I don't feel like I have enough on my plate, so I decided this past summer I'll get a job at a local restaurant (20-minute drive), so we have extra income to help pay for things. I got to work 2 wonderful days. I showed up late 4 hours on the first day and 3 hours late the second day, due to respite not showing up and having to wait for husband to get off work. Then she put her 2 weeks in, so I ended up quitting. It was a sad day for me.

Cost of everything going up, can't afford to travel. I used to travel 4 days a week for Benat's therapies now we are down to 2 days a week. He and I were going to the chiropractor which was helpful to both of us however have now stopped because of financial difficulties. I used to get mental health services but now because of some recent changes to insurance I no longer get that. Our family wears glasses. Kids need eye exams and new glasses. How do we pay for it? Clothes? Food? School lunches? How do we pay for it? The kids want to be in school activities that's extra fuel and expense. Future appointments in MN. We have already refinanced.

My last real solution is for me to work between the hours of 8pm and 5am while the family sleeps. But then when do I get to sleep.

Its not that I don't want respite help, I need respite, Benat needs respite, but it seems to not be consistent therefore makes it hard for me to be able to have a life, the whole reason for respite. To give me a break. It's seeming impossible for me to have a job. I have asked may times, why can't I be paid for my services helping my son if someone isn't showing up. I have proven time and time again that he is making great gains beyond the doctors' expectations. I am saving a lot of money and paperwork doing things myself. Benat and I have done all the work with guidance along the way. I struggle to get things I need for Benat due to financial difficulties. Things that are not covered by insurance or Medicaid. If I were to get paid that would relieve financial stress and allow Benat the things he needs to become successful instead of waiting 6 months for something to go through the system and be denied. It would also relieve the financial stress of everyday life. Maybe I could leave the house more often because I could pay for fuel.

This past December 2022 at a cardiology appointment we got confirmation that Benat has enter surgery phase meaning every day that goes by his heart is getting worse and as long as he can tolerate it and EHCO show no enlarging or thickening on the left side of heart then we wait. He needs to grow and gain as much weight as possible before surgery. Meaning soon we will be travelling back to Mayo in Rochester, MN to have another open-heart surgery to not fix but replace his aortic value. I will be talking to the doctor on Feb 3 at 3pm to find out details. Until then we wait unless something changes with him and his heart goes into failure. With that in mind I have no idea what's going to happen, when we are going or how long we will be there when it does because it is going to happen soon. Will the girls that are hired respite still be here when we get back or will I have to start over again looking for help. Could you wait as an employee for a month with no paycheck? I still don't know how we are going to afford to travel and pay for hotel?

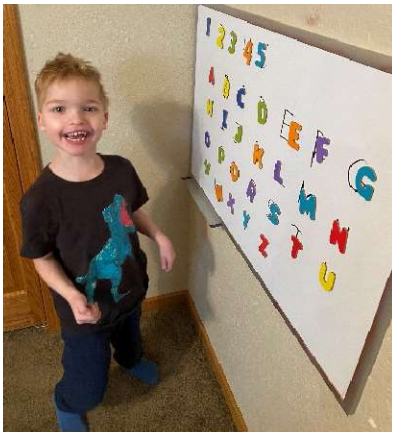
With that thought, I want to thank you for your time serving our state and for listening to my testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Lisa Kroh – imchorty@yahoo.com - (701) 319-0118

Who Am I puzzle 3pc

Learn to hold marker.

Learn to count.



Numbers and Letters

Barn farm animal puzzle.

I can draw a face!

Who Am I Puzzle.

Animal magnets.

Sight words

Color matching with Henry.

Lights board tracing.

Got to visit Herny during Muffins with Moms at school.

Mom and Benat

Independents Day Parade Mandan 2022 - Cloverdale

Safety First.

EEG 2022 I am unable to get screen shot. I've sent many requests so I can compare. No Luck. Pay for it can't see it

Henry and Benat – 2022

Benat and August.

Benat WALKED to Treat or Treat!

1st Day School 2022

Almont Parade August, Benat and Respite (Kyarra)

[redacted]

[redacted]

Hello my name is DeLainis Kroh

I am Benat's older sister. I am also his only sister. My life has changed drastically since Benat was born. My parents are so much more stressed out and are unable to care for their other children the way they used to. They still give us the basic needs for life which are very important. But if they want to spend quality time with certain individuals, they are either rushed or the plans are canceled due to the needs of my brother.

Me and my mother really enjoy spending time with each other. We like to go shopping and go out to eat alone, just me and her. But because of the lack of money, we can't do these things. When we do, she is always worried about Benat and how to pay for it when we go which really stresses her out and makes it hard for her to enjoy anything. The only time we can truly leave is after Benat is put to bed for the night but then all places we wanted to go are closed. This is also when it is dark and dangerous to drive, mom always says she's night blind. I have always tried to make her feel better and calm her down, but it never seems to work.

It has also made my life harder because when my mother is working on something so Benat can have a better life, I step in to watch him. It is extremely hard to entertain any child but for him even five minutes of a single game becomes boring and very quickly you run out of ideas. He also has a very bad habit of throwing various objects. These objects are usually solid objects. He then throws these objects; they either break something, crack something, ruin something, and or actually really hurts somebody. To clarify all those things have actually happened. Recently I have been struggling to play my saxophone. Since my mother played that very saxophone at my age, she helps me and gives me tips on how to play it better. But it is very hard to find a time to practice when she is always leaving to go tend to Benat's needs.

He is always screaming or crying for any reason at all. Like at the dinner table, most nights he refuses to eat for no reason at all. We eat dinner where everyone is present. This makes it hard to enjoy a homemade meal that someone worked really hard to make, when all you can hear is screaming. Since Benats heart is beginning to fail again he really needs to gain some weight, but he still refuses to eat, which makes my parents even more stressed which also stresses me out. It would make my mine and my parents lives so much easier if we had better help. My mom said if she could go to work to help pay for things, she would but it seems impossible.

Thank you for your time serving our state and for reading my testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis; we need help now.

DeLainis Kroh [redacted]

Support SB 2276

January 24, 2023

Chair Lee and members of the Senate Human Services Committee, my name is Tessa Miller and I live in district 34 in Mandan with my husband and two sons. SB2276 would affect families positively by allowing a legally responsible adult to get reimbursement through a medical waiver for the extraordinary medical needs of a child. This allows parents to care for their medically complex children while being financially stable. This option, families providing care, is much less of a financial burden to the state of North Dakota than residential placement. Which in some instances can be the only option for families that cannot lose that caregivers income coming into the home.

I'd like to share a little of our family's story with you. My 8-year-old son, Asher, has severe autism and is nonverbal along with other diagnosis including ADHD, OCD, and anxiety. Asher attends school in Mandan Monday through Friday with limited hours Monday, Wednesday, and Friday. In addition to school, he attends occupational and speech therapy weekly for one hour and ABA therapy (applied behavior analysis) for nine and a half hours weekly. He is on the North Dakota DD Medicaid Waiver which pays for these therapies and for respite care. Asher is approved for 38 hours of respite care per month though his waiver, but we only use approximately 17 hours per week due to staffing shortages and high turnover rate.

I am extremely fortunate that Asher qualifies for all these therapies, especially ABA therapy, because it teaches him coping skills in order to thrive in our world. This supplies him time with qualified professionals while out of my care or not in school. Autism is the only diagnosis that qualifies for this specialized therapy.

Due to the complex scheduling needs of my son, I was a stay-at-home mom for a while. Eventually, I was able to find a job in my field that allowed me to work part time with a flexible schedule to do pickups and drop offs for Asher. Eventually, that job and my son's schedule also conflicted. Fortunately, I had the resources and support to open my own small business to gain income while working a flexible 20 hours per week. If I was unable to open my business, I cannot imagine an employer that would be able to give me the flexibility I need to get Asher to and from his therapy sessions and school. It would also be impossible for me to work full-time.

Having a child with special needs adds a lot of stress to the already stressful job of parenting. According to Boston University (bu.edu), “The burden of stress is great for those with special needs. A recent study found that mothers of adolescents and adults with autism had levels of stress hormones comparable to soldiers in combat”. As parents we do what we can to alleviate some of that stress including respite for the child, seeing a therapist, or attending support groups. What should not be factoring in on these families' hardships is the financial strain. These parents have no choice but to stay home and care for their child with complex medical needs or their high behavioral outbursts because there are just not enough qualified professionals to fill the gap. Add onto that the high percentage of those in rural areas in our state that have no service providers available to them.

In closing, please consider passing this bill to support North Dakota’s children with disabilities by proving them with the most qualified person to care for them. This would give their parent or guardian the financial support they need to supply the services to them while keeping the child in the home. Thank you for your time.

Sincerely,

Tessa Miller

District 34 – Mandan

tessaadelle@gmail.com

701-400-2222

My name is Sommer Jacob, I live in Center, ND, voting District 33.

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

When my son Bennett was born, was a surprise. He came very unexpectedly after 8 years of infertility, without warning or assistance. He was born prematurely, at 33 weeks, which again surprised us, and scared me. But that was nothing compared to the surprise which followed, just four days later.

After an easy pregnancy and normal results from routine prenatal testing, I was stunned when the doctor came to my hospital room and informed us that he suspected a chromosomal abnormality. I couldn't even comprehend what he was saying, and looked to our NICU nurse, with confusion, asking "What does he mean?" When the words "Down Syndrome" fell from her lips, I could hard believe it. Initially I thought it must be a mistake. After describing some of the typical characteristics of babies with Down Syndrome, it started to sink in. Then I was crushed – devastated, really. We hadn't prepared for that. There were no indications that anything was "wrong." The ultrasound results looked normal and despite my advanced maternal age of 40, I opted out of additional testing because of those findings.

The medical team set forth with genetic testing and shortly thereafter, confirmed, that Bennett did indeed have and abnormality; Trisomy 21. They began looking for the typical health concerns associated with infants with Down Syndrome. The majority of the diagnostic test results were normal. All but those which involved Bennett's tiny little heart.

He was diagnosed with an atrial septal defect (ASD); a hole in the wall between the heart's two upper chambers and ventricular septal defect (VSD); a hole in the wall between the two lower chambers. He would need to have surgery to repair the holes, one of which the cardiac surgeon described as dime sized, on this little golf-ball sized heart -- Open heart surgery at Mayo, in Rochester, MN when he was old enough and strong enough. That would be when he was around 5-6 months old.

Around this time, we were encouraged to pursue coverage for Bennett with the Medicaid waiver program. At that time we had a good income, a fantastic health insurance plan and I didn't think it was really necessary. But after careful consideration, and a lot of handholding, Bennett was approved. I cannot express how incredibly grateful I am that I had the assistance, guidance and expertise of Roxane with Designer Genes and the team at CHI NICU during that time! It was difficult for me to form a coherent thought, never mind navigate the "system" surrounding those in the world of disabilities!

Bennett had a successful surgery and was released from the hospital after just 2 days. We stayed in town an extra night, just because I was nervous about flying home with him, so soon after surgery. On the flight home from Rochester, we had a layover and connecting flight in Minneapolis. While changing Bennett's diaper, we noticed something didn't look right. His left foot appeared to be abnormally pale and cool to the touch. To keep this brief, I'll skip the details which led us back to Mayo. Bennett ended up on a private flight from Bismarck, back to Rochester, the next day, courtesy of the medical flight team in Bismarck. He had developed a blood clot in his leg. Another brief stay at Mayo and we were given a twice daily routine of injections to dissolve the clot. Something I didn't think I could do, but it's amazing how quickly you get skilled at things you don't think you can do when your child's life depends on it.

It was shortly after that event, I left Bennett's dad. We had a challenging marriage but when I feared for Bennett's safety, for his life, one particularly difficult day, I knew we had to get out. The next 12 months, there was a protection order in place, prohibiting contact with my now ex-husband. He could see Bennett, but it would be through relatives, which he chose to do only a handful of times. During those 12 months, I filed for divorce, sold our marital home, left our mutually owned business and tried to get my feet back on the ground with my other business. My primary income and insurance benefits were all tied into the company we'd created and was then in his hands alone. I was still in a fog, trying to navigate respite care, numerous therapies, checkups and just trying to figure out what was coming next!

I lost my insurance benefits and was so grateful for the Medicaid program so Bennett had coverage. The number of hours for respite care we'd been receiving wasn't enough now that I was raising Bennett entirely on my own. Thankfully we had a great DD program coordinator and I was grated extra hours to cover my work hours and a bit of extra for some "me" time.

I'm still self-employed. I've remarried to a great man that fills in as an awesome father figure to Bennett. His home was in Center, where we eventually moved.

Bennett is doing great in the Hazen school, but is transported there 4 times a week. Most days this isn't an issue. However, there has been times, it has been. And finding reliable, trustworthy, and skilled caregivers for him, is an entirely different challenge.

I work from home most days, even thought I have an office in Bismarck. My mom was Bennett's primary caregiver until this past August. When he had to go to preschool at the age of 3, we weren't sure of the hours he'd be going or the hours we'd be approved for respite care. This was my mom's primary income as she had quit her regular job to care for him. My dad took his life two years ago, so she relies on the steady work since she survives on her own income now.

It was a concerning transition for me, to get someone new to watch Bennett during my hours of work, and when he wasn't in school. We've got a great primary respite care worker now, but she has her own family as well. Sometimes there are things that prevent her from being able to work.

The constant care and monitoring Bennett requires can and has seriously affected our family emotionally and financially. For example, my husband works 2 hours away and had to leave work early to assist with the care of Bennett when he was in a hypoglycemic state; a potentially life-threatening condition. Our family lost much needed income much needed income due to my having to leave work early. Additionally, when Bennett is ill (?), I cannot get my work done since Bennett requires one-on-one care during the time when my current respite care worker is not available. Being a sole proprietor, I have no one to cover my work when I am unable to do it.

Bennett's immune system is seriously compromised due to the DS, so he frequently develops coughs and other flu-like symptoms. The school system and the respite care worker are opposed to caring for Bennett when he is ill due to fears of contracting his illness to other children or possibly their families which results in me or my husband staying home from work to care of him. Losing the income due to the frequency of Bennett's illnesses seriously impacts the family finances.

Living in a smaller town lends itself to a very limited supply of qualified respite care workers. When we first moved to Center, I began my quest for respite care workers and did not turn up many candidates. When the one respite care worker I have has a family situation or is ill, I have no backup. This leaves me or my husband in a serious situation not being able to work. This can adversely affect my clients as well as my husband's employer.

Thank you for your time serving our state and for listening/reading my testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Name - Email - Phone number

NORTH Dakota | Health & Human Services
Be Legendary.

Testimony
Senate Bill No. 2276
Senate Human Services Committee
Senator Judy Lee, Chairman
January 24, 2023

Chairman Lee, and members of the Senate Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities (DD) Section with the Department of Health and Human Services (Department). I appear before you to provide information and propose an amendment for Senate Bill 2276.

Compensated family caregiving can be an important part of the state's system of care options. The Department believes if done thoughtfully, with appropriate attention to the nuances related to assessment, safety, and the mechanics of implementation, the new service outlined in this Bill could be a benefit to families across our systems of waivers.

The Department's position on the Bill is neutral with amendment primarily because we are concerned about the ability to effectively implement this proposed change knowing the extent of parallel system change that is likely to result from the recommendations associated with the Alvarez and Marsal Study, completed in response to 67th Legislative Assembly Senate Bill 2256.

The Department's proposed amendment is intended to identify issues that we believe would impede our ability to implement the Bill as intended. We believe the proposed amendments would allow for a more successful implementation of Senate Bill 2276 should it ultimately pass.

Section 1, page 1, lines 19-21 state " A waiver under this section which provides for coverage of self-directed in-home support services must include coverage of services provided by a legally responsible individual".

The Department proposes removing Subsection 3 as proposed in the Amendment. This does not compromise the intent of the Bill because any individuals who would be covered by Subsection 3 could already be included in Subsection 2 as written.

The service description for in home supports in the DD waiver states "the service benefits the primary caregiver by assisting the participant in activities of daily living. It also can be provided to the participant when the primary caregiver is either away from the home or is home but unavailable to care for the participant".

As per the intent of Senate Bill 2276, if the primary caregiver is the one providing the service, the intent of in-home supports as defined in the state's 1915(c) DD waiver cannot be met; if the primary caregiver is neither away from home nor at home but unavailable to care for the participant, but rather is providing care, the service cannot be deemed "in home supports" as defined in the waiver.

While the new "family caregiver" service provides in-home support, it is by definition, a different service from "in-home support" as currently defined in the waiver. Should the new family caregiver service be approved as part of the Bill, the Department anticipates being able to consider each individual's needs when authorizing services, regardless of whether the service is participant-directed or provider-managed, so long as the services that are authorized are not duplicative of each other.

Section 1, page 1, lines 17-18 indicates that the new service described in Subsection 2 of the Bill be available for "participants in the Medicaid 1915(c) waivers and any subsequent Medicaid waivers to be developed."

Section 1, page 2, lines 1-2 states "the payment rate for the legally responsible individual must be the same as the rate for the non-legally responsible individual".

To preserve the current Family Caregiver Personal Care service option that is part of the 1915(c) Aged and Disabled waiver, the proposed amendment removes the reference to "any subsequent Medicaid waivers" and the reference to payment rate in Subsection 5.

The Home and Community Based Aged and Disabled waiver has a service that allows payment to a family member that is comparable to the service outlined in Subsection 2 of this Bill; however, the rate structure is different and would need to change if the Bill passes as written.

Page 2 lines 1-2 also present a challenge for the other 1915(c) waivers that would be covered by this Bill. The Department would like to consider a daily rate for the service, both to streamline documentation and billing requirements for the family caregivers, and to streamline administration of the service by the Department; but if held to the current language that the service be paid at a rate equal to the rate paid for non-legally responsible individuals, the Department believes we may be required to utilize unit rates. The fiscal note was prepared based on the assumption that the service would need to be paid using a unit rate (rather than a daily rate).

Of note the Department was unable to provide an estimate of the impact of Subsection 5, as it is currently written, on the Aged and Disabled waiver and indicated such in the fiscal note. Should the Committee pass the Bill without the proposed amendment that replaces the current Subsection 5, the Department will need to update the fiscal note to quantify the impact to the Aged and Disabled waiver.

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

PROPOSED AMENDMENTS TO SENATE BILL NO. 2276

Page 1, line 17, remove "and any subsequent"

Page 1, line 18, remove "Medicaid waiver to be developed"

Page 1, line 19, remove "A waiver under this section which provides for coverage of self-directed in-home"

Page 1, remove lines 20 and 21

Page 1, line 22, remove "4."

Page 2, replace lines 1 and 2 with:

"4. This section does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled"

Renumber accordingly

Chairman Lee and members of the Senate Human Services Committee, my name is Kali Weinand and I am here today in support of Senate Bill 2276 to allow legally responsible individuals to provide Medicaid services to those on Medicaid waivers.

I am the mother of an autistic, developmentally delayed child who is on the North Dakota Developmental Disability Waiver. Due to her level of need, her waiver allows us to hire a caregiver to help meet her needs. She requires constant monitoring as she is a flight risk and struggles with simple daily tasks. It is not safe to leave her unattended for even a couple minutes. Due to the inability to find adequate staff to hire, I have been unable to continue working outside of the home.

We live in rural western North Dakota. The number of adequate staff to fill the services we are authorized for, is all but non-existent. I have contacted a number of potential employees in the past, with very limited success. Potential employees that I did find ended up taking other job offers that offered benefits, better hours with better pay, or more steady, consistent hours. We are living in a workforce crisis that is far reaching and can be seen everywhere. There is simply a lack of staffing for many businesses.

The next area of concern is finding staff that is adequately trained and appropriate to work with our daughter. If the hired caregiver is not well trained it is a cause for concern and can be extremely detrimental to not only my daughter, but to the caregiver and our family as a whole. We need a caregiver who is attentive and can attend to her needs. She is a flight risk and has in fact escaped our home before, in the dark. It was scary. If a caregiver was distracted and not watching, she could easily escape and put herself in serious danger.

My daughter already has a set number of care hours and I am not here to ask for more hours or more services. I am simply here to encourage you to enact this section that would allow legally responsible individuals to be eligible to be the provider of waiver services that she already qualifies for.

With me being home with our daughter, we have been able to make forward progress in areas of development and have been able to decrease the number of times she has left the house unattended because I am able to watch and care for her properly. I have been trained in her needs by her medical providers and numerous therapists. For the foreseeable future, I do not see an option to return to work. This has put a hardship on our family and we have had to make sacrifices, but living in a rural area definitely has significant staffing shortages.

I am here today to ask that you support this bill and recommend a “Do Pass.” This bill would give families like mine, that are truly in a crisis, the choice to decide what caregiver options are best for their situation. This would ensure the best quality of life and care and ensure that families will not have to place our children in unsafe situations.

Thank you for your time and consideration,
Kali Weinand

Senate Human Services
SB 2276
January 24th, 2023

Chairman Lee and members of the committee, my name is Katynka Morrissette and I am here today to share with you why I support Senate Bill 2276 to allow legally responsible individuals to provide Medicaid waiver services.

I am the mother of 3 medically complex children who are on the Medically Fragile Waiver due to their level of need and extraordinary care measures. Our waiver services allow us to hire a caregiver to help with the daily needs of our children and insure that they are able to stay living in our home. My children require constant monitoring, medications and nutrition given via their G-Tubes around the clock, blood glucose and ketone checks at least 5 times per day, breathing treatments, regular infusions through an implanted medical port, and assistance with many other tasks for daily living. These are the things we do routinely, when you add in an illness or metabolic crisis—the frequency of intervention they need multiplies.

Due to inability to hire staff to fill the service hours we are authorized for, I have been unable to continue working outside of the home. In the past 5 months I have contacted 36 potential employees and was able to cover a mere 5 hours per week. Either another job offer was made that provided them with benefits, more pay with less work, or they just didn’t show up for their interview and gave no explanation. This is the workforce crisis we are living in, and you see it every day with businesses cutting back hours of service because of a lack of staff.

Even if we were able to find people willing to work, the concern in quality of care individuals receive increases as the level of need for the individual increases . A medication error or nutritional mistake could land our children in the hospital for many days and staff being inattentive to our child could put them in immediate danger. Unfortunately, we have had a care provider fall asleep while on the job as well as a caregiver continuously texting and leaving our children unattended. This is not acceptable when working with individuals with high medical needs.

We are not asking for additional care hours or extra services. We are simply asking that you allow legally responsible individuals to have the choice to provide the waiver services that are already authorized.

In these last few months of me being home full time we have experienced a decrease in hospital admissions because I am able to provide immediate intervention and work to stabilize their metabolic status quickly. The amount of extraordinary care measures I am trained and permitted to carry out by their medical team has allowed them to remain in our home. However, it did not come without sacrifice and I do not see an option to return to employment outside of our home given the staffing shortages.

I kindly ask that you support this bill becoming effective in July 2023, as families like ours are truly in a crisis and the need is urgent. Recommending a “Do Pass” on this bill would give families the freedom and choice to decide what service option provides their family member with the best quality of life and care. This also makes sure we don’t have to face tough decisions like considering placement in a medical institution due to lack of caregivers.

Sincerely,

Katynka Morrissette

TO: Senate Human Services Committee, Committee Hearing January 24, 2023
RE: **SB 2276**,

Senator Lee and committee members:
My name is **Sam Johnson** and I reside in Grand Forks, ND, legislative **District 17**.

I am testifying in **SUPPORT of Senate Bill No. 2276** for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I am the oldest brother, and since the passing our our parents, now the legal guardian of Robert Johnson, who is a 50-yr. old man with Down Syndrome, Type II Diabetes, and Early-Onset Dementia.
Since moving with us to Grand Forks ten years ago, Robert has been trying to live a full and complete life as (in his own words) "An Independent Man."

But in order for this to happen, in order for Robert to be an active, tax-paying citizen in the community, it is necessary for him to have **support services for** his **work**, his **day program**, and most importantly, **residential living.**
And for awhile, Robert had all these things in place with proper supports … .
— Robert had a **part-time job** at SamsClub with appropriate Vocational supports, where he earned a good paycheck from which taxes, etc. were deducted;
— he received **valuable day supports** for the hours during which he was not working at SamsClub;
— and he had **good residential staff support** while living in 2-bd room condo with a housemate, both of them being supported with evening and over-night in-home staff supports **as their needs required.**

Then in 2018, DD implemented the "new payment methodology." These new provider payment changes came with a required "redetermination" for Robert and individuals like him, using new SIS and ICAP assessment tools, which ended up **negatively impacting his support services**, and actually **resulted in a serious cutback of staff supported service hours for Robert** from 60 hrs. to an impossible 34 hrs. per week!

This was disastrous! The most significant result for Robert, and others like him who were receiving similar residential support services, was that he now had to go into a larger group living situation to live with more client-housemates in order to "pool their reduced hours of service" and be served by fewer support staff in order to meet these support service reductions! **This has been a very poor situation indeed** that didn't, and still often doesn't, provide the goals of person-centered support "maximizing **independence, and self-sufficiency, to prevent institutionalization.."** In fact, in the view of many, this resulted in a step backwards toward group institutional living!

For almost half a year while trying to find a group living place for Robert, my wife and I took turns spending the evenings and nights with Robert in order to fill the gaps left by the loss of his much needed residential support staff. And since Robert has a close-knit family that includes 4 other siblings and a number of college-aged nieces and nephews, several of them also took turns staying with Robert as caregivers.

In fact, to our DD case manager we suggested hiring of one or more family members, who were very willing to be live-in residential support staff caregivers for Robert. But financial support from the state for family employment was not possible, and there was no parent/guardian caregiver compensation available at that time.

In the end, sadly, Robert had to move away from us, out of Grand Forks, relocating to Devils Lake to live in a group home with 3 other individuals and shared staff spread so thin that his individual needs are sometimes not met.

It's with this situation in mind then, that **I ask you to vote YES in support of Senate Bill 2276** that could provide for family caregiver compensation, making it possible for family members themselves to provide much needed and better residential live-in support that would be more personal and individualized, and actually lead to a higher quality of care with better outcomes, more social and community involvement, and a greater degree of independence.

On behalf of families like ours who would wish to provide more personal care for their loved one with special needs, and who need state support in order to provide this caregiving, I say **THANK YOU** for supporting SB 2276!

Sincerely, Sam Johnson — 701-350-1590. — samjohnson58201@gmail.com

Senate Human Services
SB 2276
January 24th, 2023

Senator Lee & Members of the Committee,

My name is Nicki Maddock and I represent myself as a parent of a child with a developmental disability. My son has Duchenne Muscular Dystrophy (DMD) and was diagnosed shortly after his first birthday. As a background of what that means, Weston was given a life limiting disease diagnosis. He will lose mobility and be wheel chair bound by the age of 8-12. His diaphragm and heart will start to weaken in his early teens, requiring ventilation and medication. He will also develop progressive weakness in his upper extremities. Currently, a child with DMD has a life expectancy of 29.

When our son was initially diagnosed, I was working full time as a Medical Technologist in the hospital. Weston had multiple appointments and therapy sessions that required me to be present during the middle of the day, along with clinic days every six months in St. Paul, MN. I had exhausted my paid time off and ended up leaving the field completely to take a part time job with flexibility to be able to meet Weston's needs. This was a significant loss of income for our family, but we felt we had no choice as Weston's safety and health was our main concern. We also had to factor in that Weston has a progressive disease, so his level of care needed was only going to increase.

Due to his progressive rare disease we are currently self-directing our respite hours and utilizing grandparents. We know that if we were to self-direct staff outside our immediate family it would require a significant amount of training on our part. Weston is the only child in Bismarck with DMD to my knowledge. With high turnover rate that currently exists, it would be very difficult to have competent staff taking care of Weston's needs in the appropriate manner. Weston also has a severe speech delay, which has been attributed to his diagnosis. He is unable to communicate through words to us or a caregiver when he is tired or being overworked. Those of us who are consistently in his life understand his needs through non-verbal communication. There is also very real concern that if you don't understand his disease you can do irreversible harm to his body and his muscles. Weston would be unable to voice to us if that was happening through an agency, which would put him in a vulnerable position. He is only going to get bigger and require more physical assistance. As his condition continues to deteriorate, he will lose his ability to feed himself, bathe himself, and perform basic life skills. His grandparents will eventually be unable to provide the care he needs. If this bill were to pass it would allow my husband and I to step into that role to ensure competent staff and keep Weston in our home.

With the reasons stated above my family strongly asks for a "yes" vote for Senate Bill 2276 to ensure we are always able to provide the necessary services for our son, especially as his level of care becomes more significant. Thank you for your time and consideration.

Nicki & JP Maddock
Parents of Weston Maddock
701-400-9920
nicolewesterlind@gmail.com

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2276

Senate Human Services
Tuesday, January 24, 2023
Senator Judy Lee, Chair

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

My name is Roxane Romanick and I am 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 SB 2276 and asks for your consideration of a "yes" vote. Our organization assisted in the creation of SB 2276 and acknowledge that it will be a benefit to some of our member families who have a loved one with Down syndrome. Our challenge in crafting the language of this bill was to keep it as simple as possible, while recognizing that there is nothing simple about a change to a Medicaid Waiver program. We appreciate the input from the Department of Health and Human Services (Department) on this important topic of allowing families to be paid service providers.

The main intent of SB 2276 is to allow families, most particularly parents, to be paid for the care that is above and beyond what they would do for a loved one without extraordinary needs. As you will hear from family members who support this bill, the burden to maintain employment and meet the extensive and extraordinary needs of their children is heavy and sometimes unmanageable. This tension can be exaggerated by the inability to employ quality staff (heightened now due to workforce shortage), the intensity and fragility of the child's needs, and high demands of managing a child's educational and medical needs.

The vision is that this service option would be available through our Medicaid 1915c Waivers and the language of the bill would not alter who is presently eligible and/or served. For the most part, the individuals that we are targeting for this option already have service authorizations for some type of In-Home Support or care under a ND Medicaid Waiver. Presently, ND does not have an option for a parent of an eligible child with disabilities to be paid as a service provider. While initially discussing the option, it was our hope reimbursing families as service providers could become another provider option under the already existing self-directed In-Home Supports service; however, getting input from the Department, more general terminology of a "service option" as discussed in Section 1.2 was chosen to allow flexibility to the Department in meeting the requirements for the Centers for Medicare and Medicaid (CMS). I've included a link of to a CMS presentation on Leveraging Family Caregivers: https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf . Offered in October, 2021, this presentation indicates that just over half of states allowed legally responsible individuals to provide a personal care service. While complicated, it appears that the Centers for Medicare and Medicaid understand the critical urgency to consider this issue and is creating guidance to support the approach.

To incorporate this bill if it passes as currently written, the Department will need to draft Waiver amendments for any of our state's Medicaid Waivers which provides a self-directed In-Home services service option. Section 1.2 and 1.3 creates assurances that the option to include families as paid service providers is available to the widest population possible.

It is the hope that requirements for this option will not include an onerous demonstration of failed staffing and/or placement attempts, but instead that a decision about accessing this option stems from the development of the person-centered plan for the individual including the use of any new and/or annual assessment information. The annual assessment in Section 1.4 is meant to represent something similar to the annual application for In-Home Supports that the ND Developmental Disabilities Section uses to determine need and service authorization amounts for In-Home Supports in the DD Waiver.

Finally, Section 1.5 is a placeholder to assure that rates established for paying families would be equitable to rates paid out for a similar service to a non-family member or a provider.

In regards to the fiscal note that was filed last evening, I would ask the committee to consider what duplications in cost there may already exist in SB 2012 that could offset this fiscal note. For example, some of the families that may benefit from this option are already self-directing and are probably figured into the Department's budget for the intermediary fiscal agent costs. Remembering there is not an ask for an expansion of eligibility and since these are individuals that are already being served, I would expect current service authorizations are already figured into SB 2012 which would be underutilized if families are able use this service option. In addition, presently to my knowledge, no single service option under our 1915c waivers has a solely dedicated manager.

As this concept and bill were being developed, families expressed an interest and wanted more information. While preparing this testimony, I did so with a single father in mind who is trying to maintain his professional career while managing two major surgeries for his child with Down syndrome as well as his ongoing care. He has had difficulty finding consistent staff for over a year now and is constantly worried about having to take leave without pay, putting his job at risk. SB 2276 opens the door for ND to support him and keep his family intact which we understand is way more beneficial and much cheaper than an institutional placement for his son.

For his sake and for all of the families that are asking, please consider the passage of SB 2276 and I will be willing to answer any questions.

Roxane Romanick 701-391-7421
Executive Director roxane@designergenesnd.com

Sheila Murphy Testimony

I live in Bismarck in the 47th District

Good Morning Madam Chairwoman Lee and members of the Senate Human Services Committee. I thank you kindly for this opportunity to speak today. My name is Sheila Murphy and I reside in Bismarck in the 47th District. I am for Senate Bill 2276. I am the legal guardian for my granddaughter Kelahni Walking Eagle who is almost 4 years old. Kelahni has spastic quadriplegia cerebral palsy & is a survivor of a traumatic brain injury. She is medically fragile & has developmental delays. She cannot eat like a normal child. She can barely swallow her own saliva without equipment & medication to control secretions & prevent choking. Her nourishment comes through her feeding tubes as do all her medications, her formula, & water for hydration. She needs assistance with all Activities of Daily Living. She is nonverbal. She has detached retinas in her eyes that prevent her from seeing the world properly. She has a port placed under her skin on her chest that will stay inside of her for years. This helps get medication and emergency nutrition into her body because getting a needle into her veins has been impossible. This port alone needs monthly maintenance to prevent infection. Kelahni must be watched at all times due to her inability to move her body herself. This includes positioning her head and hands correctly and stretching her arms & legs at every diaper change to prevent contractures.

Our day consists of 7 medication passes that begin at 5:30am with the last medication given at 10:00pm. She will always wear a diaper no matter how old she is. In our home when Kelahni wets a diaper we are having a good day because even her urinary system & bowels have been effected by her condition. To leave Kelahni in the care of others requires God's mercy of allowing me to have complete faith that a stranger will care for her as I would. Will my respite caregiver cheer Kelahni on after she goes number 2? Or will she wince in disgust because she has to change a messy diaper? When you have a child with a feeding tube remember this is all liquid going into her body and it is all liquid coming out. It is a tough job to find someone who is not bothered by this. I am struggling to say the least with keeping my full time job and finding & retaining adequate care for her. I feel I should be able to get paid to take care of her. Her care is a huge responsibility and it is around the clock with no breaks.

I miss countless days to months of employment. The shortest time being a few hours and the longest I've been gone from work has been 10 weeks. Kelahni's doctor recommended she go to school but do you know at her age she can only go half days? So I had to find a respite caregiver that was willing to work a split shift. My caregiver comes at 7:00am puts her on the bus at noon, leaves and comes back at 4pm to get her off the bus. She then stays at my home until 7pm until I get home from work. It has been by sheer luck and God's mercy that I found a person to do this. A point to keep in mind is I only have the one caregiver. There is no back up person. The in home healthcare service I use has not been able to find a back up caregiver for Kelahni and it has been 7 months of searching. Please keep in mind my caregiver does have family emergencies & she does get sick herself. How ironic that my caregiver was supposed to be here today to help me and she called in sick. So I cannot go back to work this afternoon as planned. Keep in mind I am a single parent. There is no second income. I also have two teenagers at home to provide for.

There is a huge problem right now finding proper care for our disabled children with special needs. When I asked an in home daycare provider if she had an opening I was instantly denied due to Kelahni needing more attention then the daycare could provide. I knew then I was in for a fight if I wanted to keep working. I’ve had caregivers who did not follow what my wishes were & safety guidelines that put Kelahni in danger. For an example my motherly instinct told me to check on my granddaughter during my workday without calling first. When I did the caregiver had her in her stander with no orthotics on her feet. This could have caused broken ankles. Not to mention a lawsuit. Problems with a hired facility to do her cares that I have experienced are: people sleeping on the job, cares not being performed correctly, g tube tubing being taped on Kelahni's belly upside down against the natural flow of gravity, pressure sores on her heels because they did not move her, being on their cell phones when they are supposed to be reading her books and stimulating her mind, stretches not being done so her joints got more stiff, not washing their hands appropriately so she gets infections from them which lead to hospitalizations, watching tv and not interacting with her.

I’ve tried a residential living facility and it was not a pleasant experience. I’m back to utilizing a service that hires the caregiver for me and they keep track of the hours of staff. My hours are going to waste because they don’t have the staff to fulfill the hours that we are granted every month. That means everyone is losing. Currently it costs the state $28,000+ to pay for Kelahni to have a caregiver for 3 months. This is for 255 hours of care per month. We have our caregiver for 168 hours per month. That is a loss of 87 hours monthly. I've asked for care on the weekends but right now I can only receive care during the weekday so I can work not rest. My wages from my job are just slightly above this amount annually. And I have caregivers quitting without two weeks notice, quitting because they can’t do the heavy work of lifting or it is too hard for them to do. We are dealing with a different working pool right now from which to choose from. If a potential employee doesn't like the work they just quit and are off to find something else. They don't think twice about switching to an easier job. This is a demanding job and for my granddaughter I have to trust who I am leaving her with. She is a special child and Kelahni should be able to have who she trusts there to care for her and for me to be able to make a living without going broke or worse becoming homeless. I love North Dakota and I’ve lived here for most of my 50 years that I’ve been alive. But, if I have to move to Minnesota where I can get paid to care for my granddaughter it may be what it comes down to. I don’t understand why I should have to move to get the golden standard of care when we are perfectly able to do that here in North Dakota. Please consider this help it just makes sense. Thank You!

Sheila Murphy-iloveelvis72@yahoo.com-701-516-6081

Testimony
Senate Bill 2276
Senate Human Services Committee
January 24th, 2023

Senator Lee and Members of the Senate Human Services Committee, my name is Brittany Armstrong Hanson, and I am here before you today, in Favor of SB 2276.

I am a single mother of three children with developmental disabilities. My daughter is 12 years old, and my sons are 10- and 14-years-old. My boys are both Intellectual Disability/Developmental Disabilities (ID/DD) Waiver recipients, Early Intervention (EI), and Early Childhood Special Education Program (BECEP) graduates. All three have an education plan, Individualized Education Plan, Individualized Learning Plan (ILP) or 504, each with an, at least, annual meeting to update and review the plan. All three children, until recently attended outpatient habilitative therapy service appointments with Speech (ST), Occupational (OT), and Physical Therapy (PT), multiple times a week, with 9, 6, and 4 appointments for by 10-, 12-, and 14-year-old, respectively. With each habilitative therapy specialty comes twice annual reevaluations, that is 3 OT, 3 ST, and 2 PT re-evaluations, which include, at a minimum, 3-4 assessments that are several pages long that I have to fill out, updates to clinic paperwork, and coordination with school staff to have school/teacher versions of my forms filled out by the school/teacher and returned to the clinic. Each of my children also have co-occurring medical conditions as well and see multiple medical specialists throughout the year, in and out of town, with each requiring completing detailed health histories and in-depth medical exams. We have had out of state referrals, but I simply have not been able to manage traveling out of state for intensive diagnostic and/or evaluation clinics.

In addition to the habilitative therapy and medical care appointments, exchanging of information, and coordination of care, there is ongoing, most often daily, communication with, and school staff, from front office staff, dietary and kitchen staff, school nurses, special education teachers, paraprofessionals, general education teachers, and other support staff. This high level of communication not only ensures my children's the health and safety but also provides for a warm handoff between myself and others who interact with and support my children on a daily basis so that varying plans of care and be carried out.

I am Mom, and in my case, working double time to desperately try to makeup for there not being another parent in the home, case manager, care coordinator, and Mom Uber extraordinaire, and still somehow have to figure out how to provide the ordinary (non-extraordinary) care to my children; feed and bathe them, wash endless loads of laundry, grocery shop, and still make time to be able to hold and hug them, help them fall asleep, listen to them when they are happy, sad, or need a shoulder to cry on, plan and celebrate birthdays and holidays, and just be with them. I am constantly reminded to incorporate self-care, not just for myself, as their caregiver, but for all of us, as we are the entire family unit. I am told to remember that I need time to breathe, bathe, and maybe even socialize, so that I can better care for my partner, all of my children, and my aging parents. Thank goodness for other parents who get it and still care for and love me despite my inability to consistently communicate or are there to pick me back up after periods of falling off the face of the earth because all that I had left in me was enough energy to retreat, for sanity's sake.

But wait, there's more! I am also an employer.

We have been utilizing ID/DD Waiver services, particularly, self-directed support services (SDS) with In-Home Supports (IHS) and Equipment and Supplies for over 12 years. That means that I have recruited, hired, trained, coordinated schedules, ensured reporting and receipt of quarterly authorization of service hours by fiscal agent, computed authorized hours with consideration of employer taxes to determine actual employee compensation rate and resulting hours, completed twice monthly payroll consisting of review and verification and submission of logged hours/timesheets, and have had the pleasure of doing so with two fiscal agents, their paper processes, online platforms, integration with the DD Division's internal processes, implantation of Electronic Visit Verification (EVV), COVID medical leave, end of year tax statements, annual employer tax rate issues, and fielding all the Q&A from employees. I have worked with numerous families who have shared in my experiences and were trying to figure out how to walk the same path without assistance from the DD Division. I say this because, with self-directed supports, we receive very little support from the DD Division.

The DD Program Managers (DDPMs) try to assist families and individuals who elect (choose) to utilize the limited-service options available in a self-directed model, to the very best of their ability, in completing the enrollment packet (a lovely stack of paperwork!) which creates an account with the State's designated fiscal agent, submits an application for an Employer Identification Number (EIN) with the Internal Revenue Service (IRS) establishing the individual or designated individual, often times, the parent or guardian of service recipients, as the employer of record. The service recipient(s) and employee(s) enroll and each separate accounts. The DDPMs are not trained to, nor do they have the ability to, assist with anything fiscal agent related. There is not a liaison or other connecting person or entity between employer of record and the recipient(s), the fiscal agent, and the DD Division to assist with this service option.

DDPMs meet with individuals and families quarterly and complete annual assessments to determine ongoing eligibility/qualification for services (PAR or SIS Assessment), annual review of the Individual Service Plan, Overall Service Plan, or Individual Family Service Plan; assessments and names of service plans vary depending on the age of the wavier recipient. Individuals and Families also work with the DDPMs to complete the annual application for in-home supports, which determines the quarterly authorization of service hours, based on classification of the type of service hours needed (respite, 2nd pair of hands, and supervision) and the need for such hours, overall. Application and determination of eligibility for the ID/DD waiver is most often a long, stressful, and complicated process. Despite the initial eligibility criteria defining "Developmental disability" as “a severe, chronic disability ... which: ... Is likely to continue indefinitely”, eligibility and level of care and an application for in-home supports services must be completed annually.

We have been lucky to have had only had three different DDPMs for my boys over the years and the same DDPM for both boys for the last 8 years. Just recently, the boys were assigned a newbie, who is a temporary employee, so the possibility of losing her with the current workforce situation, but I’m holding out hope that she will stick around. She has big shoes to fill, is still learning the ways of my busy little circus and is doing unbelievably well keeping up with my need for detail, 20 bajillion questions, in depth discussions, and has already nearly mastered the art of keeping me focused and on task despite the ever-growing list of things pulling me in other directions. Needless to say, I have been more than happy with the support we’ve received from our DDPMs.

And lastly, employment. Yes, I’ve juggled trying to maintain employment in addition to all of this.

Time off and the need for flexibility in scheduling or alternative work schedules for all the medical, therapy, and school appointments makes it all too easy to burn through any accrued paid time off/annual leave and sick leave which has left me having to choose between proving income or providing care for my family far too many times.

I have been a nurse for a decade and a half, worked rotating day/night shifts at local hospitals, did contract nursing across the state to have more flexibility in my workdays, worked in the schools as a school nurse, and was only one of three nursing working with intensive outpatient dual diagnosis treatment teams in the state. I've worked as a nurse consultant in infection control and dabbled in some legal nurse consulting and got to worked in my dream job, as a disability advocate, for a short time. Ultimately, the choice to provide income or provide care always roars its ugly head. Providing care will ALWAYS win and I will continue to pick up the pieces, figure something out, and keep going, one way or another.

But, I want to be very clear, under no circumstance, did I or will I ever choose to "forgo employment outside of the home", as the Department has phrased it. I have had to make the choice between parenting, providing all the care I've described previously, and employment, which in turn supports parenting and providing the various other care roles, and funds basic survival. A choice that no family should have to face.

You will hear lots of other testimony about more specific extraordinary cares provided to individuals by primary caretakers or legally responsible individuals, today. I encourage you to take a moment to really consider what you consider ordinary cares or typical caregiver/family member interactions and just how much each of these families here today have sacrificed, have been unable to be attain, what they have lost in the complexities of providing all the above and beyond cares, or everything that they have "forgone", in the Department's words, while trying to not only meet needs but to provide the level and quality of care that each of their families deserve.

Thank you. I will stand for any questions.

#16213

Legislative Assembly

North Dakota Senate

STATE CAPITOL
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BISMARCK, ND 58505-0360

Senator Sean Cleary
District 35
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COMMITTEES:
Human Services
State and Local Government

1/24/2023

Madam Chair Lee and members of the Senate Human Services Committee,

SB 2276 establishes an option under the 1915(c) Medicaid Waivers (home and community based services) that would reimburse family caregivers who provide “extraordinary care” to their dependents who are on these waivers.

Currently, there are individuals who are eligible for in-home services through North Dakota’s Medicaid program that don’t receive these services, often due to a lack of qualified workforce available to provide the services. This often means that a parent or other relative must try to take care of them, sacrificing income they would otherwise be earning at work to stay at home. This bill would allow for that caregiver to be reimbursed when the care they provide is beyond what is ordinarily required by a parent or legal guardian.

The Aging and Disabled Waiver for home and community-based services currently allows caregivers living in the home to be reimbursed for care — this bill would provide equal treatment under the other waivers, including the Intellectual Disabilities/Developmental Disabilities, Autism, and Medically Fragile waivers.

The goal of this bill is to:

1- Address the lack of workforce that surrounds these home-based services
2 - Provide financial stability to households that are strained by juggling work and caregiving
3 - Provide the care that these individuals are legally eligible for but not actually receiving

I am grateful for your consideration and deliberation on this important legislation.

Respectfully,

Senator Sean Cleary
District 35, Bismarck

Testimony SB2276 - Senate Human Services

Brittany Zappone Bismarck

ND District 32

Senator Chairwoman Lee and Members of the Human Service Committee.

My name is Brittany Zappone. I have two beautiful children; my son who is 7 and my daughter who is 6.

I am testifying in support of Bill No. SB 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Both of my children have special needs, stemming from one traumatic event. Our story was that of a pretty typical household until November of 2016 when our lives were turned upside down and we were soon to navigate a new world completely different from the one we had known. My daughter was in pain and wholly unresponsive. She was life flighted to the only pediatric neurosurgeon in North Dakota. As the minutes and hours turned into several days, we fought to grasp even the slightest concept of what was happening and wondered if the next test or surgery would finally reveal an answer. My daughter was violently shaken. We didn't get the diagnosis right away, but when the news came, I still remember my exact reaction. I was shattered and broken. After the diagnosis, there came interviews and a ton of other new challenges. We are immensely thankful for the ongoing family support we have through Family Voices of ND. They have been there to support us from the start and have truly made it a little easier to process.

Over the last several years, things have only gotten more complex and harder to navigate. In the beginning, I had to quit my full-time job to care for the children. I also had to find a way to utilize all the resources I knew nothing about, navigate the judicial system for a divorce, and somehow move to a new city with services for the children. I truly hit rock bottom but was always supported by those who walked this journey with us. A lot of those being therapists, doctors, friends, and agencies as I did not have family support. Throughout this time, I needed to also find a way to get her to specialists in Fargo. Due to her medical complexity, she was admitted frequently to the pediatric intensive care unit as they tried to find a medical plan that worked for her. Travel was never a cost that was covered and often left me with hard choices as I did not have an income that could even begin to cover the needs. I had a small portion of TANF but that was nowhere near the income I had previously when I was working.

My daughter transitioned out of early intervention services and qualified for the DD waiver, however when we moved to Bismarck to be closer to specialists, the lack of available and trained staff really made it difficult to work. Daycare facilities aren't trained for medically complex children and can't provide the one-on-one skilled care her condition demands, making that a non-option for her as well. She was in school half days a few days a week. I started to volunteer at her school until a position opened. I slowly made it to full time over the years and only decided to take it as she was supposed to attend school full days in kindergarten. The only reason I still have this job is because my supervisors truly understand my daughter's needs and, when I need to take her to doctors out of state or for an extended hospital stay, they are flexible enough to allow me to make up some time outside of normal hours if needed. I truly am lucky and extremely blessed that I have found this job as most would not be this understanding and flexible, but I do also fear that soon it may cause issues as my daughters' health continues to significantly decline.

With the agencies we did have for respite, it was difficult to find someone to care for her as her needs are complex and require not only someone who understands the medical knowledge, but someone who can find what she wants by her expressions, as she is nonverbal. She has a G-tube, Cecostomy tube, and a VP shunt. She is non ambulatory and has been diagnosed with global developmental delay. The medical complications alone would take me hours to explain. A few of them include encephalomalacia (softening or damage to brain tissues), epilepsy, severe scoliosis, CVI (cortical visual impairment), and cerebral palsy. I found it very difficult to find people and often would cover the shifts myself as the staff was not reliable. As of right now, I have one staff for her, and the availability doesn't allow us to use our current budget. If my staff member is ever out sick or needs a day off, I, again, must cover and leave work to do so. Keeping employment is a must as we cannot make it without an income, and we do not qualify for any assistance besides Medicaid.

My daughter has had a medical journey that none of us could possibly imagine. Since the injury she has had to fight every single day to survive. She has undergone over 25 surgeries with 10 of them being major brain surgeries. She does therapy every day of the week, sees multiple specialists, and has been attending school full time. Unfortunately, we have run into the issues of the schools not being able to provide her with the proper care and I have missed work to be home with her. She was previously at a special education program for three years, after she transitioned to general education it was a mess. Unfortunately, we've run out of time trying to fix concerns at the school.

On December 29th last year her seizures started to get worse, and they were not responding to the interventions. I administered the rescue medication that I have never had to use and called EMS. She continued to have seizures and was life flighted to her epilepsy team in St. Paul MN. No one could have ever prepared us for the outcome of that visit. Due to issues with formula we had to make the decision to either stay and add one issue to another or try our best to treat outpatient. She was already in pain; I could not knowingly put her through even more problems. I ultimately made the decision to bring her home.

Doctoring out of state is difficult and due to insurance, we have had to make several decisions like this and have had to transfer her knowing very well that she may not survive the trip while actively having seizures. Thankfully those times she did, but, looking back, we know that it was truly a higher power that made sure she did.

Since being home, things have been a roller coaster. She has had multiple medication changes and very little improvement. My fiancé and I are thankfully able to adjust our schedules, but, again, this is only because our employers know the situation. We've been very lucky in that regard. Our staff covers 2-3 hours a day, basically the gap between when his shift starts and mine ends. This has taken a huge tole on my family. Not only do we have limited time together, but the kids also have been struggling as we are never together as a family unit. Unfortunately, we still cannot make it without both of us bringing in a full-time income. I go to work, knowing that my daughter may not get better. I struggle every day when I have to leave her with my fiancé, who does his absolute best but cannot legally make decisions or calls. I check in often and am struggling daily to keep focused on the tasks for work.

Her condition is getting worse, and the seizures are still breaking through. The doctors have run out of options besides medications that will ultimately sedate her. I always knew that it was a miracle that she survived the injury and that most do not survive. The life expectancy for children with shaken baby syndrome is rarely in their teens, but I never thought that I would be making end of life decisions for my six-year-old child and have them in place so soon. The doctors are trying to slow the progression, but they will never be able to stop it. Her condition will continue to get worse, and it breaks my heart that I will not be able to take the entire journey with her. I will have to continue to work to keep a roof over our heads and food on the table as there is no other option.

I do not know whether we will be able to use these proposed services if the bill passes or not, as our time with her is truly unknown. I do, however, hope that these services will help those in similar shoes if we are no longer able to.

No one should ever have to choose between work and being with their child during the last stages of their condition to provide the quality of care that comes from the lived experience of a parent.

Thank you for your time serving our state and for listening/reading my testimony. I urge you to vote yes on Bill No. SB 2276. Families are in crisis; we need help now.

Thank you for your time and consideration.

Brittany Zappone

Maran Blair

Live in Mandan

Voting district Morton

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I am a single Mom and choose to quit working after my maternity leave so I could take care of Keegan due to him being medically fragile and his medically complexities. Keegan was born with arthrogryposis, hypotonia, microcephaly, clubfoot, a brain abnormality, and many others. The brain abnormality has caused him to have epilepsy. He got a feeding tube surgery at about a week old. He also got a trach surgery about 8 months ago due to breathing issues.

When we wake up in the morning I have to suction him a lot due to build up of secretions when he's sleeping. This can cause him to gag as well. I also give him 6 different medications in the morning and 5 at night. Every day I have to clean his trach mask he uses at night that hooks up to a humidifier machine, fill the humidifier, get out a new HME for his trach during the day, do trach cares, make formula, fill feeding bag, and homeschooling. The humidity for his trach is because since he can't breathe out of his mouth and nose so the humidity provides moisture for his throat. Every week Keegan also has 3 days of therapies consisting of 5 appointments total, this does not include the school coming into the home to provide homebound school services. My Mom and I also do a trach change every week. I choose to homeschool Keegan due to all his medical complexities and being medical fragile. His pediatrician wrote a letter strongly advising to homeschool Keegan due to these issues.

Having this bill passed would financially help to supply Keegan's needs plus bills and not having to go without things we need. It would also help get adoptive equipment that would make Keegan thrive as adoptive equipment is expensive and a lot is not paid through Medicaid such as an adoptive carrier, special swim gear, a floor play chair that is supportive, and many others.

Thank you for your time serving our state and for reading my testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Maran Blair

maranblair@yahoo.com

701-527-5040

Testimony for SB 2276

I am testifying in support of SB 2276 with regards to changes to the medicaid waiver services and I live in Mandan ND.

I have a unique perspective to the needs of this bill to pass here in ND. My son was born with severe congenital anomalies, for instance, Dextracardia situs solitus (heart on the wrong side of chest but also tilted and backward), Poland Syndrome (left major pectoralis muscle missing), 5 1⁄2 ribs missing on the left also, 100% GERD that meant every time he ate he inhaled formula into his lungs, He also had 3 holes in his heart 2 VSD 1 ASD, Restrictive Airway and Lung Disease which later became Reactive because of the chronic bronchitis and pneumonia over several years as well as tachycardia. I was a single mother and was told at Duke University Hospital they had never seen this before and that my son had a 2% chance of survival to his first bday and 0% to his 5th bday. I worked 2 and 3 jobs after 2 yrs of being told by our social worker there was no point in getting a job because child care help will only cover up to 1.75 an hour and because my son needed someone with medical experience i could not afford to get care. Finally with the help of our respite care nurse who agreed to help me by watching him for the amount i was allotted a month plus what i could afford outside of that at times i worked two and three jobs in between the constant physical and occupational therapies and many, many dr visits and specialists and hospitalizations which were either here in Bismarck, Fargo or Minneapolis. Going to Minneapolis at least 3 or 4 times a year makes it hard to keep a job when you go thinking it is a 3 or 4 day visit to see all specialists but end up there because of unexpected surgeries and hospital stays at Childrens that would last a couple weeks up to six weeks! Most employers do not understand and neither do landlords so we had to move a lot because I could not pay my rent if I had no income. After 58 surgical procedures, most were prior to age 10, and hundreds of Hospital and clinic visits. I can say my son is now 31, almost 32 yrs old and although his health issues can still cause issues he rents from his best friend as a roommate and works full time. We were lucky in some ways of having a really awesome respite care nurse that helped us and his support care worker who also helped out at times outside of our regular hours.

My unique perspective is the fact that I worked later as a respite and support care person for a couple of years and was a CNA for more than 2 decades. Now we have guardianship of our oldest grandson who is Autistic, Nonverbal, Sensory Disorder, Severe ADHD and Chiari Malformation Type 1 with a 9 mm herniation for which he is having neurosurgery on Feb 9th,2023 in St Paul at Gillette Childrens. We have been extremely lucky with the staff at school from teachers, paras, the principal and secretary and our whole IEP team being behind our grandson from the beginning and are easy to work with. From the principal on down the line they are awesome but above him there is a lot of issues unfortunately. Our grandson receives Speech, Occupational and Physical Therapy at Sanford once a week as well as ABA therapy at Anne Carlsen 3 times a week which he ends up at school a bit later on mondays and fridays and he just goes to all therapy on wednesdays no school. Because I am just getting out of my wheelchair for the first time in over 15 years I was supposed to receive help through respite and support care hours in the amount of close to 280 hrs a month but because of the shortage of staff we have our respite worker pick our grandson up every wednesday at 10am and she takes him to Sanford then when he is done at noon she takes him to grab lunch on the way to ABA so that is about 3 hrs once a week that we have that because there are too few workers to the needs that are out there. That is only 12 hrs out of 280 hrs a month. Our respite worker is great with our grandson and yes we have checked other places but they are also shorthanded. Without the support staff or respite and having nobody in the family that can care for your child that could be paid but yet the parent who knows how to care for their child the best not being allowed to and needs to worry about how to pay bills or keep their job if they are lucky enough to get one once you disclose you need to take your child to appts 2,3,6 times a weeks or every other week or even a month you end up stuck. To be scared for your child, not able to pay bills, not able to get child care or respite hours until your child is in school is really hard on families and takes a physical toll on the primary caregiver. I know because once i knew my son was ok and my husband and i married in Dec 2004 i ended up ill but it wasn't until the very beginning of 2007 i ended up in a wheelchair because of the stress and exhaustion everything i went through to make sure my son lived through every surgery and hospitalization and the constant living off 2 or 3 hours sleep every night for years. I know so many single parent families and dual parent families that are sacrificing so much to try to get through these types of issues because of the costs for just basics of rent, food, utilities, phone, car, insurance, etc when they either cannot get a job or cannot keep one because of having a sick child. If a parent was a paid caregiver that would alleviate so many problems for families and quite frankly employers who complain when you are going to be a few minutes late because you need to finish admitting your child to the hospital and even though you are only 5 min late they fire you and complain you just do not want to work which is ABSOLUTELY UNTRUE! There are several states already that do pay the parent as the caregiver and it seems to work well because in many cases the state is not paying for a registered nurse full time to care for many of these children. The cost is less to the state also in how in some cases that extra in a two parent household where one parent is working but they need a second income is the difference between a family on a lot of assistance versus paying them usually less than what you would be paying the professionals to come in and care for the child instead plus all the costs associated with those contracts.

This Bill, SB 2276, not only makes common sense, it is fiscally responsible and is just the right thing to do for the families that are already stressed and scared and worried on a daily basis. It also has a continuation of care that will improve the health and welfare of the child.

Thank You
Jody Keller
kellerskitchen17@gmail.com
701-202-1041

Hello, my name is Carrie Varner and I'm the facilitator for Advocates Leading their Lives (ALL), a self-advocacy organization that is supported by the North Dakota Developmental Disabilities Council. I live in Bismarck, North Dakota and I'm in support of Senate Bill 2276.

There are many families in North Dakota who would benefit from paid family care, particularly those who have children with disabilities. Families of children who have children with disabilities often have little to no options available for childcare and they rely on families to help them with childcare so that they don't need to institutionalize their children. When families aren't able to pay their relatives for childcare, they often have to make very tough decisions, including whether they can continue working and being a contributing member to society as they have to stay home to watch their children or whether they'll be forced to put their loved one in an institutional level of care. Families shouldn't have to make those tough decisions when the option for paid family care is available. Paid family care will help families be able to continue being in the workforce, relieve the stress and tension that often comes with having little to no options for childcare for their disabled child, and will divert the need for institutionalization, thus saving the state money. Please support bill 2276, this will be a life saver for many families and will keep them together for as long as possible. I'm available for questions if needed.

Testimony
Senate Bill 2276
Senate Human Services Committee
January 24th, 2023

Chairwoman Lee and Members of the Senate Human Services Committee, my name is Brittany Armstrong Hanson, I am here today in both a personal capacity as a parent of three children with developmental disabilities, two of which are current ID/DD waiver recipients and as the Council Chair of the North Dakota State Council on Developmental Disabilities.

Please accept this testimony in addition to my personal testimony, previously uploaded, in favor of SB 2276 and as a rebuttal to the DD Division's Testimony and submission of their fiscal note.

Data collection and reporting for purposes of quality assurances, systems integrity, and improvement in and development of services to meet the unmet and ever-changing needs of individuals with disabilities in North Dakota is also historically lacking or at least non-transparent. Requests for results of reviews, numbers of recipients in differing service options, utilization service units/hours versus authorized service units/hours have gone unfulfilled by individuals, advocacy groups, and hired consultants performing systems assessments. When discussing modifying current service options to expand who is eligible to provide the service, the DD Division indicated that they were unaware of the need for the modification and that providing for payment of services to a legally responsible caregiver has never been brought to their attention. This response directly contradicts modifications made to all ND Medicaid Waivers in response to the COVID-19 emergency, Appendix K Amendments. The State submitted Appendix K amendments, for each of the 1915(c) waivers offered in ND, modifying service options within the waivers, beginning in April 2020, with further amendments submitted in March 2021, and rollbacks of the modifications in January 2022.

Examples of modifications in the waiver amendments were:

- Allow relatives of waiver beneficiaries who reside in the home and out of the home to provide services prior to background check and training for 90 days.
    - Seen across all waivers
- Permit payment for services rendered by family caregivers or legally responsible individuals if not already permitted under the waiver
    - As seen in ID/DD Waiver modifications to multiple Service Options:
        - Residential Habilitation, Independent Habilitation, Day Habilitation, Prevocational Services, Small Group Employment Services may be rendered by legally responsible individuals, who are not residing with the participant, when they have been hired by the DD licensed provider. May be rendered by legally responsible individuals when they have been hired by the DD licensed provider agency. The DD licensed provider agency is responsible for ensuring that services are provided, and billing occurs in accordance with requirements.
- Modify provider qualifications (for example, expand provider pool, temporarily modify or suspend licensure and certification requirements)
    - As seen in HCBS Aging modification to the Family Personal Care service option:
        - Payment will only be made to legal spouses or relatives who reside in the same home. Individuals who choose a provider who is not their legal spouse or other live- in relative will be served under Medicaid State plan personal care.
        - Individual providers - Increase maximum rate for family personal care from $76.67 to no more than $150 per day. The change in rate is based on the same rate methodology included in the approved waiver. It is being increased to be competitive with other programs and is being increased to assure access to

services and the long-term sustainability of a sufficient provider pool of family caregivers.

We need efficient data collection and the ability to extrapolate the data collected to evaluate the quality and appropriateness of service options from development to implementation and receipt in a constant feedback loop that actively engages with stakeholders ensuring compliance with state and federal law and CMS guidance as a standard of measurement when determining how the State can and/or is meeting the needs and filling the unmet needs of individuals with varying disabilities in North Dakota.

The DD Division indicates in Appendix H: Quality Improvement Strategy of the Application for 1915(c) HCBS Waiver: IID/DD Traditional Medicaid Waiver 1.1.2021 that it has done a review and analysis of all settings ... where Home and Community Based Services are provided ... the state has determined ... In-Home Supports waiver service ... to fully comply with the regulatory requirements because ... individualized services are being provided in the recipient's private home and allow full access to community living according to their needs and preferences. Recipients or their primary caregiver get to choose what services and supports they want to receive and who provides them.

The Department will assure continued compliance with the HCB settings rule by implementing and enforcing policy that will assure the continued integrity of the HCB characteristic that these services provide to waiver recipients. In addition, the State monitors all individual care plans, conducts case management reviews, client interviews/ quality reviews to assure clients are free to choose what services and supports they wish to receive and who provides them.

In response to the DD Division's submitted fiscal note.

The DD Division stated that SB 2276 creates a new service, to be available in North Dakota's Medicaid 1915(c), waivers that would support a person who is served by the waiver by allowing the person's primary caregiver (legally responsible person) to *forgo* work outside of the home when the person has extraordinary care needs.

The DD Division further stated that Section 1 of SB 2276 requires the Department to create a new service for individuals who provide extraordinary care to eligible individuals.

Section 1 2. actually states that "The department shall work with the centers for Medicare and Medicaid **services to implement a service option** that will **allow payment** to a legally responsible individual who provides extraordinary care to an eligible individual. This service option must be available for participants in the Medicaid 1915(c) waivers and any subsequent Medicaid waivers to be developed.

Nothing in Section 1 **requires** the department to *"create a new service".* To clarify, there are multiple 1915(c) waivers and each waiver has multiple service options. We are talking about *one* of the service options within the waivers. *To further clarify, the service described as the in-home supports service option is currently offered in the ID/D Waiver and Children's Medically Fragile Waiver. Similar service options are currently available in the Autism Waiver, Children's Hospice Waiver, and the Aging and Disabled HCBS Waiver as Respite and Family Personal Care. Different service option names reflect the slight variations to the service options depending on the waiver recipient target population and administering division.

https://www.ndpanda.org/sites/www/files/documents/ndmedicaidchart.pdf

https://www.nd.gov/dhs/info/pubs/docs/medicaid/hcbs-waiver-1915i-comparison.pdf

None of these similar waiver service options nor the In-Home Supports option has a singular FTE specifically assigned for administration and management of the service option. For that matter, there are currently approximately 5,600 ID/DD Waiver recipients and one FTE that in-home supports and equipment and supplies requests are routed to. I am not certain that these two duties are the only duties this particular FTE is responsible for.

The DD Division stated: To be able to administer this service, the Department would need three new FTEs, one to administer the DD program, one to administer the Medical program and one who would provide service authorizations and monitoring of service delivery.

The Department does NOT currently utilize an entire FTE to separately administer "the DD Program" for any other service option within any 1915(c)-waiver.

The Department does NOT currently utilize an entire FTE to separately administer the "Medical program" for any other service option within any 1915(c)-waiver.

The Department does NOT currently utilize an entire FTE to separately "provide service authorizations and monitoring of service delivery" for any other service option within any 1915(c)-waiver.

The DD Division state: The fiscal impact related to these three FTEs would be $566,432 for the 2023-2025 biennium. The Department would contract out an Intermediary fiscal agent who would work with and on behalf of the individuals who would utilize the service. There would be an initial set up fee with the Intermediary estimated at $50,000. The Department estimates that the Intermediary fiscal agent would charge $95 per client per month, and this is set to begin July 1, 2024, with a cost of $364,800.

The department already contracts with a fiscal agent, Veridian Fiscal Services, that self-directed service recipients utilize for all billing purposes, after Department issues service authorizations.

Veridian would not need to alter service delivery as far as self-directed services are concerned, from brief idea sharing discussions I have had with higher level individuals at Veridian. There are a few minor changes to the Employee Agreement and Statement of Relationship forms currently utilized by self-directed employers. Electronic Visit Verification is also NOT required of legally responsible individuals providing in-home cares/services, per CMS.

The DD Division stated: The Department would need to build an interface to the Medicaid Management and Information System (MMIS) to be able to receive the service authorizations and issue payments to the family caregivers. The interface is estimated to cost $200,000.
The Department estimates the program would serve 320 individuals at various age levels (due to different levels of need at each different ago group). The hourly rate would be $25.26 with a maximum of 40 hours per week. The estimated cost for the service delivery for the 2023-2025 biennium is $10,914,826.

The rate stated is for self-directed services. At $25.26 per hour, the authorization amount, is further reduced by employer taxes. As the legally authorized representative, I am the employer of record for my boys in-home support services, using the tax rate that I was recently notified of, by the currently contracted fiscal agent, $25.26 x 10.03% = $22.72 per hour being available to pay an employee.

Now, compared to a licensed DD Provider rate, and self-directed services, with ND's services delivery options, cannot offer any fringe benefits, despite being able to pay an employee a full-time wage.

***The Department’s budget does not include requests for appropriation for all of the hours and units that they have authorized. The department has stated that they budget based on utilization, not authorization. I challenge you to understand that. This fiscal note is far-fetched, at best, and is based on maximum utilization and shows no offset by reduction of utilization in hours already authorized in the current in-home supports service option that would be used if the Department “creates a new service option” in that option or an equalization, a wash, of hours currently authorized that would just simply be used as currently authorized.

The DD Provider rate is reported in units, $9.10/unit or $36.40 per hour.

5,830 Waiver recipients in Waiver Year 1 – 6,830 Waiver recipients in Waiver Year 5

1.1.2021 ND ID/DD HCBS Waiver (*Appendix J: Cost Neutrality Demonstration* cost neutrality tables pgs 189-202)

A fiscal agent is used for self-directed service payments. In self-directed services, participants directly bill or invoice to the Fiscal Agent. The Fiscal Agent pays the vendor, codes the claims as to specific type, and bills through the state claims payment system. Monthly balance sheet reports are available for participants and the Department. The DDPM monitors individual budgets and account balances.

Billings flow directly from the provider of the service to the State’s claim payment system for all services except self- directed services. In self-directed services, participants directly bill or invoice the Fiscal Agent. The Fiscal Agent pays the vendor, codes the claims as to specific type, and bills through the state claims payment system.

Application for a §1915(c) Home and Community-Based Waiver [Version 3.6, January 2019] Instructions, Technical Guide and Review Criteria https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

Technical Guidance

CMS policy is that payments for personal care or similar services delivered by legally responsible individuals (as defined in state law but typically the parent of a minor child or a spouse) are not eligible for federal financial participation. Legally responsible individuals do not include the parent of an adult beneficiary (including a parent who also may be a legal guardian) or other types of relatives, except as provided in state law). 42 CFR §440.167 prohibits FFP for payments to legally responsible individuals for the provision of state plan personal care services. This prohibition is based on the presumption that legally responsible individuals may not be paid for supports that they are ordinarily obligated to provide. See also Section 4442.3.B.1 of the State Medicaid Manual.

Through an HCBS waiver, a state may elect to make payment for personal care or similar services that are rendered by legally responsible individuals when such services are deemed extraordinary care so long as the state specifies satisfactory criteria for authorizing such payments. The criteria must include how the state will distinguish extraordinary from ordinary care. By extraordinary, CMS means care exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.

State policies should include additional safeguards such as:

- *Determining that the provision of personal care or similar services by a legally responsible individual is in the best interests of the waiver participant. A state* *should consider establishing safeguards when the legally responsible individual has decision-making authority over the selection of providers of waiver services to guard against self-referral.*

• Limiting the amount of services that a legally responsible individual may furnish. For example, a state may decide to limit the amount to no more than 40 hours in a week and thereby take into account the amount of care that a legally responsible individual ordinarily would provide.

• Implementing payment review procedures to ensure that the services for which payment is made have been rendered in accordance with the service plan and the conditions that the state has placed on the provision of such services.

• Addressing other foreseeable risks that might attend the provision of services by legally responsible individuals.

In addition, states should be aware that unless the waiver uses institutional eligibility rules that disregard the family income of a child waiver participant, paying a legally responsible relative may affect the child's eligibility for Medicaid.

To summarize, when a state provides for payment to legally responsible individuals for the provision of personal care or similar services, the services will be equivalent to services supplied by other types of providers, with some additional protections. The waiver must specify:

- *Whether payment is made to the parent(s) of minor children, spouses, or both or other (as defined by state law);*
- *The waiver personal care or similar services for which payment will be made;*
- *How the state distinguishes extraordinary care from ordinary care and any limitations of the circumstances under which payment will be authorized;*
- *Limitations on the amount of services for which payment will be made;*

- *How it is established that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant; and,*
- *How it is determined that payments are made for services rendered.*

CMS Review Criteria

When the waiver provides for the payment for personal care or similar services to legally responsible individuals for extraordinary care, the waiver specifies:

- *The types of legally responsible individuals to whom payment may be made;*
- *The waiver personal care or similar services for which payment may be made;*
- *The method for determining that the amount of personal care or similar services provided by legally responsible individual is "extraordinary care," exceeding the ordinary care that would be provided to a person without a disability of the same age;*
- *Limitations on the amount of personal care or similar services for which payment may be made;*
- *How it is established that the provision of personal care or similar services by a legally responsible individual is in the best interests of the participant; and,*
- *The procedures that are used to ensure that payments are made for when the waiver provides for the payment of services furnished by relatives or legal guardians:*
    - *The types of relatives or legal guardians to whom payment may be made are specified.*
    - *The waiver services for which payment may be made to relatives or legal guardians are specified.*

- *When relatives or legal guardians may be paid to furnish waiver services only in specific circumstances, the waiver specifies the circumstances and the method of determining that such circumstances apply.*
- *Limitations on the amount of services that may be furnished by a relative or legal guardian are specified.*
- *When a legal guardian who exercises decision making authority may be paid to provide waiver services, the waiver specifies how it is established that the provision of services by the guardian are in the best interests of the participant.*
- *The waiver specifies the procedures that are employed to ensure that payment is made only for services rendered and that services are furnished in the best interest of the individual.*

23.0635.02000

Sixty-eighth
Legislative Assembly
of North Dakota

SENATE BILL NO. 2276

Introduced by

Senators Cleary, Dever, Lee

A BILL for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-24.1 of the North Dakota Century Code is created and enacted as follows:

Eligibility of legally responsible individuals.

1. As used in this section:
    - a. "Extraordinary care" means care exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical needs, and which is necessary to assure the health and welfare of the individual and avoid institutionalization.
    - b. "Legally responsible individual" includes a legal decisionmaker, guardian, or parent who is next-of-kin to an individual with extraordinary medical needs.
2. The department shall work with the centers for Medicare and Medicaid services to implement a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual. This service option must be available for participants in the Medicaid 1915(c) waivers and any subsequent Medicaid waivers to be developed.
3. A waiver under this section which provides for coverage of self-directed in-home support services must include coverage of services provided by a legally responsible individual.
4. The department may utilize an annual assessment of an eligible individual under this section to determine the level of care authorized and to determine the best interests of the individual.

5. Under this section, the payment rate for a legally responsible individual must be the same as the rate for a nonlegally responsible individual.

23.0635.02000

Sixty-eighth
Legislative Assembly
of North Dakota

SENATE BILL NO. 2276

Introduced by

Senators Cleary, Dever, Lee

A BILL for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-24.1 of the North Dakota Century Code is created and enacted as follows:

Eligibility of legally responsible individuals.

1. As used in this section:
    - a. "Extraordinary care" means care exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical needs, and which is necessary to assure the health and welfare of the individual and avoid institutionalization.
    - b. "Legally responsible individual" includes a legal decisionmaker, guardian, or parent who is next-of-kin to an individual with extraordinary medical needs.
2. The department shall work with the centers for Medicare and Medicaid services to implement a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual. This service option must be available for participants in the Medicaid 1915(c) waivers and any subsequent Medicaid waivers to be developed.
3. A waiver under this section which provides for coverage of self-directed in-home support services must include coverage of services provided by a legally responsible individual.
4. The department may utilize an annual assessment of an eligible individual under this section to determine the level of care authorized and to determine the best interests of the individual.

5. Under this section, the payment rate for a legally responsible individual must be the same as the rate for a nonlegally responsible individual.

Testimony in Support of SB 2276

2023 Legislative Session

February 8, 2023

Chairman Dever and Members of the Senate Appropriations – Human Resources Division,

My name is Toby Lunstad. I am here today with my husband Shawn and our youngest daughter Addilynn, who is 8 years old. We live in Mandan in District 31. We are here to testify in support of Senate Bill 2276 for an Act relating to paying legally responsible individuals to provide extraordinary cares to their loved one under a new Medicaid waiver service. This is an option in North Dakota's HCBS Aging and Disabled Waiver, it is not possible in our children's waivers nor the Individuals with Intellectual Disabilities/Developmental Disability Waiver (referred to as the DD wavier from this point forward).

I am also here as a representative for the many North Dakota families who are providing care to their children that is above and beyond what is expected for a typically developing child of the same age. We provide these extraordinary cares to make sure our children's health and welfare needs are met and to keep our families intact. The alternative would be to split our families and place our loved one in an institution, which unfortunately is an alternative that some families have already chosen.

Addilynn has a variant on a gene called CACNA1A, which controls communication between brain cells. She has several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, prone to hemiplegic migraines, and global developmental delay. Because of her disease, Addilynn is eligible for the DD Waiver and receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications.

As her disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, various medical specialists, pharmacists, and dieticians.

The care Addilynn receives includes:

- Medication preparation to insure accurate dosage and frequency, administration of medications via her feeding tube, and monitoring for side effects
- Completion of skilled home programming prescribed by her physical therapist, occupational therapist, and speech therapist
- Repositioning and incontinence management to maintain skin integrity
- Wound care for her feeding tube site as well as miscellaneous incisions after surgeries
- Adaptation of leisure activities to allow her to "just be a kid"
- Weighing and preparation of meals to insure her calorie needs are being met daily. Addilynn eats orally and via her feeding tube, so each meal is calculated to insure her calorie needs are met, as well as facilitating oral motor skills to maximize her safety during eating.
- Calculating fluid intake at regular intervals through the day based on her oral intake and what needs to be given via her feeding tube to insure her hydration goals are met.
- Complete assistance with bathing, dressing, eating, transfers, mobility, and toileting needs.
- Emergency medical interventions including application of oxygen mask, administration of emergency medications during a seizure or hemiplegic migraine, and monitoring of vital signs during an emergency
- Constant 1:1 monitoring for seizures

- Overnight monitoring and checks when alarms sound due to Addilynn's risk of SUDEP (sudden unexplained death of epilepsy)

While each family's story is their own and unique, we also have a lot in common.

Our children require care above and beyond what is expected for typically developing children of the same age. We have all been taught these cares by the professionals I listed above…and in order for others to care for our children, they would have to be trained in these highly skilled cares. We do not have the ability to take our children to daycare or have a teenage nanny during summer break.

Many of us have experienced a change in our employment status in order to keep our families intact. Some of us have chosen to end our careers. Some of us have been terminated. Others are struggling to maintain the balance of work and care for our children. We constantly feel the pull of our children's care while struggling to keep a source of income for our families. For those of us who have experienced job loss and have spouse or significant other who is working, we endure longer work hours, decreased income, increased cost for health insurance, and less time to together as a family.

We all have authorized service hours that are **not being utilized** due to workforce issues. I have read testimony stating that the turnover rate for agencies providing services is approximately 47% and that they are unable to fulfill the hours authorized to families. If a family chooses to attempt to hire their own staff under self-directed services, they are often unable because of the nature of the work. The workforce does not seem to have an interest in meeting the medical, developmental, and emotional needs of our complex children. Another workforce issue is the quality of staff hired. Families have experienced staff sleeping during their shifts, showing up under the influence, ignoring their children to be on the phone or read a book. Families have witnessed the use of unsafe transfer techniques, improper and unsafe use of adaptive equipment, and experienced medication errors. Families spend an extensive amount of time training staff and working with staff and agencies to make sure their loved one is well-cared for, so these experiences are not the result of lack of training. Many families also experience staff just never showing up for work or abruptly quitting.

We want to keep our families intact and build relationships in the community. We don't want to be faced with the choice to place our loved one in an institution or to pay our bills. We don't want to think about moving out of North Dakota to a state that allows us to be paid to provide these extraordinary cares to our children so we can keep our families intact.

Children and individuals with disabilities thrive on consistency. I left my job in 2020 and in the 3 years since I have been home with Addilynn full-time, we have seen tremendous gains in Addilynn's function in the midst of setbacks. She is clearly thriving from continuity of care from someone who has the knowledge and skills to care for her. She has had two unexpected surgeries and recovered well. We were able to postpone a complex surgery on her hips for 2 years because I was able to consistently complete her home exercise program. Family, friends, and her medical care team have noticed that Addilynn is blossoming with the consistent, quality care that she has been receiving since I left my full-time job.

Passage of SB 2276 would provide our loved ones with the consistency they need to grow and be part of their communities. Families would experience less hardship and more time together. Individuals would receive consistent and quality care. Their medical, developmental, and emotional needs would be met on a daily basis. We have been authorized by the state of North Dakota to receive this type of care for our loved ones, however, our loved ones are not receiving this care as authorized. We need to find another way and SB 2276 is that way.

I am Addilynn's mom. I am also her service provider because I consistently provide services that a non-legally responsible adult would be paid to do. This is why our family and the families I am representing today respectfully request a "Do Pass" from each of you on Senate Bill 2276. Please give families in North Dakota the option to be paid as service providers for the extraordinary cares they provide on a daily basis. Thank you for your time and I will answer any questions you may have.

Sincerely,

Shawn, Toby, and Addilynn Lunstad

tobylunstad@gmail.com

701-595-4386

Testimony on SB 2012
2023 Legislative Session
February 7, 2023
Sen Dever Appropriations Human Services Chairperson

Senator Dever and Members of the Committee

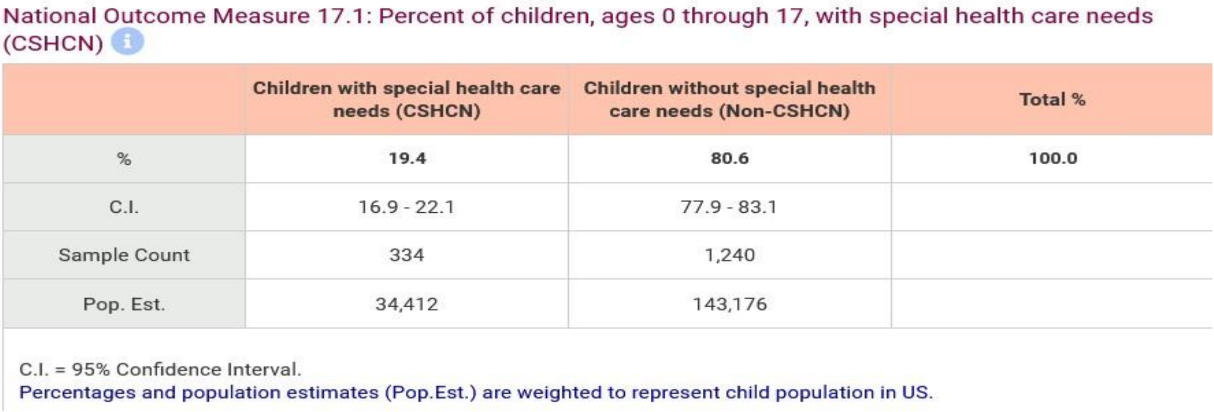
My name is Donene Feist, I am the Director for Family Voices of North Dakota. I come before you today regarding SB 2276, for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Family Voices of North Dakota is statewide family to family health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center by HRSA federally. We are that entity for ND.

According to the 2020-2021 National Survey of Children's Health, there is approximately 34,412 children and youth who have a special health care need. FVND follows the Maternal and Child Health definition of children with special health care needs, which is those children and youth who have a chronic condition of at least one year, a physical disability or mental health/behavior health diagnosis. Additionally, there are many children and youth who may have a physical disability and a chronic health illness but also may have a co-occurring mental health diagnosis. Because of many families have a co-occurring condition, it often leaves families having to understand and navigate many systems and complicated silos. We receive our referrals through agencies, physician offices, out of state hospitals where a child/youth may be receiving services.

The National Data Resource Center for Child and Adolescent Health https://www.childhealthdata.org/ provides clear data on the complexities of children and youth with special health care needs. It also compliments with statistical data, information that has been provided to you all from the Alvarez and Marsal study. The needs for our families are great. We are pleased with the outcome of that study and hope the legislative body, policymakers and families will continue to work to assure we are closing the gaps for families.

Table 1: Number of children and youth with special health care needs in North Dakota

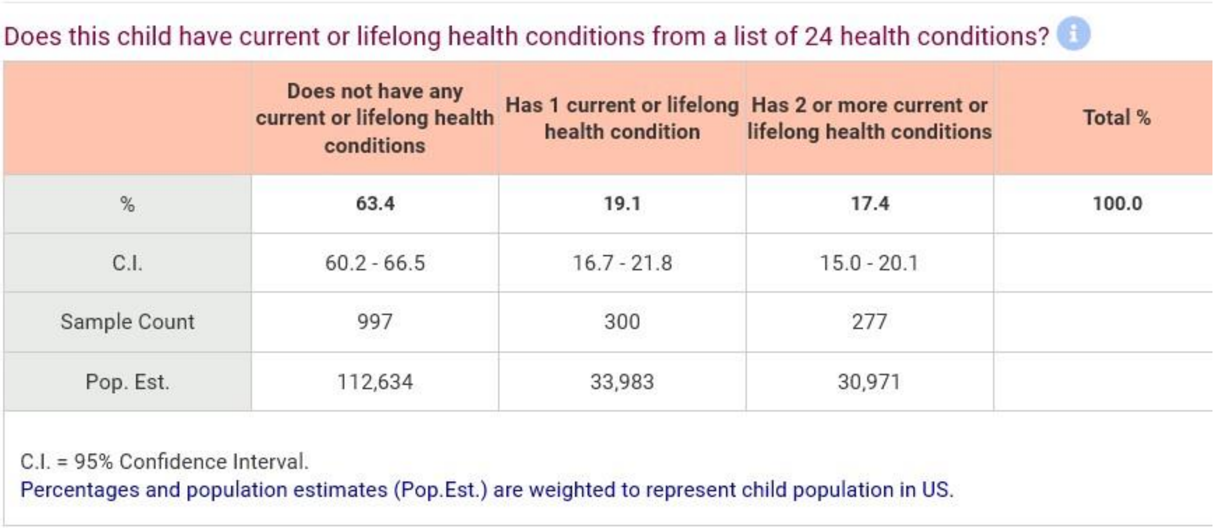


National Outcome Measure 17.1: Percent of children, ages 0 through 17, with special health care needs (CSHCN)

	Children with special health care needs (CSHCN)	Children without special health care needs (Non-CSHCN)	Total %
%	**19.4**	**80.6**	**100.0**
C.I.	16.9 - 22.1	77.9 - 83.1	
Sample Count	334	1,240	
Pop. Est.	34,412	143,176	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

As the diagram indicates the number of children in North Dakota who have one or two life long illness. Table 2:



Does this child have current or lifelong health conditions from a list of 24 health conditions?

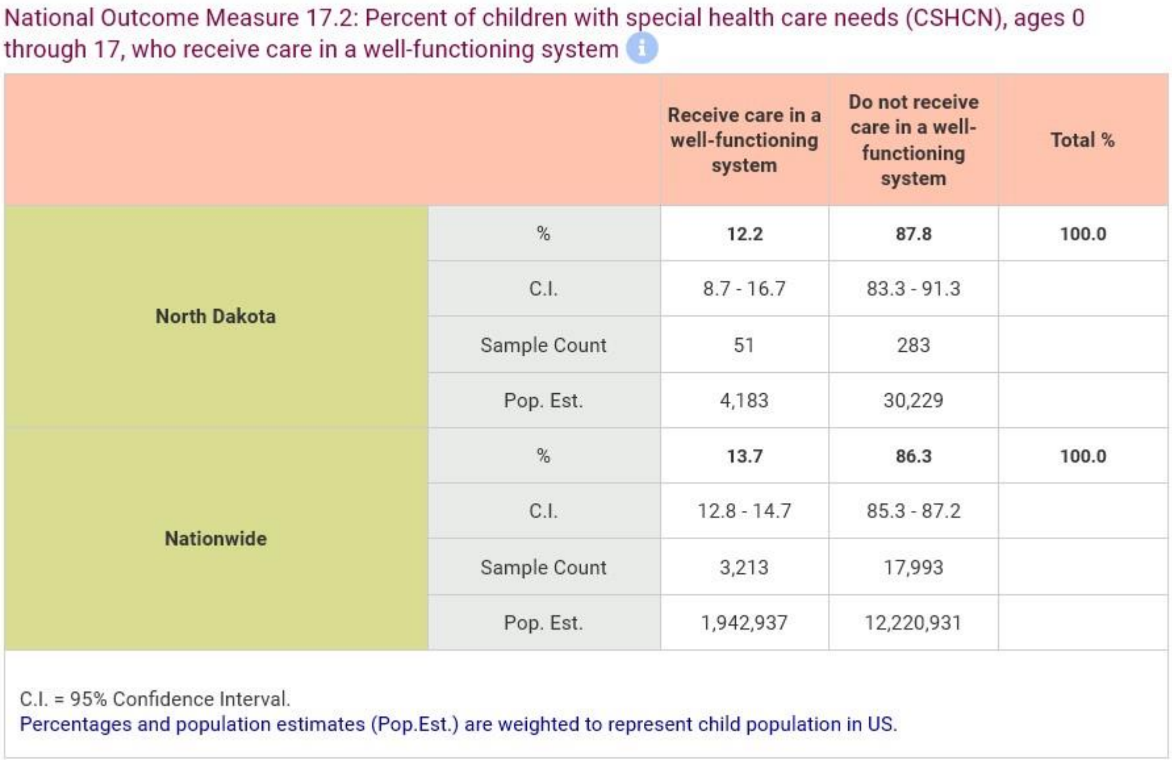
	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Has 2 or more current or lifelong health conditions	Total %
%	**63.4**	**19.1**	**17.4**	**100.0**
C.I.	60.2 - 66.5	16.7 - 21.8	15.0 - 20.1	
Sample Count	997	300	277	
Pop. Est.	112,634	33,983	30,971	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Many advocates and providers have shared over the years the gaps in services in North Dakota. The Alvarez and Marsal study did a tremendous job of aggregating those needs in their study. This illustration identifies how many of these children receive care in a well-functioning system as compared to national data.

My point in sharing this information is more and more states are already supporting a program such as this or are considering this due to the many barriers identified.

The National Academy for State Health Policy (NASHP) developed a brief that was published 1/15/21 ***State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid*** https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-childrenand-youth-with-special-health-care-needs-through-medicaid/



National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

		Receive care in a well-functioning system	Do not receive care in a well-functioning system	Total %
North Dakota	%	**12.2**	**87.8**	**100.0**
	C.I.	8.7 - 16.7	83.3 - 91.3	
	Sample Count	51	283	
	Pop. Est.	4,183	30,229	
Nationwide	%	**13.7**	**86.3**	**100.0**
	C.I.	12.8 - 14.7	85.3 - 87.2	
	Sample Count	3,213	17,993	
	Pop. Est.	1,942,937	12,220,931	

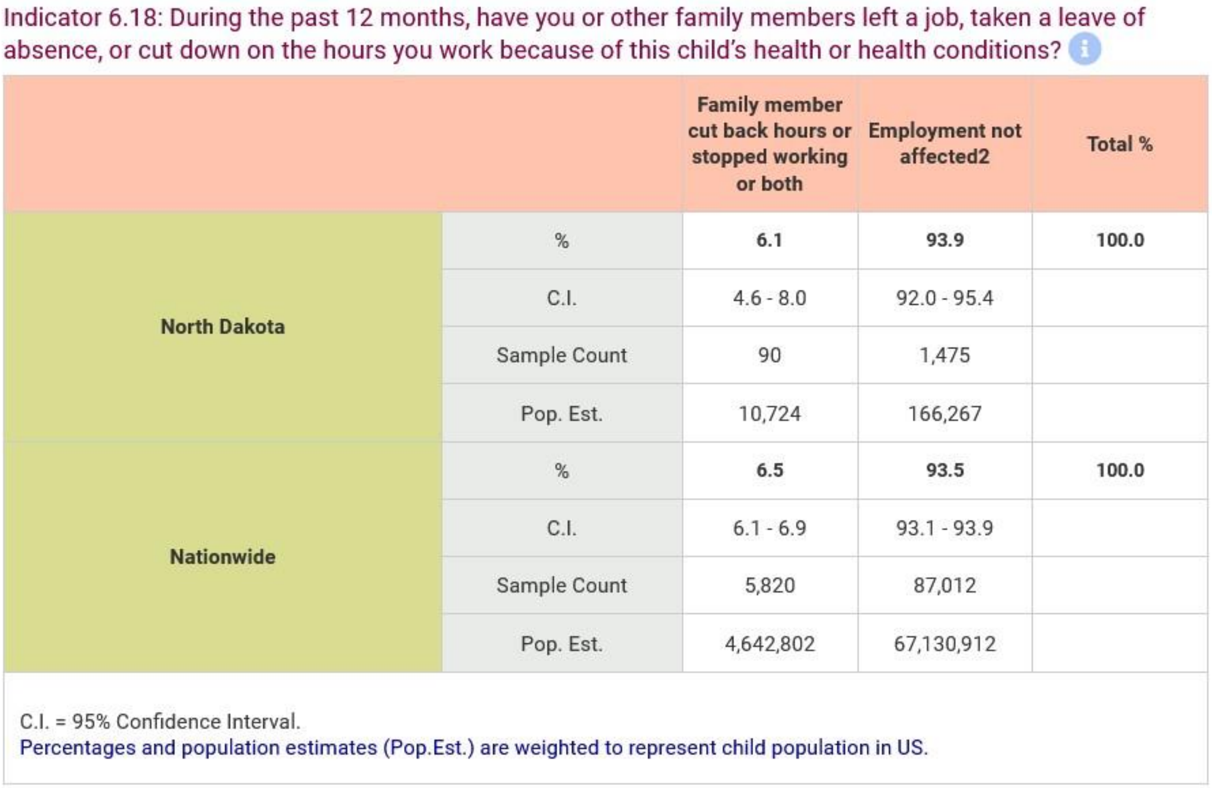
C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

The next illustration is the number of families who have had to leave a job, take a leave of absence or cut down hours because of their child's health condition.

What we know and have heard repeatedly from families for many years are heartbreaking stories of not only families who have left a job but additionally families who have been dismissed due to their child's condition, perhaps needing more time off if their child is sick, for appointments, therapy visits, hospitalizations and care.

Day care is an additional barrier for our families. Centers are full, and despite our best efforts often times providers will also say they are not adequately prepared for many of our children. This is especially true for our families who have high medical needs and care.

As you already know workforce issues impact our families tremendously. Many are struggling to hire and maintain staff. Staff availability has shrunk many times over adding additional barriers to the families we serve with complex medical needs. This diagram identifies the number of families who have left a job, taken a leave or cut hours because of their child's health condition. 6.1% of ND families fit into this category.

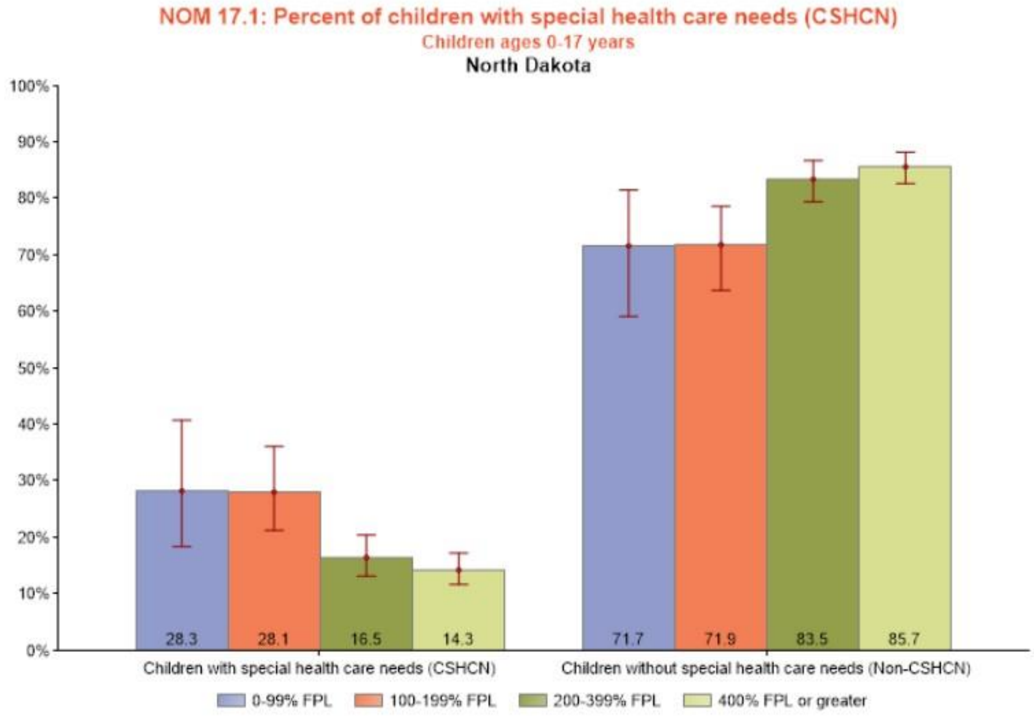


Indicator 6.18: During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child's health or health conditions?

		Family member cut back hours or stopped working or both	Employment not affected2	Total %
North Dakota	%	**6.1**	**93.9**	**100.0**
	C.I.	4.6 - 8.0	92.0 - 95.4	
	Sample Count	90	1,475	
	Pop. Est.	10,724	166,267	
Nationwide	%	**6.5**	**93.5**	**100.0**
	C.I.	6.1 - 6.9	93.1 - 93.9	
	Sample Count	5,820	87,012	
	Pop. Est.	4,642,802	67,130,912	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

I also felt it is important to illustrate the federal poverty level for our families. As you can see from the diagram, families are struggling. These additional barriers for families only adds to the many complexities that families with high medical complexities face.



NOM 17.1: Percent of children with special health care needs (CSHCN)
Children ages 0-17 years
North Dakota

Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. https://mchb.hrsa.gov/data/national-surveys

Citation: Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [www.childhealthdata.org].

Passage of The Family as Paid Service Providers bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one.

We believe, looking at new approaches to identify and amend gaps in services are necessary. A policy such as this will keep our North Dakota family units intact, close a workforce gap that feels at times that is getting larger than smaller. A policy such as this would also provide a consistent quality of care for our children and youth. Families are in crisis, we hear every day the dire needs of families who contact us for help. In neighboring states who have this option it has been lifesaving for many. Colorado and Minnesota are an example of this.

Families are not looking for handouts, but they do often need a rope to hang on to, to keep from drowning in an every changing system.

Thank you for your consideration

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

#19675

Legislative Assembly

North Dakota Senate

STATE CAPITOL
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BISMARCK, ND 58505-0360

Senator Sean Cleary
District 35
1210 Meredith Drive
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COMMITTEES:
Human Services
State and Local Government

2/8/2023

Chairman Bekkedahl and members of the Senate Appropriations Committee,

SB 2276 establishes an option under the 1915(c) Medicaid Waivers (home and community-based services) that would reimburse family caregivers who provide “extraordinary care” to their dependents who are on these waivers.

Overview: Currently, there are individuals who are eligible for in-home services through North Dakota’s Medicaid program that don’t receive these services, often due to a lack of qualified workforce available to provide the services. This often means that a parent or other relative must try to take care of them, sacrificing income they would otherwise be earning at work to stay at home. This bill would allow for that caregiver to be reimbursed when the care they provide is beyond what is ordinarily required by a parent or legal guardian.

History: The Aging and Disabled Waiver for home and community-based services currently allows caregivers living in the home to be reimbursed for care — this bill would provide equal treatment under the other waivers, including the Intellectual Disabilities/Developmental Disabilities, Autism, and Medically Fragile waivers.

The goals of this bill are to:
1 – Address the lack of workforce that surrounds these home-based services
2 – Provide financial stability to households that are strained by juggling work and caregiving
3 – Provide the care that these individuals are legally eligible for but not actually receiving
4 – Keep families together and prevent expensive and unnecessary referral to institutions

Fiscal Note – Based on feedback from advocates and the Department of Health and Human Services, as the committee reviews the fiscal note, I would encourage the consideration of the following questions on the fiscal impact of this legislation:

1- *Is this the appropriate number of FTE’s to administer this service?*
2- *Considering the amount of underutilization on other waivers, is this the appropriate level of estimated utilization?*
3- *How does the funding in this legislation interact with the funds to be appropriated under SB 2012?*

I am grateful for your consideration and deliberation on this important legislation.

Respectfully,

Senator Sean Cleary
District 35, Bismarck

Senate Human Services Committee
Senate Bill 2276 – February 7, 2023
Testimony in Support of SB 2276

Chair Lee, and members of the Senate Human Services Committee, my name is Kellie Hamre, and I reside in District 27. I am writing you on behalf of my daughter, who is 9 years old and was born with Down syndrome and a congenital heart defect. I am writing in support of SB 2276 relating to legally responsible individuals providing Medicaid waiver services.

Upon my daughter's prenatal diagnosis of Down syndrome and a congenital heart defect, my family immediately entered a world we were unprepared for. When she was four months old, we traveled to Minneapolis to get her heart repaired. What was supposed to be a straightforward repair, resulted in complications that sent us down a different path. After her first surgery, while still inpatient, she struggled with medication regulation and went into heart failure and pulmonary hypertensive crisis. The stitches on her mitral valve ruptured and the unregulated blood flow was backing up into her kidneys and lungs causing her to struggle to breathe. Fast forward through 69 days inpatient, a second open heart surgery, 14+ days on a ventilator, feeding tube, and countless meds we went home. At home, she needed 13 medications multiple times a day, was on a narcotic wean, ate only through a feeding tube, and required home oxygen. She had lost all the basic skills she entered the hospital with and was now extremely medically fragile.

At her first doctor appointment post discharge, we discussed options on care. I will never forget her doctor saying that right now my daughter needed me. She needed her mother more than anything. My husband and I wholeheartedly agreed, knowing that financially going from a two income household to a single income household would not be easy. I took an unpaid leave of absence from my job to focus on her recovery.

At this time, we were living in Moorhead, MN and I was able to utilize funding through the Minnesota Department of Human Services so I could be my daughter's in-home caregiver. Being required to hire an outside caregiver, a stranger, to provide in-home support for her would have put her at increased risk of illness, reduced her continuity of care, and created an environment of many unknowns. Thanks to the funding available in Minnesota, I was able to put my focus on where it was needed most. My daughter's recovery.

When we moved to North Dakota, I was thankful for the numerous supports the state had in place for her. However, a critical piece missing is the ability to hire a legally responsible individual for her.

Thankfully, my daughter is now a thriving 9-year-old. My husband and I firmly believe that is due to me being able to fully focus on her as her in-home caregiver during that critical time in her life, an essential support our neighboring state provides.

I often think of other families navigating similar paths as ours in North Dakota and the challenges they face. Staffing shortages are real and a challenge that isn't going away. Stability and consistency are key to so many individuals with a disability. The ability to hire a legally responsible individual will have a life changing impact on families making our community and state an even better place to live.

Please support SB 2276.

Respectfully,

Kellie Hamre
Parent of a child with a disability
Kellie.hamre@gmail.com
P: 701-238-7970

Testimony SB2276 - Senate Human Services

Brittany Zappone Bismarck

ND District 32

Senator Chairman Dever and Members of the Senate Appropriations Committee, My name is Brittany Zappone. I have two beautiful children; my son who is 7 and my daughter who is 6.

I am testifying in support of Bill No. SB 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Both of my children have special needs, stemming from one traumatic event. Our story was that of a pretty typical household until November of 2016 when our lives were turned upside down and we were soon to navigate a new world completely different from the one we had known. My daughter was in pain and wholly unresponsive. She was life flighted to the only pediatric neurosurgeon in North Dakota. As the minutes and hours turned into several days, we fought to grasp even the slightest concept of what was happening and wondered if the next test or surgery would finally reveal an answer. My daughter was violently shaken. We didn’t get the diagnosis right away, but when the news came, I still remember my exact reaction. I was shattered and broken. After the diagnosis, there came interviews and a ton of other new challenges. We are immensely thankful for the ongoing family support we have through Family Voices of ND. They have been there to support us from the start and have truly made it a little easier to process. Over the last several years, things have only gotten more complex and harder to navigate. In the beginning, I had to quit my full-time job to care for the children. I also had to find a way to utilize all the resources I knew nothing about, navigate the judicial system for a divorce, and somehow move to a new city with services for the children. I truly hit rock bottom but was always supported by those who walked this journey with us. A lot of those being therapists, doctors, friends, and agencies as I did not have family support. Throughout this time, I needed to also find a way to get her to specialists in Fargo. Due to her medical complexity, she was admitted frequently to the pediatric intensive care unit as they tried to find a medical plan that worked for her. Travel was never a cost that was covered and often left me with hard choices as I did not have an income that could even begin to cover the needs. I had a small portion of TANF but that was nowhere near the income I had previously when I was working. My daughter transitioned out of early intervention services and qualified for the DD waiver, however when we moved to Bismarck to be closer to specialists, the lack of available and trained staff really made it difficult to work. Daycare facilities aren't trained for medically complex children and can't provide the one-on-one skilled care her condition demands, making that a non-option for her as well. She was in school half days a few days a week. I started to volunteer at her school until a position opened. I slowly made it to full time over the years and only decided to take it as she was supposed to attend school full days in kindergarten. The only reason I still have this job is because my supervisors truly understand my daughter's needs and, when I need to take her to doctors out of state or for an extended hospital stay, they are flexible enough to allow me to make up some time outside of normal hours if needed. I truly am lucky and extremely blessed that I have found this job as most would not be this understanding and flexible, but I do also fear that soon it may cause issues as my daughters' health continues to significantly decline. With the agencies we did have for respite, it was difficult to find someone to care for her as her needs are complex and require not only someone who understands the medical knowledge, but someone who can find what she wants by her expressions, as she is nonverbal. She has a G-tube, Cecostomy tube, and a VP shunt. She is non ambulatory and has been diagnosed with global developmental delay. The medical complications alone would take me hours to explain. A few of them include encephalomalacia (softening or damage to brain tissues), epilepsy, severe scoliosis, CVI (cortical visual impairment), and cerebral palsy. I found it very difficult to find people and often would cover the shifts myself as the staff was not reliable. As of right now, I have one staff for her, and the availability doesn't allow us to use our current budget. If my staff member is ever out sick or needs a day off, I, again, must cover and leave work to do so. Keeping employment is a must as we cannot make it without an income, and we do not qualify for any assistance besides Medicaid. My daughter has had a medical journey that none of us could possibly imagine. Since the injury she has had to fight every single day to survive. She has undergone over 25 surgeries with 10 of them being major brain surgeries. She does therapy every day of the week, sees multiple specialists, and has been attending school full time. Unfortunately, we have run into the issues of the schools not being able to provide her with the proper care and I have missed work to be home with her. She was previously at a special education program for three years, after she transitioned to general education it was a mess. Unfortunately, we've run out of time trying to fix concerns at the school. On December 29th last year her seizures started to get worse, and they were not responding to the interventions. I administered the rescue medication that I have never had to use and called EMS. She continued to have seizures and was life flighted to her epilepsy team in St. Paul MN. No one could have ever prepared us for the outcome of that visit. Due to issues with formula we had to make the decision to either stay and add one issue to another or try our best to treat outpatient. She was already in pain; I could not knowingly put her through even more problems. I ultimately made the decision to bring her home. Doctoring out of state is difficult and due to insurance, we have had to make several decisions like this and have had to transfer her knowing very well that she may not survive the trip while actively having seizures. Thankfully those times she did, but, looking back, we know that it was truly a higher power that made sure she did. Since being home, things have been a roller coaster. She has had multiple medication changes and very little improvement. My fiancé and I are thankfully able to adjust our schedules, but, again, this is only because our employers know the situation. We've been very lucky in that regard. Our staff covers 2-3 hours a day, basically the gap between when his shift starts and mine ends. This has taken a huge tole on my family. Not only do we have limited time together, but the kids also have been struggling as we are never together as a family unit. Unfortunately, we still cannot make it without both of us bringing in a full-time income. I go to work, knowing that my daughter may not get better. I struggle every day when I have to leave her with my fiancé, who does his absolute best but cannot legally make decisions or calls. I check in often and am struggling daily to keep focused on the tasks for work. Her condition is getting worse, and the seizures are still breaking through. The doctors have run out of options besides medications that will ultimately sedate her. I always knew that it was a miracle that she survived the injury and that most do not survive.

The life expectancy for children with shaken baby syndrome is rarely in their teens, but I never thought that I would be making end of life decisions for my six-year-old child and have them in place so soon. The doctors are trying to slow the progression, but they will never be able to stop it. Her condition will continue to get worse, and it breaks my heart that I will not be able to take the entire journey with her. I will have to continue to work to keep a roof over our heads and food on the table as there is no other option. I do not know whether we will be able to use these proposed services if the bill passes or not, as our time with her is truly unknown. I do, however, hope that these services will help those in similar shoes if we are no longer able to. No one should ever have to choose between work and being with their child during the last stages of their condition to provide the quality of care that comes from the lived experience of a parent. Thank you for your time serving our state and for listening/reading my testimony. I urge you to vote yes on Bill No. SB 2276. Families are in crisis; we need help now.

Thank you for your time and consideration.

Brittany Zappone

SB 2276
Senate Appropriations Committee
Wednesday, February 8, 2023
Senator Dever, Chair

Mr. Chairman and members of the Senate Appropriations Committee,

I am writing in support of Senate Bill 2276 for an Act to create and enact a new section to chapter 50 – 24.1 of the North Dakota Century Code relating to legally responsible individuals providing Medicaid waiver services.

My name is Deborah Hellman and I am the proud mother of two beautiful daughters. My 17-year-old daughter has received in-home care services under the DD Medicaid Waiver since she was born. The waiver has allowed me to continue working part time, contributing to my family finances.

My family has been blessed with many amazing nurses who have cared for our daughter allowing us to provide for our family, and we are grateful for all of them. Last year, my daughter's nurse of 10 years accepted a job elsewhere which provided her substantially more pay and benefits such as paid leave time, insurance, and retirement benefits. With her resignation, my family was tossed into the ocean of "workforce shortage." Like so many others, we have piecemealed help together, because we have not found a replacement for the former caregiver. We are juggling help from family, friends, and a daughter of the former nurse who have stepped in to help care for our daughter, and I have been able to continue working. We cannot effectively express how much we appreciate their help.

As did so many others, I moved my workspace to my home when the Coronavirus pandemic struck. My employer has since instituted a remote work policy that allows for remote work up to 40% of total work hours. Due to the workforce shortage and our lack of caregiver, I was unable to comply with that directive. My employer has graciously allowed me a temporary exception to the new remote work policy. I signed an agreement effective January 1, 2023 that extended approval for me to work fully remotely until February 28, 2023. In conversation with my supervisor last week, she indicated that she is hopeful another remote work extension will be approved, but did not guarantee it. I cannot help but feel that my job of 23 years is in a fragile position being held together by nothing but a short string. My supervisor has asked Administration about a possible extension, but has not forwarded a response from Administration at the time of this writing.

I cried as I read the testimony from other families regarding this bill. So many families need help. So many families have rolled up their sleeves and "made-do," and are paying the price with anxiety, heartache, and fear. It is palpable in the stories they have written. And they are only the tip of the iceberg. So many families are struggling financially, emotionally, and physically as they try to juggle life and the needs of a loved-one who needs extraordinary care. Help cannot come fast enough. If ever there was a family caregiver emergency, this is it.

I respectfully ask you to pass Senate Bill 2276.

Deborah Hellman
dkhellman@yahoo.com

Testimony in Support of SB 2276

2023 Legislative Session

February 8, 2023

Madam Chair Lee and Members of the Human Services Committee,

My name is Cari Bousfield and on October 25, 2003 my daughter, Faith came into this world 11 weeks early. She weighed just 2 pounds six ounces. About 3 days after being born an MRI showed she had suffered extensive brain damage due to a loss of oxygen to her brain during my emergency C-section, which was performed at the Mayo Clinic in Rochester, MN. The reason I had her there was because I have a congenital heart condition and my cardiologists had to be present at the time of delivery.

Shortly after birth, my daughter was diagnosed with periventricular leukomalacia (PVL). After a 73-day stay in the NICU, my daughter was able to come home to Watford City. However, at 6 months of age she was diagnosed with spastic quadriplegia, which is the most severe form of cerebral palsy. This began a long journey of extensive medical care, specialists, therapies, and other interventions. Due to her medical needs, we moved to Bismarck in July of 2004. Also because of her medical needs, only one of her parents were able to work outside of the home.

Through the years, Faith required many things to improve her quality of life. Some of these things included:

- Feeding tube and feeding pump
- Orthotics for her feet and splints for her hands
- Manual wheelchair
- Standing table in which to stand in an upright position
- Adaptive toys
- Adjustable bed
- Shower chair system
- Accessible van
- Hoyer lift
- Incontinence supplies

Faith also takes anti-anxiety medication as well as several daily supplements. Also, as part of her cares, I make all of her food in a blender instead of feeding her commercial formula. Her g-tube site requires constant care as well, which includes changing it at home every 6 months.

When Faith was in school, she had trouble making it through the day because she tired very easily. We felt they were not able to adequately meet some of her needs, so we made the decision to homeschool.

During our daughter’s younger years, we were able to find some very good respite care workers. Many of them were young ladies in college. Unfortunately, once they were done with college, they either found a different job or moved out of state. It was very stressful not being able to keep good help. This lack in continuity of care was also very stressful for our daughter, who thrived on routine.

In 2020 my husband and I decided to separate and he moved to another city. We later divorced and I became Faith’s sole legal guardian. Thankfully, I had been working from home since 2014 and was able to continue doing that. However, I quickly found that it was very difficult to manage caring for my daughter, homeschooling her, doing all of the day-to-day responsibilities on my own, and trying to find time to work. When a friend of mine heard about my situation she told me she got paid to look after her disabled mother who lived with her. She told me that I should be able to get paid to look after Faith. Upon looking into it, I was told due to the DD Waiver she was on, that would not be a possibility. I asked if there was any way for that to change and the person on the phone told me the only way that would happen was to advocate for it.

As far as supports for Faith, I have one respite care worker who comes 3 hours a week (we qualify for 60 hours a month) to do my daughter's shower, her feeding, in-home therapies, and personal cares, such as getting her dressed, combing her hair, brushing her teeth, and clipping her nails. (Unless she is at her day program, I am the only other person who does all of these things for her). During respite care time, I am usually running errands.

Faith attends her day program 15 hours a week. She also goes to physical therapy, occupational therapy, and speech therapy 3 days a week. I transport her to both her day program and therapy, which means a trip to Mandan and back several times during the week.

Besides personal cares and transportation, part of Faith's cares consist of getting up at least twice during the night to change her diaper or reposition her. Sometimes she needs help every few hours, and even more often when she is sick. This means that when she is at her day program, I sometimes have to make the choice of trying to get some work done or take a nap as to not overextend myself. As I mentioned in the beginning of this testimony I have a congenital heart condition, so I have to be careful not to overdo it. It's really only by the grace of God that I can continue to keep doing what I've been doing.

I understand that by the time this bill goes through, my daughter will be almost 21 years old and hopefully at that time my daughter will be at her day program full-time. I am hoping she might also increase her independence by living in a group home. However, I know firsthand how getting paid as a caregiver in our home would have been of great benefit and would have reduced the amount of stress exponentially. If I can't take advantage of the passage of this bill, I know that there are many families who would get some much-needed relief from it.

I appreciate you taking the time to read this testimony and for considering the passage of SB2276 for families in North Dakota who are in desperate need of any help they can get.

Sincerely,

Cari J. Bousfield

(Faith's mother, service provider, and legal guardian)

cari_bous@hotmail.com

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#19739

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DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2276

Senate Appropriations – Human Resources Division
Wednesday, Feb. 8, 2023
Senator Dick Dever, Chair

Chair Dever and Members of the Senate Appropriations – Human Resources Division:

My name is Roxane Romanick and I am 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.

SB 2276 – Designer Genes is advocating for SB 2276 and respectfully requests your vote in favor of the bill. Our organization played a role in developing SB 2276, as we believe it will greatly benefit families with loved ones who have Down syndrome. While working on this bill, our goal was to simplify it as much as possible, while acknowledging that changes to Medicaid Waiver programs are complex. We appreciated the feedback from the Department of Health and Human Services on this bill.

Goals – The main intent of SB 2276 is to allow families, mainly parents, to be paid for the care that is above and beyond what they would do for a loved one without extraordinary needs. I encourage you to listen to the family testimonies during the Senate Human Services hearing. These stories highlight the challenge of balancing employment with the demanding and often overwhelming care needs of their children, compounded by difficulties in finding quality staff, the severity of the child's needs, and managing their education and healthcare.

Eligibility – SB 2276 aims to provide a service option for individuals who are already eligible for in-home supports or care under ND Medicaid Waiver. This option would be available through Medicaid 1915c Waivers and will not change current eligibility or services. Currently, ND does not have a provision for parents of children with disabilities to be paid as service providers. The Aging and Disabled Home and Community Based Waiver does offer this option, reimbursed at a daily rate, but does not serve individuals under 18.

Our aim is to keep the requirements for this option simple, without requiring a tedious demonstration of unsuccessful staffing or placement attempts. The decision to access this option should be based on the individual's person-centered plan, considering any new or annual assessment information. The annual assessment mentioned in Section 1, Subsection 3 is similar to the annual application for In-Home Supports used by ND Developmental Disabilities Section to assess the needs and authorize In-Home Supports for individuals with intellectual disabilities or developmental disabilities under the DD Waiver.

Background – While initially discussing options, it was our hope reimbursing families as service providers could become another provider option under the already existing self-directed In-

Home Supports service; however, getting input from the Department, more general terminology of a “service option” as discussed in Section 1, Subsection 2 was chosen to allow flexibility to the Department in meeting the requirements for the Centers for Medicare and Medicaid (CMS). I’ve included a link of to a CMS presentation on Leveraging Family Caregivers:

https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf . This presentation indicates that just over half of states allowed legally responsible individuals to provide a personal care service. While complicated, it appears that the Centers for Medicare and Medicaid understand the critical urgency to consider this issue and is creating guidance to support the approach.

Section 1, Subsection 4 excludes the Aging and Disabled Waiver from the changes in this bill. We want to ensure that the option exists in all of our waivers that are or will be available to eligible children. From that perspective and by a recommendation by DHHS, we did not want to affect anything within the Aging and Disabled waiver by the language in Section 1, Subsection 2.

Utilization – As you’ve listened to the Department’s testimony, especially Developmental Disabilities and considered the roughly $13 million in underutilization, please remember that the families you are hearing from today have **undelivered services** represented in that amount. In regards to the fiscal note, I would ask the committee to consider what duplications in cost may already exist in SB 2012 that could offset this fiscal note. For example, some of the families that may benefit from this option are already self-directing and are probably figured into the Department’s budget for the intermediary fiscal agent costs.

Family Finances – While preparing this testimony, I did so with a single father in mind who is trying to maintain his professional career while managing two major surgeries for his child with Down syndrome as well as his ongoing care. He has had difficulty finding consistent staff for over a year now and is constantly worried about having to take leave without pay, putting his job at risk. SB 2276 opens the door for ND to support him and keep his family intact which we understand is way more beneficial and much cheaper than an institutional placement for his son. Many families are in a similar situation, just barely hanging on.

Thank you for your consideration of SB 2276. I am available to answer any questions.

Roxane Romanick 701-391-7421
Executive Director roxane@designergenesnd.com

#19878

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SB 2276 creates a new service, to be available in ND's Medicaid 1915(c) waivers, that would support a person who is served by the waiver by allowing the person's primary caregiver (legally responsible person) to forgo work outside of the home when the person has extraordinary medical needs.

According to CMS guidelines, a legally responsible individual can provide personal care services when the care is extraordinary and **exceeds care ordinarily provided to participants of similar age without a disability.**

Three components of the fiscal note -

1. Intermediary/fiscal agent – enroll and process payments to the primary caregiver/legally responsible person.
2. HHS resources – establish program guidelines, work with CMS on approval of new service, program outreach, authorize service, quality assurance and technical assistance for families.
3. Service delivery – new service, not replacing existing services.

DAILY RATE

	Daily rate	Days/Wk	People served	Weekly Cost*	Annual Cost
Ages 0-4	150.38	5	48	$36,046	$1,874,396
Ages 5-11	75.19	5	112	$42,054	$2,186,796
Ages 12-17	75.19	5	96	$36,046	$1,874,396
Ages 18-21 In School	75.19	5	16	$6,008	$312,399
Ages 18-21 Graduate	150.38	5	16	$12,015	$624,799
Ages 22+	150.38	5	32	$24,031	$1,249,598
			320	$156,200	**$8,122,385**

*Numbers may vary due to rounding.

- **Ages 0 through 4** – 15% of likely service population; authorized services up to **40 hours/week**. No school option and child is unable to safely attend a typical childcare setting due to extraordinary care needs.

- **Ages 5 through 11** – 35% of likely service population, authorize services up to **20 hours / week***. Eligible to attend school (typical school day is 6 hours, however due to extraordinary care needs expect 4 hours of school/day) and child is unable to safely attend a typical childcare setting due to extraordinary care needs.

- **Ages 12 through 17** – 30% of likely service population; authorize services up to **20 hours/week***. Eligible to attend school (typical school day is 6 hours, however due to extraordinary care needs expect 4 hours of school/day), childcare setting is not an option and child is unable to be left home alone safely due to extraordinary care needs.

- **Ages 18 through 21 In School** – 5% of likely service population; authorize services up to **20 hours/week***. Eligible to attend school (typical school day is 6 hours, however due to extraordinary care needs expect 4 hours of school/day), childcare setting is not an option and participant is unable to be left home alone safely due to extraordinary care needs.

- **Ages 18 through 21 Graduate** – 5% of likely service population; authorized services up to **40 hours/week**. If participant graduates prior to the age of 21, Vocational Rehabilitation, day habilitation and other employment services in the waiver are service options (day hab & employment up to 40 hours/week). Service amount will vary based on individual assessed need.

- **Ages 22 and older** – 10% of likely service population; authorize hours up to **40 hours/week**. Vocational Rehabilitation, day habilitation and other employment services in the waiver are service options (day hab & employment up to 40 hours/week). Service amount will vary based on individual assessed need.

*In accordance with 42 CFR §433 Subpart D, Medicaid FFP (Federal Financial Participation) may not be claimed for services when another third party (e.g., other third-party health insurer or other federal or state program) is legally liable and responsible for the provision and payment of the service. This requirement applies to all Medicaid services, including waiver services. As a general principle the Medicaid program functions as the payer of last resort.

Testimony on SB 2276
2023 Legislative Session
March 8, 2023
Representative Weiss House Human Services Chairperson

Representative Weiss and Members of the Committee

My name is Donene Feist, I am the Director for Family Voices of North Dakota. I come before you today regarding SB 2276, for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

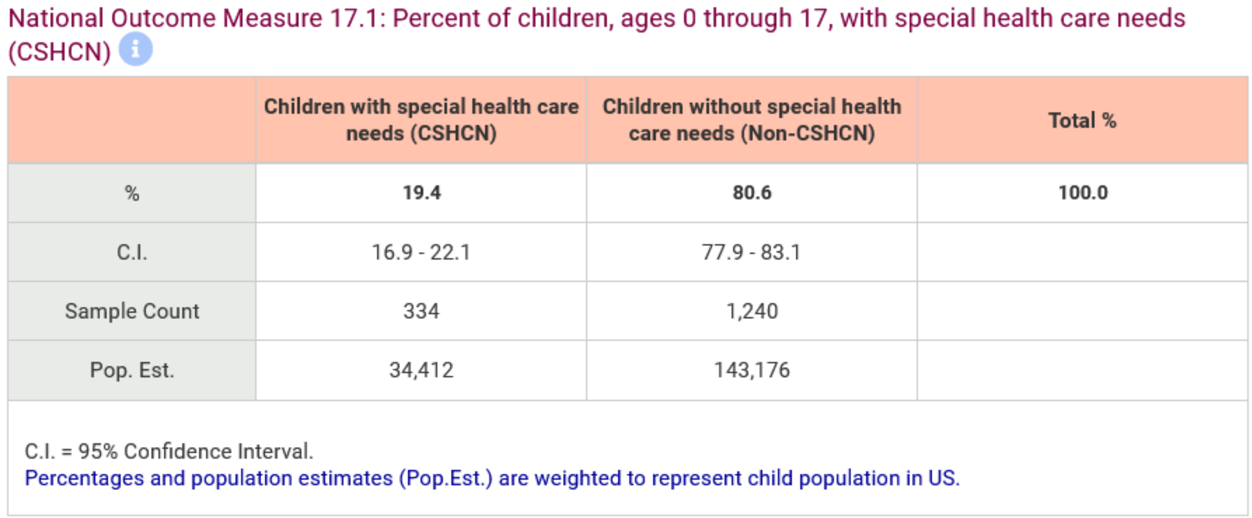
Family Voices of North Dakota is statewide family to family health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center by HRSA federally. We are that entity for ND.

According to the 2020-2021 National Survey of Children's Health, there is approximately 34,412 children and youth who have a special health care need. FVND follows the Maternal and Child Health definition of children with special health care needs, which is those children and youth who have a chronic condition of at least one year, a physical disability or mental health/behavior health diagnosis. Additionally, there are many children and youth who may have a physical disability and a chronic health illness but also may have a co-occurring mental health diagnosis. Because of many families have a co-occurring condition, it often leaves families having to understand and navigate many systems and complicated silos. We receive our referrals through agencies, physician offices, out of state hospitals where a child/youth may be receiving services.

The National Data Resource Center for Child and Adolescent Health https://www.childhealthdata.org/ provides clear data on the complexities of children and youth with special health care needs. It also compliments with statistical data, information that has been provided to you all from the Alvarez and Marsal study.

The needs for our families are great. We are pleased with the outcome of that study and hope the legislative body, policymakers and families will continue to work to assure we are closing the gaps for families.

Table 1: Number of children and youth with special health care needs in North Dakota



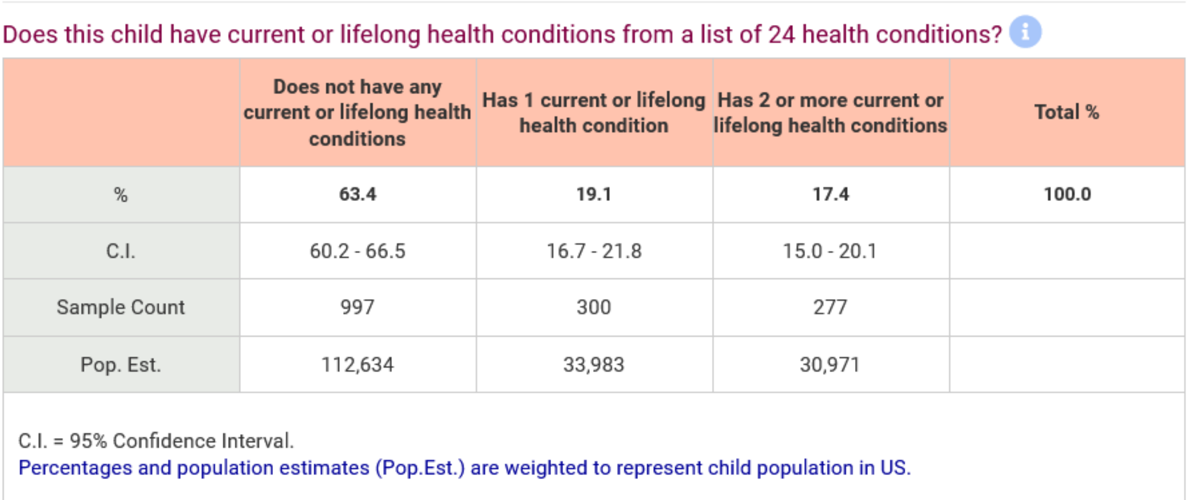
National Outcome Measure 17.1: Percent of children, ages 0 through 17, with special health care needs (CSHCN)

	Children with special health care needs (CSHCN)	Children without special health care needs (Non-CSHCN)	Total %
%	**19.4**	**80.6**	**100.0**
C.I.	16.9 - 22.1	77.9 - 83.1	
Sample Count	334	1,240	
Pop. Est.	34,412	143,176	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

As the diagram indicates the number of children in North Dakota who have one or two life long illness.

Table 2:



Does this child have current or lifelong health conditions from a list of 24 health conditions?

	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Has 2 or more current or lifelong health conditions	Total %
%	**63.4**	**19.1**	**17.4**	**100.0**
C.I.	60.2 - 66.5	16.7 - 21.8	15.0 - 20.1	
Sample Count	997	300	277	
Pop. Est.	112,634	33,983	30,971	

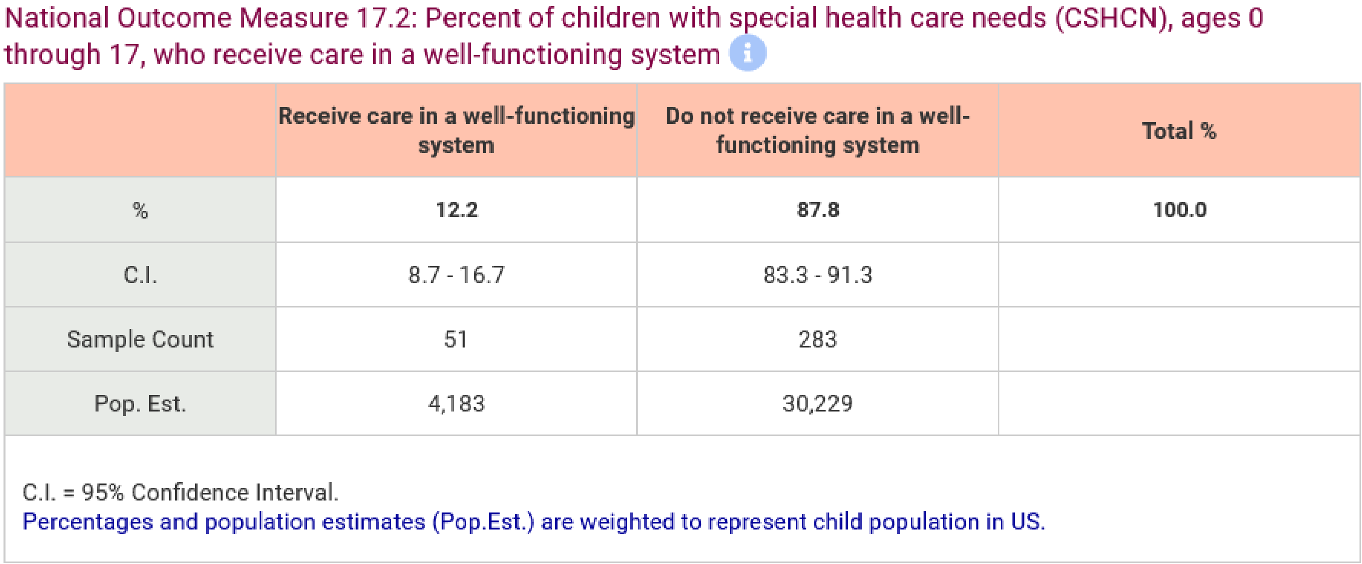
C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Many advocates and providers have shared over the years the gaps in services in North Dakota. The Alvarez and Marsal study did a tremendous job of aggregating those needs in their study. This illustration identifies how many of these children receive care in a well-functioning system as compared to national data.

My point in sharing this information is more and more states are already supporting a program such as this or are considering this due to the many barriers identified.

Across the country, policymakers are tackling this very issue. Children with medical complexity require a substantial amount of medical care and activities-of-daily-living support to live at home. However, due to a shrinking pool of available home health care workers and narrow state eligibility requirements for services, most of their care is increasingly delivered by families without pay. In response, the option to pay family caregivers for their children’s medical labor is gaining national traction.

The National Academy for State Health Policy (NASHP) developed a brief that was published 1/15/21 ***State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid*** https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/

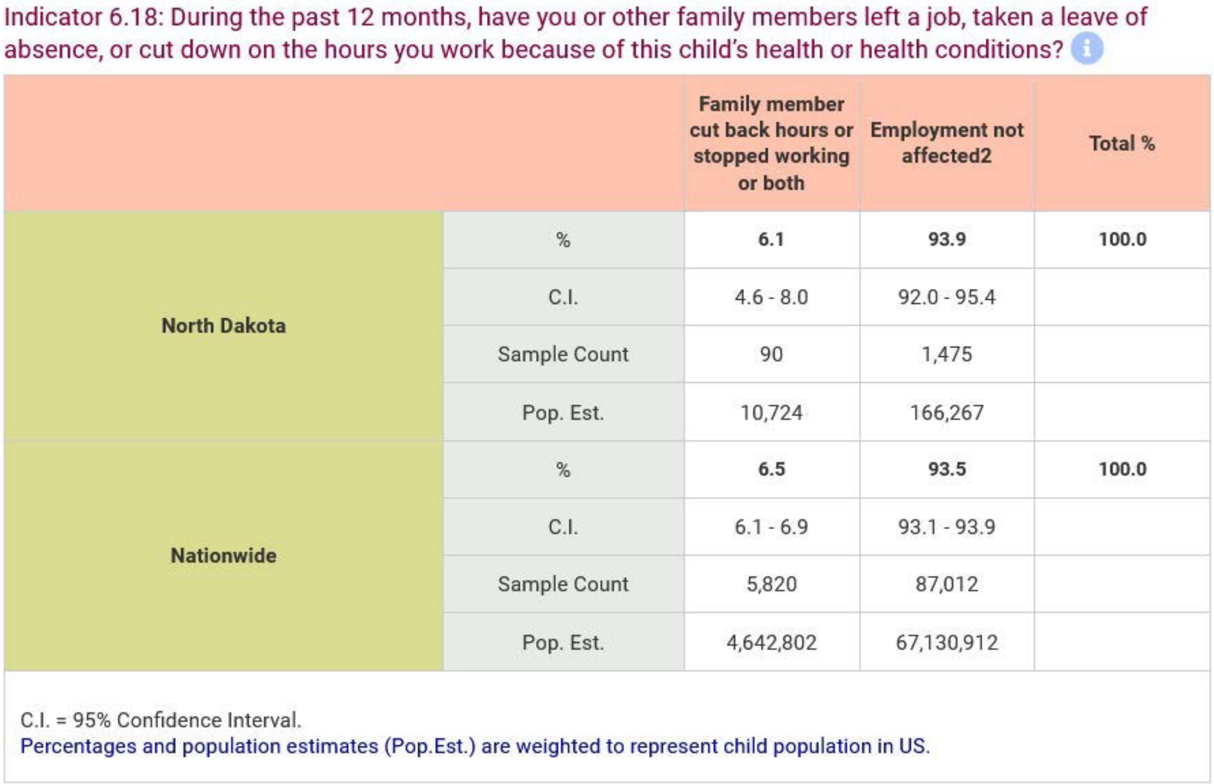


National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

	Receive care in a well-functioning system	**Do not receive care in a well-functioning system**	**Total %**
%	**12.2**	**87.8**	**100.0**
C.I.	8.7 - 16.7	83.3 - 91.3	
Sample Count	51	283	
Pop. Est.	4,183	30,229	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

The next illustration is the number of families who have had to leave a job, take a leave of absence or cut down hours because of their child's health condition.



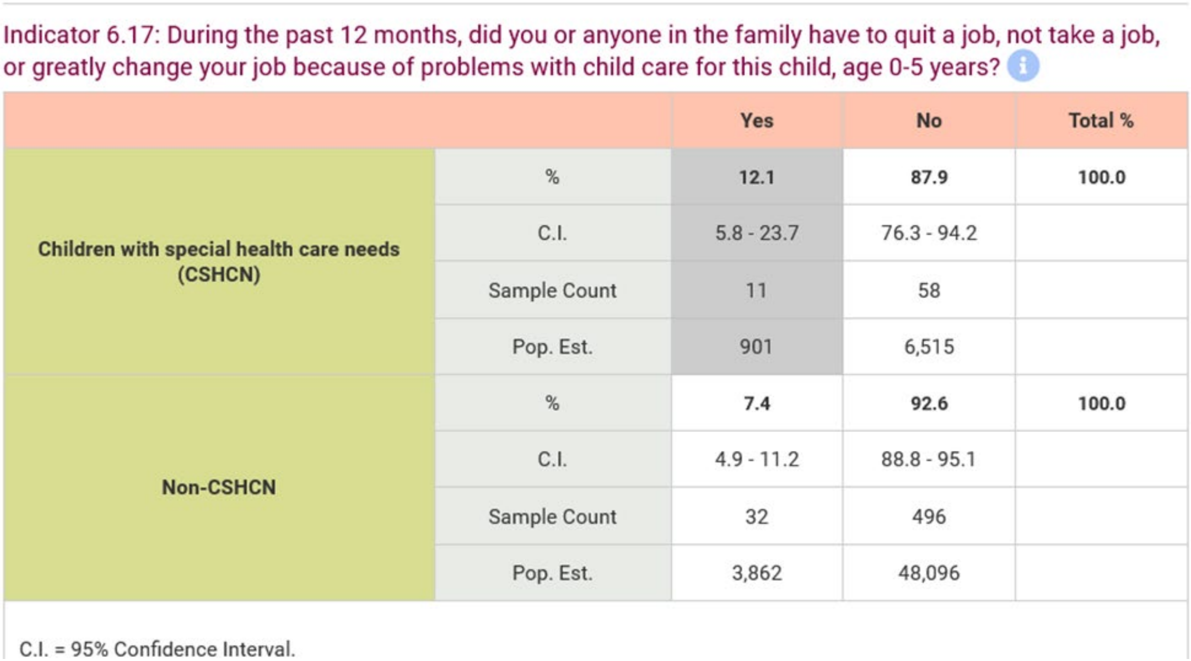
Indicator 6.18: During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child's health or health conditions?

		Family member cut back hours or stopped working or both	Employment not affected2	Total %
North Dakota	%	**6.1**	**93.9**	**100.0**
	C.I.	4.6 - 8.0	92.0 - 95.4	
	Sample Count	90	1,475	
	Pop. Est.	10,724	166,267	
Nationwide	%	**6.5**	**93.5**	**100.0**
	C.I.	6.1 - 6.9	93.1 - 93.9	
	Sample Count	5,820	87,012	
	Pop. Est.	4,642,802	67,130,912	

C.I. = 95% Confidence Interval.
Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

What we know and have heard repeatedly from families for many years are heartbreaking stories of not only families who have left a job but additionally families who have been dismissed due to their child's condition, perhaps needing more time off if their child is sick, for appointments, therapy visits, hospitalizations and care.

Day care is an additional barrier for our families. Centers are full, and despite our best efforts often times providers will also say they are not adequately prepared for many of our children. This is especially true for our families who have high medical needs and care.



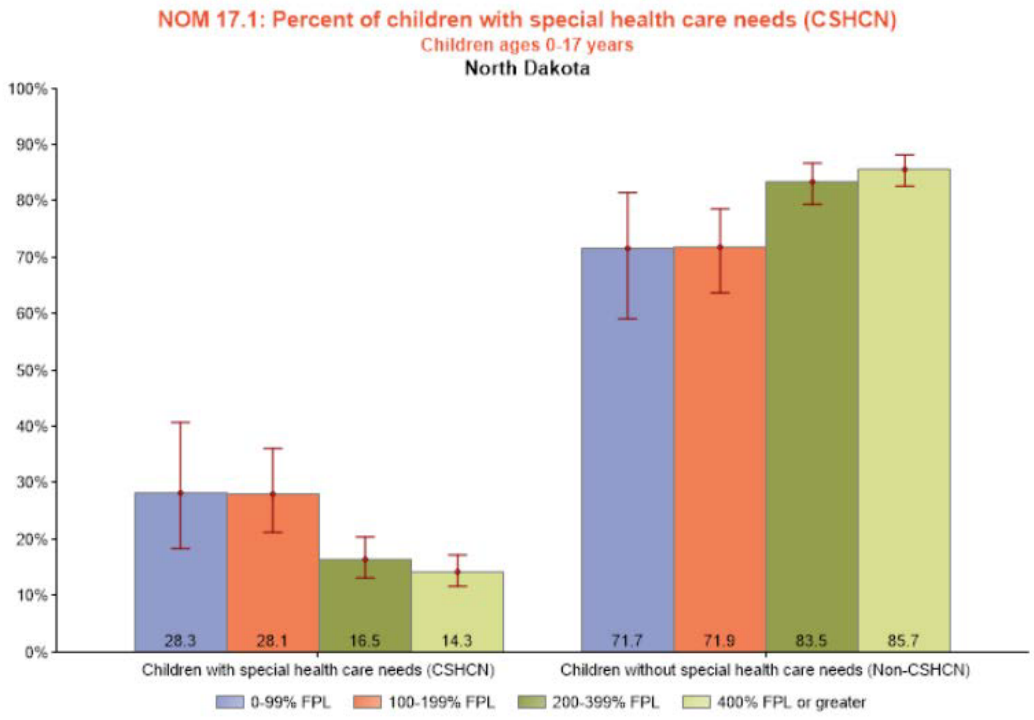
Indicator 6.17: During the past 12 months, did you or anyone in the family have to quit a job, not take a job, or greatly change your job because of problems with child care for this child, age 0-5 years?

		Yes	No	Total %
Children with special health care needs (CSHCN)	%	**12.1**	**87.9**	**100.0**
	C.I.	5.8 - 23.7	76.3 - 94.2	
	Sample Count	11	58	
	Pop. Est.	901	6,515	
Non-CSHCN	%	**7.4**	**92.6**	**100.0**
	C.I.	4.9 - 11.2	88.8 - 95.1	
	Sample Count	32	496	
	Pop. Est.	3,862	48,096	

C.I. = 95% Confidence Interval.

As you already know workforce issues impact our families tremendously. Many are struggling to hire and maintain staff. Staff availability has shrunk many times over adding additional barriers to the families we serve with complex medical needs. This diagram identifies the number of families who have left a job, taken a leave or cut hours because of their child's health condition. 6.1% of ND families fit into this category.

I also felt it is important to illustrate the federal poverty level for our families. As you can see from the diagram, families are struggling. These additional barriers for families only adds to the many complexities that families with high medical complexities face.



Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. https://mchb.hrsa.gov/data/national-surveys

Citation: Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [www.childhealthdata.org].

Passage of The Family as Paid Service Providers bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one.

We believe, looking at new approaches to identify and amend gaps in services are necessary. A policy such as this will keep our North Dakota family units intact, close a workforce gap that feels at times that is getting larger than smaller. A policy such as this would also provide a consistent quality of care for our children and youth. Families are in crisis, we hear the dire needs of families who contact us for help. In neighboring states who have this option it has been lifesaving for many. Colorado and Minnesota are an example of this.

Families are not looking for handouts, but they do often need a rope to hang on to, to keep from drowning in an every changing system.

Thank you for your consideration

Donene Feist

Family Voices of North Dakota, Director

701-493-2634; fvnd@drtel.net

I am testifying today in support of SB 2276, Family Paid Caregivers. Hello, my name is Jen Zahn, my daughter Rylie is 11 and has Non-verbal Epilepsy and a rare genetic disorder called SCN2A. I am writing this letter today to tell you about her story. Her journey started with her first seizure, which was the morning of October 8th, 2013. She was 18 months old. We took her to St. Alexius hospital where they did not do anything for her to help find out what was going on. They just told us that she had a fibral seizure and shrugged it off. We then asked for a second opinion and decided to go to Minnesota. There we got seizure control for about 1 ½ years. The seizures then came back so we decided to go for a third opinion to Boston Children's Hospital in Massachusetts where we were for 12 days. At Boston Children's Hospital they told us that they felt that she was on the wrong medication, but they could not do anything unless we moved there. We then had another decision to make, move to try another hospital. My husband did some research. Cincinnati, OH, or Phoenix Childrens Hospital were among the top choices. I had family in Phoenix, so we quit our jobs, packed up everything we owned and moved to Arizona. Due to the severity of her seizures, I then had no choice other than to be a stay-at-home mom. We could not trust anyone other than ourselves to care for our daughter. Family and friends were able to help a little bit, but they also have their own lives as well. We were living on one income, and applied for respite but were never approved. As the time went by, we found it difficult to live on just one income so we decided that I would need to go back to work. I worked during the day and my husband worked at night, in order to maintain the proper care for Rylie. Phoenix Children's Hospital doctors were able to gain seizure control. After 5 years living in Arizona, we talked to our Neurologist to see what she thought about us moving back home. She stated since she has gained seizure control, she feels like it would be ok.

We moved back to Bismarck at the end of June 2020. Luckily, we were approved for respite care, and my husband and I both started new jobs. But, having a constant worry at work to make sure a stranger, who does not know our daughter is following the correct steps, watching her, tending to her needs, and most importantly making sure she takes her daily meds that she needs for seizure control is beyond nerve racking. We have since gone through 2 agencies, both have proven that me, her mom, needs to be her full-time caregiver. We have had our respite quit numerous times. The agency has no backups, so that means that I call into work and do not get paid. Our respite has been late numerous times so that meant me going to work late and me losing hours. My employer once asked me when do you anticipate this getting straightened out? I had to tell them that I was not sure as the agency is short-handed and they are trying to find workers but are not having any luck. My job is on the line everyday as I cannot trust that the agency will have coverage for Rylie or that they will be on time, and I could get fired. We had a respite worker have a real problem with germs and one morning my daughter had made a mess in her bed during the night when she was sleeping as she is not potty trained and always wears a pull up. She texted me that it was everywhere, and she wanted advice!?!?! I am sorry you need advice on what to do. You work for an agency that deals with special needs children every day so you should not need advice on what to do. I had to tell her to put her in the bath and get her all cleaned up, get her dressed, brush her teeth, etc. It is no different than any other morning, just have to give her a bath. She also asked if we had any gloves as she did not want to get anything on her hands. We at the time did not have gloves but I told her that we could purchase gloves if it would make her more comfortable, which we did. If you have that much paranoia from germs, I feel that working with special needs kids is not the right place for you. On another occasion we had a respite worker who was taking her to therapy and got in a car accident. I had to call Red Door Therapy and let them know what happened and to cancel her appointment. Rylie has never been in a car accident under my (our) care. She was not hurt as she was checked over by the firefighters that arrived at the scene. Our daughter is completely nonverbal, so she is unable to tell you what her wants or needs are. As her parents we are familiar with her wants and needs and should be there to address them at all times. Not someone that does not know her and is not familiar with her. She also does not feed herself or able to use a fork or a spoon properly. She cannot drink from a straw or cup, is not potty trained, cannot bathe herself, dress herself, brush her teeth, brush her hair, tie her own shoes, put her jacket on or any of the normal everyday life things that kids her age can do. As her mother with everything that I have just explained as to what we have gone through over the last 9 years. Parents absolutely need to be the ones to take care of their special needs children.

I thank you for your time in consideration and I encourage a DO pass on SB 2276.

Jennifer Zahn

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My husband was getting her ready for daycare and she had her 1st seizure. He immediately called 911 and they took her to St. Alexius we packed up all our belonging and relocated to Arizona. hospital by ambulance. They did not run any tests and marked it off as a fibril seizure and sent us on our way.

Exactly a week later she had another one. Once again, we called 911 and were taken by ambulance to St. Alexius. While we were waiting our daughter had another seizure, so they started to run tests. We spent a couple of days in the hospital while they ran test after test and drugged her up to get the seizures to stop. Bismarck hospitals were not finding anything, so we traveled 6 hours to Minnesota for a second opinion. We started at Minnesota Children's Hospital where we stayed for a month while they ran more tests after test, hooked up to EEG's for days, trying all sorts of different medicines and found nothing. While one of the doctors was in the room talking to us Rylie had another seizure and he asked what that was. My husband and I just looked at each other and we said that it was a seizure. Rylie has had every kind of seizure, grand mal, drop seizures, myoclonic seizure, infantile spasms, absence seizures and focal seizures. He then realized that we were dealing with something more and made the call to Minnesota Epilepsy Group and we were transferred by ambulance. We met with Dr. Doescher and tried some other meds. We were at the Minnesota Epilepsy Group for a week while they ran more tests, EEG's, medicines changes until he found the right medicine that eventually stopped them, and we got the diagnosis that she has Epilepsy. We got to go home but had to go back every 6 months as we were also doing genetic testing to see if we could find out anything. Through all those trips we got a result back that our daughter Rylie has a rare genetic change called SCN2A and that causes Epilepsy and non-verbal autism. She went 1 ½ years without seizures. One of the doctoring trips that we took Dr. Doescher decided that we should try to wean her off of medication as he thinks that is why she is not talking. He took her off of Keppra but kept her on Topiramate. Well, that did not last exceedingly long as her speech never came back, and the seizures started back up again. He put her on a different med called Onfi instead of the one that she was on when she was seizure free from 1 ½ years. He told us that he believes these are the 2 medicines that she needs to be on, and we told him that we did not agree with his decision. We then knew that we needed to go somewhere else. We asked him who he suggested for another opinion. He mentioned Dr. Randa Jarrar at Barrow Neurological in Phoenix Arizona. So, we made the decision to move to Arizona in January of 2016. While I was in the shower Rylie was napping and she had a seizure that she bit the inside of her cheek, and it was bleeding. We called 911 and they came and checked her out and she was fine, and they told us that it would heal. We did not have an appointment with Dr. Jarrar until March, but she needed to be seen sooner. We went to the emergency room, and we were able to get in sooner. We met with Dr. Jarrar, and she told us that she spent 3 ½ hours reading Rylie's medical history. That amazed both my husband and myself as NO doctor has done that since we started this journey. We then knew that we had made the right decision. She immediately asked us why she was on Onfi. We told her we did not know and that it was the medicine that Dr. Doescher says that he believes she should be on. We told her that we did not agree with his decision and that he would not listen to us. She immediately stated we are going to change that as that is absolutely the wrong medicine for her.

Testimony in Support of SB 2276
2023 Legislative Session
March 6, 2023

Senator Robin Weisz and Members of the Human Service Committee,

My name is Amy Thom and our family resides in Bismarck, ND in District 8. I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

Our daughter Em was born with Sturge Weber Syndrome in 2013. As a result of this diagnosis she experiences life threatening seizures (which has resulted in numerous hospitalization stays), has global developmental delays, has a port wine stain which needs regular laser treatment, has had countless eye surgeries related to glaucoma, and has undergone proton beam radiation therapy for retinal detachments. She has low muscle tone, which has resulted in recent bilateral hip surgeries. She has also struggled with her immune system which lowers her seizure threshold level. In spite of how hard she has had to fight, she has the gentlest personality and is such a joy in our lives.

Because of her health struggles, and at the recommendation of our doctors not to do daycare, I resigned from my professional job as a Master Level Social Worker 7.5 years ago. I became her full-time caregiver at home. I have been trained and educated on how to best provide her care from Occupational Therapists, Physical Therapists, Speech Therapist, Pharmacists, and Physicians. She is our miracle and has thrived in our home setting.

As time went on and we had more children, I needed more respite services as our daughter continues to need 24 hour care. She needs complete assistance with feeding, drinking, medication administration, dressing, bathing, and incontinence care. She also needs 1:1 assistance with walking, and continuous safety monitoring due to her seizure activity, which also requires overnight monitoring. Her other needs include all the other typical cares; meal prep, laundry, cleaning, playtime, and all the other activities that simply help her to be a kid.

We have always used the self-directed portion of the respite waiver. My husband and I wanted the ability to hire and know exactly who would be coming into our home environment. As time has gone on, it has been more and more difficult to find high quality respite providers that can meet our daughter’s level of care. We have been very blessed to have had a family member from out-of-state move back part-time to fill in those respite care gaps for us and provide respite care, as we have been unable to find full-time respite caregivers.

If this bill is passed it would give our family the opportunity to continue to meet our goals of keeping Em in our home. My husband and I would have more flexibility to work together to meet our daughter's needs, instead of relying on an outside individual to do these very personal care needs for her as she ages. It is our deepest wish and prayer that we could be together more as a family unit to continue to make sure Em has the highest quality of life possible as well as meet the needs of our other children.

While I was working in Nebraska during college years, I was able to intern and meet countless families who were on NE Medicaid Aging and Disabled Waiver Programs. The ability for family members to provide and be paid for direct 1:1 care instead of hiring outside facilities or individuals to come into their home was such a beautiful process. Their quality of life, ability to maintain cultural practices, and to honor their family unit was so very evident. It was one of my career highlights because it exemplified my own set of values, which is the importance of the family unit. Little did I know that someday I would be one of those caregivers here in North Dakota. My only wish is that our waiver program could financially support family members who are providing extraordinary care to help keep the cohesiveness of the family unit intact.

That is why I am asking each one of you to please consider a “Do Pass” on Senate Bill 2276.

Thank you for your time.

Sincerely,
Amy Thom
jonellamy@gmail.com
701-650-8996

Chairman Weisz and members of the Human Services Committee:

My name is Quintana Linseth and I live in District 26.

I am submitting testimony in support of Senate Bill no.2276, relating to legally responsible individuals providing Medicaid Waiver services.
My husband John and I have three children, 10years, 9 years and 6 years. My husband works 10-12 hours per day in the oil field and we operate a small cow/calf farm with chickens and periodically a milk cow.
Our 6 year old has been diagnosed with Sotos Syndrome with Global development delays . She has been in therapy since she was 9 months old. We have no therapist in our rural community so two times a week we drive her to her therapy which is 100 miles round trip. She has to see multiple medical providers frequently which require a specialist, most which require long distance travel.

She is in need of 24 hour one- on- one supervision because, although she is physically able, she does not have the judgment skills necessary to keep her or others safe. Our entire family revolves around providing one-on-one care for her. She is large and strong for her age and is prone to behavioral outbursts. It is seldom that our family attends family gatherings or birthday parties to avoid her aggressive behaviors toward the other children, and because she is very often excluded by the other children and adults.

We have been unable to put her in daycare or find in home care for her due to no one available in this rural area and no one able to provide the care she needs.

It is most certainly less expensive that I provide the majority of care she needs than to place her in services outside our home. This requires that I cannot have a full time job to help bring in necessary income for a family of five.

She is progressing in her learning and social skills but certainly has a very long way to go.

She is dearly loved by her family and she loves them and her home very much, and her cats, dogs and pony.

Please consider the North Dakota families that deal with these issues in keeping their family unit together.

Vote YES on Senate Bill
no.2276.

Quintana Linseth
10951 4th St NW
Killdeer, ND 58640
Ph#: 701 764-6790, 701 290-7237
March 6, 2023

Testimony SB2276
House Human Services Committee

Brittany Zappone
Bismarck, ND
District 32

Chairman Representative Weisz and Members of the House Human Services Committee.

I am testifying in support of Bill No. SB 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

First, I would like to formally introduce myself. My name is Brittany Zappone. I have two beautiful children; my son who is 8 and my daughter who is 6. Both have special needs, stemming from one traumatic event: My daughter was violently shaken at 2 months old.

Over the last several years, things have gotten very complex and hard to navigate. Keeping a job was impossible as, due to her medical complexity, she was admitted frequently to the pediatric intensive care unit in Fargo. I had nowhere near the income I had previously when I was working.

My daughter's medical complexity and the lack of available and trained staff out there really made it difficult to work. She's nonverbal, has a G-tube, Cecostomy tube, and a VP shunt. She is non ambulatory and has been diagnosed with global developmental delay. The medical complications alone would take me hours to explain. If my staff member was ever out sick or needed a day off, I had to cover and leave work to do so. Keeping employment was a must as we could not make it without an income, and we do not qualify for any assistance besides Medicaid.

Since the injury, she has had to fight every single day to survive. Her seizures have gotten worse, and they were not responding to the interventions. She was life flighted to her epilepsy team in St. Paul MN. After getting home, she had multiple medication changes and very little improvement. I went to work, knowing that my daughter may not get better. I struggled every day when I had to leave her. I checked in often and struggled daily to keep focused on the tasks for work. Her condition is getting worse. The seizures are still breaking through and the doctors have run out of options. I never thought that I would be making end of life decisions for my six-year-old child. It breaks my heart that I was not be able to take the entire journey with her. I had to continue to work to keep a roof over our heads and food on the table as there was no other option. A few weeks ago, my daughter transitioned to hospice services. I am officially on unpaid leave (FMLA) at my current job. When it comes down to it, we will always sacrifice to take care of those we love, but we should not have to choose like this. She continues a remarkable fight each day and has lived longer than most adults at this stage.

Due to these recent changes, we will not be able to use these proposed services if the bill passes. I do hope that this will help the next family, and that they will not have to fight as much as we have for adequate care. The children referenced in this bill are remarkable children who deserve to have the same care as any other child without significant needs. No one should ever have to choose between work and being with their child during the last stages of their condition to provide the quality of care that comes from the lived experience of a parent.

Thank you for your time serving our state and for listening/reading my testimony.
I urge you to vote a yes, a do pass on SB 2276. Families are in crisis; we need help now.

Hello, my name is Matthew Ferderer.
My wife and I live in Mandan in voting district 34.

We are testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

I was raised on a dairy farm just west of Mandan. This upbringing prepared me to handle many life situations with more ease than the average person. As a lot of North Dakotans know, farmers must wear many hats in order to be successful. You must be a veterinarian, an electrician, a mechanic, a welder, an equipment operator, a plumber, an accountant, a businessman, an agronomist and work 100 hours a week. The list goes on and on and you must constantly improve your abilities in this ever-changing world. The same is true for parents of special need children. You have to be a doctor, a nurse, a phlebotomist, an occupational therapist, a physical therapist, a speech pathologist, a nutritionist, a respiratory therapist, a psychologist, a pharmacist. You must specialize in GI and IR and learn everything there is to know about heart transplants and rejection and worry about sickness and infections constantly. And at the end of the day, the transplant surgeon's voice echoes in our mind. He said to us, "that is a good heart, it will last her 30 years." 30 years! Sometimes we look at each other and say we will bury her someday. We should be enjoying these days but the guilt of not working with her so that she can develop and be the best that she can be and the fear of taking her out in public because she is immunosuppressed and could get sick and have to take another antibiotic and risk heart rejection. Things that most parents don't have to worry about. Raising a child is a feat of its own, but nothing can prepare you for a child with special health needs. A person could never understand unless you have gone through it yourself. We are wearing more hats now than ever and our backs are tired. Most of the time we feel so numb that it is hard to think of the future. We also have another child that we are trying to raise to be the best he can be. The hand we have been dealt has limited us. It has affected our marriage, our bank account, our jobs, our mental and physical health, our relationships with family and friends, opportunities and ultimately our livelihood. I am not standing up here asking for sympathy from anyone in the room but rather empathy. I am just trying to paint a picture so that maybe you can understand. That being said, we wouldn't change it for the world. Our little Elliott brings us many challenges, but also so much joy. We love her in indescribable ways.

My wife and I have worked hard to get to where we are at in life. We planned to have our son and we planned to have our daughter, but we could never have planned for what has happened in the last 2.5 years. We enjoy our jobs. We enjoy what we do with our money that we have rightfully earned. We have had to drain resources we worked hard for due to all the time we have had to take off work unpaid for appointments, therapies, hospital admissions but most of all when we don't have staff to care for her. She deserves to have opportunities to participate in therapies that will dramatically help her abilities, but they are so expensive, not covered by insurance and we as parents obviously have to be with her to participate. This bill would allow us to help fill the gap of no paychecks while we travel for these therapies. Changing this legislation would help us and so many other families in similar situations.

I am not a political person, but I do stand up for what I believe in and for others that need help. This bill just makes sense.

We were told that she had a heart condition at her 20 week ultrasound. At 36 weeks, my wife relocated to Minneapolis as she would have to deliver there. Our daughter, Elliott, was born with an extremely rare heart defect. She was diagnosed with pulmonary atresia and intact ventricular septum with severe hypoplastic right ventricle complete RV-dependent coronary circulation with bilateral atresia of coronary ostia. Shortly after her birth she underwent surgery that involved atrial septectomy, BT shunt and aorto-tricuspid RV shunting. These are medical terms that moms and dads shouldn't need to know, unless you're a pediatric cardiac doctor. Elliott has traveled a very long road in her short life already. The first two open heart surgeries allowed her to survive until transplant. She received a heart transplant at the age of 2 months old. It is very difficult to put the emotions into words, but that day came with several complications. Elliott spent the first 8 months of her life in the hospital. Because of how long Elliott was inpatient, sedated with medications, intubated and immobile along with the complications from surgeries (mainly right after the heart transplant) she suffered seizures and two strokes. The second stroke was more substantial, and the left side of her brain was hit hard. She has right sided hemiparesis as a result, which means she can't move her right arm or leg as effectively as her left. She has also been diagnosed with Cerebral Palsy because of the stroke. Another complication from the day of her transplant was that she lost blood flow to her right foot. Her toes and her heal on her right foot turned black and eventually self-amputated. She does not eat or drink enough orally, so she gets her nutrition via a GJ tube. She has PT, OT and speech therapy that come to our home daily and often several therapists each day. She takes meds twice a day to suppress her immune system in order to prevent rejection of the heart. We could write a book on our journey so far. My wife and I have fought until we are numb so that Elliott has a fighting chance at life and so that she has the best possible outcome.

Now imagine struggling to balance work, other children at home, finances, meds, therapy schedules, medical supplies, sports schedules, marriage, a social life; while constantly worrying if your son or daughter is getting the care she needs. We have gone through several caregivers. Some just don't show up, some show up but obviously don't care, most can only work very limited hours, one we even had to let go because she was intoxicated while caring for our daughter. It is very difficult to find quality caregivers that care about Elliott and impossible to find someone that cares about her as much as her parents. Elliott has special needs. A simple illness can severely threaten her life. Completing PT exercises, OT exercises, range of motion, speech, feeding therapy, g tube feedings; these are just a few of the things in Elliott’s daily schedule. Her daily care takes specialized training and medical knowledge/experience. Because Elliott is immunosuppressed and has these special needs, we cannot take her to a daycare. There are countless days, weeks, and months where my wife or I need to stay home from work because there is simply no staff. We have no PTO. We don't get paid. We cannot afford to have one parent stay home as we both have essential roles in the workforce and need paychecks and benefits to provide for both of our children. Allowing us as parents to be paid when we must stay home from work due to not having staff would alleviate so much stress. It would also give us the option to stay home more often and possibly full-time if we ever chose that. Most importantly it would give Elliott the best care possible. We are her parents, and we are already providing all these cares. We are the experts and best people for the job. A stranger can get paid to take care of our daughter, but we can’t. The funds are already approved and allocated to Elliott and her care.

Having a child with a disability is hard. We shouldn't have to choose between leaving her at home in someone else's care verses going to work to pay the bills. The right solution is to let Moms and Dads have the option to stay home and care for their child and be paid. That solution has the best outcome for everyone involved.

Kris is a program coordinator at HIT Incorporated. She has been there for 12 years. Her extensive knowledge has helped us navigate this process with our daughter. She overseas plans for individuals with developmental disabilities. She lives it day in and day out; caring for her clients and their families. She not only does it for employment, but she lives it.

I am the Service Manager for Titan Machinery in Bismarck. My company has been more than helpful in our situation. I manage 7 people and take care of a statewide community of customers. My customers include farmers, ranchers, and construction contractors.

We both excel in our careers. We enjoy our careers. We, as everyone, strive to live the American dream. Help others, live a meaningful life and enjoy life. If this bill passes it would make that possible for the minority of people now struggling with unforeseen and unchangeable circumstances.

Thank you for your time serving our state and for listening to our testimony. I urge you to vote yes on Senate Bill No. 2276 and for it to go into effect July 1, 2023. Families are in crisis, we need help now.

Testimony in Support of SB 2276

2023 Legislative Session

March 8, 2023

Chairman Weisz and Members of the Human Services Committee,

My name is Trevor Vannett. I support Bill 2276. I think it's a great think to have family caregivers get paid as this is a burden on families. I would appreciate the committee's consideration and I fully support the bill as it stands. Thank you for your consideration.

Trevor Vannett

Testimony in Support of SB 2276

2023 Legislative Session

March 8, 2023

Chairman Weisz and Members of the Human Services Committee,

My name is Toby Lunstad. I am here today with my husband Shawn and our youngest daughter Addilynn, who is 8 years old. We live in Mandan in District 31.

We are here to testify in support of Senate Bill 2276 for an Act relating to legally responsible individuals providing Medicaid waiver services. This Act would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one. This is an option in North Dakota's Home and Community Based Services (HCBS) Aging and Disabled Waiver, it is not possible in our children's waivers or the Individuals with Intellectual Disabilities/Developmental Disability Waiver (also known as the DD Waiver).

Addilynn has a rare disease. In the United States, the definition of a rare disease is one that affects less than 200,000 individuals. She has variant on a gene called CACNA1A, which controls communication between brain cells. Her specific variant is ultra-rare because she is the only one in the world with it.

The variant on Addilynn's CACNA1A gene has changed how her brain cells communicate, causing several CACNA1A-related disorders including a form of epilepsy that doesn't respond well to medications, being a high risk for hemiplegic migraines, and global developmental delay. At 8 years of age, Addilynn has been hospitalized for more days than we can count and receives care above and beyond what is expected for a typically developing 8-year-old. She started showing developmental delays at 6 months and since the age of 3, she has experienced 4 life-threatening neurological events that have significantly changed her life and the care she requires. Each of these events come with waves of grief, anger, and frustration…But we continue to make sure she receives the care needed to ensure her health and welfare needs are met, to avoid institutionalization, and to keep our family together.

Due to her disability, Addilynn is on the DD Waiver and receives in-home supports, case management, equipment and supplies, environmental modifications, and medical care including specialist appointments and medications.

As Addilynn's rare disease has changed and progressed, we have learned how to meet her needs from her therapists, nurses, different medical specialists, pharmacists, and dieticians. Our days are filled with meeting her extraordinary needs.

If Addilynn is doing well, I complete two medication passes per day. Her medications are given via her feeding tube. This involves accurate measurement of liquid medications and dissolving medications in syringes. I constantly monitor her for side effects of her medications. If she is feeling ill, the frequency of medication passes and the preparation increases.

If she experiences a medical emergency such as a seizure or hemiplegic migraine, I swipe her vagal nerve stimulator (device implanted in her chest to help with seizure management), administer emergency medications, monitor vital signs, and give her oxygen to hopefully stop the seizure or hemiplegic migraine. A seizure or hemiplegic migraine can occur at any time, without warning.

Illness, lack of sleep, or stress can also trigger a neurological event. She is monitored 24 hours a day, 7 days a week and requires 1:1 care so we can assess and intervene at a moment's notice. Addilynn also has a high risk of SUDEP or sudden unexplained death of epilepsy, so throughout the night, I check her if alarms sound, reposition her for safety and skin integrity, and attend to neurological emergencies if they occur.

Addilynn requires complete assistance with bathing, dressing, transfers, mobility, and toileting needs. I reposition her and complete incontinence management to maintain her skin integrity. I complete wound care of her feeding tube site and any other miscellaneous incisions after surgeries. She uses a wheelchair to get from place to place and a communication device to let us know her wants, needs, and feelings.

Addilynn eats and drinks orally and using her feeding tube. She does not independently scoop her food with utensils and bring it to her mouth, so I assist her during every meal. She has a calorie goal to meet each day prescribed by her dietician. Aside from cooking her meals and feeding her, I also weigh and calculate what she will eat orally and what will be given through her feeding tube. Each meal has the goal to increase her oral motor skills, decrease food aversions, and meet her calorie needs.

Addilynn also has a hydration goal she must meet each day that is prescribed by her dietician. Since she drinks both orally and with her feeding tube, I am constantly calculating and adjusting how much fluid is given through the tube to make sure she meets this goal. She does not independently reach for or hold her water bottle, so I assist with this as well.

Addilynn's days are also filled with school and various medical appointments, skilled home programming prescribed by her physical therapist, occupational therapist, and speech therapist, and adapted play and leisure activities so she can experience as much fun and independence as possible.

The extraordinary, specialized cares I just described are cares that a non-legally responsible adult would be paid to complete for Addilynn. These are all cares that I have trained staff to complete for her. We do the same work, except the non-legally responsible adult is paid, thereby supporting their family and contributing to the economy…and I am not.

Up until February of 2020, I worked as an occupational therapist and manager. Addilynn's health took a turn for the worse and we realized that her developmental, physical, and medical needs were not being met by in-home support staff despite repeated efforts of training and education of staff and agency management. We experienced staff sleeping during their shifts, being more engaged in their phones or a book than Addilynn, improper set up of feeding tube equipment, unsafe transfer techniques, and staff taking pictures and being on social media in our home. We attempted to hire in-home support staff using self-directed services, but were unable to recruit staff that were willing to provide all of the extraordinary cares I have described …everyone was intimidated by Addilynn's medical, physical, and developmental needs. We lost my employer paid health, dental, and vision benefits and now pay nearly double for a private health insurance plan, my husband works longer hours, and while our family is intact, we have less time to make memories with our daughter whose future is uncertain.

Addilynn has in-home support service hours authorized under the DD waiver that are not being utilized both because of the quality of staff available and because of the workforce shortage. I am frustrated knowing that the cares I provide to Addilynn are valued enough for a non-legally responsible adult to be paid to provide them…but I cannot be paid for the same cares despite the fact that I am a highly trained, compassionate caregiver to Addilynn who is wholly invested in her future and well-being.

In the 3 years since I have been home with Addilynn full-time, we have seen tremendous gains in Addilynn's function in the midst of setbacks. She is clearly thriving from continuity of care from someone who has the knowledge and skills to care for her. She has had two unexpected surgeries and recovered well. We were able to postpone a complex surgery on her hips for 2 years because I was able to consistently complete her home exercise program…a program that was not being completed when we had in-home support staff caring for Addilynn. Family, friends, and her medical care team have noticed that Addilynn is blossoming with the consistent, quality care that she has been receiving since I left my full-time job.

Individuals with all different levels of care are struggling to receive the in-home support services they have been authorized. I have read testimony that direct service provider agencies have a turnover rate of 47% and that they are unable to fill authorized service hours. In previous testimony, it was stated that 13 million dollars of authorized service hours were unused. This is not because individuals didn't need them…it was because there was no one to fulfill these hours. This situation is not going to improve unless SB 2276 passes and legally responsible adults are able to be paid to fill the gaps in the workforce. Passage of SB 2276 would free up demand for those individuals whose care plan states that a non-legally responsible adult is the best person to provide in-home supports. It would give parent caregivers who have been out of the workforce, a place in the workforce. We are all doing the same work.

According to the Kaiser Family Foundation study titled *Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services (HCBS) Programs: Findings from a 50-State Survey* published November 2022, every state is experiencing workforce shortages of direct care workers. The study states and I quote "As the pandemic persisted, HCBS workforce shortages contributed to provider closures. Most states (44) reported a permanent closure of at least one Medicaid HCBS provider during the pandemic, up from 30 states in 2021. This trend suggests that even as the broader economy returns to normal, HCBS providers continue to struggle." This study also reports that 48 states allow legally responsible individuals to be paid caregiver, which is up from 36 states in 2020. Both the workforce shortage and the paying legally responsible individuals are nationwide issues that states need to address. (link to the study below)

Ongoing Impacts of the Pandemic on Medicaid Home & Community-Based Services (HCBS) Programs: Findings from a 50-State Survey | KFF

As I stated before, Addilynn is on the DD Waiver. She also qualifies for an institutional level of care. According to slide 77 in the North Dakota Developmental Disabilities Study completed by Alvarez & Marsal, North Dakota's share of DD waiver spending for individuals to live in institutions is 29%, which is significantly higher than national figures of 19%. Families have to turn to institutionalization because they have no other options to care for their loved one. I believe SB 2276 has

What Does it Cost To Serve People with Developmental Disabilities in Different Settings?

In both North Dakota and across the country, it costs less per person to serve someone with I/DD on a DD waiver than in an Intermediate Care Facility (ICF)

Waiver Cost Per Person (2018): $39,693

ICF Cost Per Person (2018): $175,049

5,157 North Dakotans receiving LTSS from the State IDD Agency (2018)

State	ICF Spend as % of Total IDD $	Waiver Spend as % of Total IDD $
North Dakota	29%	71%
United States	19%	81%

Waiver Cost Per Person (2018): $47,835

ICF Cost Per Person (2018): $137,560

1,308,659 Americans receiving LTSS from State IDD Agencies (2018)

*North Dakota's share of DD spending in institutions is significantly higher than national figures, indicating there is an opportunity to invest in the home and community-based settings supported by the DD Waiver.

See Appendix, Peer State Benchmarking, for more detailed analysis of ICF and waiver spending.

*Citation: Residential Information Systems Project. (2021). Living Arrangements of LTSS Recipients by Fiscal Year Over Time. University of Minnesota. https://risp.umn.edu/viz/living-arrangements/living-arrangements-of-ltss-recipients-by-fiscal-year-over-time

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Alvarez & Marsal
LEADERSHIP. ACTION. RESULTS.

the potential to reduce spending in this area of the DD wavier because paying families to provide care is much less expensive than paying for institutional care. Paying families as service providers would reduce the need for institutionalization and would keep the family unit intact.

Link to the full A&M study and report

North Dakota Developmental Disabilities Study (ndlegis.gov)

I am Addilynn's mom. I am also her service provider because I consistently provide the extraordinary care services that a non-legally responsible adult would be paid to do. This is why our family respectfully requests a "Do Pass" from each of you on Senate Bill 2276. Please give families in North Dakota the option to be paid as service providers for the extraordinary cares they provide to their loved one. Thank you for your time and I will answer any questions you may have.

Sincerely,

Shawn, Toby, and Addilynn Lunstad

tobylunstad@gmail.com   701-595-4386

The Arc.
North Dakota

House Human Services
SB 2276
January 24th, 2023

Rep. Weisz and committee members. I am Kirsten Dvorak, Executive Director of The Arc of North Dakota; we have six chapters throughout the state of North Dakota that advocate on behalf of individuals with intellectual and/or developmental disabilities (IDD) for full inclusion in their community of choice.

We support SB 2276

Family caregivers of individuals with IDD play an invaluable role in providing the necessary care and support that their loved one needs. Unfortunately, with the changing demographics, such as a lack of workforce, family caregivers often need to meet increasing demands on their time and resources. We must recognize the tremendous dedication of these family caregivers and provide them with the necessary resources and support they need to ensure that individuals with IDD can receive the highest quality of care.

Position:

- Strengthen the caregiving efforts of families, with particular emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction.
- Enable families to make informed choices regarding the nature of community supports for themselves and their members with disabilities.
- Help families with minor members stay intact, preventing out-of-home placements for a minor child, particularly in institutions or congregate settings.
- Ensure aging caregivers can care for their loved one as long as necessary and appropriate while honoring self-determination.

At The Arc of North Dakota, we understand the importance of providing lifelong care for individuals with intellectual and/or developmental disabilities. We also recognize that not all families have the resources to provide lifelong care and that paying families as caregivers should not be used as a substitute. We are committed to advocating for policies that support families through financial assistance, home-based services, and respite care so that they can continue to provide quality caregiving for their loved ones. We believe that it is essential for families to be supported to ensure that individuals with disabilities receive the best possible care.

Kirsten Dvorak
701-222-1854

I am writing in support of Senate Bill 2276 in regard to families as paid service providers.

In 2005, I drove 3 hours to Mandan to tell my daughter in person that I would not be able to be of much help to her for a while because I had been diagnosed with breast cancer and would spend most of the next year with surgery, chemo and radiation and that she could not try to help me. She openly struggled with the understanding that she, as a nurse, would not be able to help her mother through this. She was stretched emotionally and physically already, having learned just months before that her one-year-old was going blind from tumors in his brain.

I write this because it illustrates how family often cannot help physically or financially during a time when young parents need help the most - how, to make ends meet financially, these young parents must work when their heart, mind, and soul knows they need, and want, to be the present caregiver for their fragile child.

Enabling a young parent to be home with their children at such times by allowing them to be paid with dollars already designated for others to come into their home to provide this care makes sense.

I ask for the passage of SB 2276. I think about the difference this would have made for my daughter and her family over the last 8 years. Thank you for your serious consideration.

Rebecca Busby

1111 N 28th St, Bismarck ND

My name is Lisa Kroh.

Our address is rural New Salem. We live 17 miles west of New Salem on a farm. We are in the voting district 36.

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

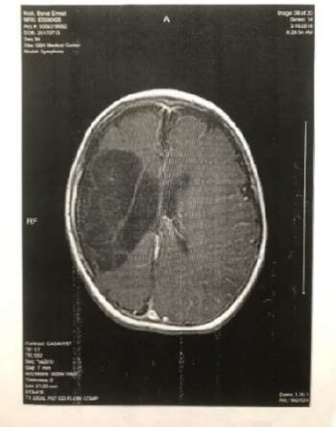
Our Story

In our family we have 6 children, 5 boys and 1 girl. Ages 15, 13, 11, 7, The last 2 are twin boys 5 years old. 2 of our children have disabilities, only one receives services. His name is Benat. I stay home and my husband works full-time and is also a full-time student.

Benat was born premature at 33 weeks and is a twin. 7/13/2017

Within minutes after birth, we were told he had a **heart defect** and was flown to Mayo Clinic in Rochester, MN within 24 hours after birth. We were told he has a bicuspid aortic valve with severe stenosis of his aorta. At 10 days old he had open heart surgery. Luckily, he got to come home after only 4 weeks in the hospital. We were told that the fix was only temporary and by age 2 will more than likely have to have another surgery.

A about 6 months of age I noticed his left hand smelled bad and was clenched all the time. Asking BECEP why this might be, prompted me to further investigate. He had a head ultrasound done which showed there was damage. Then the MRI. He at some point in his short life had a stroke and is missing 80% of the right side of his brain. Meaning **cerebral palsy**. This affects him mentally and his left side physically.

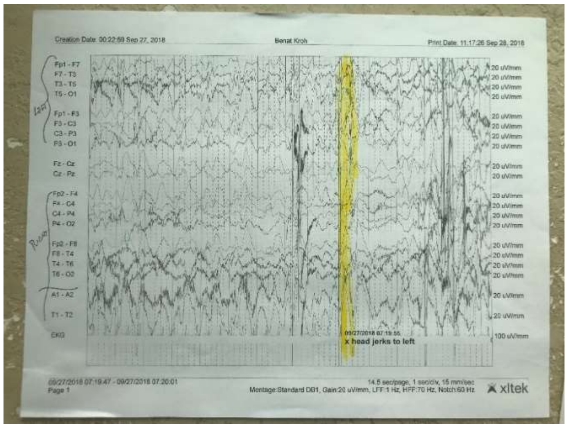


MRI 3/16/2018

Shortly after finding this out, I noticed his eyes roll to back of head and he would twitch. Again, back to a doctor. 2 neurologists in ND then I asked to be sent to an epilepsy specialist in MN. After spending 10 days in the hospital, we found he was having 7-12 seizures and day and they were lasting 2-15 minutes. Partial and focal seizures. Basically, what I found out is his brain is so lit up they can't tell between brain activity and seizures. We now have it under control and have been seizure free for 4 years.

MN Epilespy Group

It was like he was buring up!



Snap shot of EEG. WHAT?!?
How can someone function like this?

He has also been diagnosed with **visual issues (CVI), autism, speech delay, eating issues** (a lack of wanting to eat or drink without being continually prompted to eat) **and physical/mental processing delay**.

However, when tasks are programed and learned it is evident that he is capable of things that are unimaginable to doctors given certain medical conditions and diagnosis that he has.

From the beginning of birth all I heard from doctors was "I'm sorry." With no answers. Preparing for a life with a wheelchair and feeding tubes. Multiple appointments, lots of time traveling for unnecessary appointments. Paperwork. Wasting time and getting nowhere. I am a "listen to your gut" type person. We have got lots of guidance on our journey but it was Benat and I who get the job done.

Learning to eat, see, walk, talk, and now educate. He is an amazing little man.

My Daily Life:

Mondays, Thursdays, Fridays

5:45am – wake up 6 kids, Potty training Benat, Benat seizure meds and applesauce cocktail with miralax, help kids get ready for school.

6:45am – Bus picks up kids for school. Start laundry, vacuum, pick up house, work on morning dishes. Benat assists me with all these tasks. Some days we take the time for him to do them by himself with assistance. Takes forever!

8:00am – We go to learning room. I have set up a room in my house designated to Benat's learning and therapies only. I have purchased mats, swings, wedges, therapy items, and school supplies out of pocket to help me with my son over the years.

9:30am – snack time/breakfast – takes him roughly 45 minutes with the use of tablet playing Blippi or Jack Hartmann to eat a bowl of cereal and drink a glass a milk through a straw with continual reminding to eat and drink. If he does not have a tablet, he will not eat.

10:15am – learning room

11:30am – free time

12:15am – Lunch (peanut butter and jelly with chips and cheese, glass of milk with straw)

1pm – Benat's Nap time. I take dogs outside and tend to rabbits and chickens.

2pm – Finish house chores I didn't get done in the morning.

3pm – wake up Benat. He is usually very crabby, lots of screaming, very mean for 45 minutes no matter what I try.

3:45-4pm – kids come home from school.

4pm – unpack backpacks, remind kids to get chores done, schoolwork all while Benat is at my side.

5pm – start to make dinner. We have a family dinner every night. All while Benat is at my side.

5:45pm – family dinner. I feed Benat and make sure that he eats. Again, can take 45 minutes+ for him to finish a meal. Often, I end up not eating.

6:30pm – family playtime

7pm – Bath time

7:30pm – Meds and TV time

8pm – Bedtime. Benat usually falls asleep around 8:45-9pm.

3rd Monday of the month is IEP PT at Prairie View Elementary 10:30-11:15am

Tuesdays and Wednesdays

Mornings are the same but no learning time at 8:00am, instead we leave to go to town for therapies and shopping.

Tuesday 9:30am-10:30am Sanford PT in Bismarck then shopping (Walmart or TSC)

Home by 1pm for naptime. This is the only day I get to go to Bismarck/Mandan.

1st Tuesday of the month IEP PT at Brave center 8:30am-9:15am

Wednesday 8-8:45am OT and 8:45-9:15am SLP with Little Lights Therapy from Bismarck but services are at PVE in New Salem, (they travel). Then we head to Mandan Brave Center for vision therapy at 10am for 30 minutes. Home by 11:30am.

Weekends my husband does schoolwork for the past 3 years. So, between tending to Benat and trying to spend time with other kids I am just existing.

Benat does receive Respite. He has received respite care starting with 10 hours weekly 7 months after birth to currently max hours weekly. I was going through agencies here in Bismack for these services. Poppy's Promise, Easter Seals and was going to attempt trying a 3rd before going self-directed. My issue with the agency's is no one wanted to travel. And when someone did accept the position, they only worked 1 time or she was 70 years old and only came for 8 hours a week. She had a hard time getting up off the floor, where we spend 80% of our time. She came for only 8 hours a week when there was a possibility of 75 hours a week. Then someone was clocking in under wrong client and they sent me a bill. They pay an employee $13 per hour but charge me $33.80 per hour. WHAT!?! That is the day I went self-directed.

I find my help through Care.com, posting flyers in New Salem / Glen Ullin and word of mouth. The problems I mainly have is no one wants to travel. The weather prevents people from wanting to travel. Benat can be very challenging and loud. If one kid gets sick in our family, they don't want to work and get sick themselves. I totally understand but that sometimes can take 8-16 weeks to run through a household of 8.

If an employee quits it takes 30+ email to individuals through Care.com and over 3 months to get a response. When I do get a response it's an additional 2 weeks before interview, another 6-8 weeks for paperwork and background checks. I had gals come to interview, fill out paperwork and never hear from them again. I've had gals only work 1 day some 1 week. Most 3 months. I had an employee give me her 2 weeks in July this past year. I was unable to find help until October only for the new hire to work a week or two then have a family emergency and need to take a leave of absence until January. Currently I have 3 respite workers employed, but still can't seem to fulfill hours or have consistency.

I never had to put my kids in daycare because I was fortunate enough to stay home.

Benat should have been in kindergarten this year with his twin brother but due to severe issues with the school system in rural town the past 2 years and the fact that he has certain needs that they can't address, he is not attending school this year and might not be attending in the future. There is nothing but problems in that school for kids with disabilities and if I want Benat to be educated and become productive at all then I am forced to homeschool, which has been mention as an option multiple times during meetings.

Everyone is feeling the financial burdens recently with what is going on in the world. Everyone seems to be affected. I don't feel like I have enough on my plate, so I decided this past summer I'll get a job at a local restaurant (20-minute drive), so we have extra income to help pay for things. I got to work 2 wonderful days. I showed up late 4 hours on the first day and 3 hours late the second day, due to respite not showing up and having to wait for husband to get off work. Then she put her 2 weeks in, so I ended up quitting. It was a sad day for me.

Cost of everything going up, can't afford to travel. I used to travel 4 days a week for Benat's therapies now we are down to 2 days a week. He and I were going to the chiropractor which was helpful to both of us however have now stopped because of financial difficulties. I used to get mental health services but now because of some recent changes to insurance I no longer get that. Our family wears glasses. Kids need eye exams and new glasses. How do we pay for it? Clothes? Food? School lunches? How do we pay for it? The kids want to be in school activities that's extra fuel and expense. Future appointments in MN. We have already refinanced.

My last real solution is for me to work between the hours of 8pm and 5am while the family sleeps. But then when do I get to sleep.

It's not that I don't want respite help, I need respite, Benat needs respite, but it seems to not be consistent therefore makes it hard for me to be able to have a life, the whole reason for respite. To give me a break. It's seeming impossible for me to have a job. I have asked may times, why can't I be paid for my services helping my son if someone isn't showing up. I have proven time and time again that he is making great gains beyond the doctors' expectations. I am saving a lot of money and paperwork doing things myself. Benat and I have done all the work with guidance along the way. I struggle to get things I need for Benat due to financial difficulties. Things that are not covered by insurance or Medicaid. If I were to get paid that would relieve financial stress and allow Benat the things he needs to become successful instead of waiting 6 months for something to go through the system and be denied. It would also relieve the financial stress of everyday life. Maybe I could leave the house more often because I could pay for fuel.

This past December 2022 at a cardiology appointment we got confirmation that Benat has enter surgery phase meaning every day that goes by his heart is getting worse and as long as he can tolerate it and EHCO show no enlarging or thickening on the left side of heart then we wait. He needs to grow and gain as much weight as possible before surgery.

May 30, 2023 we will be travelling back to Mayo in Rochester, MN to have another open-heart surgery to not fix but replace his aortic value. Until then we wait unless something changes with him, and his heart goes into failure. With that in mind I have no idea what's going to happen or how long we will be there when it does. Will the girls that are hired respite still be here when we get back or will I have to start over again looking for help. Could you wait as an employee for a month with no paycheck? I still don't know how we are going to afford to travel and pay for hotel?

With that thought, I want to thank you for your time serving our state and for listening to my testimony. I urge you to vote yes on Senate Bill No. 2276. Families are in crisis, we need help now.

Lisa Kroh – imchorty@yahoo.com - (701) 319-0118

Tiffany Peterson

Lincoln, ND

Voting district 8

I am testifying in support of Senate Bill No. 2276 for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

My eight-year-old son Cooper, along with families like mine are the reason I implore you to vote yes on Senate Bill No 2276. At ten months old Cooper was diagnosed with a brain tumor that has fingered its way through many parts of his brain. This resulted in complete blindness at about 14 months old, seizures, hydrocephalus requiring shunting of three of the four ventricles in his brain, speech issues, an abnormal gait, excess growth hormone, precocious (early) puberty, thyroid hormone imbalance, etc. About two years ago, Cooper was also diagnosed with small tumors and lesions on his spine and some of the spinal nerves, as well as scoliosis that will most likely require bracing soon and possibly surgery further down the road.

At the time of his brain tumor diagnosis, Cooper was also diagnosed with a genetic disorder called Neurofibromatosis, type 1 (NF1). This is a disorder that causes tumors to be formed throughout the body, along with other medical problems. Many NF tumors are benign, but others are considered cancerous. Cooper has been on one form of chemotherapy or another for his brain tumors for seven of the last eight years. The manifestation of NF1 in people varies from mild to very severe, sometimes ending in early death. There is no way to predict the future with this disorder, but we do know that Cooper will continue to have numerous health problems and medical appointments, likely more surgeries, and will never be able to live independently.

I am so thankful that Cooper qualified for a Developmental Disabilities Waiver shortly after his diagnosis, therefore qualifying us for in home caregivers. This saved me from having to quit my job as a nurse and kept my family from incurring even more unexpected debt than we have over the last eight years. As thankful as I am for the in-home caregivers, this has also been very wearing and hard on our family. This is in part due to their lack of experience, the frequent turnover, and the sheer number of people who have come through our home. After eight years of caregivers, I would guess that we have had nearly fifty different caregivers through the agency we contract with -some have been there for one shift, others have been there for a couple of years, sharing Cooper's schedule with other caregivers. Some caregivers are absolutely AMAZING, but others are not. For some this is due to the lack of adequate time to provide them with needed training, but for others it is a lack of desire or ability to learn what is needed. Much of the training ends up in the hands of the caregivers already working with Cooper. Just like the game of telephone though, once a message goes through so many people, the message gets lost and becomes something completely different.

Nobody ever wants to think of having to ask to be paid to take care of their own child, and I'm sure some may think of this bill as doing just that. However, after all my family has been through in the last eight years, Senate Bill No 2276 is a beacon of hope for us, a family that has been "JUST SURVIVING" for so long. In addition to Cooper, I have a son named Owen who is 10 years old and has seen and heard more things than any child his age should have had to, and missed out on more time with his parents than any child his age should have to. If this bill had existed about five years ago when we put 17,000 medical miles on our car, probably spent more time in medical facilities than at home, and Cooper had at least 14 brain surgeries in 12 months, I could have been home with both of my boys when they needed me the most. Instead, I was back to work just days after each of Cooper's brain surgeries – just surviving, trying to make enough money to keep us afloat, and spending just enough time at work to keep me from losing my job– FMLA only takes you so far. That year, Owen spent a lot of time with grandparents, aunts, and uncles that we could leave him with on our way to Minneapolis where most of Cooper's medical care is. Then, as soon as we came home, often after traumatic and emergent trips, my husband and I were right back to work and Owen was right back to daycare, when one of us should have been home looking after our children – one who was experiencing the emotional trauma of continuously being uprooted and not being able to understand what was going on; the other going through a physical and emotional trauma over and over again.

If Senate Bill 2276 passes, it has great potential to improve the mental wellbeing of my entire family, it will allow me to provide the best care for both of my children, help Cooper's development of new skills and retaining of old ones because of the consistency I can provide, and would significantly help my family financially. After eight years of taking so much time off of work without pay, we are always coming from behind, and never able to get ahead. Senate Bill No 2276 may even help us step out of the role of "JUST SURVIVING" to "THRIVING".

I Thank you for your time serving our state and for hearing my testimony. So many families like mine are in crisis, and we need help now. I urge you to vote yes on Senate Bill No 2276 and for it to go into effect July 1, 2023.

I welcome any questions you may have for me.

Tiffany Peterson

Peterson.tiffanyr@gmail.com

701-426-6631

NORTH Dakota | Health & Human Services
Be Legendary.

Testimony
Engrossed Senate Bill No. 2276
House Human Services Committee
Representative Weisz, Chairman
March 8, 2023

Chairman Weisz, and members of the House Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities (DD) Section with the Department of Health and Human Services (Department). I am here today to provide information on Engrossed Senate Bill 2276 for your consideration as you review the Bill.

Compensated family caregiving can be an important part of the state's system of care options. The Department believes if done thoughtfully, with appropriate attention to the nuances related to assessment, safety, and the mechanics of implementation, the new service outlined in this Bill could be a benefit to families across our systems of waivers.

The Department's position on the Bill is in support though we are concerned about the ability to effectively implement this proposed change knowing the extent of parallel system change that is likely to result from the recommendations associated with the Alvarez and Marsal Study, completed in response to 67th Legislative Assembly Senate Bill 2256.

While the Adult and Aging system does allow this option, this addition will apply to waivers that serve children under the age of 18, living with their parents.

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

March 8, 2023
Testimony in Favor of SB2276

Chairman Weisz and members of the House Human Services Committee,

My name is Katynka Morrissette and my family lives in Bismarck , ND, in District 7. My husband, Joe, and I have 3 medically complex children who are on the Medically Fragile Waiver. I am writing to you to ask for your support of SB 2276, that allows a legally responsible individual to be paid for the extraordinary cares they provide in the home to their child that requires care far beyond what a typically developing child their age would require.

Due to our children's metabolic condition they require constant supervision, multiple blood glucose checks and ketone level checks per day, medications and nutritional supplements given via g-tube around the clock, care for their implanted medical ports and medication to be administered in that central line, regular infusions, breathing treatments and chest percussion vest therapy, as well as intervention and assistance with multiple daily living tasks.

No two days in our home look the same, with my living room becoming a space for rescue medication, IV poles, feeding pumps, scales, syringes, formula bags, heating blankets, and emesis bags at a moments notice. We try all possible intervention when our kids are in metabolic crisis, to avoid a lengthy and costly hospital stay. Too much physical activity, too little sleep, a common cold, a late dose of cornstarch in their tube, or an unsafe food being given can all trigger a crisis with life threatening hypoglycemia or acidosis.

With our waiver we are authorized for in home support and care, but due to staff shortages we have not had those hours fulfilled in months. I have contacted or interviewed now 39 potential employees in the last 6 months. We have been able to staff a mere 5 hours a week, some weeks. Those hours are filled by a previous employee who is now advancing in her education and professional career.

People are taking other jobs that offer benefits or more pay, they just don't feel like working many hours and want something easier, or they do not give me a response at all and don't show up for the interview. This is the reality of the workforce crisis we are in. Even if we found somebody willing to fulfill these hours, it is hard to get someone trained to do this level of care and mistakes have been made by previous staff. My husband and I have spent many hours being trained by their teams of specialists on how to give them the safest care and keep them in our home, some of those extraordinary cares would have to be performed by a Registered Nurse but as the legally responsible individuals we are able to do them.

With this bill you would allow the legally responsible adult that is giving these extraordinary cares the ability to be compensated for the care we are authorized for and not receiving, as well as making us a part of the workforce that so many of us have been forced to leave due to staff shortages not allowing us to work outside the home. This would also free up staff from agencies that have been giving some coverage to the higher level of need children who qualify for this service option, and allow them to provide better coverage for the families who this service option is not considered in the best interest of the child's needs per the child's DDPM on annual assessment.

In these months without staff in our home, I have no longer been able to keep my employment outside of our home. While this has been a sacrifice for our family, we have also been able to see improvements in their stability and wellbeing. We believe this is because the best quality of care for these children often comes from the parents who work closely with teams of doctors and therapists and are fully invested in the health and care of their child and child's best interest.

We are not asking to be paid to be parents, we are asking for the compensation that would be given and has been authorized to be given to a total stranger coming into my home and performing these tasks, but only after spending weeks being trained by me. No amount of training can substitute for the years of "on the job" experience in managing my child's medical conditions.

I wanted to be able to testify in person today, but without in home staff support for our kids and the extensive cares required, I am unable to leave them with an untrained caregiver or drop-in daycare on a good day, let alone when one is sick.

I kindly ask that you give a DO PASS recommendation on SB2276 so that families are not faced with hard decisions like placing their child in an institutional setting. Keeping families together, children in their own communities, and increasing health outcomes when care is being compensated for and given by a loved one should be a priority in this state.

Thank you for your time and DO PASS recommendation,

Katynka Morrissette

House Human Services Committee

Senate Bill 2276 – March 8, 2023

Testimony of Daniel Gulya, Attorney, Protection and Advocacy

Chairman Weisz and members of the House Human Services Committee:

My name is Dan Gulya; I am an attorney with the North Dakota Protection & Advocacy Project (P&A). P&A protects the human, civil and legal rights of people with disabilities. The agency's programs and services seek to make positive changes for people with disabilities where we live, learn, work and play.

P&A supports this effort to create a path for household members- parents, siblings, children - to be paid service providers to meet the extraordinary care needs of their family members. This bill supports person-centered home- and community-based services, so that families can ensure the essential level of care their loved one needs.

If these families were to make the gut-wrenching decision to not care for their loved ones at home, it would have a significant fiscal impact on the state. The average cost of care for these individuals in an intermediate care facility is $175,000 per year; home based services are about half as expensive.[i] Helping these North Dakotans care for their loved ones at home is the fiscally responsible choice.

Many of these families come to you after being told by the Department that they are authorized for more hours of service than providers can supply; some come to you after deciding that they are the best help for their loved ones. You can help them and make a prudent fiscal choice for North Dakota at the same time. I respectfully request support for SB 2276. Thank you, and I would be glad to answer any questions.

Daniel Gulya, Protection & Advocacy
danigulya@nd.gov
328-3946

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[i] These numbers are from page 75 and 76 of the Alvarez and Marsal study presented to the 21-23 Interim Human Services Committee.
https://ndlegis.gov/files/committees/67-2021/23_5168_03000_appendixf.pdf

Chairman Weisz and Members of the House Human Services Committee,

SB 2276 establishes an option under the 1915(c) Medicaid Waivers (home and community-based services) that would reimburse family caregivers who provide “extraordinary care” to their dependents who are on these waivers.

Overview: Currently, there are individuals who are eligible for in-home services through North Dakota’s Medicaid program that don’t receive these services, often due to a lack of qualified workforce available to provide the services. This often means that a parent or other relative must try to take care of them, sacrificing income they would otherwise be earning at work to stay at home. This bill would allow for that caregiver to be reimbursed when the care they provide is <u>beyond what is ordinarily required by a parent or legal guardian.</u>

History: The Aging and Disabled Waiver for home and community-based services currently allows caregivers living in the home to be reimbursed for care — this bill would provide equal treatment under the other waivers, including the Intellectual Disabilities/Developmental Disabilities, Autism, and Medically Fragile waivers.

The goals of this bill are to:

1 – Address the lack of workforce that surrounds these home-based services
2 – Provide financial stability to households that are strained by juggling work and caregiving
3 – Provide the care that these individuals are legally eligible for but not actually receiving
4 – Keep families together and prevent expensive and unnecessary referral to institutions

I am grateful for your consideration and deliberation on this important legislation. If you have any questions, please do hesitate to contact me.

Sincerely,

Sean Cleary
North Dakota State Senate
District 35 — Bismarck

ed

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2276

House Human Services

Wednesday, March 8, 2023

Representative Robin Weisz, Chair

Chair Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I am here today 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.

SB 2276 – Designer Genes is advocating for SB 2276 and respectfully requests your vote in favor of the bill. Our organization played a role in developing SB 2276, as we believe it will greatly benefit families with loved ones who have Down syndrome as well as many of individuals with disabilities. While working on this bill, our goal was to simplify it as much as possible, while acknowledging that changes to Medicaid Waiver programs are complex. We appreciated the feedback from the Department of Health and Human Services on this bill.

Goals – The main intent of SB 2276 is to allow families, mainly parents, to be paid for the care that is above and beyond what they would do for a loved one without extraordinary needs. I encourage you to listen to all of the family testimonies that have occurred during the hearing of this bill. These stories highlight the challenge of balancing employment with the demanding and often overwhelming care needs of their children, compounded by difficulties in managing the workforce shortage, finding quality staff, considering the severity of the child's needs, and managing demands of education and healthcare.

Eligibility – SB 2276 aims to provide a service option for <u>individuals who are already eligible for in-home supports or care under ND Medicaid Waiver</u>. This option would be available through Medicaid 1915c Waivers and will not change current eligibility or services. Currently, ND does not have a provision for parents of children with disabilities to be paid as service providers. The Aging and Disabled Home and Community Based Waiver does offer this option, reimbursed at a daily rate, but does not serve individuals under 18.

Our aim is to keep the requirements for this option simple, without requiring a tedious demonstration of unsuccessful staffing or placement attempts by the family. The decision to access this option should be based on the individual's person-centered plan, considering any new or annual assessment information. The annual assessment mentioned in Section 1, Subsection 3 is similar to the annual application for In-Home Supports used by ND Developmental Disabilities Section to assess the needs and authorize In-Home Supports for individuals with intellectual disabilities or developmental disabilities under the Individuals with Intellectual Disabilities/Developmental Disabilities (DD) Waiver.

Background – While initially discussing options, it was our hope reimbursing families as service providers could become another provider option under the already existing self-directed In-Home Supports service; however, getting input from the Department, more general terminology of a “service option” as discussed in Section 1, Subsection 2 was chosen to allow flexibility to the Department in meeting the requirements for the Centers for Medicare and Medicaid (CMS). I’ve included a link of to a CMS presentation on Leveraging Family Caregivers:

https://www.medicaid.gov/medicaid/home-community-based-services/downloads/leveraging-family-care.pdf . This presentation indicates that just over half of states are allowing a legally responsible individuals to provide a personal care service. While complicated, it appears that the Centers for Medicare and Medicaid understand the critical urgency to consider this issue and is creating guidance to support the approach.

Section 1, Subsection 4 excludes the Aging and Disabled Waiver from the changes in this bill. We want to ensure that the option exists in all of our waivers that are or will be available to eligible individuals. From that perspective and by a recommendation by DHHS, we did not want to affect anything within the Aging and Disabled waiver by the language in Section 1, Subsection 2.

Utilization – In other testimony, the Department has reported roughly $13 million in underutilization in the area of In-Home Supports with in the DD Waiver. It’s important to remember that the families you are hearing from today have **undelivered services** represented in that amount. Families are going without care, that’s the plain simple truth. In regards to the fiscal note, I would ask the committee to consider what duplications in cost may already exist in SB 2012 that could offset this fiscal note. For example, some of the families that may benefit from this option are already self-directing and are probably figured into the Department’s budget for the intermediary fiscal agent costs. We would also like to assure equity across the waivers in how this service option is paid out.

Family Finances – SB 2276 is aimed to support families who do not have a broad array of options open to them for caring for their loved one, many of them unable to attend child care, day programming, or even school. While preparing this testimony, I did so with a single father in mind who is trying to maintain his professional career while managing two major surgeries for his child with Down syndrome as well as his ongoing care. He has had difficulty finding consistent or even any staff at all for over a year. He is constantly worried about having to take leave without pay, putting his job at risk. SB 2276 opens the door for ND to support him and keep his family intact which we understand is way more beneficial and much cheaper than an institutional placement for his son.

Thank you for your consideration of SB 2276. I am available to answer any questions.

Roxane Romanick	701-391-7421
Executive Director	roxane@designergenesnd.com

Testimony
SB2276
Human Service Committee
03/08/2023

Chairman Weisz and members of the Human Services Committee.

I thank you for all being here today to listen to me on why you should support Bill 2276.

My Name is Jessica Neigum Dargis, and I reside in District 30. I am here on behalf of my daughter Belle who is 4 years old and is developmentally delayed due to being born with an occipital meningocele.

I also work for a developmental disability provider and I'm a local business owner so I can understand the staffing shortage that faces the North Dakota workforce. While all organizations will remain nameless during my testimony, please know that I sit on the executive team at the organization I serve so I know firsthand the staffing struggles that many DD providers are facing and the difficult decisions that are made daily; Many DD providers are having staffing crisis with a turnover ratio of 40-50% which can be proved through Alvarez and Marsal case, please see page 105.

https://ndlegis.gov/files/committees/67-2021/23_5168_02000presentation1230.pdf

Unfortunately, most of the agencies that provide in home supports provide other services such as day programing, residential support, or intermediate care facilities, so when the organization is short staffed and need someone to cover at a location they manage, they often cut family support care first as there is a "back-up" also known as the parent, which doesn't exist in other care settings. Leaving parents caught in the middle of being at work or caring for their child, which in all cases the parent picks their child. Once a parent misses enough work because they don't have adequate care for their child, the parents' employer starts to consider the parent an unreliable employee.

I can respect agencies being short staffed or having sick staff as I hear about it at the agency daily, however as a parent it can be frustrating to find out 20 minutes before work that you will not have care for their child that day.

At some point parents give up their jobs, to ensure their child has continuity of care. While some may suggest daycare, there are very few daycares that will provide care to medically complex children. My daughter Belle attends Bismarck Early Childhood Education Program and receives a 1 to 1 aid while there, most daycares will not provide a 1 to 1 as that is not cost effective to their programs when in most other situations for a 4-year-old they can have 6-8 children or more to 1 teacher or aid. If daycares are willing to provide care, they want to charge the family for that 1 to 1 staff which in most cases negates the point of the parent working as their hourly wages goes to pay for the hourly wage of the staff taking care of their child as public daycares are not certified to bill the state for Medicaid. Which then pushes parents back to using a certified agency that can charge Medicaid yet is short staffed and always cutting care hours.

The state has really left a hole for parents of children with disabilities or special health care needs and forced many to quit their jobs. I am lucky enough that my mother retired after 39 years with the state of ND several of which were served in the Department of Public Instruction and is caring for my daughter.

I don't have to worry about my staff not showing up, because my mother is always there for her and me. However, if something was to happen to my mother, I would likely be without care.

Thank you for your time and consideration in voting in favor of bill 2276

I would like to close with a final thought.

Children are a vulnerable population. **Individuals with disabilities** are a vulnerable population.

Children strive on routine as they understand what is expected of them. **Individuals with disabilities** strive on routine as they are familiar with the process.

So why not provide **Children with disabilities** the stability of a familiar caregiver such as their parent so they can successfully navigate life?

Jessica Neigum Dargis
Parent of a child with a disability
612.695.8150
jess.neigum@gmail.com

#23022

2021 SENATE JUDICIARY

SB 2276

2021 SENATE STANDING COMMITTEE MINUTES

Judiciary Committee
Peace Garden Room, State Capitol

SB 2276
2/3/2021
AM Hearing

A BILL for an Act to amend and reenact section 44-04-18.3 of the North Dakota Century Code, relating to confidentiality of law enforcement personnel records.

Chairwoman Larson calls the meeting to order, all Senators are present: Myrdal, Luick, Dwyer, Bakke, Fors, Larson

Discussion Topics:

- Difference between confidential and exempt records
- Protection of law enforcement officer's personal data

Senator Judy Lee introduced the bill and provided oral testimony in favor [10:00]

Aaron Birst from the North Dakota Association of Counties provided testimony in favor [10:05]

Major Aaron Hummel, Chief of Staff of the North Dakota Highway Patrol provides neutral written and oral testimony #5189 [10:15]

Katie Paulson Recorder and Tax Director of McKenzie County provides testimony in favor [10:30]

Mary Kay Kelsh Assistant Attorney General provided testimony in favor [10:35]

Hearing Adjourned [10:45]

Jamal Omar, Committee Clerk

#5189

Senate Bill 2276
Senate Judiciary Committee
Senator Diane Larson, Chairman
February 3, 2021

Chairman Larson and members of the Senate Judiciary Committee, my name is Major Aaron Hummel, chief of staff for the North Dakota Highway Patrol. I am here to provide testimony in support of Senate Bill 2276, but feel some language needs to be amended.

In light of things going on around the country, I feel the expansion of those officials protected under 44-04-18.3 by adding prosecutors, district court judges, and judicial referees is appropriate. Under the current law, the phone number and home address of those officials is a confidential record and shall not be made public.

There are a couple points I would like to provide additional clarification on and recommend an amendment.

First, the bill adds the language in lines 9-10 on page 1, "in any personnel record." What this language does is narrow the scope of confidential records only to personnel records held by entities. Current law encompasses all records containing the phone number and home address. For example, a state trooper in the course of their employment or otherwise, could have their home address listed on a state crash report and that information is an open record to anyone. We have worked with the ND Department of transportation over time to try and keep that information confidential. I can't list all other records held by entities that may contain that information, but in any regard, adding the language in the bill would open those records up potentially revealing the address and phone number.

The second area I believe needs to addressed is the exception provided in page 1 subsection 1, line 9 and outlined in page 2 with the addition of subsection 5, lines 13-17. As provided in the bill, the language makes GIS, title, and tax records held by entities exempt records, which allows for the discretionary release. These are the most common records that the public would have access to and you can find them on many county websites. There certainly needs to be some work done in this area, but the language provided will make these records no longer confidential which is concerning. As an agency we have, and I believe other law enforcement agencies in the Bismarck-Mandan areas have worked with the county tax officials to ensure their information is updated annually to ensure those records aren't being released. As an agency we have been updating our employee list and allowing our employees not to be listed if they chose and we provide the list to the entities holding those records. By having the information not listed publicly, it does create some hassles if the individual is working with people like realtors and insurance adjustors who use that information regularly. In those cases, the individual who's records are protected would have the additional burden of retrieving those records. There definitely needs to a balance struck between convenience and privacy.

The amendment I have provided replaces page 2 subsection 5 with the following language:

> "An address of an individual in subsection 1 which is included in a geographic information system, a property title record, or tax parcel data is an exempt record. However, upon request of an individual in subsection 1 or their employer, the information shall be confidential for the remainder of the calendar year. Requests must be made by individuals in subsection 1 or their employers annually to maintain the confidentiality for subsequent years."

In my discussions with Mr. Birst and Senator Lee, I believe this accomplishes the goal that was sought with this bill. It still maintains the confidentiality of the protected officials phone and home address, but it does put the responsibility on the individual or the agency to request their phone and home address records be made confidential, while making it reasonable for those entities holding the records to actually maintain the confidentiality.

Thank you Chairman Larson and members of the committee, this concludes my testimony and I would be glad to answer any questions you may have.

PROPOSED AMENDMENTS TO SENATE BILL 2276

44-04-18.3 Records of juvenile court supervisors and probation officers and law enforcement and correctional employees – Law enforcement work schedules – Confidential Informants.

Page 1, subsection 1, lines 9-10 replace with:

> "Except as provided in subsection 5, a telephone number and home address of a prosecutor, district court judge, judicial referee, judicial" (removes "<u>in any personnel record</u>")

Page 2, subsection 5, remove lines 13-17, replace with:

> "An address of an individual in subsection 1 which is included in a geographic information system, a property title record, or tax parcel data is an exempt record. However, upon request of an individual in subsection 1 or their employer, the information shall be confidential for the remainder of the calendar year. Requests must be made by individuals in subsection 1 or their employers annually to maintain the confidentiality for subsequent years."

Renumber accordingly.

2021 SENATE STANDING COMMITTEE MINUTES

Judiciary Committee
Peace Garden Room, State Capitol

SB 2276
2/3/2021

A BILL for an Act to amend and reenact section 44-04-18.3 of the North Dakota Century Code, relating to confidentiality of law enforcement personnel records.

Chair Larson calls the committee meeting to order. Present are Senators Myrdal, Luick, Dwyer, Bakke, Fors, and Heitkamp. [2:02]

Discussion Topics:

- Confidentiality in law enforcement records

Mary Kay Kelsch presents an amendment to the committee as testimony #5250. [2:13]

Senator Dwyer moves to adopt an amendment [21.0907.01001]. [2:16]
Senator Heitkamp seconds. [2:16]

Senator	Vote
Chair Larson	Y
Senator Myrdal	Y
Senator Luick	Y
Senator Dwyer	Y
Senator Bakke	Y
Senator Fors	Y
Senator Heitkamp	Y

Motion passes 7-0-0. [2:16]

Senator Luick moves DO PASS AS AMENDED. [2:17]
Senator Myrdal seconds. [2:17]

Senator	Vote
Chair Larson	Y
Senator Myrdal	Y
Senator Luick	Y
Senator Dwyer	Y
Senator Bakke	Y
Senator Fors	Y
Senator Heitkamp	Y

Motion passes 7-0-0. [2:18] Senator Luick carries.

Chair Larson adjourns the meeting [2:20]

Jamal Omar, Committee Clerk

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2/3
1 of 1

21.0907.01001
Title.02000

Adopted by the Judiciary Committee

February 3, 2021

PROPOSED AMENDMENTS TO SENATE BILL NO. 2276

Page 1, line 9, remove the second "in"

Page 1, line 10, remove "any personnel record"

Page 2, line 15, remove "the address may not be accessible to the public through the geographic"

Page 2, replace lines 16 and 17 with "upon request of an individual in subsection 1 or the individual's employer, the information is confidential for the remainder of the calendar year. Requests must be made by the individual in subsection 1 or the individual's employer annually to maintain the confidentially for subsequent years."

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2276: Judiciary Committee (Sen. Larson, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (7 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2276 was placed on the Sixth order on the calendar.

Page 1, line 9, remove the second "in"

Page 1, line 10, remove "any personnel record"

Page 2, line 15, remove "the address may not be accessible to the public through the geographic"

Page 2, replace lines 16 and 17 with "upon request of an individual in subsection 1 or the individual's employer, the information is confidential for the remainder of the calendar year. Requests must be made by the individual in subsection 1 or the individual's employer annually to maintain the confidentially for subsequent years."

Renumber accordingly

#5250

PROPOSED AMENDMENTS TO SENATE BILL NO. 2276

Page 1, Lines 9-10, remove "in any personnel record"

Page 2, Lines 14-17, replace "the address may not be accessible to the public through the geographic information system, property title record, or tax parcel data via a search of the individual's name only" with "upon request of an individual in subsection 1 or the individual's employer, the information is confidential for the remainder of the calendar year. Requests must be made by individuals in subsection 1 or the individuals' employers annually to maintain the confidentiality for subsequent years."

Renumber accordingly

2021 HOUSE JUDICIARY

SB 2276

2021 HOUSE STANDING COMMITTEE MINUTES

Judiciary
Room JW327B, State Capitol

SB 2276
3/22/2021
AM

Relating to confidentiality of law enforcement personnel records.

Chairman Klemin called the hearing at 10:38 AM

Present: Representatives Klemin, Karls, Becker, Christensen, K Hanson, Jones, Paulson, Paur, Roers Jones, Satrom, and Vetter. Absent: Magrum, Cory, Buffalo

Discussion Topics:

- Confidential information
- GIS use
- Exempt records

Aaron Burst, Association of Counties: Verbal testimony 10:39

Senator Lee: Introduced the bill. Verbal testimony 10:55

Carrie Krause, **Wells County Recorder**: Verbal testimony 11:07

Major Tom Iverson – Chief of Operations, Highway Patrol; Testimony #10324

Mary Kay Kelsh, Attorney General's office: Verbal testimony 11:23

Chairman Klemin recessed the hearing at 11:40.

Additional written testimony: #10153

DeLores D. Shimek
Committee Clerk

#10324

Senate Bill 2276
House Judiciary Committee
Representative Lawrence Klemin, Chairman
March 22, 2021

Chairman Klemin and members of the House Judiciary Committee, my name is Major Tom Iverson, chief of operations for the North Dakota Highway Patrol. I am here to provide testimony in support of Senate Bill 2276.

Considering things going on around the country, I believe the expansion of those officials protected under NDCC 44-04-18.3 by adding prosecutors, district court judges, and judicial referees is appropriate. Under the current law, the phone number and home address of those officials is a confidential record and shall not be made public.

There was considerable discussion during Senate hearings about the additional language added in sections 1 and 5. Major Aaron Hummel, the highway patrol's chief of staff, provided testimony regarding our agency's concerns and submitted a proposed amendment. The Senate adopted that amendment, and we believe the bill, in its current form, is a good compromise to help protect the identity of individuals listed in NDCC 44-04-18.3.

The updated language still maintains the confidentiality of the protected officials' phone numbers and home addresses, and it puts the responsibility on the individual or the individual's employer to request that an individual's phone number and home address remain confidential. This request would have to be submitted annually. This change makes it simpler for those entities holding the records to actually maintain confidentiality because they would receive a notification annually rather than trying to keep track of who meets the criteria and who doesn't.

Thank you Chairman Klemin and members of the committee, this concludes my testimony and I would be glad to answer any questions you may have.

Senate Bill 2276
House Judiciary Committee
Testimony Presented by Sara Behrens
March 22, 2021

Good morning Chairman Klemin, members of the committee. My name is Sara Behrens and I am a staff attorney with the State Court Administrator's Office. I am submitting this testimony on Senate Bill No. 2276 in a neutral capacity with a proposed amendment. It was noted that district court judges and referees were included but justices of the supreme court were not. The attached proposed amendment simply adds justices of the supreme court on page 1, line 10. Justices would also have reason to want their home addresses to be removed from public databases. We ask for your thoughtful consideration of the proposed amendment.

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

Page 1, line 10, after “referee,” insert “<u>justices of the supreme court,”</u>

Renumber accordingly

2021 HOUSE STANDING COMMITTEE MINUTES

Judiciary
Room JW327B, State Capitol

SB 2276
3/24/2021

Relating to confidentiality of law enforcement personnel records.

Chairman Klemin called the meeting at 11:22 AM.

Present: Representatives Klemin, Karls, Becker, Christensen, K Hanson, Cory, Magrum, Jones, Paulson, Paur, Roers Jones, Satrom, and Vetter. Absent: Cory

Discussion Topics:

- Confidential records
- Annual renewal for confidential record

Chairman Klemin: Introduced proposed amendment 21.0907.02002 Testimony #10655

Rep. Karls: Motion to adopt amendment 21.0907.02002
Rep. Satrom: Seconded

Voice vote carried

Rep. Karls: Do Pass as amended
Rep. Satrom: Seconded

Roll call vote:

Representatives	Vote
Chairman Klemin	Y
Vice Chairman Karls	Y
Rep Becker	Y
Rep. Christensen	N
Rep. Cory	A
Rep T. Jones	Y
Rep Magrum	N
Rep Paulson	Y
Rep Paur	N
Rep Roers Jones	N

Rep B. Satrom	Y
Rep Vetter	N
Rep Buffalo	Y
Rep K. Hanson	Y

8-5-1 Motion carried

Carrier: Chairman Klemin

Stopped 11:47.

DeLores D. Shimek
Committee Clerk

Da 3/24/21
1 of 1

21.0907.02002
Title.03000

Prepared by the Legislative Council staff for
Representative Klemin
March 23, 2021

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

Page 1, line 10, after the first underscored comma insert "supreme court justice,"

Page 2, line 13, replace "An" with "A home"

Page 2, line 14, replace "an exempt record" with "confidential only if an individual in subsection 1 or the individual's employer submits a written request to the custodian of the records. The request will remain confidential for the remainder of a calendar year and must be renewed annually"

Page 2, remove lines 15 through 18

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2276, as engrossed: Judiciary Committee (Rep. Klemin, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (8 YEAS, 5 NAYS, 1 ABSENT AND NOT VOTING). Engrossed SB 2276 was placed on the Sixth order on the calendar.

Page 1, line 10, after the first underscored comma insert "<u>supreme court justice,</u>"

Page 2, line 13, replace "<u>An</u>" with "<u>A home</u>"

Page 2, line 14, replace "<u>an exempt record</u>" with "<u>confidential only if an individual in subsection 1 or the individual's employer submits a written request to the custodian of the records. The request will remain confidential for the remainder of a calendar year and must be renewed annually</u>"

Page 2, remove lines 15 through 18

Renumber accordingly

#10655

21.0907.0200
2

FIRST ENGROSSMENT

Sixty-seventh
Legislative Assembly
of North Dakota

ENGROSSED SENATE BILL NO. 2276

Introduced by

Senators Lee, Dwyer, Hogue

Representatives Nathe, Roers Jones

A BILL for an Act to amend and reenact section 44-04-18.3 of the North Dakota Century Code, relating to confidentiality of law enforcement personnel records.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. AMENDMENT. Section 44-04-18.3 of the North Dakota Century Code is amended and reenacted as follows:

44-04-18.3. Records of juvenile court supervisors and probation officers and law enforcement and correctional employees - Law enforcement work schedules - Confidential informants.

1. ~~Any~~Except as provided in subsection 5, a telephone number and the home address of a prosecutor, supreme court justice, district court judge, judicial referee, juvenile court director or probation officer, an employee of a law enforcement agency, employee of a state or local correctional facility, and an employee of the department of corrections and rehabilitation are confidential. Information contained in a personnel record of an employee of the department of corrections and rehabilitation may not be disclosed to an inmate in the legal custody of the department of corrections and rehabilitation confined in a jail, prison, or other correctional facility unless authorized by the director of the department of corrections and rehabilitation. Information contained in a personnel record of a law enforcement officer of a state or local law enforcement agency or in the personnel record of a correctional employee of a correctional facility subject to chapter 12-44.1 may not be disclosed to an inmate confined in a state correctional facility or correctional facility subject to chapter 12-44.1 unless authorized by the employing agency.

2. Records or other information that would reveal the identity, or endanger the life or physical well-being, of an undercover law enforcement officer is confidential. For purposes of this subsection, an "undercover law enforcement officer" means a full-time, salaried employee of a local or state law enforcement agency who acts surreptitiously or poses as someone other than a law enforcement officer while engaging in the investigation of a violation of law.

3. Any record containing the work schedule of employees of a law enforcement agency is exempt.

4. A law enforcement officer or prosecutor, within the scope of the employment of the officer or prosecutor, may provide assurances of confidentiality to a person providing information regarding violations of the law. Any information that would identify or provide a means of identifying a confidential informant, if the identity of the informant is not otherwise publicly known, is confidential and may be disclosed only as permitted by law.

5. ~~An~~A home address of an individual in subsection 1 which is included in a geographic information system, a property title record, or tax parcel data is ~~an exempt record~~ confidential only if an individual in subsection 1 or the individual's employer submits a written request to the custodian of the records. The request will remain confidential for the remainder of a calendar year and must be renewed annually. ~~However, upon request of an individual in subsection 1 or the individual's employer, the information is confidential for the remainder of the calendar year. Requests must be made by the individual in subsection 1 or the individual's employer annually to maintain the confidentially for subsequent years.~~

21.0907.02002
Title.

Prepared by the Legislative Council staff for
Representative Klemin
March 23, 2021

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

Page 1, line 10, after the first underscored comma insert "supreme court justice,"

Page 2, line 13, replace "An" with "A home"

Page 2, line 14, replace "an exempt record" with "confidential only if an individual in subsection 1 or the individual's employer submits a written request to the custodian of the records. The request will remain confidential for the remainder of a calendar year and must be renewed annually"

Page 2, remove lines 15 through 18

Renumber accordingly

Testimony on SB 2276
January 24, 2023
House Human Services Committee

Good day, Chairman Weisz and members of the House Human Services committee. My name is Sarah Carlson. I live in Dickinson, ND and I am writing this, representing my own thoughts and not on behalf of my employers. I am in support of SB 2276.

I have a 10-year-old son, Beckett, who has severe multiple disabilities. He has had these since birth and they are lifelong conditions.
SB2276 allows families, specifically members who reside with the person with the disability to be paid caregivers. For the sake of this letter, I will refer to the dominate role as 'parents,' but this would also include older siblings, multigenerational families, etc.

As a parent to Beckett, every week I must decide how I will juggle his appointments, medical needs, and my work life. I direct services for adults with disabilities and am a critical part of our organization. Not only do I provide leadership to my team of about 75+ staff, I also fill in for staff shortages and work 50+ hours weekly. Leaving my job will only increase the strain on community providers with workforce shortages. This has been something I have needed to consider, though, because of my sons needs and the lack of workforce available to support him. I am grateful that my husband, with a less-demanding full-time job, can be counted on to be home every day after work and adjust to be home if Beckett is ill and I am counted on for my job. He also has not pursued leadership within his vocation because of Beckett's needs and my own leadership role. We make decisions like this daily.

As a parent, I will always be dedicated to my child. But Beckett's needs are extraordinary and the work that I do for him is simply beyond that of typical parents. I will always be "mom," but there are many days that reading, making meals, and monitoring his tablet usage would be simpler. I juggle additional roles of physical, occupational and speech therapist, special education teacher, social worker, medical specialist, pharmacist, etc. A peak year, he had over 200 appointments in a year. As a ten-year old, the department of human services says that he can be left alone for approx. 2 hours. Beckett's supervision needs are beyond that—with his seizure disorder and support needs, we would not be able to do that, nor is that likely in the future. I sleep in the same room as him to monitor for seizures, relying on my light sleep patterns to wake if I hear him starting a seizure. Beckett weighs 75 lbs—we lift and reposition him several times a day as he relies on full support for all movement. These are all adjustments that our lives have adapted to, but speak to the extraordinary hours and dedication families commit to.

The workforce shortage does not meet our needs. We have met the authorized hours with paid caregivers one quarter out of 1 year, out of the 10 years. In the last 5 months, we will have cycled through 3 different staff. Supporting Beckett is challenging, but rewarding work. The economy is an employees arena. Providing self-directed support is not enticing for some staff, as I am unable to provide benefits or a competitive wage. I understand that there are fiscal impacts to commit to provide this for families, but downstream, if we don't do something, we are looking at other fiscal impacts, like children needing to be institutionalized so families can work outside the home.

Thank you for your time and consideration. Please vote in favor of SB2276.

Sarah Carlson
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#27025

23.0635.03001

Sixty-eighth
Legislative Assembly
of North Dakota

FIRST ENGROSSMENT

ENGROSSED SENATE BILL NO. 2276

Introduced by

Senators Cleary, Dever, Lee

A BILL ~~for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.~~ for an Act to create and enact a new section to chapter 50-06 of the North Dakota Century Code, relating to a cross-disability advisory council; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

~~**SECTION 1.** A new section to chapter 50-24.1 of the North Dakota Century Code is created and enacted as follows:~~

~~**Eligibility of legally responsible individuals.**~~

~~1. As used in this section:~~
   - ~~a. "Extraordinary care" means care exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical needs, and which is necessary to assure the health and welfare of the individual and avoid institutionalization.~~
   - ~~b. "Legally responsible individual" includes a legal decisionmaker, guardian, or parent who is next-of-kin to an individual with extraordinary medical needs.~~

~~2. The department shall work with the centers for Medicare and Medicaid services to implement a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual. This service option must be available for participants in the Medicaid 1915(c) waivers.~~

~~3. The department may utilize an annual assessment of an eligible individual under this section to determine the level of care authorized and to determine the best interests of the individual.~~

~~4. This section does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.~~

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

Cross-disability advisory council - Appointment - Duties.

1. The cross-disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers. This subsection does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.
2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.
3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.
4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism,

traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

5. The cross-disability advisory council shall:
   a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;
   b. Provide for the active participation of stakeholders, including consumers and providers; and
   c. Receive information from the department and its consultants.

6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

SECTION 2. REPEAL. Section 50-06-32 of the North Dakota Century Code is repealed.

23.0635.03001
Title.

Prepared by the Legislative Council staff for
Representative M. Ruby
March 29, 2023

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2276

Page 1, line 1, after "A BILL" replace the remainder of the bill with " for an Act to create and enact a new section to chapter 50-06 of the North Dakota Century Code, relating to a cross-disability advisory council; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA:

SECTION 1. A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

Cross-disability advisory council - Appointment - Duties.

1. The cross-disability advisory council shall participate with and provide feedback to the department regarding the implementation, planning, and design of the cross-disability children's waiver, level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver, and a service option that will allow payment to a legally responsible individual who provides extraordinary care to an eligible individual through the Medicaid 1915(c) waivers. This subsection does not apply to the Medicaid 1915(c) waiver for home and community-based services, aged and disabled.

2. The department shall contract with a qualified, independent third party to facilitate and provide support services to the council. The contracted facilitator shall appoint the cross-disability advisory council members in accordance with subsection 3 and establish the length of member terms and the structure of the cross-disability advisory council. A representative from the contracted facilitator shall serve as the presiding officer of the advisory council.

3. The cross-disability advisory council consists of up to fifteen voting members. A majority of the members of the council must be family members of individuals with a disability, or must be individuals with a disability, who receive Medicaid home and community-based services. The remaining members of the council must be appointed based on their professional subject matter expertise in or knowledge of the needs and interests of individuals with disabilities. The council's membership must represent different regions of the state and a broad range of disabilities that pertain to the Medicaid home and community-based services. Upon request of the department, state agency representatives shall participate with the cross-disability advisory council in a nonvoting role.

4. The cross-disability advisory council shall meet at least quarterly and may appoint subcommittees to address specific topics or disabilities, which may include autism, traumatic brain injury, and fetal alcohol spectrum disorder. A majority of the voting members of the council constitutes a quorum.

5. The cross-disability advisory council shall:

    a. Discuss strategies to address gaps or needs regarding individuals with disabilities and Medicaid home and community-based services, including eligibility of legally responsible individuals;

    b. Provide for the active participation of stakeholders, including consumers and providers; and

    c. Receive information from the department and its consultants.

6. The cross-disability advisory council members, excluding the contracted facilitator, are entitled to reimbursement from the department for travel and lodging at the same rate as provided for state officers and employees.

SECTION 2. REPEAL. Section 50-06-32 of the North Dakota Century Code is repealed."

Renumber accordingly

SECTION 1. Family Caregiver service pilot project – Legislative management report – Appeal.

1. The department of health and human services shall establish a service pilot project beginning April 1, 2024, to assist in making payments to a legally responsible individual who provides extraordinary care to an eligible individual who is a participant in the Medicaid 1915(c)waivers, excluding the HCBS Aged and Disabled Waiver.
2. The program may include funding for extraordinary care, which means care exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of an individual without extraordinary medical or behavioral needs, and which is necessary to assure the health and welfare of the individual and avoid institutionalization. A legally responsible individual includes a legal decisionmaker, guardian, or parent who is next-of-kin to an individual with extraordinary medical or behavioral needs.
3. The department may adopt rules addressing management of this service program pilot project and establishing the eligibility requirements and exclusions for this service pilot project. The department shall utilize an assessment of an eligible individual to determine the level of care authorized and to determine the best interests of the individual. The pilot may not provide a payment for any care that is otherwise compensated through a Medicaid 1915(c) waiver or the Medicaid State Plan.
4. decision on an application which is issued by the department under this section may be appealed as provided under chapter 28-32. A person may not appeal a denial, revocation, reduction in payment, or the termination of the program of service by the department due to the unavailability of funding received for the purpose of issuing payments as part of the family caregiving service pilot project for the biennium beginning July 1, 2023, and ending June 30, 2025.
5. The department of health and human services shall report to the legislative management regarding the family caregiver service pilot project.

SECTION 2. Department of Health and Human Services Cross-Disability Waiver. The department of health and human services, during the biennium beginning July 1, 2023 and ending June 30, 2025, shall [insert the language re cross disability council and Alvarez report work – Sec 1 from House version of 2276]

SECTION 3. Appropriation – Department of health and human services family caregiver service pilot coordinator. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $300,000 or so much of the sum as may be necessary, to the department of health and human services for the purpose of hiring a state family caregiver service pilot coordinator who would be responsible for implementing the service pilot and for establishment of a payment portal, for the biennium beginning July 1, 2023, and ending June 30, 2025. The department of health and human services is authorized one full-time equivalent position for this purpose. The funding providing under this section is a one-time funding item.

SECTION 4. Appropriation – Department of health and human services – Family Caregiving Service Pilot Project. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of $5,000,000, or so much of the sum as may be necessary, to the department of health and human services, for the purpose of issuing payments as part of the family caregiving service pilot project, beginning January 1, 2024. Participation in this service pilot is capped at 160 individuals. The funding providing under this section is a one-time funding item.

SECTION 5 – Appropriation – Department of health and human services – Cross Disability Council and Waiver. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated the sum of $726,813 and from special funds derived from federal funds and other income, the sum of $726,813, or so much of the sum as may be necessary, to the department of health and human services, for the purpose of supporting the work of the Cross Disability Council and the work of developing the cross disability waiver, beginning August 1, 2023.

SECTION 6. Expiration Date. Given availability of appropriated funds, Section 1 of this Act is effective until such time as an approximately equivalent family caregiving service is available through a Centers for Medicare and Medicaid approved home and community-based waiver(s). Once this service is available via an approved Medicaid waiver, section 1 of this bill is ineffective.