

**2023 SENATE HUMAN SERVICES**

**SB 2335**

# 2023 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**  
Fort Lincoln Room, State Capitol

SB 2335  
2/13/2023

Relating to training and screening for fetal alcohol spectrum disorder and creating a fetal alcohol spectrum disorder council and to provide a report.
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11:18 AM **Madam Chair Lee** called the hearing to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** were present.

## **Discussion Topics:**

- Diagnosis
- Development disorders
- Treatment
- Prenatal exposure to substance drugs
- Brain disfunction

11:19 AM **Senator K. Roers** introduced SB 2335 in favor. #20577

11:21 AM **Carl Young, Executive Director of North Dakota Fetal Alcohol Spectrum Disorder (FASD)**, testified in favor and proposed amendment. #20624, 20625

11:37 AM **Rachel Sinness, Legal Director, North Dakota Protection and Advocacy Project**, testified in favor. #20503

11:42 AM **Kristen Dvorak, Executive Director, The ARC of North Dakota**, testified in favor verbally.

11:44 AM **Larry Burd, Professor and Director of North Dakota Fetal Alcohol Syndrome Center, UND School of Medicine and Health Sciences**, testified online in favor. #20475

11:52 AM **Denise Stopplesworth, foster parent**, testified online in favor. #20570

11:57 AM **Cathy Ferderer, Juvenile Court Coordinator, North Dakota Court System**, testified in opposition and included amendment testimony. #20491

12:03 PM **Tina Bay, Developmental Disabilities Section Director, North Dakota Department of Health and Human Services**, testified neutral. #20562

12:10 PM **Cory Pederson, Director Children and Family Services, ND Department Health and Human Services**, verbally testified neutral.

Senate Human Services Committee

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**Additional written testimony:**

**Donene Feist, Director, Family Voices of North Dakota**, in favor #20555

**Roger and Bobbie Loven**, in opposition #20601

**Mary McCarvel-O'Connor, Special Education Director, North Dakota Department of Public Instruction**, neutral #20578

**Kristen Baesler, State Superintendent, North Dakota Department of Public Instructions**, neutral #20579

12:13 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 2335  
2/15/2023

Relating to training and screening for fetal alcohol spectrum disorder and creating a fetal alcohol spectrum disorder council and to provide a report.
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9:51 AM **Madam Chair Lee** called the meeting to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** are present.

## **Discussion Topics:**

- Symptoms
- Early formal screening
- Health track screening
- Training
- Disability counsel
- Assessment

**Senator Lee** handed out Mary McCarvel-OConner proposed amendment #20577 and discussed it.

10:08 AM **Madam Chair Lee** closed the meeting.

*Patricia Lahr, Committee Clerk*

# 2023 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**  
Fort Lincoln Room, State Capitol

SB 2335  
2/15/2023

Relating to training and screening for fetal alcohol spectrum disorder and creating a fetal alcohol spectrum disorder council and to provide a report.
--

10:30 AM **Madam Chair Lee** called the meeting to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston, Hogan** are present.

**Discussion Topics:**

- Training
- Disability counsel
- Amendment

**Senator Lee** calls for discussion.

**Senator K. Roers** directs intern to distribute amendment, deleting section 1 and 3.

10:32 AM **Madam Chair Lee** closed the meeting.

*Patricia Lahr, Committee Clerk*

# 2023 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**  
Fort Lincoln Room, State Capitol

SB 2335  
2/15/2023

Relating to training and screening for fetal alcohol spectrum disorder and creating a fetal alcohol spectrum disorder council and to provide a report.
--

4:23 PM Madam **Chair Lee** called the meeting to order. **Senators Lee, Cleary, Clemens, K. Roers, Weston** are present. **Senator Hogan** was absent.

**Discussion Topics:**

- Amendment
- Training

**Senator Lee** calls for discussion

**Lindsey Pouliot, Legislative Intern, Legislative Council** provided amendment #20931.

**Senator K. Roes** moved to adopt amendment LC23.0881.01001.

**Senator Weston** seconded the motion.

Roll call vote.

<b>Senators</b>	<b>Vote</b>
Senator Judy Lee	Y
Senator Sean Cleary	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	AB
Senator Kristin Roers	Y
Senator Kent Weston	Y

The motion passed 5-0-1.

**Senator K. Roers** moved **DO PASS** as **AMENDED**.

**Senator Weston** seconded the motion.

Roll call vote.

<b>Senators</b>	<b>Vote</b>
Senator Judy Lee	Y
Senator Sean Cleary	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	AB
Senator Kristin Roers	Y
Senator Kent Weston	Y

Motion passed. 5-0-1

**Senator Cleary** will carry SB 2335

**Additional Testimony:**

**Julie Horntvedt, Executive Director, North Dakota State Council on Developmental Disabilities** in neutral #20929

4:30 PM **Madam Chair Lee** closed the meeting.

*Patricia Lahr, Committee Clerk*

February 15, 2023

AB  
2-15-23  
(1-2)

PROPOSED AMENDMENTS TO SENATE BILL NO. 2335

Page 1, line 1, after "enact" insert "a new section to chapter 1-03,"

Page 1, line 1, after "50-06" insert a comma

Page 1, line 3, replace the first "and" with a comma

Page 1, line 3, replace "fetal alcohol spectrum disorder council" with "cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder"

Page 1, line 4, remove "section 15.1-32-01,"

Page 1, line 4, remove ", and section 27-20.3-04"

Page 1, line 5, remove "; and to provide a report"

Page 1, remove lines 7 through 24

Page 2, replace lines 1 through 18 with:

"**SECTION 1.** A new section to chapter 1-03 of the North Dakota Century Code is created and enacted as follows:

**Fetal alcohol spectrum disorder awareness day.**

To celebrate the life of all affected by fetal alcohol spectrum disorder, reaffirm the dignity and value of every human being, and to create awareness of the number of people affected by the disorder, the ninth day of September of each year is designated and established as fetal alcohol spectrum disorder awareness day for the state of North Dakota.

Page 3, remove lines 9 through 30

Page 4, remove lines 1 through 29

Page 5, remove lines 1 through 31

Page 6, replace lines 1 through 3 with:

"**SECTION 3.** 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 and level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver.
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 members 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.

AG  
2-15-23  
(2-2)

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;
  - 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."

Page 6, remove line 7

Page 6, line 8, remove "complete a course of instruction related to fetal alcohol spectrum disorder."

Page 6, line 9, replace "create the training or provide the training through a third-party vendor" with "integrate fetal alcohol spectrum disorder instruction into the training programs for public and private child welfare providers and foster parents, and further shall integrate a formal fetal alcohol spectrum disorder screening into the early and periodic screening diagnostic and treatment services"

Renumber accordingly

**REPORT OF STANDING COMMITTEE**

**SB 2335: Human Services Committee (Sen. Lee, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (5 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2335 was placed on the Sixth order on the calendar. This bill does not affect workforce development.

Page 1, line 1, after "enact" insert "a new section to chapter 1-03,"

Page 1, line 1, after "50-06" insert a comma

Page 1, line 3, replace the first "and" with a comma

Page 1, line 3, replace "fetal alcohol spectrum disorder council" with "cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder"

Page 1, line 4, remove "section 15.1-32-01,"

Page 1, line 4, remove ", and section 27-20.3-04"

Page 1, line 5, remove "; and to provide a report"

Page 1, remove lines 7 through 24

Page 2, replace lines 1 through 18 with:

**"SECTION 1.** A new section to chapter 1-03 of the North Dakota Century Code is created and enacted as follows:

**Fetal alcohol spectrum disorder awareness day.**

To celebrate the life of all affected by fetal alcohol spectrum disorder, reaffirm the dignity and value of every human being, and to create awareness of the number of people affected by the disorder, the ninth day of September of each year is designated and established as fetal alcohol spectrum disorder awareness day for the state of North Dakota."

Page 3, remove lines 9 through 30

Page 4, remove lines 1 through 29

Page 5, remove lines 1 through 31

Page 6, replace lines 1 through 3 with:

**"SECTION 3.** 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 and level of care reform for the comprehensive developmental disabilities Medicaid home and community-based waiver.
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 members 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;
    - 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."

Page 6, remove line 7

Page 6, line 8, remove "complete a course of instruction related to fetal alcohol spectrum disorder."

Page 6, line 9, replace "create the training or provide the training through a third-party vendor" with "integrate fetal alcohol spectrum disorder instruction into the training programs for public and private child welfare providers and foster parents, and further shall integrate a formal fetal alcohol spectrum disorder screening into the early and periodic screening diagnostic and treatment services"

Renumber accordingly

**2023 HOUSE HUMAN SERVICES**

**SB 2335**

# 2023 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Pioneer Room, State Capitol

SB 2335  
3/14/2023

Relating to training and screening for fetal alcohol spectrum disorder, creating a cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder.
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Chairman Weisz called the meeting to order at 9:32 AM.

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

### **Discussion Topics:**

- Definition of FASD
- Public awareness
- Formal screening

Sen. Roers introduced SB 2335 with supportive testimony.

Carl Young, Executive Director of Fetal Alcohol Spectrum Disorder North Dakota, supportive testimony #27151, #27152.

Rachell Sinness, Legal Support, supportive testimony #24527.

Kim Jacobson, Director for the Agassiz Valley Human Service Zone, supportive testimony #24597.

Kirsten Dvorak, Executive Director of the ARC of North Dakota, supportive testimony.

Tina Bay, Director of the Developmental Disabilities Section with the Department of Health and Human Services, supportive testimony #27153.

Roger Loven, North Dakota citizen, opposition testimony #24735.

Cory Pederson, Director of the Children and Family Services Section with the Department of Health and Human Services, opposition testimony #24576.

### **Additional written testimony:**

Larry Burd, Professor, UND #24537

Donene Feist, Director, Family Voices of ND #24168

Chairman Weisz adjourned the meeting at 10:05 AM.

*Phillip Jacobs, Committee Clerk*

# 2023 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Pioneer Room, State Capitol

SB 2335  
3/20/2023

Relating to training and screening for fetal alcohol spectrum disorder, creating a cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder.

Chairman Weisz called the meeting to order at 3:48 PM.

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

### Discussion Topics:

- Committee work
- Amendments

Chairman Weisz called for a discussion on SB 2335.

Rep. Porter moved to amend SB 2335 by removing section 4.

Seconded by Rep. Frelich.

Motion carries by voice vote.

Rep. Dobervich moved a do pass as amended on SB 2335.

Seconded by Rep. Davis.

### Roll Call Vote:

Representatives	Vote
Representative Robin Weisz	Y
Representative Matthew Ruby	Y
Representative Karen A. Anderson	N
Representative Mike Beltz	Y
Representative Jayme Davis	Y
Representative Gretchen Dobervich	Y
Representative Clayton Fegley	Y
Representative Kathy Frelich	Y
Representative Dawson Holle	N
Representative Dwight Kiefert	Y
Representative Carrie McLeod	Y
Representative Todd Porter	Y

Representative Brandon Prichard	AB
Representative Karen M. Rohr	N

Motion carries 10-3-1.

Carried by Rep. Dobervich.

Chairman Weisz adjourned the meeting at 3:57 PM.

*Phillip Jacobs, Committee Clerk*

**Reconsidered on 3/21/23.**

March 20, 2023

*OK*  
*3-20-23*  
*121*

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2335

Page 1, line 1, replace the comma with "and"

Page 1, line 2, remove ", and section 50-11-01.7"

Page 1, line 2, remove "training and"

Page 1, line 3, remove "screening for fetal alcohol spectrum disorder,"

Page 1, line 3, remove the second comma

Page 3, remove lines 18 through 24

Renumber accordingly



# 2023 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Pioneer Room, State Capitol

SB 2335  
3/21/2023

Relating to training and screening for fetal alcohol spectrum disorder, creating a cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder.

Chairman Weisz called the meeting to order at 11:29 AM.

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

### Discussion Topics:

- Committee work
- Amendments

Chairman Weisz called for a discussion on SB 2335.

Vice Chairman Ruby moved to reconsider the committee's previous actions on SB 2335.

Seconded by Rep. Dobervich.

Motion carries by voice vote.

Vice Chairman Ruby moved to adopt amendment 23.0881.02002 to SB 2335.

Seconded by Rep. Dobervich.

Motion carries by voice vote.

Vice Chairman Ruby moves a do pass as amended on SB 2335.

Seconded by Rep. McLeod.

### Roll Call Vote:

<b>Representatives</b>	<b>Vote</b>
Representative Robin Weisz	Y
Representative Matthew Ruby	Y
Representative Karen A. Anderson	N
Representative Mike Beltz	Y
Representative Jayme Davis	Y
Representative Gretchen Dobervich	Y

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

Motion carries 10-2-2.

Carried by Rep. Dobervich.

Chairman Weisz adjourned the meeting at 11:34 AM.

*Phillip Jacobs, Committee Clerk*

**Reconsidered on 3/29/23.**

March 21, 2023

*OR*  
*171*  
*3-21-23*

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2335

Page 1, line 4, remove the first "and"

Page 1, line 6, after "disorder" insert "; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force"

Page 3, after line 24, insert:

**"SECTION 5. REPEAL.** Section 50-06-32 of the North Dakota Century Code is repealed."

Re-number accordingly

**REPORT OF STANDING COMMITTEE**

**SB 2335, as engrossed: Human Services Committee (Rep. Weisz, Chairman)** recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (10 YEAS, 2 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2335 was placed on the Sixth order on the calendar.

Page 1, line 4, remove the first "and"

Page 1, line 6, after "disorder" insert "; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force"

Page 3, after line 24, insert:

**"SECTION 5. REPEAL.** Section 50-06-32 of the North Dakota Century Code is repealed."

Renumber accordingly

# 2023 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Pioneer Room, State Capitol

SB 2335  
3/29/2023

Relating to training and screening for fetal alcohol spectrum disorder, creating a cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder.
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Chairman Weisz called the meeting to order at 3:15 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
- Reconsideration

Vice Chairman Ruby moved to reconsider the committee's previous actions on SB 2335.

Seconded by Rep. Anderson.

Motion carries by voice vote.

Chairman Weisz adjourned the meeting at 3:16 PM.

*Phillip Jacobs, Committee Clerk*

# 2023 HOUSE STANDING COMMITTEE MINUTES

## Human Services Committee Pioneer Room, State Capitol

SB 2335  
3/29/2023

Relating to training and screening for fetal alcohol spectrum disorder, creating a cross-disability advisory council, and establishing an annual day of awareness for fetal alcohol spectrum disorder.

Chairman Weisz called the meeting to order at 3:30 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
- Amendment

Chairman Weisz called for a discussion on SB 2335.

Vice Chairman Ruby moved to adopt amendment 23.0881.02003 to SB 2335.

Seconded by Rep. Anderson.

Motion carries by voice vote.

Vice Chairman Ruby moved a do pass as amended on SB 2335.

Seconded by Rep. Porter.

### 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 Rep. Dobervich.

Chairman Weisz adjourned the meeting at 3:34 PM.

*Phillip Jacobs, Committee Clerk*

3-29-23  
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PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2335

In lieu of the amendments adopted by the House, as printed on page 1330 of the House Journal, Senate Bill No. 2335 is amended as follows:

Page 1, line 1, remove ", a new section to chapter"

Page 1, line 2, remove "50-06, and section 50-11-01.7"

Page 1, line 2, remove "training and"

Page 1, remove line 3

Page 1, line 4, remove the first "and"

Page 1, line 6, after "disorder" insert "; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force"

Page 2, remove lines 13 through 31

Page 3, replace lines 1 through 24 with:

"**SECTION 3. REPEAL.** Section 50-06-32 of the North Dakota Century Code is repealed."

Re-number accordingly



**REPORT OF STANDING COMMITTEE**

**SB 2335, 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 2335 was placed on the Sixth order on the calendar.

In lieu of the amendments adopted by the House, as printed on page 1330 of the House Journal, Senate Bill No. 2335 is amended as follows:

Page 1, line 1, remove ", a new section to chapter"

Page 1, line 2, remove "50-06, and section 50-11-01.7"

Page 1, line 2, remove "training and"

Page 1, remove line 3

Page 1, line 4, remove the first "and"

Page 1, line 6, after "disorder" insert "; and to repeal section 50-06-32 of the North Dakota Century Code, relating to the autism spectrum disorder task force"

Page 2, remove lines 13 through 31

Page 3, replace lines 1 through 24 with:

**"SECTION 3. REPEAL.** Section 50-06-32 of the North Dakota Century Code is repealed."

Re-number accordingly

**2023 CONFERENCE COMMITTEE**

**SB 2335**

# 2023 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**  
Fort Lincoln Room, State Capitol

SB 2335  
4/24/2023  
Conference Committee

Relating to establishing an annual day of awareness for fetal alcohol spectrum disorder; and to the autism spectrum disorder task force.
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11:30 AM **Roers** opened the conference committee meeting. **Senators K. Roers, Cleary, Hogan and Representatives M. Ruby, Frelich, Dobervich** are present.

## **Discussion Topics:**

- Proposed amendment
- Conference committee decision

**Senator Roers** calls for discussion.

**Committee discussion** SB 2335.

**Senator Hogan** moved Senate accede to House Amendments.

**Senator Cleary** seconded the motion.

**Roll call vote-motion passed 6-0-0.**

**Representative M. Ruby** is the House bill carrier.

**Senator K. Roers** is the Senate bill carrier.

11:32 AM **Chair K. Roers** closed the conference committee meeting.

*Patricia Lahr, Committee Clerk*

Date April 24, 2023

Roll Call Vote #: 1

**2023 SENATE CONFERENCE COMMITTEE  
ROLL CALL VOTES**

BILL/RESOLUTION NO. SB 2335 as 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: Senator Hogan                      Seconded by: Senator Cleary

Senators					Representatives				
	4/24		Yes	No		4/24		Yes	No
K. Roers, Chair	X		Y		M. Ruby, Chair	X		Y	
Cleary	X		Y		Frelich	X		Y	
Hogan	X		Y		Dobervich	X		Y	
Total Senate Vote			3		Total Rep. Vote			3	

Vote Count            Yes: 6                      No: 0                      Absent: 0

Senate Carrier K. Roers                      House Carrier M. Ruby

LC Number \_\_\_\_\_ . \_\_\_\_\_ of amendment

LC Number \_\_\_\_\_ . \_\_\_\_\_ of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

**REPORT OF CONFERENCE COMMITTEE**

**SB 2335, as engrossed:** Your conference committee (Sens. K. Roers, Cleary, Hogan and Reps. M. Ruby, Frelich, Dobervich) recommends that the **SENATE ACCEDE** to the House amendments as printed on SJ page 1702 and place SB 2335 on the Seventh order.

Engrossed SB 2335 was placed on the Seventh order of business on the calendar.

**TESTIMONY**

**SB 2335**

Chairperson Lee,

My name is Dr. Larry Burd. I am a Professor in the Department of Pediatrics at the University of North Dakota School of Medicine and Health Sciences. Thank you for the opportunity to provide testimony today on SB 2335. My testimony provided today are my own opinions and are not on behalf of the University.

8.4% (1 out of 12) pregnant women in North Dakota drink throughout pregnancy. Based on four separate prevalence studies in North Dakota, the prevalence of fetal alcohol spectrum disorders (FASD) ranges from 1 to 5% of live births. In North Dakota, we have about 107 new cases of FASD each year. The mortality rate is over 5%. The recurrence risk within that family is increased by 77%. The annual cost of care for a child with fetal alcohol spectrum disorder (FASD) is increased by \$22,800 and for adults over \$24,300. As a point of comparison fetal alcohol spectrum disorders are twice as common as autism spectrum disorders and the annual cost of care is over 26% greater for FASD.

FASD is a lifetime condition increasing risk for learning impairments, mental health disorders, severe health problems, increased risk for placement in foster care, special education, and contact with juvenile and adult corrections systems. The peak severity of FASD in North Dakota typically occurs at between 22 and 30 years of age.

The North Dakota Fetal Alcohol Syndrome Center diagnostic and treatment center provides services for all of North Dakota. This program has provided services for families from every part of North Dakota. In my 43 years with the University of North Dakota School of Medicine and Health Sciences, I have evaluated and treated over 18,000 children and adults with developmental disorders and severe mental health disorders from every county in North Dakota. We have provided hundreds of training opportunities on FASD for social workers, physicians, nurses, teachers, substance use disorder treatment programs, and corrections and court personnel.

People with FASD require early intervention, appropriate treatment, and care from multiple service systems. After 40 plus years of working with people with FASD, I assure you it is not less expensive or



more efficient to utilize a poorly coordinated system of services for people with FASD and serve them occasionally or only when diagnosed with some other condition.

**Senate Bill No. 2335**  
**Senate Human Service Committee**  
**Testimony Presented by**  
**Cathy Ferderer, Juvenile Court Coordinator**  
**February 13, 2023**

For the record, my name is Cathy Ferderer, and I am the Juvenile Court Coordinator for the State Court Administrator's Office. I am appearing today on Senate Bill 2335 to offer testimony in opposition to a section of the bill.

SB 2335 amends Chapter 27-20.3-04 Powers and Duties of Director of Juvenile Court beginning on Section 3 lines 20-21. The amendment designates the director of the juvenile court to assess or screen each child in need of service or child in need of protection for fetal alcohol spectrum disorder. The court has several concerns with this language. First, the director of the juvenile court does not provide case management services to children subject to a child in need of service or a child in need of protection referral. Those referral types are sent to the Human Service Zone who provide services.

Secondly, according to the National Institutes of Health, screenings for Fetal Alcohol Spectrum Disorders should include checks for intellectual disabilities and developmental delays, screening for specific physical features such as small head, small eyes, thin upper lip, below average weight and height, short attention span, problems with impulse control, poor coordination, vision and hearing impairment. This would require the director to meet with each of these children in person to make such observations as well as require specific training. The director of the juvenile court does not have the access to children referred to the human service zones, the specific training, or the background to complete these screenings.

I will stand for any questions.

**Senate Human Services Committee**  
**Senate Bill 2335 – February 13, 2023**  
**Testimony of Rachel Sinness, P&A Legal Director**

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 provides testimony in favor of SB 2335 relating to changes in statute to accommodate fetal alcohol spectrum disorder. Approximately 1 in 20 North Dakotans have or will be diagnosed with a fetal alcohol spectrum disorder (FASD). The average annual cost in North Dakota for FASD cases is \$470 million. FASD accounts for 1% of live births in North Dakota and is 2.5 times more prevalent than Autism. Despite its prevalence, North Dakota's definition of "developmental disability" currently does not include FASD, and students with FASD are currently not considered students with a disability. These exclusions, lack of training, and lack of screening and treatment result in an inability to receive developmental disability services, high rates of incarceration and recidivism among those who have FASD, and higher than average school exclusion rates.

Alaska, New York, and neighboring state Minnesota have already included FASD in their statutory definitions of "developmental disability." Individuals diagnosed with FASD are entitled to the same level of services as for any other developmental disability and have a basis to get those services provided immediately.<sup>1</sup> Minnesota has also implemented training on the prevention of FASD,<sup>2</sup> as well as prenatal alcohol exposure

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<sup>1</sup> [FASD: Identification and Advocacy \(americanbar.org\)](https://www.americanbar.org/resources/publications/fasd-identification-and-advocacy/)

<sup>2</sup> [Sec. 245A.175 MN Statutes](#)

screening for children entering foster care,<sup>3</sup> much like the efforts put before the North Dakota Legislature through this proposed legislation. While Minnesota's legislation is relatively new, having been adopted in 2022, the state is seeing encouraging results in the identification of children with prenatal exposure to alcohol and FASD training,<sup>4</sup> and families are receiving much needed supports.<sup>5</sup>

P&A would like to see vast improvements in this area in North Dakota; we are concerned about the prevalence of FASD, its economic impact on North Dakota and North Dakota families, and the lack of services available to those who are diagnosed with FASD. P&A supports any and all efforts to make FASD more visible in North Dakota and to make treatments available to individuals whom P&A serves. P&A urges a DO PASS on SB 2335.

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<sup>3</sup> [Sec. 260C.219 MN Statutes](#)

<sup>4</sup> [Landmark Legislation: A Victory for the FASD Community - Proof Alliance](#)

<sup>5</sup> [Support - Proof Alliance](#)

Senate Human Services Committee  
Senate Bill 2335 – February 13, 2023

Senator Lee and Committee Member,

My name is Donene Feist and I am the Director of Family Voices of North Dakota

We are providing favorable testimony in favor of SB2335.

We have heard from many families of children with FAS who fall into the gaps. Because of ND definition of developmental disabilities does not include FASD, many of these children have few to no resources.

Family Voices is very concerned about the continued gaps for families, lack of resources and economic impact for these families. The most we can do is provide 1:1 emotional support or connect them to others who are also facing the same issues or provide a referral to the North Dakota Fetal Alcohol Syndrome Center diagnostic and treatment center which provides wonderful services to families.

Families are struggling.

A council would be beneficial to understand and identify next steps, ongoing needs and impact. Having a council that focuses on the needs of all affected by FASD is vital.

Thank you for your time

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

**Testimony  
Senate Bill No. 2335  
Senate Human Services Committee  
Senator Lee, Chairman  
February 13, 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 am here today to provide information on Senate Bill 2335 for your consideration as you review the bill.

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

The second eligibility determination must be completed if the individual wishes to access long term care services that are funded through the Centers for Medicare and Medicaid Services (CMS). To meet this eligibility, the individual must meet the criteria that has been established

for the Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/IID) level of care.

States are advised that this level of care is defined in 42 CFR §440.150(a)(2) as serving persons with “intellectual disability or persons with related conditions.” Participants linked to the ICF/IID level of care must meet the “related condition” definition when they are not diagnosed as having an intellectual disability.

It is important to note that people who qualify as having a “developmental disability” under the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 do not always meet an ICF/IID level of care. While there is overlap between “developmental disability” and “related conditions”, they are not equivalent. The definition of related conditions (42 CFR §435.1009) is functional; it is not tied to a fixed list of conditions.

Section 2 of the Bill, page 2, lines 23 through 25, appears to communicate intent is to create automatic eligibility for Medicaid-funded DD services for individuals diagnosed with Fetal Alcohol Spectrum (FAS) disorders. SB 2335 amends the definition of developmental disability in section 25-01.2-01 of the North Dakota Century Code, and therefore automatic eligibility via 75-04-06, access to the waiver and then Medicaid.

As per CMS guidelines, if an individual does not have a diagnosis of intellectual disability, they must meet the definition of “related condition” under 42 CFR §435.1009 to qualify for level of care and waiver services. CMS does not allow states the option to establish automatic eligible by

diagnosis for the DD HCBS waiver; an individualized determination of eligibility is required.

Section 4, pages 4 and 5, calls for the creation of an FAS Council. The Alvarez and Marsal report, which was drafted in response to 67<sup>th</sup> Legislative Assembly Senate Bill 2256, and HB 1035 which is being considered in the 68<sup>th</sup> Legislative Assembly, recommend the creation of a cross disability advisory council. FAS would be encompassed in the cross-disability advisory council. The Alvarez and Marsal report also recommends that the level of care for the DD waiver be updated to recognize adaptive social deficits. The implementation of this, and other recommendations, would likely affect individuals with FAS. The Department's ability to work with stakeholders to move this work forward will depend both on legislation under consideration and resources the legislature will make available to support the effort.

Regarding Section 5 the Department requests that the Committee consider removing the requirement, found on page 6 lines 7 through 10, that would require all foster parents "before initial licensure or licensure renewal" to "complete a course of instruction related to fetal alcohol spectrum disorder".

The Department provides training and resources to foster parents related to a variety of the complex needs that children in their care may have. This bill would call out training on FAS as the only diagnosis-specific training requirement for foster families.

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



Hello,

My name is Denise Stoppleworth and I am the mother of three brothers who are all diagnosed with FASD. I want to talk to you today to implore you to pass these measures and consider other measures that can help support kids like mine. But first, I would like to share a bit of our story.

Seven years ago, our three children were in high school, and college and life had quieted down a bit for us. Then, one day my middle daughter and I convinced my husband to try being a foster parent. We love kids and our hearts broke for those kids who had been traumatized and felt unloved and abandoned. My husband reluctantly agreed. Shortly after we got our license, we got a call to do respite care for another foster parent. It was a weekend placement only and it was two little boys aged 4 years and 3 months. Shortly after that respite weekend, we received a call that those boys needed to be moved because things weren't working out. We were told it would be a short placement – maybe 3 months -- and then they would be going to a relative. We agreed to take these boys making a pact that we would not move them no matter what because we didn't want to add to the trauma. Little did we know that within 3 weeks, that short placement would turn into a "longer term" placement and a year later, we would be faced with the decision to welcome their baby brother into our home as well. I will never forget that day. The younger of the two boys we were fostering was barely sleeping at night and we were exhausted. He would often need to be held all the time. He had digestive issues that meant when he had a bowel movement, he would scream, there would be blood and he would get so worked up milk would come out of his mouth and nose. I was exhausted and trying to run my business and maintain my sanity. We were given an hour to decide if we would accept their 4-week-old little brother. I went into my husband's office and cried as I told him I didn't know that I could take another child. Then, this amazing husband and father who hadn't wanted to take on fostering in the first place, looked at me and said "They are brothers. We owe it to them to at least try." And just like that, we went to the parking lot of the grocery store and picked up another baby.

The new baby also had digestive issues and he threw up all the time. We would change his clothes four or more times a day. We had no idea why and would ask doctors but got no answers. Soon our second foster son started biting kids at daycare multiple times a day. He was only a year old, and it seemed odd to be biting. He seemed too young. We almost got kicked out of daycare. By this time, they were terminating parental rights and we faced the decision to apply for adoption of the boys. This was more than we had planned on, and we were in uncharted waters. We were the only family the two youngest ever knew and all of them already felt like our family. But we knew we had a lot on our plate and didn't know what the future would hold. We were getting the boys whatever help we could to address behavioral issues and what seemed like willful disobedience to not listen to directions or lie about things. We asked the counselors what the substance abuse by mom during pregnancy meant for the future. We got very general and broad answers like they might have issues with attention or impulse but we were always told it's hard to tell. We didn't know what any of that meant.

We moved forward with adoption. Meanwhile, we saw behavior issues getting worse and shoes were being thrown at teachers in daycare, sugar became an addiction, sleep never got better and biting and digestive issues persisted. We upped the talk therapy hoping that if they worked through the trauma, we would get on top of it. We learned how to offer consequences for bad behavior and yet we didn't see any changes. Finally, we were sent to a doctor for testing, and we got a diagnosis of FASD and ADHD, but again that meant nothing to us. They were letters and spectrums, but they didn't really tell us a lot. We saw learning disabilities in school and had to fight for help for our kids because apparently being in the 45% is considered acceptable for students, even though this will set them up for failure as they get older and need the reading for every other subject. We also found out that sensory processing was an issue and that is likely why we saw the biting, so we got a biting necklace to help. But I still knew nothing of what to do or how to help.

Time passed and the boys grew and suddenly we started seeing amplified lashing out at home. Things were intentionally broken, small things would suddenly blow up into words that were just awful and heartbreaking. Things so mean were said to me that I would break down crying. I could see after that my boys felt awful and would cry over how they had hurt me, but then the next day the same thing happened all over again. If they were told no, meltdowns would begin. We started having behavioral issues at school and I was told my son was losing friends. We then saw behavior issues at home where he would physically attack me and his father, threaten to kill us or his siblings, say he was going to run out into the street in front of a car and kill himself. Trust me when I say I have experienced and heard things from a 5-, 6- and 7-year-old that you could never comprehend. I would watch while time after time my sons would impulsively run out into the middle of traffic without looking or thinking and even after being lectured 100 times about the danger, it happens again and again. Our kids started licking shopping carts, eating paper, chewing on all kinds of things and I became frustrated. Notes from 1<sup>st</sup> grade and Kindergarten teachers have gotten more and more negative and I fear my kid is getting labeled as a bad kid. Now it is what they are calling stealing and lying. My kids are being labeled and their self-esteem is plummeting. We've lost friends because they can't handle our kids and we are isolated.

In desperation I finally found an online support group and training for \$1,000 that promised to give us hope. Slowly I am learning to do different. I am learning that everything I did – we did – was wrong or not enough. I am trying to share this with the school but because my kid looks normal and talks normal, they don't recognize the disability and still punish behaviors. I ask for the supports they need but because there is not training, they don't understand and don't accommodate and therefore my son doesn't get the help and things get worse. There is so much we could have done to support our sons and help them with success. There is so much yet to do by us and by our schools and communities. And it all starts with you. If we know better. We can do better.

Have you heard any of the information about the concussion issues in football? Have you seen the movie concussion? Well, that is my kids. Except rather than getting it from playing football, they were born with a brain injury. For them to process anything is so much harder than for you

and me. And so little is understood about this. But what we do know is that as soon as we can change the environment and give them support – rather than continuing to get worse like with CTE – our kids will stabilize and maybe even improve. Key to that is early diagnosis so instead of continuing to make our kids feel bad about the outbursts and shame them for impulse control when it is their brain function, we can intervene to avoid triggers and support them to build self-control. We hound them about school and make them go to summer school rather than provide them the support they need to be successful and recognize that our expectations of these kids can't be the same. We wouldn't expect a paraplegic to run laps in gym. So why are we expecting these kids to write neat, or complete as much work as we expect those who don't have their disability do.

Do you know that my kids – though I will love them and treat them the same as my straight A kids one of whom received the National Merit Scholarship – are going to be much more likely to end up in trouble with the law, teen parents, homeless, or even deceased. Some studies show that kids with FASD will die by age 35. Pretty grim. The only thing that will help? Meeting them where they are. Providing the support, they need. Putting accommodations in place to help them. Changing their environment. These are the things we can do to stabilize their brain and give them hope for success. These are the things that can keep them out of our jails or foster care systems. But we can't do that if we don't know. We can't do it if we don't have the system in place. That's your job. You can dedicate the resources now or pay for it later in the legal system or homeless and addiction issues. We need testing and awareness for all foster and adoptive parents. We need classes on what the FASD and sensory issues mean in real life and how to support our kids through it. We need education for our school teachers and mandated help for these kids. Please help us get education and supports in our schools because they are failing kids like mine. They are beating them down and making them feel worse. They are singling them out and making them the bad kid. It's not because they are awful people. It's because they don't understand and they don't have the education. I didn't either and I would have judged these kids to just be rotten kids. Now I know these kids have so many amazing strengths to share but we need to learn how to tap into them.

My kids each have special gifts. They are sweet, funny, amazing at gymnastics and basketball, dedicated to helping others. They are prayer warriors for anyone in need and defenders of those getting bullied. They have so much to offer. They just need us to believe in them and provide the support and help they need. We need everyone to recognize that their disability is no different than paralysis or blindness. It does not diminish their value as a person but rather requires a special kind of love and support. Please pass this bill and continue to work to help these kids.

23.0881.01000

Sixty-eighth  
Legislative Assembly  
of North Dakota

**SENATE BILL NO. 2335**

Introduced by

Senators K. Roers, Dever, Lee

Representatives Beltz, Nelson

1 A BILL for an Act to create and enact a new section to chapter 50-06 and section 50-11-01.7 of  
2 the North Dakota Century Code, relating to training and screening for fetal alcohol spectrum  
3 disorder and creating a fetal alcohol spectrum disorder council; and to amend and reenact  
4 section 15.1-32-01, subsection 3 of section 25-01.2-01, and section 27-20.3-04 of the North  
5 Dakota Century Code, relating to fetal alcohol spectrum disorder; and to provide a report.

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

7 **SECTION 1. AMENDMENT.** Section 15.1-32-01 of the North Dakota Century Code is  
8 amended and reenacted as follows:

9 **15.1-32-01. Definitions.**

10 As used in this chapter:

- 11 1. "Related services" means transportation and developmental and corrective or  
12 supportive services required to assist a student with disabilities to benefit from special  
13 education.
- 14 2. "Special education" means instruction designed to meet the needs of a student with  
15 disabilities, transportation, and corrective and supporting services required to assist a  
16 student with disabilities in taking advantage of, or responding to, educational programs  
17 and opportunities.
- 18 3. "Student who is gifted" means an individual who is identified by qualified professionals  
19 as being capable of high performance and who needs educational programs and  
20 services beyond those normally provided in a regular education program.
- 21 4. a. "Student with a disability" means an individual who is at least three years of age  
22 but who has not reached the age of twenty-one before August first of the year in  
23 which the individual turns twenty-one and who requires special education and  
24 related services because of:

- 1 (1) An intellectual disability;
- 2 (2) A hearing impairment, including deafness;
- 3 (3) Deaf-blindness;
- 4 (4) A speech or language impairment;
- 5 (5) A visual impairment, including blindness;
- 6 (6) An emotional disturbance;
- 7 (7) An orthopedic impairment;
- 8 (8) ~~Fetal alcohol spectrum disorder;~~
- 9 ~~(9)~~(8) Autism;
- 10 ~~(9)~~~~(10)~~(9) A traumatic brain injury;
- 11 ~~(10)~~~~(11)~~(10) Other health impairment; or
- 12 ~~(11)~~~~(12)~~(11) A specific learning disability.

- 13 b. "Student with a disability" includes a student age eighteen through twenty-one
- 14 who is incarcerated in an adult correctional facility and who, in the last
- 15 educational placement prior to incarceration, was identified as being a student
- 16 with a disability and did not have an individualized education program or was
- 17 identified as being a student with a disability and had an individualized education
- 18 program.

19 **SECTION 2. AMENDMENT.** Subsection 3 of section 25-01.2-01 of the North Dakota  
20 Century Code is amended and reenacted as follows:

- 21 3. "Developmental disability" means a severe, chronic disability of an individual which:
  - 22 a. Is attributable to a mental or physical impairment or combination of mental and
  - 23 physical impairments, including Down syndrome and fetal alcohol spectrum
  - 24 disorders, including fetal alcohol syndrome, partial fetal alcohol syndrome, and
  - 25 alcohol-related neurodevelopmental disorder;
  - 26 b. Is manifested before the individual attains age twenty-two;
  - 27 c. Is likely to continue indefinitely;
  - 28 d. Results in substantial functional limitations in three or more of the following areas
  - 29 of major life activity:
    - 30 (1) Self-care;
    - 31 (2) Receptive and expressive language;

- 1 (3) Learning;
- 2 (4) Mobility;
- 3 (5) Self-direction;
- 4 (6) Capacity for independent living; and
- 5 (7) Economic sufficiency; and
- 6 e. Reflects the individual's needs for a combination and sequence of special,
- 7 interdisciplinary, or generic care, treatment, or other services which are of lifelong
- 8 or extended duration and are individually planned and coordinated.

9 **SECTION 3. AMENDMENT.** Section 27-20.3-04 of the North Dakota Century Code is  
10 amended and reenacted as follows:

11 **27-20.3-04. Powers and duties of director of juvenile court.**

- 12 1. For the purpose of carrying out the objectives and purposes of this chapter and
- 13 subject to the limitations of this chapter or imposed by the court, a director shall:
  - 14 a. Make investigations, reports, and recommendations to the juvenile court.
  - 15 b. Receive and examine referrals of a child in need of services or child in need of
  - 16 protection for the purpose of considering diversion of services.
  - 17 c. Make a determination upon intake of referrals regarding the appropriate manner
  - 18 to handle delinquent conduct, a child in need of services, or a child in need of
  - 19 protection under this chapter.
  - 20 d. Assess or screen each child in need of services or child in need of protection for
  - 21 fetal alcohol spectrum disorder.
  - 22 e. Make appropriate referrals to other private or public agencies of the community if
  - 23 their assistance appears to be needed or desirable.
  - 24 e.f. Issue a temporary custody order concerning a child who is referred to the
  - 25 director's supervision or care as a child in need of services or a child in need of
  - 26 protection. Except as provided by this chapter, a director does not have the
  - 27 powers of a law enforcement officer.
  - 28 f.g. Take acknowledgments of instruments for the purpose of this chapter.
  - 29 g.h. Make such temporary order not to exceed ninety-six hours for the custody and
  - 30 control of a child alleged to be in need of services or protection as may be

1                   deemed appropriate. The order must be reduced to writing within twenty-four  
2                   hours, excluding holidays and weekends.

3           h.i.   Perform all other functions designated by this chapter or under section 27-05-30  
4                   or by order of the court, including, if qualified, those of a referee.

5           i.j.   Issue an order to a law enforcement authority to transport a child to and from a  
6                   specified location.

7           j.k.   Receive and examine requests for review of a child's placement at a qualified  
8                   residential treatment program under the Family First Prevention Services Act  
9                   [Pub. L. 115-123; 132 Stat. 64; 42 U.S.C. 675].

10          2.   Any of the foregoing functions may be performed in another state if authorized by the  
11               court of this state and permitted by the laws of the other state.

12          **SECTION 4.** A new section to chapter 50-06 of the North Dakota Century Code is created  
13          and enacted as follows:

14          **Fetal alcohol spectrum disorder council - Appointment - Duties - Annual reports to**  
15          **governor and legislative management.**

16          1.   The fetal alcohol spectrum disorder council consists of:

17           a.   The executive director of the department, or the executive director's designee;

18           b.   The superintendent of public instruction, or the superintendent's designee;

19           c.   The executive director of the North Dakota protection and advocacy project, or  
20               the director's designee;

21           d.   The director of the fetal alcohol spectrum disorder clinic at the university of North  
22               Dakota, or the director's designee;

23           e.   A member of the house of representatives from an even-numbered legislative  
24               district and a member of the house of representatives from an odd-numbered  
25               legislative district appointed by the majority leader of the house of  
26               representatives to serve two-year terms;

27           f.   A member of the senate from an even-numbered legislative district and a  
28               member of the senate from an odd-numbered legislative district appointed by the  
29               majority leader of the senate to serve two-year terms;

- 1           g. The executive director of an organization that provides services and support to  
2           the fetal alcohol spectrum disorder community, or the executive director's  
3           designee;
- 4           h. The director of the state council on developmental disabilities, or the director's  
5           designee; and
- 6           i. The following members appointed by the governor:
- 7           (1) A pediatrician with expertise in the area of fetal alcohol spectrum disorder;  
8           (2) A college of education faculty member with expertise in the area of fetal  
9           alcohol spectrum disorder;
- 10          (3) A behavioral specialist;
- 11          (4) A representative of a licensed residential care facility providing care and  
12          services to an individual with fetal alcohol spectrum disorder;
- 13          (5) An enrolled member of a federally recognized Indian tribe;
- 14          (6) An adult self-advocate with fetal alcohol spectrum disorder; and
- 15          (7) Four parents of a child with fetal alcohol spectrum disorder.
- 16          2. The council shall elect a chairman.
- 17          3. The council shall meet at least quarterly at the call of the chairman.
- 18          4. The council shall examine:
- 19           a. Early intervention services;
- 20           b. Family support services enabling an individual with fetal alcohol spectrum  
21           disorder to remain in the least restrictive home-based or community setting;
- 22           c. Programs transitioning an individual with fetal alcohol spectrum disorder from a  
23           school-based setting to adult day programs;
- 24           d. Workforce development programs;
- 25           e. The cost of providing services; and
- 26           f. Federal resources providing services for individuals with fetal alcohol syndrome  
27           disorder.
- 28          5. The council shall develop a state fetal alcohol spectrum disorder plan and present the  
29          plan to the governor and a legislative interim committee designated by the chairman of  
30          the legislative management before July 1, 2024. The council shall continue to review  
31          and periodically update or amend the plan to best serve the needs of individuals with



1           fetal alcohol spectrum disorder and provide an annual report to the governor and a  
2           legislative interim committee designated by the chairman of the legislative  
3           management regarding the status of the plan.

4           **SECTION 5.** Section 50-11-01.7 of the North Dakota Century Code is created and enacted  
5 as follows:

6           **50-11-01.7. Fetal alcohol spectrum disorder training.**

7           Before an initial licensure or licensure renewal under this chapter, each foster parent shall  
8 complete a course of instruction related to fetal alcohol spectrum disorder. The department shall  
9 create the training or provide the training through a third-party vendor. The course may be  
10 provided electronically.

**From:** [Lee, Judy E.](#)  
**To:** [-Grp-NDLA Senate Human Services](#); [Wolf, Sheldon](#); [Lahr, Pat](#); [NDLA, Intern 02 - Pouliot, Lindsey](#)  
**Subject:** FW: private schools and IEPs  
**Date:** Sunday, February 12, 2023 10:29:49 PM  
**Attachments:** [image002.png](#)  
[image005.png](#)

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Information about amendment to 2335.

Senator Judy Lee  
 1822 Brentwood Court  
 West Fargo, ND 58078  
 Home phone: 701-282-6512  
 Email: [jlee@ndlegis.gov](mailto:jlee@ndlegis.gov)

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**From:** McCarvel-O'Connor, Mary K. <[moconnor@nd.gov](mailto:moconnor@nd.gov)>  
**Sent:** Thursday, May 19, 2022 2:23 PM  
**To:** Baesler, Kirsten K. <[kbaesler@nd.gov](mailto:kbaesler@nd.gov)>; Lee, Judy E. <[jlee@nd.gov](mailto:jlee@nd.gov)>  
**Subject:** RE: private schools and IEPs

Kirsten,

Even though ISPs are given to a student with a disability in private schools some may not receive an ISP because the LEA is only required to spend a proportionate amount of their IDEA federal funds to provide equitable services for this group. So, when the LEA consults with the private school to determine which services to provide it may not meet the needs of all the students so therefore that student might not receive an ISP.

As far as your question if a private school is required to accept students with learning disabilities, IDEA is silent about this issue. This might fall under Section 504 but I am not sure if all private schools must follow that law or only those who receive some sort of federal funding.

Mary



**Mary McCarvel-O'Connor**  
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[www.nd.gov/dpi](http://www.nd.gov/dpi)




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**From:** Baesler, Kirsten K. <[kbaesler@nd.gov](mailto:kbaesler@nd.gov)>  
**Sent:** Thursday, May 19, 2022 1:18 PM  
**To:** McCarvel-O'Connor, Mary K. <[moconnor@nd.gov](mailto:moconnor@nd.gov)>; Lee, Judy E. <[jlee@nd.gov](mailto:jlee@nd.gov)>

**Subject:** RE: private schools and IEPs

Mary,

Are private schools **required** to accept students with learning disabilities? And the subsequently provide an ISP?



**Kirsten Baesler**

State Superintendent  
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-

---

**From:** McCarvel-O'Connor, Mary K. <[moconnor@nd.gov](mailto:moconnor@nd.gov)>

**Sent:** Thursday, May 19, 2022 1:08 PM

**To:** Baesler, Kirsten K. <[kbaesler@nd.gov](mailto:kbaesler@nd.gov)>; Lee, Judy E. <[jlee@nd.gov](mailto:jlee@nd.gov)>

**Subject:** RE: private schools and IEPs

Senator Lee,

When parents choose to enroll their child in an approved private school, either nonsectarian or religiously affiliated, the student is placed on an Individualized Service Plan (ISP) rather than an Individualized Education Program (IEP). On the ISP, the student is entitled to some special education and related services provided by the local LEA but not all the services he/she would receive if on an IEP. Please let me know if you have any other questions.

Mary



**Mary McCarvel-O'Connor**

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---

**From:** Baesler, Kirsten K. <[kbaesler@nd.gov](mailto:kbaesler@nd.gov)>

**Sent:** Thursday, May 19, 2022 12:22 PM

**To:** McCarvel-O'Connor, Mary K. <[moconnor@nd.gov](mailto:moconnor@nd.gov)>; Lee, Judy E. <[jlee@nd.gov](mailto:jlee@nd.gov)>

**Subject:** FW: private schools and IEPs

Senator Lee,

I believe you are correct that there are no requirements for private schools to offer IEP services, but I include Mary McCarvel-O'Connor on this message to provide confirmation and more information if needed. Mary is the Director of NDDPI's Office of Special Education.



**Kirsten Baesler**

State Superintendent

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-

From: **Lee, Judy E.** <[jlee@nd.gov](mailto:jlee@nd.gov)>

Date: Wed, May 18, 2022 at 5:35 PM

Subject: private schools and IEPs

To: Kirsten Baesler <[baesler.kirsten@gmail.com](mailto:baesler.kirsten@gmail.com)>

Kirsten –

I just got a call from a constituent who is the father of an infant with some significant health issues which may result in intellectual challenges and an IEP, although there is no way to know right now. The little boy and his parents are receiving services through Anne Carlsen Center and others, so all is going fine now.

The father has been reading about the new Capstone Academy here, and the school is now taking names for 4 years out, so he'd like to enroll his baby now for entry down the road. I suggested he find out about pre-K and K, as well as learning more about what services are available in the public schools, because they're pretty darned good. Capstone is planning for 600 students.

He spoke with a Capstone employee who told him that they will not be dealing with IEPs. Along with him, I have concerns about that. I told him that the private school students receive services, including extra-curricular activities, from the public schools, but that he needs to learn more about how Capstone plans to cooperate with the public schools and whether or not they will offer any special services. It does not sound like it, at first blush.

So the question he has that I cannot answer is whether or not there are any requirements for private schools to provide services. I did tell him that private and home school can access services, but I do not know if there is any requirement that they do so.

Can you clarify that for us, please?

Senator Judy Lee

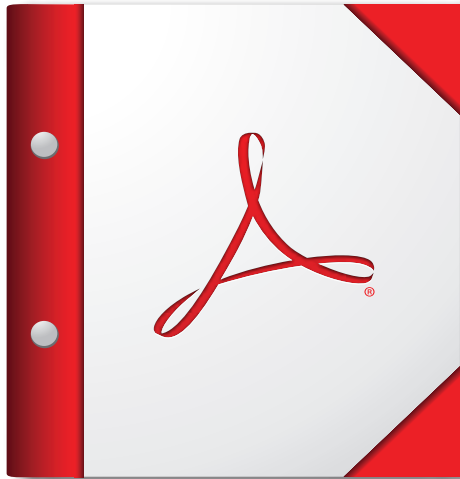
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**Senate Bill number 2335**  
**Senate Human Service Committee**  
**Testimony by Roger Loven**  
**February 13, 2023**

Chairman Lee and Honorable Senators of the Human Services Committee, I am writing in opposition to Section 5 of Senate Bill 2335.

My name is Roger Loven. My wife and I have been foster parents in Burleigh County since 1991. Over the past 32 years we have been privileged care for nearly 70 North Dakota children who have needed care outside of their home. I am a retired physician, having practiced anesthesiology in Bismarck for 35 years.

I am very much in favor of the State of North Dakota doing what it can to prevent Fetal Alcohol Syndrome. This syndrome can be very debilitating to the victim of FAS and challenging to the family members.

I am not in favor of requiring annual training for every foster parent for licensure renewal. Foster parents are required to have at least 12 hours of CEUs each year and there is a wide variety of opportunities for that training. Fetal Alcohol Syndrome has been part of the continuing education that my wife and I have attended. This bill lists at least 9 other diagnosis that foster parents deal with consistently and there are many other diseases/syndromes that foster children have been diagnosed with. Foster parents should not have a list of syndromes/diseases which require annual mandated training. I find that foster parents seek out information on the conditions that their current foster children are facing.

Senator Lee, members of the committee, my name is Carl Young. I am the Executive Director of FASD-ND. Formerly known as Family Services Network, Inc. We are a small organization that supports families across North Dakota. From the oil fields of the Bakken to the Red River Valley, no part of our state is untouched by Fetal Alcohol Spectrum Disorder. I will reference the disorder as FASD throughout the remainder of my testimony.

If I may begin with a brief education about just what FASD is. FASD is an umbrella diagnosis much like Autism Spectrum Disorder that encompasses a number of diagnoses. These diagnoses include fetal alcohol syndrome, partial fetal alcohol syndrome, and alcohol-related neurodevelopmental disorder. More than 50 years ago clinicians made the link between alcohol consumption and developmental delays caused during the pregnancy this is where the first references to "Fetal Alcohol Syndrome" can be found. While it is still a diagnosis under the umbrella term of FASD, it does not include a significant number of those individuals affected by exposure to drugs in the womb.

Why FASD? Why not opioid spectrum disorder or meth spectrum disorder? Alcohol is more harmful on the developing embryo than any drug you buy on the street today. Most birth moms that we have communicated with were drinking up until they discovered that they were pregnant. From the moment of conception, alcohol consumed will harm the developing baby. No amount of alcohol is safe. The THC in cannabis is far less harmful to the developing baby.

As research evolves, I can only imagine that additional discoveries will be made, and other diagnoses will be added to the umbrella.

For years, we have struggled with finding adequate supports for children born substance exposed. Often parents pull from a myriad of services for other disorders or mental health conditions. I know some pediatricians who refuse to give a diagnosis of FASD because of the lack of services available for the child and their family. Instead, the child is given a diagnosis of Autism.



FASD is two times more common than autism spectrum disorder. For example, if the average classroom size in North Dakota is 25 students, (at least in the larger communities) this would mean that 1 child in every classroom likely has some degree of FASD. Most of those children are undiagnosed. If everyone in North Dakota who has FASD were properly diagnosed, it would rival the population of the city of Mandan in size.

Schools struggle with behaviors in the children under their care. I propose that at least a portion of those children have FASD and are exhibiting symptoms of the disorder, and not behaviors. Changing how we view those with FASD, and understanding that these children are displaying symptoms will change how we treat them. It can change how their peers treat them.

Recently in a conversation with a school administrator, he indicated that there were likely at least 3 kids in his care that might have FASD. Not based on facial features. But based on their symptoms. FASD harms the prefrontal cortex. It limits Executive Function. It disables that internal voice that says "don't do this". As a result, you have a child with impulse control issues, a strong fight or flight instinct, and limited social emotional abilities. They have a difficult time relating to their peers, and can present to be much more functional than they actually are.

In the foster care system, I hear from families that struggle. The result is that the foster child is bumped from home to home. This causes great instability and a lack of trust. Most of the families that I work with are foster to adopt families.

As a parent of a child with FASD, I can tell you with certainty that the school to prison pipeline is an unmitigated success. Our son was diagnosed at age 15. Because he lacked the facial features that were in the initial diagnostic criteria for FAS, he was given the diagnosis of prenatal alcohol exposure. He is 21 currently and housed at the Cass County jail in Fargo. Prior to that, he was in prison for arson. He has had more than a dozen charges in the last 3 years, including 6 felonies. We don't excuse his behaviors.

We blame his symptoms. To quote him, "Dad, I can't get support. Most don't have what they call the capacity to help me." In addition because of the felony convictions, he has a difficult time finding adequate employment and housing. Outside of prison and jail, he is homeless.

My son is 21 physically, developmentally he is about 10. It wasn't until he turned 19 that he was granted services through the states developmental disability system.

I have reviewed this bill at length since its inception. I would recommend a couple of small modifications if I may. First, the FASD Council should have a sunset clause. Give them 10 years. Second, Given the severity of this particular issue, I would add a Section 6 to the bill. Declare September 9<sup>th</sup> of each year as FASD Awareness Day across North Dakota.

I will stand for any questions.

**SECTION 6.** A new section to chapter 1-03 of the North Dakota Century Code is created and enacted as follows:

**Fetal Alcohol Spectrum Disorder Awareness Day.**

To celebrate the life of all affected by Fetal Alcohol Spectrum Disorder, reaffirm the dignity and value of every human being, and to create awareness of the number of people affected by this disorder, the ninth day of September of each year is designated and established as Fetal Alcohol Spectrum Disorder Day.

**SECTION 2. EMERGENCY.** This Act is declared to be an emergency measure.



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# A REPORT TO THE NORTH DAKOTA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

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Comprehensive Review and Analysis for the 2022-2026 State Plan



MAY 1, 2020  
JOANNE HOESEL, MA

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## Introduction

The North Dakota State Council on Developmental Disabilities (Council) requests a comprehensive review and analysis (CRA) of North Dakota's services, supports, and unmet needs in the intellectual and developmental disability (IDD) service system. The CRA helps select priorities for the Council's 2022-2026 state strategic plan. This report contains information to understand systems and trends in eight areas better: 1) Health and Healthcare, 2) Employment, 3) Education and Early Intervention, 4) Transportation, 5) Child Care, 6) Housing, 7) Informal and Formal Services and Supports, and 8) Recreation.

## Methodology

The author relied on a variety of resources and methods to complete this report. Information was found via internet and database searches from PubMed, Google Scholar, federal and state government websites, advocacy agency websites, and contact with key informants. Relevant material was identified through a combination of keywords, phrases, topical searches. The report synthesizes this information to provide the Council with a thorough description of how the services and supports currently function in meeting the needs of individuals with IDD.

## North Dakota Demographics Overlay

North Dakota (ND) has a population of 762,062, according to the July 1, 2019, U.S. Census population estimates.<sup>1</sup> There has been a shift in rural-to-urban ratios, whereas, in 1980, 63 percent of the state's population lived in rural areas, the 2018 data indicates 49 percent of the population lives in these areas.<sup>2</sup> Table 1 illustrates the population loss, growth, and urbanization experienced in ND between 2010 and 2017, which has implications for service delivery.

Table 1: ND Rural/Urban Population Shift 1980-2018.

ND Population Shift				
Year	Rural	Urban	Total	Rural %
1980	412,267	240,450	652,717	63%
1990	375,270	263,530	638,800	59%
2000	352,138	290,099	642,237	55%
2010	341,155	331,421	672,576	50%
2018	375,113	384,964	760,077	49%

Source: US Department of Agriculture <sup>3</sup>

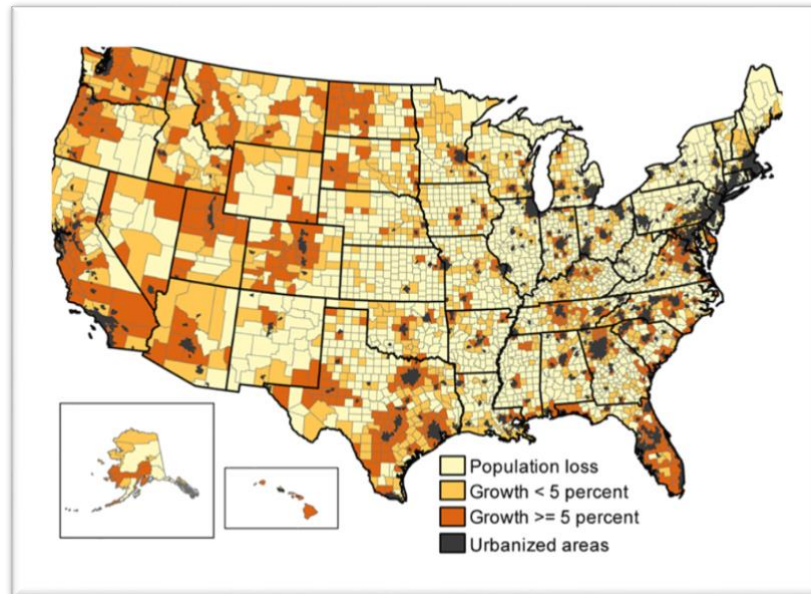
<sup>1</sup> U.S. Census. Retrieved from: <https://www.census.gov/quickfacts/fact/table/ND/PST045219#>

<sup>2</sup> United States Department of Agriculture Economic Research Service. Retrieved from: <https://data.ers.usda.gov/reports.aspx?StateFIPS=38&StateName=North%20Dakota&ID=17854>

<sup>3</sup> Ibid.



Figure 1: US Population Change 2010-2017



Source: US Department of Agriculture <sup>4</sup>

Further analysis of ND's population reveals that 23.5 percent of the population is under 18 years of age (179,085), and 15.3 percent are 65 years of age and older (116,595). According to the U.S. Census bureau's July 1, 2019 estimates, 7.1 percent (54,106) of ND residents under age 65 have a disability of any kind. The 2018 U.S. Census American Community Survey (ACS) one-year estimate provides a snapshot of ND citizens who have a cognitive disability. For children between the ages of 5 and 17, there are 4,209 children with a cognitive difficulty; for those between the ages of 18 – 64, there are 16,957 people with a cognitive disability; and for people over the age of 65, 6,916 people have a cognitive disability.<sup>5</sup>

<sup>4</sup> United States Department of Agriculture Economic Research Service. Retrieved from: <https://www.ers.usda.gov/webdocs/charts/57704/popmap1017.png?v=3470.3>

<sup>5</sup> United States Census Bureau. Retrieved from: [https://data.census.gov/cedsci/table?q=disability%20status&g=0400000US38\\_0100000US&hidePreview=true&tid=ACSS1Y2018.S1810&t=Disability&vintage=2018&moe=false&cid=S1810\\_C01\\_001E](https://data.census.gov/cedsci/table?q=disability%20status&g=0400000US38_0100000US&hidePreview=true&tid=ACSS1Y2018.S1810&t=Disability&vintage=2018&moe=false&cid=S1810_C01_001E)

# Portrait of State Services

## Health & Healthcare

Access to quality healthcare is essential for all people, especially those with disabilities. Healthcare helps maintain health but also assists in having a positive quality of life. In 2019, the Commonwealth Fund's Scorecard on State Health System Performance rated ND 16<sup>th</sup> in the U.S. ND's ranking reflects a low incidence of frequent physical and mental distress, a high ranking (49<sup>th</sup>) for excessive drinking, and a ranking of 37 for the percentage of children under 35 months who receive recommended vaccinations.<sup>6</sup> The County Health Rankings & Roadmaps' annual rankings measure health factors such as high school graduation rates, obesity, smoking, unemployment, access to healthy foods, the quality of air and water, income inequality, and teen births.<sup>7</sup> Figure 2 shows ND's county rankings and provides a view of health variation by county.<sup>8</sup>

Figure 2: ND 2019 County Health Rankings & Roadmaps Illustrating the Healthiest and Least Healthy Counties

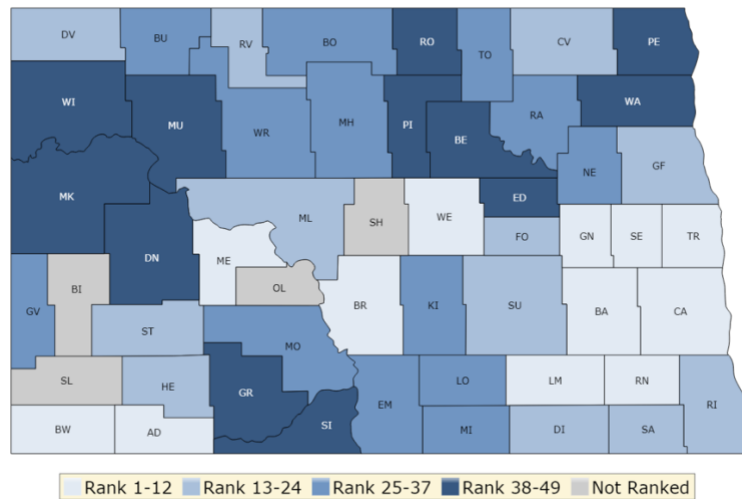


Table 2 highlights the disparity between the healthiest and least healthy ND counties. There is a 19 percent difference in residents having poor or fair health. Thirty-two percent of the residents in the least healthy county have poor or fair health, whereas only 13 percent of the residents in the healthiest county have a similar health status. The rankings vary dependent upon racial and ethnic groups as well; Twenty-nine percent of the ND Native American Indian population presents with poor or fair health versus 13 percent of white residents.<sup>9</sup>

<sup>6</sup> The Commonwealth Fund. Retrieved from: <https://interactives.commonwealthfund.org/2018/state-scorecard/state/north-dakota/>

<sup>7</sup> County Health Rankings & Roadmaps. Retrieved from: <https://www.countyhealthrankings.org/about-us>

<sup>8</sup> County Health Rankings & Roadmaps. Retrieved from: <https://www.countyhealthrankings.org/app/north-dakota/2019/overview>

<sup>9</sup> Ibid.

Table 2: ND's 2019 Healthiest versus Least Healthy County Variations<sup>10</sup>

	Healthiest ND County	Least Healthy ND County	AI/AN	Asian/PI	Black	Hispanic	White
<b>Premature Death (years lost/100,000)</b>	6,700	26,300	19,100	3,400	7,800	6,200	5,900
<b>Poor or Fair Health (%)</b>	13%	32%	29%	N/A	28%	27%	13%
<b>Poor Physical Health Days (avg)</b>	2.6	5.7	5.9	N/A	4.5	3.8	2.7
<b>Poor Mental Health Days (avg)</b>	2.7	4.9	3.6	N/A	2.3	5.9	3.0
<b>Low Birthweight (%)</b>	5%	7%	7%	7%	9%	6%	6%

American Indian/Alaskan Native (AI/AN), Asian/Pacific Islander (Asian/PI)

N/A = Not available. Data for all racial/ethnic groups may not be available due to small numbers

Source. County Health Rankings and Roadmaps 2019

### Access to Public/Private Health Insurance

Three insurers offer insurance coverage to ND residents: Medica, Sanford, and Blue Cross/Blue Shield. According to the U.S. Census bureau's July 1, 2019 estimates, 7.1 percent (54,106) of ND residents under age 65 have a disability. Table 3 displays the 2013 - 2017 ACS 5-year estimates of the ND's population categorized by those with a disability, insurance status, and type of insurance coverage by age groups.<sup>11 12</sup>

<sup>10</sup> County Health Rankings & Roadmaps. Retrieved from: <https://www.countyhealthrankings.org/app/north-dakota/2019/overview>

<sup>11</sup> United States Census Bureau. Retrieved from: [https://data.census.gov/cedsci/table?q=insurance%20by%20disability&g=0400000US38\\_0100000US&hidePreview=true&tid=A\\_CSDT5Y2017.B18135&t=Disability&vintage=2018](https://data.census.gov/cedsci/table?q=insurance%20by%20disability&g=0400000US38_0100000US&hidePreview=true&tid=A_CSDT5Y2017.B18135&t=Disability&vintage=2018)

<sup>12</sup> United States Census Bureau. Retrieved from: <https://www.census.gov/topics/health/disability/about.html>

Table 3 ND 2013-2017 Population Estimates by Disability and Insurance Status and Type

Population Group	# of people in ND
Under age 19 – total count	180,510
with a disability	6,573
without health insurance	544
with health insurance:	6,029
with private health care coverage	3,967
with public health care	2,930
Age 19 – 64-total count	447,594
with a disability	37,603
Without health insurance	3,881
With health insurance coverage:	33,722
with private health care coverage	21,920
with public health care coverage	16,105
65 years and over-total count	101,175
with a disability	33,884
Without health insurance	84
With health insurance coverage:	33,800
with private health care coverage	24,277*
with public health care coverage	33,496*

More individuals, birth through age 64, with disabilities have private insurance than those over age 65. The highlighted cells in Table 3 illustrate that people over the age of 65 may have both Medicare and private insurance. Due to the multiple insurance sources, the public and private insurance numbers for this age group will not equal the total number of people with health insurance.

### Uninsured in ND

The July 2019 ACS rate for non-institutionalized people under the age of 65, and uninsured, is 8.4 percent (64,013).<sup>13</sup> The 2017 ND uninsured rate for non-institutionalized individuals aged 21 – 64 with a cognitive disability is 8.2 percent. The national rate for the same group is 9.6 percent.<sup>14</sup> In reviewing the information in Table 3, there are 4,509 people with disabilities in ND that are uninsured.

### Insurance Coverage Change

About 1 in 54 children have been identified with autism spectrum disorder (ASD) according to estimates from the Center for Disease Control and Prevention's Autism and Developmental

<sup>13</sup> United States Census Bureau. Retrieved from: <https://www.census.gov/quickfacts/ND>

<sup>14</sup> Disability Statistics. Retrieved from: <http://www.disabilitystatistics.org/reports/acs.cfm?statistic=11>

Disabilities Monitoring (ADDM) Network.<sup>15</sup> There have been previous attempts nationally and in ND to pass legislation to mandate insurance coverage for autism. In 2018, the ND Insurance Commissioner issued a bulletin notifying insurance companies that treatments for autism can no longer be excluded from an insurance policy. The bulletin does not mandate coverage for autism, just as insurance plans are not mandated to cover mental health or substance abuse disorders. However, if they do provide coverage for these conditions, deductibles, co-pays, and treatment limitations cannot be more stringent than for other medical care. Also included in the bulletin, insurance carriers can no longer exclude applied behavioral analysis (ABA) on the basis that this therapy is an experimental or investigative treatment.<sup>16</sup>

## **Medical Assistance**

Medicaid provides health coverage to eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. The program is funded jointly by ND and the Centers for Medicare and Medicaid Services (CMS).<sup>17</sup> In ND, the Department of Human Services (DHS), Medical Services Division administers the Medicaid program. In the 2017-2019 biennium, 65 percent of the DHS budget (\$2,388,042,849) which totals over 3 billion dollars DHS (\$3,658,110,494) paid for medical assistance grants. There are four categories of medical assistance grants:

- Traditional Medicaid and Healthy Steps (CHIP) \$585,090,227 (16%),
- Medicaid Expansion \$570,521,018 (16%),
- Developmental Disabilities Grants \$584,948,726 (16%), and
- Long-Term Care Services \$647,482,878 (18%).<sup>18</sup>

## **Traditional Medicaid**

The ND traditional Medicaid program is a fee-for-service payment program, which means that a medical provider is paid a fee for each specific service provided. To qualify for the traditional Medicaid, a person must be an ND resident, be a United States citizen, and meet the applicable asset and income limits. When these criteria are met, the Traditional Medicaid program provides coverage to the following groups of people:

- Low-income individuals from birth
- Children in foster care or subsidized adoption
- Former foster care children up to age 26, under certain circumstances
- Children with disabilities (birth to 19)
- Pregnant women
- Women with breast or cervical cancer
- Workers with disabilities
- Older, blind, and disabled individuals
- Low-income Medicare beneficiaries (Medicare Savings Programs)

<sup>15</sup> Center for Disease Control and Prevention. Autism Spectrum Disorder. Retrieved from: <https://www.cdc.gov/ncbddd/autism/data.html>

<sup>16</sup> ND Insurance Department. Retrieved from: <https://www.nd.gov/ndins/news/insurance-commissioner-issues-bulletin-supporting-treatments-autism-spectrum-disorder>

<sup>17</sup> Medicaid.gov. Retrieved from: <https://www.medicaid.gov/medicaid/index.html>

<sup>18</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/17-19-biennial-report-dhs.pdf>

ND's traditional Medicaid program is a comprehensive coverage plan ranging from preventative, acute, and long-term care services. A full listing of covered services is available in Appendix A. Typically, if a person's income level changes, they must inform the Medicaid program since income changes may affect program eligibility. The need to inform Medicaid of income changes differs for children because a continuous eligibility policy is in place. Continuous eligibility means that once a child under age 19 is determined to be eligible for Medicaid, they stay eligible for up to 12 months without regard to changes in income. Also, most pregnant women receiving Medicaid remain eligible regardless of income changes for at least 60 days after the pregnancy ends. For all people eligible for Medicaid, coverage begins up to 3 calendar months before the month of applying for the program.<sup>19</sup>

### **Children's Health Insurance Plan (CHIP)**

The CHIP program provides healthcare coverage to uninsured children age 18 and younger in qualifying families who earn too much to qualify for Medicaid, but not enough to afford private insurance.<sup>20</sup> Single 18-year-olds may also be eligible. ND implemented the CHIP on October 1, 1999. During the 2019 ND Legislative session, several changes were made to the program. The ND plan, formerly called Healthy Steps, is now known as the CHIP.<sup>21</sup> The administration of the program transferred from contracts with Blue Cross Blue Shield of North Dakota and Delta Dental of Minnesota to the DHS Medical Services division. The CHIP coverage now matches that of the traditional Medicaid plan. Children covered by the CHIP now have access to a yearly screening and well-child checkup, no co-payments, and removal of service limits on physical therapy, speech therapy, and occupational therapy. Also, there is no dollar limit for Medicaid-covered dental services.<sup>22</sup> This change, effective January 2020, transitioned about 2,000 children from the CHIP to the traditional Medicaid program. ND's CHIP enrollment in December 2019 was 2,029.<sup>23</sup>

### **Children with Disabilities Medicaid Coverage**

Children with disabilities often have higher medical bills that can go over the qualifying limits of private health insurance. Children with Disabilities Medicaid coverage allows families who do not qualify for the traditional Medicaid program to "buy-into" the Medicaid program by paying a monthly premium based on the family's income.<sup>24</sup> The income eligibility for this buy-in program as of July 1, 2019, is 250 percent of the federal poverty level.<sup>25</sup> A monthly premium equal to five percent of a family's gross countable income is required.<sup>26</sup>

<sup>19</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/medicalserv/medicaid/eligible.html>

<sup>20</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/testimony/2019/house-human-services/sb2106-chip-2019-3-4.pdf>

<sup>21</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019-2020-interim/admin-rules/2019-12-3-medicaid-chip-eligibility.pdf>

<sup>22</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/news/2019/12-31-chip-transition-traditional-medicaid-jan1.pdf>

<sup>23</sup> Medicaid.gov. Retrieved from: <https://www.medicare.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>

<sup>24</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/medicaid/fact-sheet-children-w-disabilities-medicaid-buy-in.pdf>

<sup>25</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/earlyintervention/ndicc/docs/20190925-26-minutes.pdf>

<sup>26</sup> ND Department of Human Services. Recipient Liability Fact Sheet. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/medicaid/fact-sheet-medicaid-recipient-liability.pdf>

## Child Participation Rate

The Medicaid child participation rate is the percentage of eligible children ages birth to 18 who enroll in Medicaid and the CHIP.<sup>27</sup> 2016 data shows that while 93.7 percent of the eligible children in the United States were enrolled in Medicaid and the CHIP programs, ND's participation rate was 83.2 percent.<sup>28</sup> A sampling of Medicaid child and the CHIP monthly enrollment data for 2015 – 2019 is displayed in Table 4. Enrollment appears to be consistent over time.

Month	Enrollment
September 2015	41,383
September 2017	43,853
September 2019	42,183
December 2019	42,063

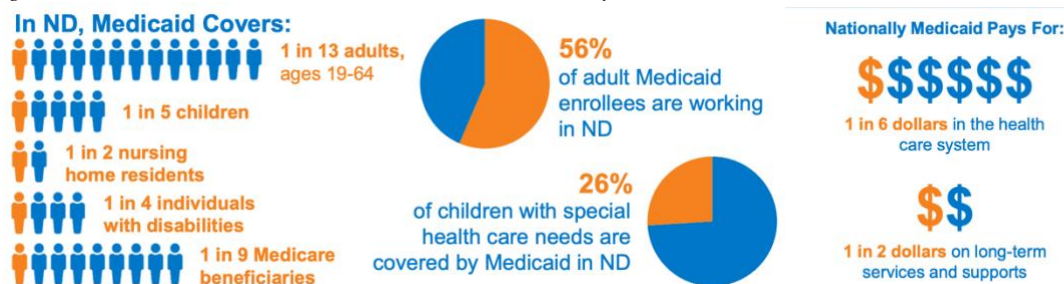
Table 4. North Dakota Child Medicaid and CHIP Monthly

## Medicaid Expansion

The ND legislature (2013) opted to expand the Medicaid program to all qualifying individuals under age 65. Many of the newly eligible individuals are men with low incomes and no children. The expansion allows these individuals to have insurance coverage, preventative services, and greater economic security in the event of accidents or illnesses.<sup>29</sup> In 2018, 20,173 individuals enrolled in the ND Medicaid Expansion Program.<sup>30</sup>

As of December 2019, the total Medicaid/CHIP enrollment in ND, inclusive of both adults and children, was 89,370 people.<sup>31</sup> Figure 3 illustrates the significant role Medicaid plays in insurance coverage in ND. For example, Medicaid covers 1 in 2 people for long-term supports and services.

Figure 3: ND Medicaid Fact Sheet, 2019. Source: Kaiser Family Foundation <sup>32</sup>



<sup>27</sup> Kaiser Family Foundation. Retrieved from: <https://www.kff.org/medicaid/state-indicator/total-medicaid-and-chip-child-enrollment/?currentTimeframe=0&selectedRows=%7B%22states%22:%7B%22north-dakota%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

<sup>28</sup> Kaiser Family Foundation. Medicaid and CHIP Child Participation Rates. Retrieved from: <https://www.kff.org/medicaid/state-indicator/medicaidchip-child-participation-rates/?currentTimeframe=0&selectedDistributions=child-participation-rate-2013-child-participation-rate-2016&sortModel=%7B%22colId%22:%22Child%20Participation%20Rate%202013%22,%22sort%22:%22asc%22%7D>

<sup>29</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/medicaid/medicaid-expansion-brochure.pdf>

<sup>30</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/medicaid/technical-report-measurement-medicaid-expansion-2018.pdf>

<sup>31</sup> Kaiser Family Foundation. Retrieved from: <https://www.kff.org/medicaid/state-indicator/total-medicaid-and-chip-child-enrollment/?currentTimeframe=0&selectedRows=%7B%22states%22:%7B%22north-dakota%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

<sup>32</sup> Kaiser Family Foundation. Retrieved from: <http://files.kff.org/attachment/fact-sheet-medicaid-state-ND>

## Health Tracks

The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program is known in ND as Health Tracks. Health Tracks is a preventative health care program for newborns, children, and young adults through age 20 who enroll in the Medicaid program. The program provides comprehensive periodic screenings and well-child checkups that help prevent and identify health problems.<sup>33</sup> The services included in a child's plan are individualized based on need. Health Tracks may cover:

- Physical exams
- Hearing and vision checks
- Glasses and hearing aids
- Vaccines (shots) and labs
- Dental care, braces, fluoride varnish
- Behavioral health screenings
- Growth and development checks
- Nutrition counseling

## Rebalancing

There is a national effort to rebalance Medicaid programs and remove its institutional bias. This bias is exhibited by the fact that Medicaid typically pays for institutional versus community-based care. A waiver is required to pay for services delivered outside of an institution or not included in the traditional Medicaid plan. This rebalancing effort places emphasis on providing services in appropriate, permanent, and integrated community-based settings instead of more costly institutional settings. In FY2015, the average institutional cost per person was \$210,110.00, while the average waiver cost per person was \$46,481. For the average cost to provide residential supports to one person in an institution, 4.5 people could receive HCBS waiver supports.<sup>34</sup> ND's waiver spending ranks high in that compared to the national per capita spending rate, ND's HCBS waiver spending per capita is more than double. ND's 2017 waiver spending rate per capita is \$281 versus the US rate of \$124.<sup>35</sup>

## ND Medicaid Waivers

In order to pay for services not covered through the traditional Medicaid state plan, CMS must approve a waiver. A waiver allows for 1) care to people who would otherwise reside in a nursing home or intermediate care facilities for a person with intellectual and developmental disabilities (ICF/IDD) and 2) care for people who might not otherwise be eligible under Medicaid.<sup>36</sup> An approved waiver, 'waives' the usual traditional Medicaid rules. CMS has several types of waivers, and states can choose the type that best fits their needs. ND Medicaid has six waivers, and each is a 1915(C) Home and Community-Based Waiver (HCBS). HCBS waivers

<sup>33</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/medicalserv/health-tracks/>

<sup>34</sup> Coleman Institute for Cognitive Disabilities. Retrieved from: [http://stateofstates.wpengine.com/wp-content/uploads/publications/SOS-Brief-2018\\_2\\_Rebalancing.pdf](http://stateofstates.wpengine.com/wp-content/uploads/publications/SOS-Brief-2018_2_Rebalancing.pdf)

<sup>35</sup> State of the State in Intellectual Disabilities. Retrieved from: <https://stateofstates.wpengine.com/create-idd-chart/idd-comparison-chart>

<sup>36</sup> Center for Medicare and Medicaid. Retrieved from: <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/state-medicaid-policies>



allow states to pay for services delivered in homes or communities instead of in an institution.<sup>37</sup>

The six ND Medicaid waivers are:

1. Home and Community Based (previously known as the Aged and Disabled)
2. Traditional Intellectual Disabilities and Developmental Disabilities
3. Autism Spectrum Disorder Birth through age 13
4. Children with Medically Fragile Needs
5. Technology Dependent
6. Children's Hospice Waiver

Each waiver has a specific required level of care (LOC), which a person must meet in order to qualify for a waiver's benefits. For example, a person must meet the eligibility of an ICF/IDD in order to access either the Autism or Traditional IDD waiver. The eligibility requirement of a person needing to meet the LOC shows evidence of providing care in the community versus an institution. Each ND waiver is available to eligible people statewide, and each waiver is renewed every five years. Table 5 displays information about the six ND waivers. Overall, ND's waiver focus is to increase service options for children in the community since five of the six waivers include a child focus.

*Table 5: ND Department of Human Services 1915C HCBS Waiver Details by Specific Waiver, Number of Slots, Level of Care, Responsible Division, and Target Group*

Waiver Name	# of Slots in the final waiver year	Most Recent Waiver Renewal	Level of Care Required	DHS Division	Self-Directed?	Target Group	Comments
Home and Community-Based	580	7/1/2018	Nursing Home	Aging Services	No	Aged and disabled	Eligibility groups- Aged, blind, disabled, Medicaid buy-in, Medically Needy
Traditional IDD/DD	6830, as amended	4/1/2019	ICF/IDD	DD Division	Yes	DD/IDD	Reserved Slots: Infant Dev - 170 Supported Employment - 5 Emergency - 15
Autism	96	1/1/2020	ICF/IDD	Medical Services	Yes	Birth through 13	
Medically Fragile	25	6/1/2018	Nursing Home	Medical Services	Yes	Age 3 to 17	Cost limit = \$18,996
Technology Dependent	3	4/1/2017	Nursing Home	Medical Services	No	Minimum age is 18	Vent dependent minimum of 20 hours per day
Children's Hospice	30	7/1/2018	Nursing Home	Medical Services	Yes	Maximum age is 21	

<sup>37</sup> Center for Medicare and Medicaid. Retrieved from: <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/national-overview-1915-c-waivers>

## Waiver Changes

There have been several changes to ND's waivers in the last two years. The changes to three waivers are highlighted below.

1. Home and Community Based Waiver (formerly known as the Aged and Disabled Waiver)- Amended 2019
  - Add residential habilitation - formalized training and supports.
  - Add community support services- formalized training and supports.
  - Add companionship services- to reduce social isolation.
  - Waived conflict-free case management rules for Tribal nations that want to provide culturally competent case management services to eligible Tribal members.
  - Expand the definition of adult foster care to include agency adult foster care facilities.
  - Modify language to comply with changes made in SB 2124, which designates that HCBS Case Managers will become state employees (due to the county social service redesign project, these agencies are now called Human Service Zones).<sup>38</sup>
2. Tradition Intellectual and Developmental Disabilities Waiver - Amended effective April 2020<sup>39</sup>
  - Increased number of slots for vacancy and absence reasons.
  - A higher acuity medical level may be available for those receiving Residential Habilitation, Day Habilitation, Prevocational Services, and Small-Group Employment Services. A higher acuity level results in a higher reimbursement rate.
  - The adjusted number of reserved waiver slots for the following purpose(s) are:
    - Infant Development - 170 slots
    - The transition from Supported Employment to Individual Employment Support services -5 slots
    - Emergency- 15 slots
  - The waiver uses a new payment system, which began on April 1, 2018. Funding did not decrease, but the funds are distributed more consistently and equitably. The new methodology uses standardized rates and bases staffing levels on third-party assessed client needs.<sup>40 41</sup>
3. Autism Waiver
  - Waiver coverage changes increase the age through the age of 13 versus through the age of 11.<sup>42</sup>

## Waiting Lists

In the traditional Medicaid program, a state must provide the state plan benefits to all eligible and enrolled people. There cannot be any waiting list for benefits. Waivers offer exclusive services for a defined group of people, and enrollment has a limited number of slots per waiver year. These restrictions contribute to wait lists for many waiver services in states throughout the

<sup>38</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/publicnotice/2019/9-4-public-comment-notice-medicare-hcbs-waiver-amendments.pdf>

<sup>39</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/draft-amendment-traditional-iid-dd-hcbs-waiver-proposed-effective-4-1-2020.pdf>

<sup>40</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/news/2018/3-23-nd-changes-how-it-pays-for-services-provided-to-people-with-developmental-disabilities.pdf>

<sup>41</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/services/disabilities/dd-rate-methodology.html>

<sup>42</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/publicnotice/2019/8-28-public-notice-asd-waiver-amendments.pdf>

country. In 2017, there were over 707,000 people on HCBS waiver waiting lists in 40 states. People with IDD comprise about two-thirds of the national waiver waiting list enrollment, and over one-quarter are seniors and adults with physical disabilities.<sup>43</sup> According to the Kaiser Foundation Data, in 2017, ND had eight people on a wait list for the Traditional IDD waiver; Three people were on the wait list for the Medically Fragile Waiver.<sup>44</sup> As of April 25, 2020, no people are waiting for the Traditional IDD waiver.<sup>45</sup>

### **1915i Medicaid State Plan Amendment**

In addition to waivers, there are other methods used to gain reimbursement for services Medicaid does not typically cover. One method is a 1915i state plan amendment, where a state can target the HCBS benefit to one or more specific populations and provide the services through the traditional Medicaid state plan.<sup>46</sup> During the 2019 legislative session, ND lawmakers authorized the DHS to create a Medicaid 1915(i) state plan amendment. The proposed 1915i plan adds considerable services and supports to eligible people with a diagnosis of mental illness, substance use disorder, or traumatic brain injury; eligibility excludes those with an IDD.<sup>47</sup> 1915i coverage is expected to begin on July 1, 2020.

### **Voucher Programs**

A voucher program approves a symbolic ticket or coupon to eligible recipients, which may be spent only for specific reasons or goods. The ND Legislature provides funds for mental illness, substance use disorders, and autism services voucher programs.

#### **Autism Voucher Program**

House Bill 1038 (2013) created the autism voucher program for children ages 3 through 17 diagnosed with an Autism Spectrum Disorder. Eligibility for this program requires that family income is within 200% of the Federal Poverty level, and their child does not receive services through a Medicaid waiver. The goal of this voucher program is to fill coverage gaps in non-therapy related services and provide support to families who may not qualify for other help.<sup>48</sup> Examples of services and supports paid for with an autism voucher include but are not limited to respite care, assistive technology, and adaptive sports and activities. The autism voucher program was amended in March 2020 to remove the requirement that a child must be recommended for the program by a qualified professional.

### **Maternal and Child Health**

The DOH manages the Title V maternal and child health grant (MCH). This grant is a crucial source of support for promoting and improving the health and well-being of mothers and

<sup>43</sup> Kaiser Family Foundation. Retrieved from: <https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/>

<sup>44</sup> Kaiser Family Foundation. Retrieved from: <https://www.kff.org/report-section/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists-appendix-tables/>

<sup>45</sup> Email from DHS-DD Division Director, Tina Bay.

<sup>46</sup> Medicaid.Gov. Retrieved from: <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915i/index.html>

<sup>47</sup> ND Department of Human Services. Retrieved from: <https://www.behavioralhealth.nd.gov/1915i>

<sup>48</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/autism/docs/dn-345-autism-voucher-brochure.pdf>

children, including children with special needs and their families.<sup>49</sup> ND's FY 2018 federal grant allocation was:

- Federal allocation \$1,739,627
- State MCH Funds \$1,337,350
- Local MCH funds \$68,089<sup>50</sup>

In the 2017-2019 biennium, the special health care needs program provided care coordination services to up to 600 families. In 2018, 771 individuals were provided with health care transition education and training services. They also provided funding to Family Voices of ND who in turn supported 1,292 families and 66 professionals.<sup>51</sup> DOH also manages the autism spectrum disorder (ASD) database, which became effective January 1, 2016. Over 450 ASD reports have been submitted since the database began.<sup>52</sup> Fifteen statewide cleft lip/palate clinics were held, and the Cardiac Care for Children Program provided care coordination and payment for the initial pediatric cardiology examination and routine testing for approximately 950 children.<sup>53</sup> The Children with Special Health Care Needs program covers:

- Diagnostic testing and evaluation for children under the age of twenty-one if the child has or may potentially have a condition included on a list of more than one hundred eligible conditions. Financial eligibility is not required for diagnostic services.
- Treatment support for children under the age of twenty-one who have an eligible condition and a family income at 185 percent of the federal poverty level.<sup>54</sup>

## Newborn Screening

Every baby born in ND is required by state law to have a newborn bloodspot screening test that identifies nearly fifty disorders.<sup>55</sup> The Newborn Screening Program began with screening for PKU in 1964.<sup>56</sup> According to the DOH, in 2019, there were 12,056 babies screened in ND. This number may include babies that were screened in ND but born in another state. This means the number may be higher than the number of babies born in ND. There were twenty-eight true positive disorders and 166 carriers identified through the screening.<sup>58</sup>

Effective January 2020, (NDCC 23-07-01 and NDAC 33-06-01) the following are among several conditions added to the list of mandatory reportable conditions:

<sup>49</sup> ND Department of Health. Retrieved from: <https://mchb.hrsa.gov/maternal-child-health-initiatives/title-v-maternal-and-child-health-services-block-grant-program>

<sup>50</sup> U.S. Department of Health and Human Services. Retrieved from: <https://mchb.tvisdata.hrsa.gov/State/Detail/ND>

<sup>51</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf), page 28

<sup>52</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf), page 23

<sup>53</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf), page 27

<sup>54</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/Files/HSC/SHS/Diagnostic-Treatment\\_services\\_fact-sheet.pdf](https://www.health.nd.gov/sites/www/files/documents/Files/HSC/SHS/Diagnostic-Treatment_services_fact-sheet.pdf)

<sup>55</sup> ND Department of Health. Retrieved from: [https://nbs.health.nd.gov/image/cache/NS\\_022616\\_WebsiteGraphic.pdf](https://nbs.health.nd.gov/image/cache/NS_022616_WebsiteGraphic.pdf)

<sup>56</sup> Note. Phenylketonuria (fen-ul-key-toe-NU-ree-uh), also called PKU, is a rare inherited disorder that causes an amino acid called phenylalanine to build up in the body. <https://www.mayoclinic.org/diseases-conditions/phenylketonuria/symptoms-causes/syc-20376302>

<sup>57</sup> ND Department of Health. Newborn Screening Program. Retrieved from: <https://nbs.health.nd.gov/program-info/>

<sup>58</sup> Email received on 4-14-2020 from Joyal Meyer, RN, MSN, Newborn Screening Program Director, Division of Special Health Services, DOH

- Fetal Alcohol Syndrome
- Neonatal Abstinence Syndrome
- Acute Flaccid Myelitis
- Critical Congenital Heart Disease.<sup>59</sup>

**A snapshot of FASD in North Dakota**  
 New cases born each year 110-550  
 Annual cost for new cases (330 cases = \$7.5 million)  
 Birth - 18 years of age cohort (1,980-9900)

*Figure 4: Occurrence and Cost of Fetal Alcohol Syndrome in ND. UND Fetal Alcohol Syndrome Center 2019*

In their 2019 report to the ND Task Force on Substance-Exposed Newborns, the ND Fetal Alcohol Syndrome Center at the UND reported that 3,400 women used alcohol during their pregnancies. Of all the substances of abuse, alcohol produces by far the most severe adverse effects for the fetus.<sup>60</sup> Figure 4 provides a snapshot of FASD in ND, showing that 110 children are born each year with FASD. Table 6 illustrates the impact of five substances on twelve fetal effects. Alcohol can impact all twelve fetal effects, whereas other substances have serious but fewer types of fetal effects.

*Table 6: Serious Adverse Health Effects for the Fetus by Detailed by Substance <sup>61</sup>*

Effect	Alcohol	Marijuana	Cocaine	Heroin	Tobacco
Low Birth Weight	Yes	No	Yes	Yes	Yes
Impaired Growth	Yes	No	No	No	No
Facial Malformation	Yes	No	No	No	No
Small Head Size	Yes	No	No	No	No
Intellectual and Development Delays	Yes	Yes	No	No	No
Hyperactivity, Inattention	Yes	Yes	No	Yes	Yes
Sleeping Problems	Yes	No	Yes	Yes	Yes
Poor Feeding	Yes	No	Yes	No	No
Excessive Crying	Yes	Yes	Yes	Yes	No
Higher Risk for Sudden Infant Death Syndrome	Yes	No	No	Yes	Yes
Organ Damage, Birth Defects	Yes	No	No	No	No
Respiratory Problems	Yes	No	No	Yes	Yes

## Immunization

DOH manages the state's immunization program. The National Immunization Survey estimates the percentage of children and adults that are up to date with their 2016-2017 immunizations. ND has several areas where the vaccination goals in the Healthy People 2020 program were not met. (See Table 7) As reported earlier, the Commonwealth Fund Scorecard ranked ND 37th for the percentage of children under thirty-five months of age who received recommended vaccinations. Table 7 illustrates that adolescent vaccination goals are met, whereas vaccination goals for children age 19 to 35 months and all but one for those in kindergarten are not met. Of children entering kindergarten, 3.14 percent of ND parents or guardians claimed an exemption to the school immunization requirements.<sup>62</sup>

<sup>59</sup> ND Department of Health. Mandatory Reportable Conditions. Retrieved from: <https://www.health.nd.gov/sites/www/files/documents/Files/OSE/Reportable/OnePageQA.pdf>

<sup>60</sup> Burd, Larry, PhD, (2019). *A Report to North Dakota on Fetal Alcohol Exposure and Fetal Alcohol Spectrum Disorder*. North Dakota Fetal Alcohol Syndrome Center. Retrieved from: [https://med.und.edu/fetal-alcohol-syndrome-center/\\_files/fas-center-report-2019.pdf](https://med.und.edu/fetal-alcohol-syndrome-center/_files/fas-center-report-2019.pdf)

<sup>61</sup> Burd, Larry, PhD, (2019). *A Report to North Dakota on Fetal Alcohol Exposure and Fetal Alcohol Spectrum Disorder*. North Dakota Fetal Alcohol Syndrome Center. Retrieved from: [https://med.und.edu/fetal-alcohol-syndrome-center/\\_files/fas-center-report-2019.pdf](https://med.und.edu/fetal-alcohol-syndrome-center/_files/fas-center-report-2019.pdf)

<sup>62</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf) , page 41

Table 7: Estimated ND Vaccination Compliance Data by Type and Age Group

Type	Age group	Healthy People 2020 Goal	Estimated ND Percentages
DTaP, polio, MMR, Haemophilus influenzae type B, hepatitis B, chickenpox, and pneumococcal	children ages 19 to 35 months	80 percent	68.2 percent
tetanus, diphtheria, and pertussis (Tdap) vaccine	adolescents	80 percent	92 percent
meningococcal vaccine	adolescents	80 percent	92 percent
human papillomavirus (HPV) vaccine		80 percent	45.5 percent- boys 60.2 percent-girls
polio	Kindergarten	95 percent	93.98 percent
diphtheria/ tetanus/pertussis	Kindergarten	95 percent	93.79 percent
measles/mumps/ rubella	Kindergarten	95 percent	93.84 percent
hepatitis B	Kindergarten	95 percent	95.58 percent
chickenpox	Kindergarten	95 percent	92.95 percent

### ND DOH Certification Responsibilities

- The DOH licenses or certifies the following programs in ND<sup>63</sup>:
- Long-term care nursing facilities – 80
- Hospitals – 36 critical access hospitals, 6 general acute hospitals, 2 long-term acute care hospitals, 3 psychiatric hospitals, and 1 rehabilitation hospital
- Intermediate care facilities for individuals with intellectual disabilities – 73
- Home health agencies –18
- Hospice programs –13
- Rural health clinics – 57
- Clinical laboratories – 669
- Ambulatory surgical centers – 13
- End-stage renal dialysis units – 16
- Portable X-ray units – 1
- Psychiatric residential treatment facilities – 6

The list provides a snapshot of medical institutions and agencies serving ND citizens. Note that DOH certifies 73 ICF/IDD – all but one being private entities.

<sup>63</sup> ND Department of Health. Retrieved from: [https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf) , page 35

## Developmental Disabilities -DHS

The ND DHS-Developmental Disabilities Division manages the early intervention and the IDD system. The system comprises private DD providers, the state institution, regional human service centers, and early intervention providers. The DD Program Managers, who provide care coordination for people with IDD, are located in the regional human service centers.<sup>64</sup> A central objective is to serve people with IDD in the least restrictive setting possible. During the 17-19 biennium, over ninety people transitioned or were diverted from an institutional setting. A significant agency realignment occurred during the biennium in that direct supervision of DD program administrators and program managers shifted from the regional human service centers to the DD Division. According to DHS, this restructuring was done to support consistent service delivery, quality, and better alignment with policy.<sup>65</sup>

## Life Skills and Transition Center (LSTC)

The LSTC is the state's ICF/IDD facility and provides residential, vocational, and outreach services. Residential services include 24-hour comprehensive medical and clinical programming services and supports, services for adults with IDD and sex offending behaviors, individuals requiring skilled nursing and behavioral health services, and youth transitioning from the facility to a community setting. Vocational services provide work sites on campus and in the community.<sup>66</sup> The LSTC celebrated thirty years of accreditation through the Council of Quality and Leadership (CQL) during the 2017- 2019 biennium.<sup>67</sup> The adult population on June 30, 2018, was 53, which was the lowest census reported since 2006 (131). (see Fig.5) The youth population on the same date was 11, whereas both 2015 and 2016 had the highest child census with 19 each year. In both 2017-2018, there was 15 youth in care.

**FACT:** From 2000 to 2017, the number of adults residing on campus dropped from 149 to 53.

*Figure 5: ND Department of Human Services, 2019 Biennial Report*

## Oral Health

More than one-half of ND children have had tooth decay, and more than one in five have untreated tooth decay.<sup>68</sup> There are several dental support programs in ND to address dental needs. The DOH's Oral Health Program works with the public and Bureau of Indian Education schools throughout the state to assess pediatric oral health. During the 2018-2019 school year, 1,998 kindergartners enrolled in the forty-three participating schools received a dental screening.<sup>69</sup> The DOH also manages the Seal!ND program, which is a school-based fluoride varnish and sealant program. This program provided services to 3,000 students in the 17-19 biennium. Services include initial screening, sealant placement, and fluoride varnish application.<sup>70</sup> DOH collaborates with the Ronald McDonald Care Mobile to provide oral health services to children in the western part of the state. The Ronald McDonald Care Mobile is a mobile dental clinic that delivers dental care to underserved children ages birth through twenty-

<sup>65</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/17-19-biennial-report-dhs.pdf>

<sup>66</sup> <https://www.legis.nd.gov/files/resource/committee-memorandum/19.9037.01000.pdf>

<sup>67</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/testimony/2019/house-approp-hr/sb2012-overview-lstc-2019-3-7.pdf>

<sup>68</sup> Ronald McDonald House Charities. Retrieved from: <https://rmhcbismarck.org/caremobile/Default.asp>

<sup>69</sup> Center for Rural Health, University of North Dakota. Retrieved from: <https://ruralhealth.und.edu/what-we-do/oral-health>

<sup>70</sup> ND Department of Health. Retrieved from:

[https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017\\_2019\\_Biennial\\_Report.pdf](https://www.health.nd.gov/sites/www/files/documents/About%20Us/2017_2019_Biennial_Report.pdf), page 24.

one. The Care Mobile is a 40-foot long dental clinic with a dentist, hygienist, and dental assistant.<sup>71</sup> The Care Mobile, owned by the Ronald McDonald House Charities of Bismarck, partners with Bridging the Dental Gap, Inc. of Bismarck, which is a non-profit community dental clinic serving those covered by Medicare or who are uninsured, under-insured, or have low incomes.<sup>72</sup>

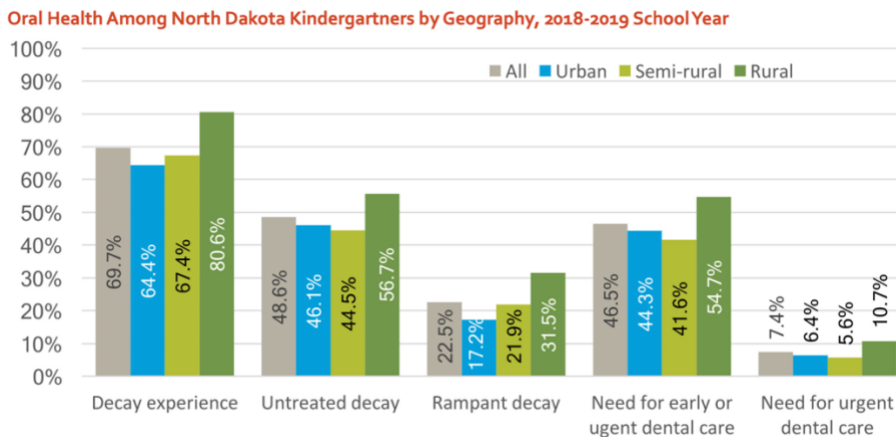
The Donated Dental Services program provides free, comprehensive dental treatment to people with disabilities or who are elderly or medically fragile. The program operates through a volunteer network of 15,000 dentists and 3,500 dental labs across the United States. Since its inception in ND in 2000, it has served 932 patients. According to the website on April 8, 2020, due to long wait lists, applications are only being accepted in the following counties: Barnes, Burleigh, Foster, McKenzie, Pierce, Ramsey, Richland, Rolette, Stark, Stutsman, Ward, Wells, Williams.<sup>73</sup> Figure 6 shows that 65 people were on a wait list in 2018-2019.



Figure 6: Donated Dental Patient Treatment Information  
Source: Dental Life Line

The UND Center for Rural Health's February 2020 Fact Sheet indicates that there are dental health disparities by geography and race and ethnicity.<sup>74</sup> Figure 7 illustrates that in all five dental problem categories listed, kindergarten-age children in rural areas of ND have worse dental health. Figure 8 highlights health disparities by race and ethnicity in ND. Using the same five dental problem categories, American Indian children outpaced other races in dental health problems. Note that 18 percent of American Indian children needed urgent dental care.

Figure 7: ND Oral Health by State Geography.



<sup>71</sup> Ronald McDonald House Charities. Retrieved from: <https://rmhcbismarck.org/caremobile/Default.asp>

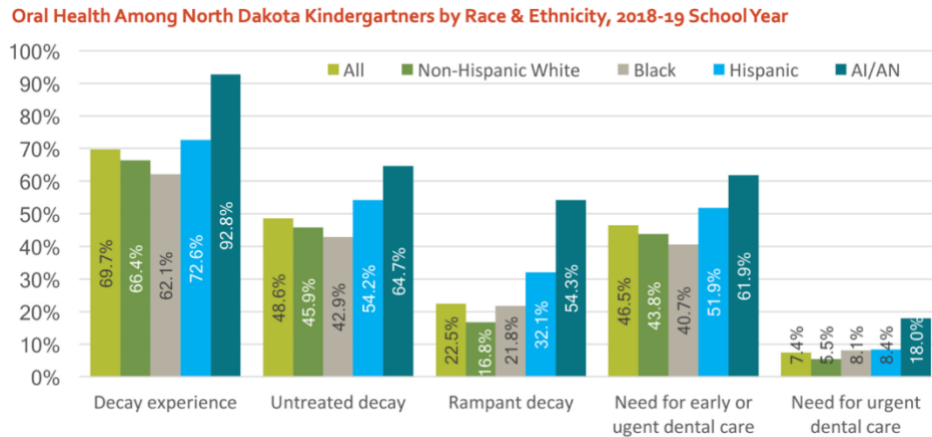
<sup>72</sup> Bismarck-Mandan Chamber. Retrieved from: <http://business.bismarckmandan.com/list/member/bridging-the-dental-gap-inc-5457>

<sup>73</sup> Dental Lifeline Network. Retrieved from: <https://dentallifeline.org/about-us/our-programs/>

<sup>74</sup> Center for Rural Health, University of North Dakota. Retrieved from: <https://ruralhealth.und.edu/what-we-do/oral-health>



Figure 8: ND Oral Health by Race and Ethnicity. Source UND Center for Rural Health 75



## Behavioral Health Information

Eight regional human services centers (HSC) and the State Hospital in Jamestown provide public behavioral health services.

## Regional Human Service Centers

The HSCs provide a continuum of mental health and substance abuse services, including open access, community outreach, crisis residential, and private community hospital services. The services are provided directly by HSC staff or through contracts with private providers. The DHS Field Services division manages the HSCs. Sixty percent of the staff at the regional human service centers are involved with providing behavioral health-related services. The remaining 40 percent provide a combination of developmental disabilities, child welfare, adult protection, and vocational rehabilitation services.<sup>76</sup> Figure 9 illustrates the number of clients and the variety of services they received in 2018. Note the significant increase in telehealth delivered services. Telehealth is a method to increase access to services, especially those living in rural areas and people with mobility challenges.

### 2018 AT A GLANCE – Human Service Centers

- **18,146 individuals received 536,301 services**
- **2,920 youth** received behavioral health services
- **1,049 pregnant women and/or individuals who inject drugs** received substance use disorder services
- 3,017 clients received **7,818 telehealth services (38% 1-year increase)**
- 5,364 clients received **12,469 emergency services**
- 7,134 clients received **12,819 assessments**
- 3,072 clients received **82,400 days of residential treatment services**

Figure 9: ND DHS Regional Human Service Center 2018 Statistics 77

<sup>75</sup> Center for Rural Health, University of North Dakota. Retrieved from: <https://ruralhealth.und.edu/assets/3506-14138/nd-high-rates-of-decay.pdf>

<sup>76</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/interim/19-5030-03000-meeting-minutes.pdf>

<sup>77</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/17-19-biennial-report-dhs.pdf>,

## **State Hospital**

The ND State Hospital located in Jamestown, provides acute services, sub-acute services, specialized rehabilitation hospital services for individuals with severe and persistent mental illnesses and substance use disorders, specialized residential addiction services for adults in the custody of the Department of Corrections and Rehabilitation, and specialized residential services for individuals in the sex offender treatment and assessment program.

## **2018 Behavioral Health Study**

The DHS contracted with the Human Services Research Institute (HSRI) to complete a comprehensive behavioral health system analysis.<sup>78</sup> The 2018 study analyzed HSC service and client data; individuals who received both behavioral health and DD services were kept in the analysis. The study removed 4,837 individuals from the analysis since they received HSC services only for an IDD disability. The study provides a framework for legislation and planning for the state. Key findings in the study reveal several items relevant to people with disabilities and minority populations:

- ND's behavioral health system spends the majority of its resources on institutional-based services versus community-based services.<sup>79</sup>
- There are significant regional variations in the proportions of individuals receiving outpatient services—ranging from 70 people per 1,000 in one region to 28 per 1,000 in another.
- Although over 40% of working-age adults who receive publicly funded outpatient mental health services are unemployed, evidence-based employment support programs are limited.
- A lack of affordable housing is one of the significant barriers that people with behavioral health issues in North Dakota encounter, and a significant contributor to homelessness across the state.
- Significant disparities were discovered, particularly for American Indian populations, LGBTQ individuals, and New Americans.
- American Indian populations are overrepresented in HSC and the Medicaid data—and also in child welfare and criminal justice settings—compared to census estimates. The overrepresentation emphasizes the need for more culturally appropriate services.
- There are complicated issues for older adults and people with physical and IDD disabilities who also have a SUD. Screening, assessment, referral, and transition support is needed to ensure that people are supported before, during, and after the transition.

## **Mental Health Services for those with Developmental Disabilities**

There continue to be challenges for people with both IDD and behavioral health conditions. Persons with IDD and mental illness currently do not have equal access to psychiatric inpatient treatment, nor do they have equal access to therapeutic interventions and counseling services.<sup>80</sup> Most behavioral health professionals are not trained in methods that best serve individuals with

<sup>78</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/mhsa/2018-4-nd-behavioral-health-system-study-final-report-hsri.pdf>

<sup>79</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/mhsa/2018-4-nd-behavioral-health-system-study-final-report-hsri.pdf> page 2

<sup>80</sup> National Association of Dual Diagnosis. Retrieved from: <https://thenadd.org/wp-content/uploads/2019/10/eliminate-discriminative-practices-against-persons-mental-illness-id-policy-update.pdf>

IDD. It is estimated that between 30-40% of all persons with IDD have a psychiatric disorder compared to 27% of the general population, and 10-20% have challenging behavior (self-injury, aggression, destructive behavior) severe enough to impair daily life.<sup>81</sup> It is estimated that one in three children with Down syndrome will have behaviors severe enough to be referred and treated by a behavioral health specialist.<sup>82</sup> In ND legislative testimony, it was reported that there is a significant difference in how special educators and mental health professionals address behavioral health concerns. This difference can lead to special educators not considering referrals for mental health services or mental health professionals overlooking the need for special education and related services to make school more successful.<sup>83</sup>

The Life Skills and Transition Center provides behavioral health and crisis outreach services to individuals with IDD living across the state through the Clinical Assistance Resources and Evaluation Services (CARES) team.<sup>84</sup> The CARES team is comprised of applied behavioral analysts and psychologists. In 2018, they had a caseload of 238. The CARES team provides both in-person and telephone/video consultation.

<sup>81</sup> Association of University Centers on Disabilities. Retrieved from:

<https://www.aucd.org/docs/webinars/Mental%20Health%20Diagnosis%20in%20IDD%20-%20AUCD.pdf>

<sup>82</sup> The Developmental Medical Center. Retrieved from: <https://dsagsl.org/wp-content/uploads/2014/04/Behavior-Guide-for-Down-Syndrome.pdf>

<sup>83</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/66-2019/21\\_5093\\_03000appendixj.pdf](https://www.legis.nd.gov/files/committees/66-2019/21_5093_03000appendixj.pdf)

<sup>84</sup> ND Legislature. Retrieved from: <https://www.legis.nd.gov/files/resource/committee-memorandum/19.9037.01000.pdf>

## Employment

Work gives people a sense of purpose and self-worth. All individuals, regardless of disability, deserve the opportunity to be full members of their community where they can live, learn, work, and play through all stages of life.<sup>85</sup>

### ND Employment Landscape

North Dakota had a total of 15,886 job openings in February 2020. Cass County reported the most significant number of job openings (4,358), followed by Burleigh County (2,682) and Grand Forks County (1,544). 56.8 percent of the job openings required a high school diploma or equivalent or no educational credential.<sup>86</sup> Because of the rapidly changing landscape caused by the COVID 19 pandemic, and its unprecedented impact, employment data is quickly evolving. Unemployment claims filed the week of March 7, 2020, totaled 517; For the week ending March 21, 2020, unemployment claims totaled 5,976.<sup>87 88</sup> Initial unemployment claims for the week ending April 4, 2020, totaled 16,167.<sup>89</sup>

### Disability-Related Employment Information

Statistics from the Disability Statistics Compendium show that Americans with disabilities saw a slowdown in job gains compared to those of the previous year.<sup>90</sup> This report also shows that geography has an impact on employment outcomes for Americans with disabilities. People with disabilities in North Dakota are twice as likely to have jobs as West Virginians with disabilities. ND leads the nation with 56.3 percent of its citizens with disabilities employed.<sup>91</sup> According to the National Report on Employment Services and Outcomes Through 2017, ND's unemployment rate in 2017 was 2.6 percent.<sup>92</sup> According to the U.S. Census, the percent of ND working-age people employed in 2017 was 81.5 percent compared to 74.8 percent in the U.S.<sup>93</sup> The percent of working-age people with any disability working was 55.3 percent compared to 36.3 percent in the U.S.<sup>94</sup> Table 8 illustrates ND's employment data as it relates to individuals with or without a disability plus includes data specific to individuals with cognitive disabilities. 33% of people with cognitive disabilities live below the poverty level, whereas 8.7% of those with no disability live below the poverty level.

<sup>85</sup> National Association of County Behavioral Health and Developmental Disability Directors. Retrieved from:

<https://www.autism-society.org/wp-content/uploads/2018/04/IDD-BRIEFING-Employment-importance-Final-2.22.18.pdf>

<sup>86</sup> Labor Market Information Center. Retrieved from: [https://www.ndlmi.com/admin/gsipub/htmlarea/uploads/lmi\\_ojornd.pdf](https://www.ndlmi.com/admin/gsipub/htmlarea/uploads/lmi_ojornd.pdf)

<sup>87</sup> ND Job Service. Retrieved from: <https://www.ndlmi.com/gsipub/index.asp?docid=687>

<sup>88</sup> ND Response Center. Retrieve from: <https://ndresponse.gov/covid-19-resources>

<sup>89</sup> Labor Market Information Center. Retrieved from: <https://www.ndlmi.com/gsipub/index.asp?docid=687>

<sup>90</sup> Houtenville, A. and Boege, S. (2019). Annual Report on People with Disabilities in America: 2018. Durham, NH: University of New Hampshire, Institute on Disability. Retrieved from: <https://disabilitycompendium.org/sites/default/files/user-uploads/Final-Annual-Report-2018.pdf>

<sup>91</sup> Disabled World. Retrieved from <https://www.disabled-world.com/disability/statistics/2019-chart.php>

<sup>92</sup> State Data.Info. Retrieved from: [https://www.statedata.info/bbstates/North\\_Dakota.pdf](https://www.statedata.info/bbstates/North_Dakota.pdf)

<sup>93</sup> State Data.Info. Retrieved from: <https://www.statedata.info/data>

<sup>94</sup> Ibid.

Table 8: ND 2017 Employment Data -Described by People Having No Disability, Any Disability and Cognitive Disability <sup>95 96</sup>

North Dakota 2017 Data	No Disability	Any Disability	Cognitive Disability
% of working-age people employed	81.5%	55.3%	38.1%
Hours Worked – weekly	40 <sup>97</sup>	39	32
% below Poverty	8.7%	24.4%	33%

In ND, using the 2018 ACS 1-year estimates, 459,075 people living in ND were between the ages of 18 and 64. 382,875 of these were in the labor force. 76,200 (16.5%) of those between the ages of 18 and 64 (459,075) were not in the labor force, meaning they were working-age but were **not** looking for work. Of these 76,200 people, 15,110 (19.8%) had any disability, and 8,165 (10.7%) of those not in the labor force had a cognitive disability. Table 9 further illustrates that when the group with cognitive disabilities is analyzed, 48% are not in the labor force. (8,165 of 16,957

Table 9: ND 2018 Employment Status by Disability and Type <sup>98</sup>

Employment Status North Dakota Population 18-64 = 459,075	No Disability N=420,860	Any Disability N=38,215	Cognitive Disability* N=16,957
Employed N=372,455	350,857 (83% of those with no disability are employed)	21,598 (56.5% of those with any disability are employed)	7,838 (46% of those with a cognitive disability are employed)
Unemployed N= 10,420	8,913 (2% of those with no disability are unemployed)	1,507 (3.9% of those with any disability are unemployed)	954 (5.6% of those with a cognitive disability are unemployed)
Not in Labor Force N=76,200	61,090 (14.5% of those with no disability are not in the labor force)	15,110 (39.5% of those with any disability are not in the labor force)	8,165 (48% of those with a cognitive disability are not in the labor force)

\*The cognitive disability numbers are a subset of the 'any disability' numbers and should not be included in calculations to arrive at the total number in the first column.

## Employment Data for Young Adults

When the employment data is analyzed further for individuals between the age of 16-30, it reveals that while ND has more people in this age group employed, they earn less annually than their national counterparts. The U.S. Census shows that, for ND people age 16-21, 55 percent of those with cognitive disabilities were employed. The mean annual earnings were \$3,602 (2013 dollars) compared to the US, where 20 percent were employed and had a yearly salary of \$5,772. For the age group of 22 – 30, there were 2,877 individuals, and 68 percent of them were

<sup>95</sup> Disability Statistics. Retrieved from: <https://www.disabilitystatistics.org/reports/acs.cfm?statistic=2>

<sup>96</sup> State Data.Info. Retrieved from: <https://www.statedata.info/data>

<sup>97</sup> Ibid.

<sup>98</sup> U.S. Census. Retrieved from:

[https://data.census.gov/cedsci/table?q=B18120%3A%20EMPLOYMENT%20STATUS%20BY%20DISABILITY%20STATUS%20AND%20TYPE&g=0100000US\\_0400000US38&hidePreview=true&tid=ACSDT1Y2018.B18120](https://data.census.gov/cedsci/table?q=B18120%3A%20EMPLOYMENT%20STATUS%20BY%20DISABILITY%20STATUS%20AND%20TYPE&g=0100000US_0400000US38&hidePreview=true&tid=ACSDT1Y2018.B18120)

employed and had an average of \$9,790 in annual earnings. Nationally for this group, 34 percent were employed with \$14,846 in yearly earnings.<sup>99</sup>

## **ND Employment Councils**

There are numerous ND councils and committees that focus on methods to increase employment options for the state's citizens.

1. ND Workforce Development Council advises the Governor and the public on workforce development needs and studies workforce opportunities and challenges.<sup>100</sup>
2. ND State Rehabilitation Council advises the DVR on program, policy, delivery of services, and methods to increase access to their services. The Committee on Employment of People with Disabilities was consolidated into the State Rehabilitation Council through House Bill 1135 during the 2017 Legislative session.<sup>101</sup>
3. ND State Independent Living Council guides the ND independent living system. ND has four Centers for Independent Living (CIL's) that provide IL services to individuals with disabilities of all ages.<sup>102</sup>
4. ND Community of Practice for Transition – (formerly called the Statewide Transition Council) helps improve transition outcomes for young adults with disabilities.

## **Employment-related Laws**

Three laws aim to assist people with disabilities with their employment experience: 1) The American with Disabilities Act (1991), 2) the Olmstead Decision (1999), and 3) the Workforce Innovation and Opportunity Act (WIOA). WIOA, enacted in 2014, is a comprehensive federal law intended to streamline, consolidate, and improve workforce development and training services for various groups, including youth and workers with disabilities.<sup>103</sup> In ND, WIOA programs are located across three state agencies (Job Service North Dakota, DPI/Division of Adult Education, and DHS/Division of Vocational Rehabilitation).<sup>104</sup> In 2014, there were 57 charges filed under the Americans with Disabilities Act in ND. The most common issue identified was employment discharge (58.9%), followed by a lack of providing reasonable accommodations (35%).<sup>105</sup>

## **Ticket to Work**

The Ticket to Work program provides Social Security disability beneficiaries with access to free employment support services via Ticket to Work service providers.<sup>106</sup> The program allows people to keep their benefits while exploring employment options.<sup>107</sup> Everyone age 18 through 64 who receives either or both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits because of his or her disability is eligible to participate in the

<sup>99</sup> State Data.info. Retrieved from: [https://www.statedata.info/sites/statedata.info/files/files/Transition\\_Report\\_2015.pdf](https://www.statedata.info/sites/statedata.info/files/files/Transition_Report_2015.pdf)

<sup>100</sup> Ibid.

<sup>101</sup> ND Legislature. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/session-laws/documents/pwelf.pdf>

<sup>102</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/dvr/individual/independent.html>

<sup>103</sup> Federal Registry. Retrieved from: <https://www.federalregister.gov/documents/2016/08/19/2016-15980/state-vocational-rehabilitation-services-program-state-supported-employment-services-program>

<sup>104</sup> ND Job Service. Retrieved from: <https://www.workforce.nd.gov/uploads/8/WDCReportFINAL2018.pdf>

<sup>105</sup> Disability Statistics. Retrieved from: <https://www.disabilitystatistics.org/eeoc/custom.cfm>

<sup>106</sup> Social Security Administration. Retrieved from: <https://choosework.ssa.gov/>

<sup>107</sup> Social Security Administration. Retrieved from: <https://choosework.ssa.gov/about/index.html>

Ticket to Work program. Participants will work with either an Employment Network or the state Vocational Rehabilitation agency, depending on individual needs.<sup>108</sup>

### **The ND Division of Vocational Rehabilitation (DVR) Division**

The DVR assists individuals with disabilities to achieve competitive employment and increased independence by providing training. DVR also offers assistance to businesses in finding solutions to their disability-related issues.<sup>109</sup> In FFY 2018, 61 percent of the DVR case expenditures were for training services to individuals with disabilities. The training consists of postsecondary tuition, on-the-job-training, work experience, job development, adaptive aids and equipment, benefits planning, and transportation. DVR must spend at least 15 percent of its federal funds on work readiness activities for students age 21 and younger. According to their 2019 annual report, ND's DVR spent 19 percent of their funds on this activity.<sup>110</sup> DVR also established contracts with fifteen school districts to provide pre-employment transition services to transition-age youth with disabilities and served 2,219 students with disabilities.<sup>111 112</sup>

In 2019, 27% of people served by NDVR and achieved employment had a cognitive impairment.

Figure 10: Source: ND Division of Vocational Rehabilitation

As Figure 10 indicates, 27 percent of people served by DVR had a cognitive disability.

### **Employment Support for People with Significant Support Needs**

People that access vocational rehabilitation services have a wide range of support needs. There are two programs designed for those with significant needs: supported employment and extended services programs.

1. Supported Employment provides training for individuals with the most significant disabilities who, because of the severity of their physical or mental impairments, have never been employed or have a history of sporadic employment. A job coach or employment specialist provides the interventions.<sup>113</sup> ND uses a "place and train" model until employment stability is achieved for a period not to exceed 24 months.<sup>114</sup> Supported Employment is also available through the Traditional IDD/DD Waiver.
2. Extended Services is a program for people who have received supported employment but continue to need support after their DVR services end.<sup>115</sup> The extended services program is available through VR, Behavioral Health, and the DD Divisions in DHS.

### **Employment Support in the Traditional IDD Waiver**

There are additional employment services available within the Traditional IDD waiver.

<sup>108</sup> Social Security Administration. Retrieved from: <https://choosework.ssa.gov/about/how-it-works/index.html>

<sup>109</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/dvr/about/index.html>

<sup>110</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/testimony/2019/senate-approp/sb2012-overview-vr-2019-1-16.pdf>

<sup>111</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/dvr/docs/2019-Annual-Report.pdf>

<sup>112</sup> Ibid.

<sup>113</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/dvr/individual/supported.html>

<sup>114</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/dvr/docs/Policy-Supported-Employment-SE.pdf>

<sup>115</sup> Ibid.

- **Individual Employment Support** assists participants in maintaining paid employment in an integrated setting or self-employment. Service includes on or off-the-job support to assist in obtaining or maintaining employment. The employer pays participants at or above minimum wage.<sup>116</sup>
- **Prevocational Services** prepare participants for paid employment in integrated community settings. Services are structured to develop general abilities and skills that help employability in a work setting. Services may include training in effective communication within a work setting, workplace conduct and attire, following directions, attending to tasks, problem-solving, and workplace safety.<sup>117</sup>
- **Small-Group Employment Support** helps maintain paid employment in an integrated setting. Services include support for small groups of participants needing intervention to assist them in obtaining and maintaining employment as a group. Supports are provided to groups of two to eight employed participants.<sup>118</sup>

## Self-Employment

Social entrepreneurship is a growing trend that supports the position that entrepreneurship and self-employment are viable employment options for people with disabilities. Entrepreneurship can promote autonomy, reduce dependence on entitlement-based services, and reduce employment disparities while stimulating business and job creation. The DVR has a self-employment program that identifies a step-by-step process for clients pursuing self-employment.<sup>119</sup> In a very small study, "social entrepreneurship" was found to be gaining momentum in the IDD community. Although it has the potential to be an empowering source of job creation and social innovation, it also has the potential to disenfranchise the IDD population further.<sup>120</sup> Given this, it is essential to match employment type to individual needs and strengths.

## Client Assistance Program (CAP)

The Client Assistance Program (CAP) is a federally funded program designed to assist individuals with disabilities in resolving challenges they may experience with federally funded rehabilitation programs. In ND, assistance related to the State Vocational Rehabilitation Program, Centers for Independent Living, and Tribal Vocational Rehabilitation Programs is available.<sup>121</sup> CAP is administered by the ND Protection & Advocacy Project (P&A)

<sup>116</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/traditional-iid-dd-hcbs-waiver-2019.pdf>

<sup>117</sup> Ibid.

<sup>118</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/traditional-iid-dd-hcbs-waiver-2019.pdf>

<sup>119</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/dvr/individual/self.html>

<sup>120</sup> Kate Caldwell, Sarah Parker Harris and Maija Renko, (2019). Inclusive Outcomes for Social Entrepreneurs With Intellectual Disability: "What Happens When They Act", *Inclusion*, 10.1352/2326-6988-7.4.204, 7, 4, (204-219). Retrieved from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12662>

<sup>121</sup> ND Protection and Advocacy Project. Retrieved from: <http://www.ndpanda.org/cap/>



## Education and Early Intervention

There are 1,136 public and private prekindergarten through grade 12 schools in ND.<sup>122</sup> The enrollment in the 2018-2019 academic year was 113,646, and there were 6,947 graduates. There were 15,103 students enrolled in 42 private schools in FY 2019. According to the Kids Count Data Center, in 2018, there were 10,886 special education students in ND.<sup>123</sup> Of this total, there were 769 students with IDD, which equates to 4.8 percent of the special education enrollment. Of the 15,103 children in private schools, 215 were children with disabilities.<sup>124</sup> <sup>125</sup> Per pupil public spending for the 2017-2018 academic year was \$11,606.<sup>126</sup>

### Special Education

The Individuals with Disabilities Education Act (IDEA) ensures that all children and youth with disabilities have a free appropriate public education (FAPE), and special education and related services are designed to meet students' unique needs. Public education is to prepare students for further education, employment, and independent living.<sup>127</sup> The IDEA requires public schools to develop an Individual Education Plan (IEP) for every student with a disability who meets the federal and state requirements for special education. Federal regulations require that children with disabilities, including preschool-aged children and, in particular, students with IDD, be educated with children who are nondisabled to the maximum extent appropriate.<sup>128</sup> The requirement of educating students in the Least Restrictive Environment (LRE) has been part of IDEA since its inception in 1975.

ND DPI Special education performance data provides information on how the state's special education system is performing.<sup>129</sup> Table 10 highlights performance targets that measure the amount of time children with IEPs spend inside or outside of a regular classroom or separate school.

<sup>122</sup> Great Schools.org. Retrieved from: <https://www.greatschools.org/north-dakota/>

<sup>123</sup> Kids Count Data Center. Retrieved from: <https://datacenter.kidscount.org/data/tables/4425-children-enrolled-in-special-education-in-public-schools-by-type-of-impairment-percent-of-special-education-enrollment#detailed/2/any/false/37,871,870,573,869,36,868,867,133,38/693,694,695,3547,3548/9934,9935>

<sup>124</sup> ND Department of Public Instruction. Retrieved from:

<https://www.nd.gov/dpi/sites/www/files/documents/SpEd/ProportionateShare201819.pdf>

<sup>125</sup> National Center for Educational Statistics. Retrieved from:

[https://nces.ed.gov/surveys/pss/privateschoolsearch/school\\_list.asp?Search=1&State=38&SchoolPageNum=1](https://nces.ed.gov/surveys/pss/privateschoolsearch/school_list.asp?Search=1&State=38&SchoolPageNum=1)

<sup>126</sup> ND Department of Public Instruction. State Summary 2017-2018. Retrieved from:

<https://insights.nd.gov/Education/State/Summary>

<sup>127</sup> ND Department of Public Instruction. Retrieved from: <https://www.nd.gov/dpi/education-programs/special-education>

<sup>128</sup> ND Department of Public Instruction. Retrieved from:

<https://www.nd.gov/dpi/sites/www/files/documents/SpEd/Guidelines/IDGuidelinesFinalVersionPosted.pdf>

<sup>129</sup> ND Department of Public Instruction. Retrieved from:

<https://insights.nd.gov/Education/State/SPED/LeastRestrictiveEnvironment>

Table 10: Select ND Special Education Data for the 2018-2019 Academic Year

Target	Target	Actual	Target Met?
Percent of children with IEPs aged 6 through 21 served inside the regular class 80% or more of the day.	76%	73.52%	No
Percent of children with IEPs aged 6 through 21 served inside the regular class less than 40% of the day.	4.80%	5.82%	No
Percent of children with IEPs aged 6 through 21 served in separate schools, residential facilities, or homebound/hospital placements.	1.97%	1.58%	Yes
Percent of children with IEPs aged 3 through 5 attending a separate special education class, separate school, or residential facility.	≤27.6%	32.97%	No

Two additional measures reflect the ND four-year graduation rate and the dropout rate for students with IEPs. ND youth with IEPs graduating from high school in the 2016-2017 academic year with a regular high school diploma and within four years of the first time they entered the 9<sup>th</sup> grade is 66.2 percent.<sup>130</sup> ND did not meet the goal of 89 percent. ND defines dropouts as students who leave school before graduation for reasons other than to transfer to another school. Students who receive special education services and leave school with a certificate of completion are designated as dropouts. The ND dropout rate for students with IEPs for the 2016-2017 academic year is 16.7 percent. ND met this goal, which is 18 percent.<sup>131</sup>

The EdWeek Research Center reports its comprehensive analysis of data in its *Quality Counts* report card. The report card shows where each state ranks for educational opportunities and performance.<sup>132</sup> States are graded and ranked in three categories:

- 1) The chance for success
- 2) school finance
- 3) K-12 achievement

In the 2019 report, ND finished 14th among the 50 states, with an overall score of 78.8 out of 100 points and a grade of C-plus. The nation as a whole scored a grade of C. ND earned a B in the Chance-for-Success and school finance categories and ranks tenth. For the K-12 Achievement Index, ND finished 38th with a grade of D-plus.

<sup>130</sup> ND Department of Public Instruction. Retrieved from: <https://insights.nd.gov/Education/State/SPED/GraduationDropout>

<sup>131</sup> Ibid.

<sup>132</sup> Education Week. Retrieved from: <https://www.edweek.org/ew/articles/2019/01/16/highlights-report-north-dakota.html>

## Head Start

Head Start and Early Head Start are child development programs, serving children in low-income families, children with disabilities from birth to age five, and expectant mothers and families. The overall goal of Head Start is to increase the social ability of children and improve the chances of success in school. Head Start is federally funded, but each program is required to provide a 20 percent local funding match. There have been Head Start programs in North Dakota since 1965.<sup>133</sup> According to the Head Start Program Information Report data, ND's enrollment was 2,149 participants in 2017-2018 and 2,410 children and 60 pregnant women in 2018-2019.<sup>134</sup>

## Secondary Transition

Transition planning is required for all students receiving special education services as they move from high school to adult living.<sup>135</sup> A review of the transition performance data shows that ND narrowly missed the target for the percent of youth aged 16 and above whose IEP includes transition services that will reasonably enable the student to meet the postsecondary goals. ND's rate was 99.52 percent for the 2018-19 academic year, whereas the target set by the Office of Special Education Programs is 100 percent.<sup>136</sup> The ND Community of Practice for Transition Council seeks to improve transition outcomes for young adults with disabilities.<sup>137</sup>

## Part C-Early Intervention

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal program that provides funds to develop and implement a statewide early intervention program for children from birth through age two with disabilities and their families.<sup>138</sup> In ND, the program is called Infant Development, and the lead agency responsible for the program is the DHS-DD Division. There is at least one early intervention provider in each ND region, including reservations. In total, there are ten contracted providers. Any child under the age of 3 who may have a delay or a medical condition that could result in a developmental delay or disability is eligible for referral to the program.<sup>139</sup> ND's program uses a parent-coaching model, and services are provided in the child's home. Each eligible child has a service team that determines the type, frequency, and duration of services necessary to meet the child and caregiver needs.

Four services comprise the Infant Development program:

1. Home visits: Home visits allow professionals to coach the primary caregiver(s) in how to address the needs of their child. Home Visits must occur at least once a month.
2. Consults: Consultations allow team members to coach both the primary caregiver(s) and home visitor in the area of their specialty.

<sup>133</sup> ND Department of Public Instruction. Retrieved from: <https://www.nd.gov/dpi/education-programs/early-childhood-education/head-start>

<sup>134</sup> ND Department of Public Instruction. Retrieved from: <https://www.nd.gov/dpi/sites/www/files/documents/Early%20Learning/2019%20North%20Dakota%20Head%20Start%20Collaboration%20Office%20Needs%20Assessment.pdf>

<sup>135</sup> Individuals with Disabilities Education Act. Retrieved from: <https://sites.ed.gov/idea/statute-chapter-33>

<sup>136</sup> ND Department of Public Instruction. Retrieved from: <https://www.nd.gov/dpi/sites/www/files/documents/SpEd/December%20IDEA%20Advisory%20Meeting%20Minutes.pdf>

<sup>137</sup> ND Department of Human Services, Division of Vocational Rehabilitation. Retrieved from: <https://www.nd.gov/dhs/dvr/councils-partners/ndcop.html>

<sup>138</sup> U.S. Department of Education. Retrieved from: <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html>

<sup>139</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/interim/19-5055-03000-meeting-minutes.pdf>

3. Evaluation/Assessment: An evaluation determines eligibility for Developmental Disabilities Program Management, as well as Infant Development services. An annual assessment determines progress made on the Individual and Family Service Plan (IFSP) outcomes.
4. IFSP Development/Update: The IFSP directs early intervention supports and services.<sup>140</sup>

In the 2017 report, the ND infant development program served 4.17 percent of the state's child population under the age of three. Of the children served, 8.94 percent were Native American compared to the U.S. early intervention programs overall rate of .73 percent. The program measures the percent of children that were functioning within expectations by the time they turned age three or exited the program. While the target is 45.10 percent, ND's actual percent was 37.5 percent or 123 out of 328 children. The Department noted they are focusing on monitoring the data. Since a new outcome tool was recently implemented, they hope to see increased fidelity as well as valid and reliable data.<sup>141</sup>

#### Recent Early Intervention Program Changes

- A full-time coordinator for the Part C program was hired in May of 2018.
- Costs for Infant Development services within the IDD Medicaid Waiver appear in the DHS Quarterly Budget Insight Report. In the 2017 – 2019 biennium report, Infant Development had a monthly average of 1,237 children receiving the services at a monthly average cost of \$843.<sup>142</sup>
- The program collects a large amount of performance data. Up until the fall of 2017, ND used the Oregon Early Childhood Assessment Tool. Since this tool is no longer supported or used by the creators, a new tool was chosen. ND now uses the Assessment, Evaluation, and Programming System (AEPS).<sup>143</sup>
- A core working group formed to address the concern over the increased amount of the federal Part C grant dollars used for direct services, which leaves less for coordinating efforts.<sup>144</sup>
- The 64<sup>th</sup> Legislative session passed Senate Bill 2324 to study the early intervention program. The 2017 Health Services Interim Committee directed the early intervention study.<sup>145</sup> It does not appear that any program or policy changes resulted from this legislative study.
- The workgroup evolved into a broader stakeholder group that held a summit on November 29, 2017, and reported its findings to the interim committee.<sup>146</sup>

<sup>140</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/traditional-iid-dd-hcbs-waiver-2019.pdf>

<sup>141</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/earlyintervention/partcinfo/doc/FFY-ND-Part-C-Application.pdf>

<sup>142</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/pubs/docs/qtrly-budget-insight-july2017-june2019.pdf>

<sup>143</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/earlyintervention/partcinfo/doc/ffy-2017-spp-apr.pdf>

<sup>144</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/65-2017/19\\_5055\\_03000appendixd.pdf](https://www.legis.nd.gov/files/committees/65-2017/19_5055_03000appendixd.pdf)

<sup>145</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/documents/17-0806-05000.pdf>

<sup>146</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/65-2017/19\\_5091\\_03000appendixb.pdf](https://www.legis.nd.gov/files/committees/65-2017/19_5091_03000appendixb.pdf)

As noted previously, there are other components to the Part C program in addition to the infant development direct services. They are:

- Experienced Parents- Parents of children with developmental delays or disabilities who provide information to parents of children currently receiving Early Intervention services regarding system issues and provide input regarding procedures and parent material.<sup>147</sup>

- Child Find

The regulations for Part C require that each state has a comprehensive Child Find system to identify, locate, and screen all infants and toddlers with disabilities birth through age two as early as possible.<sup>148</sup> Two child find activities in place in ND are:

- Birth Review--This activity is a cooperative effort with the ND DHS, the ND DOH, and all birthing hospitals. New parents are sent postcards and presented with the opportunity to have additional information sent to them or to be connected to their local Right Track provider. If interested, the hospital makes a referral to the family's regional human service center.<sup>149</sup>
- Right Track- provides free in-home developmental screening for children from birth to three years of age. It is a family-centered program offered to every child so they can experience the "best start" in physical, social, emotional, motor, and intellectual development. There is at least one right track provider in each region of the state. Right Track coordinators work with staff and families to determine the frequency of follow up visits based on the screening results, observations, and parental questions.<sup>150</sup> From October 2016 through August 2017, 6,434 Right Track visits occurred.<sup>151</sup>
- Technical Assistance-Contracted support to implement quality measures, analyze data, and improve the supervision system.<sup>152</sup>
- Audiologists -Individual contracts with local audiologists to train Infant Development staff and interpret hearing screening results (OAE and tympanograms).
- Family Liaison- provide training and information to parents.
- Interagency Committee

The mission of North Dakota's Interagency Coordinating Council is to provide leadership and advise and assist ND DHS-DD Division in the effort to implement a statewide system for the delivery of appropriate services to children at-risk and children with disabilities (ages birth through 5) and their families.<sup>153</sup>

<sup>147</sup> ND Department of Human Services. Retrieved from:

<https://www.nd.gov/dhs/services/disabilities/earlyintervention/partcinfo/doc/FFY-ND-Part-C-Application.pdf>

<sup>148</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/65-2017/19\\_5091\\_03000appendixh.pdf](https://www.legis.nd.gov/files/committees/65-2017/19_5091_03000appendixh.pdf)

<sup>149</sup> ND Department of Human Services. Retrieved from:

<https://www.nd.gov/dhs/services/disabilities/earlyintervention/partcinfo/doc/FFY-ND-Part-C-Application.pdf>

<sup>150</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/interim/19-5055-03000-meeting-minutes.pdf>

<sup>151</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/65-2017/19\\_5055\\_03000appendixe.pdf](https://www.legis.nd.gov/files/committees/65-2017/19_5055_03000appendixe.pdf)

<sup>152</sup> ND Department of Human Services. Part C Annual Performance Report 2017. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/earlyintervention/partcinfo/doc/ffy-2017-spp-apr.pdf>

<sup>153</sup> ND Department of Human Services. Retrieved from:

<https://www.nd.gov/dhs/services/disabilities/earlyintervention/ndicc/docs/standard-operating-procedures.pdf>

### **Early Intervention Funding**

ND's funding for the Infant Development program is two-fold: 1) Federal Grant and 2) Medicaid Traditional IDD waiver funds. Parents can choose to apply for Medicaid, which covers the program under the Traditional IDD Waiver. If parents decide to have their child covered by Medicaid, they have the benefit of income and asset disregard plus access to other Medicaid medical benefits for the child. If parents decide to apply for Medicaid, Part C federal funding is used for the additional early intervention system components. The current trend is that more families are choosing not to apply for Medicaid. This trend puts pressure on the ability to maintain the other required components of the system, which are also paid with the Part C grant. It is important to note that when a state accepts the federal Part C grant, the state must implement all required components regardless of whether the grant funds are sufficient to cover the costs.<sup>154</sup> ND does not collect third party insurance or assess a parent fee for this program.

### **Part B- Early Childhood Special Education**

When a child exits the Part C-Early Intervention program, they are referred, if appropriate, to the Part B -early childhood special education program to continue maximizing a child's development. Eligibility for Part B requires a child to have a disability and need special education and related services.<sup>155</sup> <sup>156</sup> In the ND Part B 2017 report, 2,139 children were served by the program.<sup>157</sup> NDDPI provided information on the transition of children from Part C to Part B programming, which is displayed in Figure 11.<sup>158</sup> It appears that annually, between 60-70 percent of children referred from early intervention are found eligible for early childhood special education services.

<sup>154</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/65-2017/interim/19-5055-03000-meeting-minutes.pdf>

<sup>155</sup> National Center for Hearing Assessment and Management. Eligibility and Service Delivery Policies: Differences Between IDEA Part C and IDEA Part B: A Comparison Chart, 2016. Retrieved from: <https://www.infanthearing.org/earlyintervention/docs/aspect-idea-part-c-and-idea-part-b.pdf>

<sup>156</sup> U.S. Department of Education. Retrieved from: <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html>

<sup>157</sup> Retrieved from: <https://idc.clicdata.com/v/5MF4CZvDTX6A>

<sup>158</sup> ND Legislative Management. Retrieved from: [https://www.legis.nd.gov/files/committees/65-2017/19\\_5091\\_03000appendixg.pdf](https://www.legis.nd.gov/files/committees/65-2017/19_5091_03000appendixg.pdf)

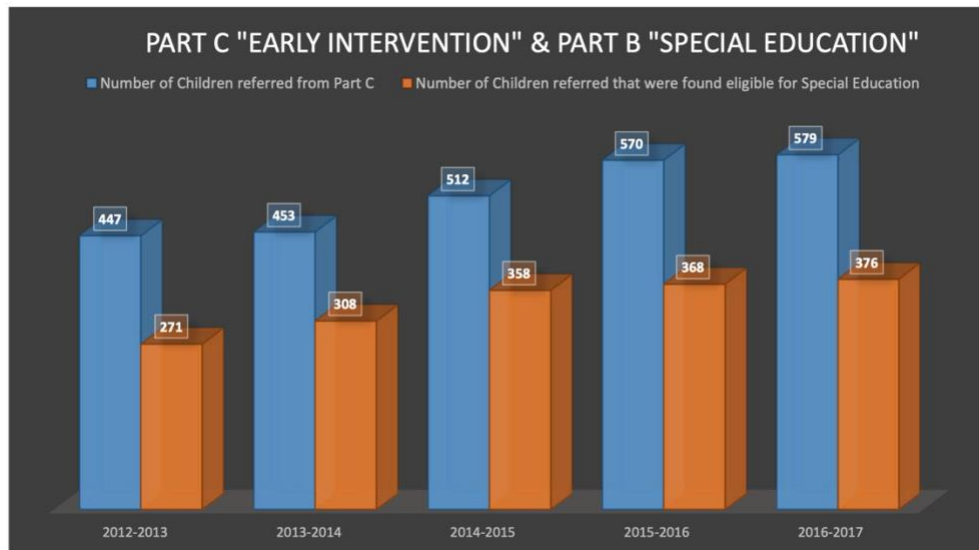


Figure 11: Number of Children Referred from Part C and Found Eligible for Part B Programs. Source ND Department of Public Instruction

### IDEA Advisory Committee

ND's IDEA advisory committee exists to make recommendations and to advise the DPI concerning the administration of, preparation of general regulations for, and evaluation of Special Education programs in the state.<sup>159</sup> In the December 2019 IDEA Advisory committee, ND DPI presented several special education-specific outcomes.<sup>160</sup> Table 11 illustrates that ND does not meet the graduation target for students with IEPS, and students with IDD are found least proficient in math and reading.

<sup>159</sup> ND Department of Public Instruction. Retrieved from:

<https://www.nd.gov/dpi/sites/www/files/documents/SpeEd/IDEA%20Bylaws.pdf>

<sup>160</sup> ND Department of Public Instruction. Retrieved from:

<https://www.nd.gov/dpi/sites/www/files/documents/SpeEd/December%20IDEA%20Advisory%20Meeting%20Minutes.pdf>

Table 11: ND Special Education Outcomes, reported by DPI in December 2019 to the ND IDEA Committee<sup>161</sup>

Outcome	Results
Indicator -Graduation Rate: Percent of youth with IEPs graduating from high school with a regular diploma.	Target 89% Actual 68.48%
Who is most likely to graduate: Environment: regular classroom	77% • SLD 82% • SI 65% • OHI 74% Ethnicity – White
Who is least likely to graduate: Environment: students in separate classrooms?	<b>Environment:</b> • students in separate classrooms: 30% • Students in resource room: 55%  <b>Primary Disability:</b> • ID – 37% • Autism: 50% • ED – 53%  <b>Ethnicity:</b> • Native American: 55% • Black or African American: 56%  <b>4-year graduation rate:</b> • 87.99% All students, • 90.57% Non-IEPs, • 68.48% IEPs.
Who is least likely to score proficient in Math?	<ul style="list-style-type: none"> <li>• Students in resource room: 5.35%</li> <li>• ID: 1.11%</li> <li>• Grade 10: 4.36%</li> <li>• With Accommodation: 5.74%</li> <li>• Native American: 7.17%</li> </ul>
Who is most least likely to score proficient in Reading?	<ul style="list-style-type: none"> <li>• ID: 0.00% • Residential Facility: 0.00%</li> <li>• Pacific Islander: 4.00%</li> <li>• Inside Regular Class 40% to 79% of Day: 4.48%</li> <li>• American Indian: 7.25%</li> <li>• Took NDSA with Accommodation: 7.40%</li> <li>• SLD: 7.69%</li> </ul>

## Children's Cabinet

Senate Bill No. 2313 (2019) created a Children's Cabinet to assess, guide, and coordinate the care for children across the state's branches of government and the tribal nations.<sup>162</sup> The Cabinet is to develop strategies to address gaps or needs regarding early care and education, medical and behavioral health, community, child welfare, and juvenile justice.<sup>163</sup> Governor Doug Burgum

<sup>161</sup> ND Department of Public Instruction. Retrieved from:

<https://www.nd.gov/dpi/sites/www/files/documents/SpEd/December%20IDEA%20Advisory%20Meeting%20Minutes.pdf>  
<sup>162</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/66-2019/committees/joint/childrens-cabinet>

<sup>163</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/66-2019/documents/19-1121-05000.pdf>



appointed 12 members in the fall of 2019.<sup>164</sup> The Cabinet met two times since its inception as of February 2020.<sup>165</sup>

### **Teacher Training**

The ND DPI provides a teacher training support system to build the support system in each school in the state. The ND Teacher Support System has mentored 2,295 new teachers since 2010. Approximately 78 percent of the teachers that receive the mentoring support continue to teach in ND today. Over 430 Instructional Coaches have been trained with the ND Teacher Support System.<sup>166</sup> There have been several legislative actions to provide teachers with training on behavioral health issues. Senate Bill 2048 (2019) mandates a mental health competency course for all initial teacher licenses.<sup>167</sup>

<sup>164</sup> ND Office of the Governor. Retrieved from: <https://www.governor.nd.gov/news/burgum-announces-members-newly-established-childrens-cabinet>

<sup>165</sup> Public New Service. Retrieved from: <https://www.publicnewsservice.org/2020-02-26/childrens/new-nd-childrens-cabinet-gets-its-feet-wet/a69362-1>

<sup>166</sup> ND Education Standards and Practices Board. Retrieved from: <https://www.nd.gov/espb/welcome-north-dakota-teacher-support-system>

<sup>167</sup> ND Education Standards and Practices Board. Retrieved from: <https://www.nd.gov/espb/licensure/license-information/mental-health-requirement>

# Transportation

## Transit

The ND Department of Transportation (DOT) administers the state's federal transit grant and state-aid funding for transit projects. Transit service is for the general public, students, veterans, the elderly, and persons with disabilities.<sup>168</sup> State funding for public transit is determined by the state legislature and distributed by a formula outlined in the ND Century Code.<sup>169</sup> According to the DOT, all fifty-three ND counties have transit service three to five days a week. There are approximately thirty-four bus programs that provide public transportation for anyone who needs a ride in rural ND. The ND DOT website provides county maps where the transit providers, services, hours, cost, and contact information, are listed.<sup>170</sup>

There are five types of transit services in ND.

1. Fixed route – These are scheduled and regular routes.
2. Demand/Response – Rides are reserved by calling ahead to reserve a seat.
3. Medical Rides - Travel for medical appointments, dialysis, or chemotherapy. This service may be formally structured or provided as needed.
4. Dial-A-Ride/Para Transit- This accessible door-to-door service is for persons with disabilities and seniors.
5. Intercity - A fixed route schedule to and from major ND population centers. Providers are Jefferson Lines, Standing Rock Public Transit, and Souris Basin Transportation. Passengers can connect to local transit to travel into rural areas of the state.

According to ND DOT, the top reasons riders use transit are:

- Medical
- Shopping
- Employment
- Education/Training<sup>171</sup>

In 2019, the DOT developed a statewide transportation plan, called "ND Moves." This plan serves as a guide and a resource in the development of state and local transportation systems and programs.<sup>172 173</sup> Meetings were held around the state to gain input for the transportation plan. Participants were asked to identify the most significant barriers in accessing bicycle, pedestrian, and transit systems in their areas. The top three obstacles identified in each system are illustrated in Figure 12.<sup>174</sup>

<sup>168</sup> ND Department of Transportation. Retrieved from: <https://www.dot.nd.gov/divisions/localgov/transit-aboutus.htm>

<sup>169</sup> Ibid.

<sup>170</sup> ND Department of Transportation. Retrieved from: <https://www.dot.nd.gov/divisions/localgov/transit-providers.htm>

<sup>171</sup> ND Department of Transportation. Retrieved from: <https://www.dot.nd.gov/divisions/localgov/transit.htm>

<sup>172</sup> ND Department of Transportation. Retrieved from: <https://www.dot.nd.gov/plans/statewide/ndmoves.htm>

<sup>173</sup> Ibid.

<sup>174</sup> ND Department of Transportation. Retrieved from: <https://www.dot.nd.gov/plans/statewide/docs/NDMovesAppendix.pdf>



Figure 12: 2020 ND Department of Transportation. ND Moves Plan-Identified Barriers, Source. ND DOT

The study's findings identified that mobility is a top issue for most people with disabilities and often determines the extent to which they can participate in the community and retain employment. DOT indicated they found no clear pattern that emerged in the analysis of transit issues as it relates to people with disabilities.<sup>175</sup>

### Transportation Supports in Medicaid Programs

There are several transportation services covered through ND DHS-Medicaid. The traditional Medicaid plan includes non-emergency medical transportation services to and from a recipient's home to the closest medical provider.<sup>176</sup> Within the traditional IDD waiver, several services allow for non-medical transportation. They are:

- **Day Habilitation** may include transportation costs to access program-related activities in the community. Transportation costs from a participant's residence to their workplace are available when a participant needs it as a support intervention for the participant to maintain employment. It is not allowed as a substitute for personal, public, or generic transportation.
- **Prevocational Services** may include transportation costs to access program-related activities in the community.
- **Adult Foster Care** - Non-medical transportation is included in the foster care rate.
- **Small group employment** - Transportation costs from a participant's residence to their workplace may be included in the service rate when a participant needs it as a support intervention for the participant to maintain employment. It is not allowed as a substitute for personal, public, or generic transportation.<sup>177</sup>

The proposed 1915i Medicaid state plan amendment also includes coverage for non-medical transportation with a 200-vehicle mile and four taxi/bus ride per month limit.<sup>178</sup>

<sup>175</sup> ND Department of Transportation. Retrieved from:

<https://www.dot.nd.gov/plans/statewide/docs/NDMovesPlanWithExecSummary.pdf>, page 19

<sup>176</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/services/medicalserv/medicaid/covered.html>

<sup>177</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/approved-nd-1915c-hcbs-waiver-for-individuals-w-idd-addendum-effective-4-1-2020.pdf>

<sup>178</sup> ND Department of Human Services. Retrieved from: <https://www.behavioralhealth.nd.gov/1915i/snapshot>

## Child Care

Quality childcare enables people to work or go to school. The DHS-Children & Family Service Division (DHS-CFS) manages the early childhood program in ND. The Child Care and Development Block Grant (CCDBG) is the primary source of federal funding for child care subsidies for low-income working families and funds to improve child care quality.<sup>179</sup> The CCDBG requires several tasks: Consumer Education and Referral, Quality Rating Improvement System, and Early Childhood Work Force Registry. DHS-CFS contracts with Lutheran Social Service who provides the required tasks through the following programs: <sup>180</sup>

1. Child Care Aware® of North Dakota performs the consumer education function. It collects and maintains data about the child care industry in ND annually.<sup>181</sup> This online child care database provides information on the state's child care providers.<sup>182</sup>
2. Bright & Early is ND's quality rating improvement system. The program seeks to assess, improve, and communicate the level of quality in childcare and early education programs across the state.<sup>183</sup> Programs that participate receive exclusive benefits that support and sustain their quality. Some of the benefits include free or low-cost training, access to grants used to purchase new materials and equipment, Quality Rating award dollars, and marketing materials to showcase their program.
3. Growing Futures performs the workforce registry and provides the process to approve childcare training. Only approved training counts toward license renewal. The registry is the central clearinghouse of information and resources for people who work with children.<sup>184</sup>

## Child Care Assistance for Parents

Part of the CCDBG is the Child Care Assistance Program (CCAP). The CCAP helps income-eligible families pay for child care while they work or attend school or training. DHS-CFS uses the county social service (human service zone) offices to carry out the eligibility determination process for the program. In 2018, continuous eligibility began for this program. Continuous eligibility means that households continue to be eligible for an additional 12 months if the household's income meets the guidelines.<sup>185</sup> The DHS CCAP information indicates that, on average, 1,747 families per month receive 788 dollars for child care assistance through this program.<sup>186</sup> The CCDBG 2019-2021 plan indicates there is no waitlist for the program; however, in the case a waitlist occurs, children experiencing homelessness would be prioritized for the service.<sup>187</sup>

<sup>179</sup> Federal Grants Wire. Retrieved from: <https://www.federalgrantswire.com/child-care-and-development-block-grant.html#.XnJQmZnKhQI>

<sup>180</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

<sup>181</sup> Child Care Aware of North Dakota. Retrieved from: <https://ndchildcare.org/data-pub/data.html>

<sup>182</sup> Child Care Aware of North Dakota. Retrieved from: <https://ndchildcare.org/parents/find-child-care/>

<sup>183</sup> Bright and Early of North Dakota. Retrieved from: <https://www.brightnd.org/faq>

<sup>184</sup> Zero to Three. Retrieved from: <https://www.zerotothree.org/resources/868-north-dakota-growing-futures>

<sup>185</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

<sup>186</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/qtrly-budget-insight-july2019-dec2019.pdf>

<sup>187</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

Another child care assistance program supports teen parents. The Crossroads program supports teen parents by providing case management services to help them complete their high school or GED education and supports them up to age 21. CCAP will waive co-payments for Crossroads eligible participants. Services are also prioritized for Temporary Assistance for Needy Families (TANF) recipients, as CCAP will waive the co-payment.<sup>188</sup>

### **Assistance for Child Care Providers**

The **Early Childhood Education Grant Program** was established in the 2015 Legislative session to increase the capacity of child care in ND and provide funding for public and private Early Childhood Education programs serving four-year-old children. Eligibility requires the children to be eligible for free or reduced lunches.<sup>189</sup> The **Child Care Loan Program**, through the ND Commerce Department's Commerce Development Fund, provides financial assistance to child care providers.<sup>190</sup> Licensed child care providers may borrow up to \$100,000 at a fixed rate of 2.5 percent.

Ongoing training is required for licensed child care providers, and DPI reports new 2018 ND early learning standards: birth to kindergarten. The standards include 1) Approaches to Play and Learning; 2) Social and Emotional Development; 3) Language, Communication, and Literacy; 4) Mathematics and Logical Thinking; 5) Scientific Reasoning; 6) Social Studies; 7) Creative Arts; and 8) Perceptual, Motor, and Physical Development. According to the news release, the standards provide a common set of expectations for young children's learning and development in a variety of early learning settings across the state.<sup>191</sup>

### **Child Care Licensing Categories**

There are several types of child care provider licenses in ND.<sup>192</sup>

- **Licensed Family Child Care:** Family providers may care for up to 7 children with no more than three children under the age of 24 months, plus two additional school-age children.
- **Licensed Group Child Care:** Group child care programs may be licensed in a home or a facility. Groups may be licensed for up to 30 children, with the actual license capacity determined by available space, staff to child ratios, and sometimes local ordinances.
- **Licensed Child Care Center:** Child care centers are licensed for at least 19 children in a facility, with the actual license capacity determined by available space, staff to child ratios, and sometimes local ordinances.
- **Licensed Preschools:** Preschools provide educational and socialization experiences for children age two years to kindergarten and may operate sessions for no more than 3 hours per day.

<sup>188</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

<sup>189</sup> ND Department of Commerce. Retrieved from: <https://www.workforce.nd.gov/workforce/EarlyChildhoodEducationGrantProgram/>

<sup>190</sup> ND Department of Commerce. Retrieved from: [https://www.business.nd.gov/development\\_fund/NDDEFPrograms/#Child%20Care](https://www.business.nd.gov/development_fund/NDDEFPrograms/#Child%20Care)

<sup>191</sup> Zero to Three. Retrieved from: <https://www.zerotothree.org/resources/2666-north-dakota-releases-new-early-learning-standards>

<sup>192</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/childcare/info/>

- **Licensed School-Age Programs:** School-age programs are licensed for at least 19 children in a facility, with the actual license capacity determined by available space, staff to child ratios, and sometimes local ordinances. School-age programs offer services before and after school, and sometimes on school holidays and through the summer months.
- **Multiple License Facility:** This type of program has more than one type of license, such as a center and preschool.
- **Self-declared Providers:** Care for five or fewer children or three infants in a home. These providers must meet some minimal standards, including a background check and basic health and safety training, are inspected before approval, and receive one monitoring visit per year. Self-declared providers are eligible to participate in the Child Care Assistance Program and the USDA Food program.<sup>193</sup>
- **Approved Relatives:** Care for five or fewer children or three infants; are also eligible to participate in the Child Care Assistance Program. By federal law, the 'approved' relatives must be related by marriage, blood relationship, or court order and include grandparents, great-grandparents, aunts, and uncles.

### **Child Care Programs for Children with Disabilities**

According to the CCDBG, all providers shall make appropriate accommodations, as required by the ADA, to meet the needs of children with special needs. The requirements include that the provider shall ensure staff members must receive proper instructions as to the nature of the child's special needs and potential for growth and development.<sup>194</sup>

The Inclusion Support program seeks to create and maintain an inclusive environment that supports children who have disabilities or developmental delays.<sup>195</sup> The program has received legislative funding since its inception in 2011. Program funds can be used for supporting staff needs, modifying a child care setting, or purchase items such as sensory equipment or software to help children with special needs. Any licensed or self-declared provider can apply for these funds. A 2017 DHS news release indicates that at that time, 87 licensed, and self-declared providers received funding from this program.<sup>196</sup>

Child Care Consultation services are available through partnerships with Child Care Aware of ND and the ND Center for Persons with Disabilities. The service offers phone and on-site assistance to child care programs that have children with special care concerns (developmental, physical, and health-related). Child care providers can access a free screening completed by an Inclusions Specialist through Child Care Aware.<sup>197</sup>

<sup>193</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

<sup>194</sup>Ibid.

<sup>195</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/services/childcare/inclusion.html>

<sup>196</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/news/2017/7-14-taking-applications-inclusion-support-grant-.pdf>

<sup>197</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/cfs/amended-2019-2021-ccdf-state-plan.pdf>

Child care providers can care for children ages 13 through 18 when the child is physically or mentally incapable of caring for themselves as verified in writing by a physician or a licensed or certified psychologist.

### **Child Care Capacity in ND**

Demand for child care continues to be high in ND. Child Care Aware prepares a capacity report quarterly. In the latest report (2019), child care supply meets only 36% of potential demand.<sup>198</sup> The report indicates that 70.7 percent of children ages 0 through 5 and 78.6 percent of children ages 6 through 13 have all parents in the workforce. It is anticipated that 45,377 children ages 0 through 5 and 53,439 children ages 6 to 12 need child care. This equals a potential need for 98,816 child care slots. The current state capacity is 35,954 slots, which creates a deficit of 62,862 slots.

In addition to the lack of sufficient child care slots, Child Care Aware reports what appears to be a shortage of child care options available outside of traditional work hours. Of 1,235 child care programs, there are 314 child care programs available before 7 am; forty-nine are open after 6 PM; twenty providers are open on weekends. Due to many parents having non-traditional work schedules, these limited provider options likely add to the challenge.<sup>199</sup>

<sup>198</sup> Child Care Aware of North Dakota. Retrieved from: <https://ndchildcare.org/data-pub/data.html>

<sup>199</sup> Ibid.

## Housing

Housing is central to people's opportunities for living long and well. Stable and affordable housing is an essential element of healthy communities.<sup>200</sup> Housing is considered affordable when housing costs are no more than thirty percent of a household's gross income.<sup>201</sup> Over the past decade, nationally, housing costs have increased by 24 percent, and rental prices have increased by 52 percent.<sup>202</sup> ND's median household income was \$63,837, according to the 2018 ACS 1-year estimates.<sup>203</sup> In ND, 10% of households spend more than half of their income on housing costs.<sup>204</sup>

### Federal Income Assistance

There are several federal programs available for general income assistance, which can be used to pay for housing.

1. **Social Security Retirement (SS)**-In order to receive social security retirement benefit (SS), a person needs 40 work credits or have worked at least approximately ten years.<sup>205</sup>
  - a. More than 29,000 people in ND rely on SS for 90 percent or more of their income. The annual average 2020 SS benefit in ND is \$17,591.<sup>206 207</sup>
  - b. ND was one of 13 states that taxed SS benefits; however, this changed during the 2019 legislature with the passage of House Bill 1174 which eliminated the state tax on SS benefits for single filers who have SS benefits up to \$50,000 and married couples filing jointly with benefits up to \$100,000. <sup>208</sup> This change affects about 30,000 North Dakotans.<sup>209</sup>
2. **Supplemental Security Income (SSI)** pays benefits to adults and children who are disabled and have limited income and resources. These benefits are also available to people 65 years and older who do not have a disability but meet the financial limits.
  - a. The mean SSI income in ND is \$9,723 annually (2017), which is approximately \$810 per month.<sup>210</sup>

<sup>200</sup> County Health Rankings and Roadmaps. Retrieved from: <https://www.countyhealthrankings.org/reports/state-reports/2019-north-dakota-report>

<sup>201</sup> ND Housing Finance Agency. Retrieved from: <https://www.ndhfa.org/Publications/Reports/NDHFA%20Publications/AffordableHousingFacts4-19.pdf>

<sup>202</sup> U.S. Census Bureau, 2017 American Community Survey 5 and 1-year estimates

<sup>203</sup> U.S. Census Bureau. Retrieved from:

<https://data.census.gov/cedsci/table?q=S0201%3A%20SELECTED%20POPULATION%20PROFILE%20IN%20THE%20UNITED%20STATES&g=0400000US38&hidePreview=true&tid=ACSSPP1Y2018.S0201>

<sup>204</sup> County Health Rankings and Roadmaps. Retrieved from: <https://www.countyhealthrankings.org/reports/state-reports/2019-north-dakota-report>

<sup>205</sup> Social Security Administration. Retrieved from: <https://www.ssa.gov/pubs/EN-05-10035.pdf>

<sup>206</sup> Yahoo Finance. Retrieved from: <https://finance.yahoo.com/news/heres-every-states-average-social-132355610.html>

<sup>207</sup> Average SS methodology: Social Security's *most current data* during 2018- add 2.8%, representing Social Security's cost-of-living increase for 2019-add 1.6% — the cost-of-living increase for 2020 — to determine the average benefit for a retired worker in each state during 2020.

<sup>208</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/66-2019/bill-actions/ba1174.html>

<sup>209</sup> U.S. News and World Report. Retrieved from: <https://www.usnews.com/news/best-states/north-dakota/articles/2019-04-24/legislature-cuts-state-taxes-on-social-security-benefits>

<sup>210</sup> U.S. Census Bureau, 2017 American community survey 1 – year estimates



- b. In ND, the percentage of non-institutionalized persons aged 21 – 64 with a cognitive disability who receive SSI benefits in 2017 was 19.7% compared to the U.S. estimate of 25.8 percent.<sup>211</sup>
3. **Social Security Disability Insurance (SSDI)** To qualify for SSDI benefits, a person must have worked long enough in jobs covered by Social Security (usually ten years) and have a medical condition that meets Social Security's definition of a disability.<sup>212</sup>

## ND Affordable Housing Challenges

Households with incomes eighty percent of the median income are considered 'low income.' Those with incomes, fifty percent of the median are considered, 'very low income,' and those with incomes below thirty percent are considered "extremely low income."<sup>213</sup> According to the U.S. Census 2014-2018 5-year estimates, ND's median income is \$63,473.<sup>214</sup> According to the 2019 ND Affordable Housing Fact Sheet published by the ND Housing Finance Agency, there are 26,485 extremely low income renter households in ND. There are only 51 affordable and available rental homes per 100 extremely low renter households.<sup>215</sup>

Two surveys and reports document the difficulties of low-income individuals and families and housing: The HUD Worse Case Survey and the Priced-Out reports.

1. The 2017 HUD Worse Case Report provides national data and analysis of the critical problems facing low-income renting families using the report draws on data from the American Housing Survey (AHS).
  - a. The AHS is a crucial source of national data on housing markets, conditions, and dynamics. In 2009, this survey began assessing the presence of disabilities or functioning limitations.
  - b. The most frequently occurring type of disability was ambulatory limitations (walking or climbing stairs), which affects 49.2 percent of very low-income renter households that include a nonelderly person with a disability.
  - c. The second most prevalent disability is cognitive limitations (serious difficulties concentrating, remembering, or making decisions), affecting 46.3 percent of these households.<sup>216</sup>
2. The 2016 Priced-Out report highlights the challenge of meeting rental housing costs with the monthly income of a person living solely on SSI benefits. Key findings of this report include:
  - a. The average annual income, in 2016, of a single person receiving SSI payments was \$9,156 - about 22 percent below the 2016 federal poverty level, and equal to only 20 percent of the national median income for a one-person household.

<sup>211</sup> Erickson, W., Lee, C., von Schrader, S. (2017). Disability Statistics from the American Community Survey (ACS). Ithaca, NY: Cornell University Yang-Tan Institute (YTI). Retrieved from Cornell University Disability Statistics website: [www.disabilitystatistics.org](http://www.disabilitystatistics.org)

<sup>212</sup> Social Security Administration. Retrieved from: <https://faq.ssa.gov/en-us/Topic/article/KA-01771>

<sup>213</sup> U.S. Census Bureau, 2017 American Community Survey 5 and 1-year estimates

<sup>214</sup> U.S. Census Bureau. Retrieved from: [https://www.census.gov/search-results.html?q=median+income+by+state&page=1&stateGeo=none&searchtype=web&cssp=SERP&\\_charset\\_=UTF-8](https://www.census.gov/search-results.html?q=median+income+by+state&page=1&stateGeo=none&searchtype=web&cssp=SERP&_charset_=UTF-8)

<sup>215</sup> North Dakota Housing Finance Agency. Retrieved from: <https://www.ndhfa.org/Publications/Reports/NDHFA%20Publications/AffordableHousingFacts4-19.pdf>

<sup>216</sup> U.S. Department of Housing and Urban Development. Retrieved from: [https://www.huduser.gov/portal/sites/default/files/pdf/Worst-Case-Housing-Needs.pdf\\_page\\_16](https://www.huduser.gov/portal/sites/default/files/pdf/Worst-Case-Housing-Needs.pdf_page_16).

- b. The 2016 national average rent for a studio/efficiency unit was \$752, equal to 99 percent of monthly SSI payments.
- c. In 220 housing market areas, one-bedroom rents exceeded 100 percent of monthly SSI payments -an increase of almost 60 markets since the 2014 Priced Out report.

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The Priced-Out report highlights six ND counties facing this challenge. Table 12 provides details on the ND counties where households pay over 100 percent and up to 147 percent of their monthly SSI payment on housing.<sup>218</sup>

<b>ND County</b>	<b>Percent Above the Monthly SSI Payment</b>
<b>Dunn</b>	147%
<b>Golden Valley</b>	112%
<b>Mountrail</b>	117%
<b>Stark</b>	103%
<b>Ward</b>	122%
<b>Williams</b>	130%

Table 12: ND Priced-Out Counties. Source: TAC, 2016.

According to the ND Housing Finance Agency, ND faces many housing challenges:

- Aging housing inventory,
- Lot or land costs have increased dramatically,
- High level of competition for affordable housing,
- Limited affordable housing options,
- Resources for affordable housing are limited,
- Housing needs for the state's aging population is increasing, and
- People with disabilities, the homeless, and those at risk of homelessness have unmet needs for housing with supportive services.

<sup>217</sup> Technical Assistance Collaborative, Inc. Retrieved from: <http://www.tacinc.org/media/59493/priced-out-in-2016.pdf>

<sup>218</sup> Ibid.

The National Residential Information Systems Project (RISP) gathers and analyzes longitudinal data on Medicaid funded residential and in-home supports for people with IDD.<sup>219</sup> According to the FY 2016 RISP Profile, the number of people served by IDD agencies is categorized by type and size. Figure 13 illustrates that in ND, it appears that the majority live in their own home or with family, followed by living in facilities with 7 – 15 people.

**ND HCBS Transition Plan**

The CMS issued a final rule that became effective on March 17, 2014, and requires states to review and evaluate HCBS settings, including residential and non-residential settings paid for through ND's six Medicaid waivers.<sup>220</sup> CMS intends to ensure that individuals have full access to the benefits of community living and can receive services in the most integrated setting.<sup>221</sup> From April 2014 through October 2014, the DHS conducted a review and analysis of all HCBS settings and developed the State's initial Statewide Transition Plan. The DHS conducted surveys of all providers of HCBS residential and non-residential services that focused on each setting's physical location, surroundings, community integration, and other environmental characteristics. ND received initial approval of its Statewide Transition Plan on November 1, 2016, with final approval in 2018.<sup>222</sup>

The review and transition plan revealed situations where people needed to be relocated to compliant settings. According to the transition plan, all client transitions must be completed no later than March 17, 2022. The problems identified during the review are found in Table 13, along with the status of each.

**North Dakota**

Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

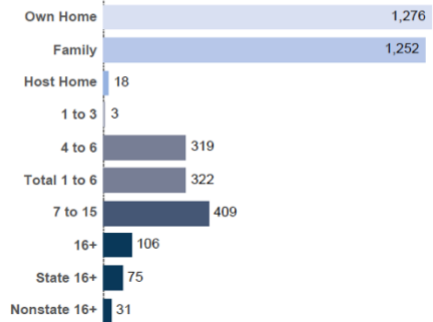


Figure 13: ND 2016 RISP Profile.

<sup>219</sup> University of Minnesota. Retrieved from: <https://risp.umn.edu/about>

<sup>220</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/medicaid/nd-revised-preliminary-statewide-transition-plan-submitted-for-cms-final-approval-11-1-18.pdf>

<sup>221</sup> Medicaid.gov. Retrieved from: <https://www.medicaid.gov/sites/default/files/2019-12/final-rule-fact-sheet.pdf>

<sup>222</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/docs/medicaid/2-01-2019-nd-approved-statewide-transition-plan-hcbs-settings.pdf>

Table 13: ND Department of Human Services 2018 HCBS Transition Plan Issues and Status

Service/Waiver	Issue	Status	Comments
Adult Foster Care	Need more control over schedule, funds, visitors, meals.	Appears completed but transition plan contains several comments in 2019 that need to be addressed in specific locations	
Extended Services (name changed to Prevocational Services)	Need more community interaction	Completed	
Residential Habilitation	Need leases to comply with ND landlord-tenant laws	Completed	
Day Supports (name changed to Day Habilitation and Prevocational Services)	Cannot be provided in an ICF or on the grounds of an ICF	LSTC program relocated	
Adult Residential	No determination made on whether this meets the HCBS requirements	May submit for heightened scrutiny review – staff gathering information on each setting	The plan indicates January of 2020 as the target date
Adult Day Care provided in Nursing Homes	Does not meet HCBS requirements	Removed as a waiver service in this setting	Completed
Day Supports in an ICF setting	Relocated to other community settings	Completed	
Adult Day Health	Does not meet HCBS requirements	Removed from waiver – was not utilized	
Autism Waiver	Compliant		
Tech Dependent Waiver	Added several items to policy manual but no service changes needed		
Hospice Waiver	Compliant		
Medically Fragile	Compliant		

To avoid future problems and avoid people moving into housing that does not meet the community waiver standard of CMS, DHS has incorporated the Heightened Scrutiny Process. This process is triggered when a waiver recipient is potentially moving to 1) Settings in a publicly or privately-operated facility that provides inpatient institutional treatment; 2) Settings in a building on the grounds of, adjacent to, a public institution; 3) Settings with the effect of isolating individuals from the broader community.

To address the current and ongoing housing challenges for people accessing waiver services, DHS: 1) formed a workforce development initiative with the ND Supportive Housing Collaborative, 2) invests Money Follows the Person (MFP) rebalancing funds, and 3) provides staff resources to increase the number of direct service providers. A rural differential rate for some waiver services is available to encourage providers to offer services in the most rural settings.

## ND Housing Resources and Safeguards

There are several laws and funding sources that assist communities with low-income housing challenges and help individuals achieve safe and appropriate housing.

- The Community Services Block Grant (CSBG) Program helps communities implement anti-poverty programs. The CSBG Program, through the state's seven Community Action Agencies (CAAs), provides emergency assistance, money management, and housing counseling, self-sufficiency services, case management, and outreach and referral services.<sup>223</sup>
- The Fair Housing Act prohibits discrimination in the sale, rental, and financing of dwelling based on race, color, national origin, religion.
- Title VI of the Civil Rights Act prohibits discrimination based on race, color, or national origin in programs and activities receiving federal financial assistance.
- Title II of the Americans with Disabilities Act prohibits discrimination based on disability in programs, services, and activities provided or made available by public entities.<sup>224</sup>
- Section 504 of the Rehabilitation Act of 1973 is a federal law that prohibits discrimination based on disability in any program or activity that receives financial assistance from any federal agency, including HUD, as well as in programs conducted by federal agencies including HUD.<sup>225</sup>

HUD has a variety of housing assistance programs through the ND Housing Finance Agency. The programs fall into three categories:

- 1) Rehab programs. Examples are Helping HAND, Low Income Tax Credit, and Major Home Improvement programs.<sup>226</sup>
- 2) Financial resources. Examples are Construction Loan Guarantees, Exemption from Property Taxation, and the Housing Incentive Fund.<sup>227</sup>
- 3) Rental Assistance. Examples are the Moderate Rehabilitation Program, Opening Doors Landlord Mitigation Risk Fund, and Section 8 program.<sup>228</sup>

## Money Follows the Person (MFP)

The MFP program helps individuals who are elderly or have physical or other disabilities and who live in nursing homes, the LSTC, or other institutions move to 1) their own home or apartment, 2) a family member's home, 3) an assisted living facility or 4) other community housing options. In ND, the MFP grant began in 2007 with a 5-year, 8.9 million dollar award from CMS.<sup>229</sup> To qualify for this voluntary MFP program, an individual must be a Medicaid recipient, live in an institutional setting for 90-consecutive days or more, and want to return to community living. Participants must be directly responsible for their living expenses. Program

<sup>223</sup> ND Department of Commerce. Retrieved from:

<https://www.communityservices.nd.gov/lowincomeprograms/CommunityServicesBlockGrantCSBG/>

<sup>224</sup> ND Fair Housing Laws. Retrieved from: <https://www.bing.com/search?q=nd+fair+housing+laws&FORM=QSRE2>

<sup>225</sup> HUD.gov. Disabilities. Retrieved from:

[https://www.hud.gov/program\\_offices/fair\\_housing\\_equal\\_opp/disabilities/sect504faq](https://www.hud.gov/program_offices/fair_housing_equal_opp/disabilities/sect504faq)

<sup>226</sup> North Dakota Housing Finance Agency. Retrieved from: <https://www.ndhfa.org/Rehab/Programs.html>

<sup>227</sup> North Dakota Housing Finance Agency. Retrieved from: <https://www.ndhfa.org/Development/Programs.html>

<sup>228</sup> North Dakota Housing Finance Agency. Retrieved from: <https://www.ndhfa.org/RentalAssistance/Programs.html>

<sup>229</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/pubs/mfp/overview.html>

participants work with a transition coordinator from a center for independent living (CILS) to create a written transition plan, arrange for services and supports in the individual's home and ensure their needs are met. They are monitored for one year following their transition. The program provides up to \$3,000 in one-time moving costs, 24-hour backup nursing call services, rental assistance, and access to state and Medicaid-funded community-based services like personal care services, home modifications, assistive technology, transportation, and other services.<sup>230</sup>

MFP funding ended in December of 2018; however, congress passed the Medicaid Extenders Act, and transitions restarted in ND on April 1, 2019, using unspent grant dollars. MFP transitions continue at the time of this writing, and future congressional action determines what will happen after 2020.<sup>231</sup> ND intends to continue transitions with available funding as long as possible.<sup>232</sup> In order to find an ongoing funding source for the MFP program, ND DHS added the MFP Transition Costs (\$3,000) as a service in the Traditional IDD Waiver. Within the waiver, this service is called "Community Transitions." ND's cumulative 2007-2019 MFP grant total is \$31,340,262.<sup>233</sup> Table 14 illustrates the annual transitions and within which eligibility group they occurred. Throughout this grant, there have been 156 transitions for people with IDD.

Table 14: ND MFP Transitions by year and Client Type, 2007 - 2020

Grant Year	Older Adult	Individuals with a physical disability	Individuals with an Intellectual disability	Children	TOTAL Year/All
2007	0	0	0	0	0
2008	1	1	3	0	5/5
2009	4	7	4	0	15/20
2010	4	6	16	0	26/46
2011	5	8	19	0	32/78
2012	13	21	11	1	46/124
2013	14	18	19	1	52/176
2014	17	27	14	2	60/236
2015	14	28	17	5	64/300
2016	15	28	17	4	64/364
2017	9	16	10	3	38/402
2018	13	23	15	2	53/455
2019	5	20	8	2	35
2020	0	2	3	0	5
<b>Totals</b>	<b>114</b>	<b>205</b>	<b>156</b>	<b>20</b>	<b>495</b>

Received from Jake Reuter, MFP Coordinator, DHS, Aging Services Division, March 25, 2020.

<sup>230</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/news/2019/5-28-dhs-continues-helping-people-transition-from-institutional-care-to-community%20living.pdf>

<sup>231</sup> Email from MFP Coordinator March 25, 2020.

<sup>232</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/news/2019/5-28-dhs-continues-helping-people-transition-from-institutional-care-to-community%20living.pdf>

<sup>233</sup> Medicaid.gov. Retrieved from: <https://www.medicaid.gov/sites/default/files/2020-01/mfp-grant-awards-12162019.pdf>

## **MFP Tribal Initiative**

ND is one of five states granted the MFP Tribal Initiative (TI) funds in 2013 to build sustainable community-based long-term services and supports in Indian country. This initiative helps people with functional limitations or cognitive impairments with activities of daily living such as bathing, dressing, eating, or other basic activities. Eligibility is the same as the main MFP program. The MFP TI can also be used to develop the system infrastructure to implement supports for American Indians.<sup>234</sup>

## **MFP -Rental Gap Assistance Program**

The MFP program also has a housing program to help people who are elderly or disabled access decent, safe, and affordable housing. There are four consumer housing resource specialists, located in Minot, Grand Forks, Fargo, and Bismarck that assist MFP recipients to find housing to assist in their transitions from institutions.<sup>235</sup>

## **Housing Assistance in the Traditional IDD Waiver**

The traditional IDD waiver contains the following housing supports.<sup>236</sup>

1. **Environmental Modifications** - funds modifications to a home or vehicle that are necessary to ensure the health, welfare, and safety of the participant or/and enable the participant to function with greater independence in the home. Without this, the participant would require institutionalization. The amount of service for environmental modifications cannot exceed \$20,000 per participant for the duration of the 5-year waiver period.
2. **Equipment and Supplies** enable a participant to remain in their home, to prevent or delay placement in an institution. With an annual limit of \$4,000 per participant per waiver year, items such as devices, controls, or appliances, assistive technology, personal monitoring, or tracking systems are available.
3. **In-Home Supports** help prevent or delay unwanted out of home placement. The supports benefit the primary caregiver as they assist the participant in activities of daily living when these tasks require more than one person to accomplish.
4. **Homemaker Services** help complete environmental tasks that a participant is not able to complete, such as housework, meal preparation, laundry, shopping, communication, and managing money.

## **Other Housing Support and Assistance Options**

1. Aging and Disability Resource Centers (ADRC) –ND's ADRC assists people to find long-term supports and services for older adults and people with disabilities, including home health care and assistive technology.<sup>237</sup>
2. The ND Assistive program assists people with a variety of assistive technology options such as equipment demonstration, short-term equipment trials, specialized phone equipment, device training and set-up, assessments, consultations, and evaluations. ND

<sup>234</sup> Medicaid.Gov. Retrieved from: <https://www.medicaid.gov/medicaid/long-term-services-supports/money-follows-person/index.html>

<sup>235</sup> ND Center for Persons with Disabilities. Retrieved from: <http://www.ndcpd.org/mfp/about-us.html>

<sup>236</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/docs/traditional-idd-hcbs-waiver-2019.pdf>

<sup>237</sup> ND Department of Human Services. Retrieved from: <https://carechoice.nd.assistguide.net>

Assistive has a variety of items available through their Home First Centers in Mandan and Fargo.<sup>238</sup>

- a. Assistive technology devices and services can help individuals with learning, cognition, and developmental disabilities improve their day-to-day interactions and increase their ability to live in the least restrictive environment possible.

Examples of assistive technology available are:

- Text-to-speech software for reading and writing
- Recorded textbooks
- Voice Recognition software for writing
- Recording devices for taking notes
- Mobile devices for tasks and scheduling
- Door alarms and motion detectors
- Locked medication dispensers
- Offset door hinges to widen doorways without construction
- Voice-activated home automation<sup>239 240</sup>

<sup>238</sup> ND Assistive Technology. Retrieved from: <https://ndassistive.org/blog/get-to-know-smart-home-technology-at-nd-assistive/>

<sup>239</sup> ND Assistive Technology. Retrieved from: <https://ndassistive.org/services-for-individuals/daily-living-environmental-adaptations/>

<sup>240</sup> ND Assistive Technology. Retrieved from: <https://ndassistive.org/services-for-individuals/learning-cognition-developmental/>



## Informal and Formal Supports

Informal supports are the forms of help that people freely give to each other in daily life. Informal support ranges from providing a ride to an event, problem-solving, listening, or a reminder up to long-term, full-time support and services that are unpaid. Formal supports are the paid supports that assist individuals to live in the least restrictive setting possible.

According to the Coleman Institute and Department of Psychology, University of Colorado, in FY 2015, there were 11,893 persons with IDD living in ND, and 67 percent lived with a family caregiver. The majority of this support is provided informally. It is estimated that ND's IDD agencies financially support only 10 percent of caregiving families. Of these caregivers, 28 percent were age 60 and over. Figure 14 illustrates the significant role families play in supporting people with IDD in ND.<sup>241</sup>

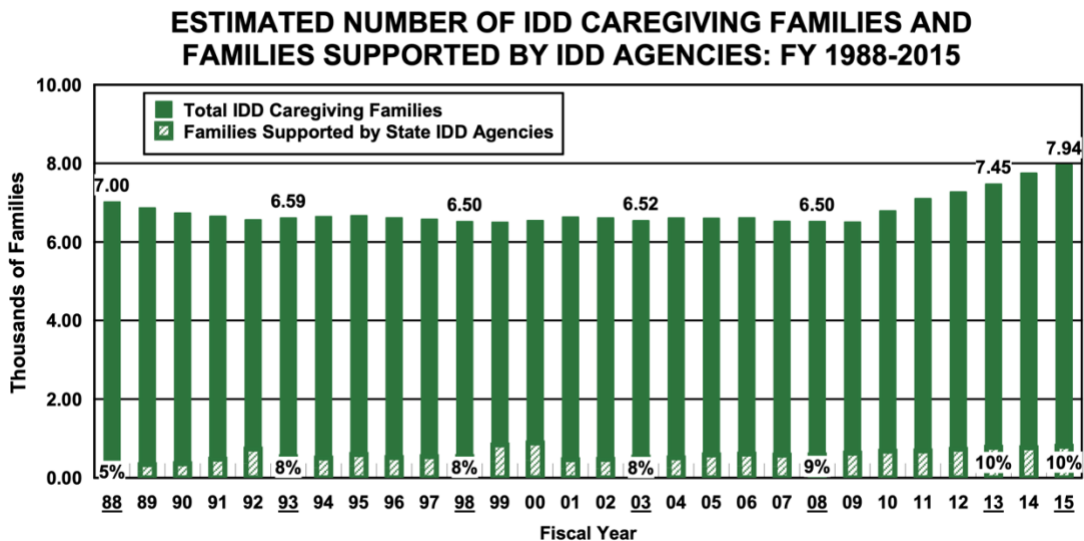


Figure 14: ND Caregiving Families. Source: Braddock et al. Coleman Institute and Department of Psychology, University of Colorado, 2017.

### Guardianship

Guardianship is a legal process where a court determines if an individual is "incapacitated."<sup>242</sup> When a guardianship is appointed, a guardian makes decisions on behalf of the incapacitated person. Guardianship is designed to protect members of vulnerable populations while maintaining their rights whenever possible. A guardian makes decisions to ensure that medical, social, and emotional needs are met.<sup>243</sup> Guardianship is a very serious decision, and considerations are needed to ensure that it is necessary for the individual's protection. It is difficult to find information on the rate of guardianships for individuals with IDD, but according

<sup>241</sup> Braddock et al. State of the State.org (2017) Retrieved from: <https://stateofthestates.org/wp-content/uploads/documents/NorthDakota.pdf>

<sup>242</sup> The ARC.org. Retrieved from: <https://thearc.org/wp-content/uploads/forchapters/Guardianship-White-Paper.pdf>

<sup>243</sup> US Legal. Retrieved from: <https://guardianships.uslegal.com/guardian-compensation/>

to the 2017-2018 National Core Indicator Survey, of thirty-five states with a sample size of 25,671 people, 2 in 5, or 43 percent have a full or partial guardian.<sup>244</sup>

There have been several changes since 2016 to guardianship laws in ND. A statewide guardianship monitoring program became effective on January 1, 2018, and minimum training qualifications were established for guardians of adults. Professional guardians must maintain certification through the Center for Guardianship Certification.<sup>245</sup> Since the statewide monitoring program began, 32 adult guardianship cases were referred by the district courts to the monitoring program. Primary reasons for referrals include the following: 1) a guardian not performing duties, 2) a guardian requesting to be discharged, and 3) problems with annual reports from the guardian to the court.

It is challenging to find a guardian if a family member is not available or willing to serve this function. Court petitioning costs, which can total up to \$2,500, can present a barrier. While there are state general funds available for guardianships, it does not meet the demand. The Guardianship Establishment program, through ND DHS, provides financial assistance to people who are petitioning for guardianship of an incapacitated adult.<sup>246</sup> According to the 2019 legislative testimony by DHS, the program served 174 adults between 2015-2017. One hundred forty-one people were served between 2017-2019. For the entire state of ND, between 2015-2017, there were 730 guardianships, and as of December 12, 2018, there were 515 guardianships established since July 2017.<sup>247</sup> The DHS-DD division has funds for a limited number of guardianships and guardianship petitions. This corporate guardianship program provided by Catholic Family Services provides a guardian when one is not found for a person with IDD.<sup>248</sup> According to the DHS DD Division, their 19-21 biennium's contract with Catholic Charities is for 489 wards, which is an increase of 20 from the previous biennium. As of December 2019, there is a wait list of 119. Of this waitlist number, not all will need a guardian when one is available, and some are on the list in anticipation of a future need for guardianship.<sup>249</sup>

In 2011, an ND Legislative study on guardianship was completed. Winsor C. Schmidt provided a 2012 report to the ND Legislative management and indicated that at that time, the unmet need for full public guardian services in ND was 149 individuals.<sup>250</sup>

There are times when a family feels pressure to establish guardianship for their child with disabilities as they approach the age of 18. This pressure can be direct or indirect. Some professionals may feel it is essential to assist the young person with important life decisions,

<sup>244</sup> National Core Indicators.org. Retrieved from: [https://www.nationalcoreindicators.org/upload/core-indicators/NCI\\_AtAGlanceReport\\_1718\\_Final\\_May2019.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/NCI_AtAGlanceReport_1718_Final_May2019.pdf)

<sup>245</sup> ND Courts. Retrieved from: <https://www.ndcourts.gov/Media/Default/Court%20Administration/Annual-Report/2018annualreport.pdf>

<sup>246</sup> ND Courts. Retrieved from: <https://www.ndcourts.gov/legal-self-help/adult-guardianship>

<sup>247</sup> ND Department of Human Services. (2019) Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019/house-appropriation/sb2012-overview-aging-2019-3-7.pdf>

<sup>248</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/dd-overview.html>

<sup>249</sup> Email received from Department of Human Services Developmental Disabilities Division, Tina Bay, Director. April 23, 2020.

<sup>250</sup> ND UND Law. Retrieved from: This Article is based on a Final Report submitted to the Human Services Committee, North Dakota Legislature: Winsor Schmidt, Study of Guardianship Services for Vulnerable Adults in North Dakota (May 30, 2012). [https://law.und.edu/\\_files/docs/ndlr/pdf/issues/89/1/89ndlr77.pdf](https://law.und.edu/_files/docs/ndlr/pdf/issues/89/1/89ndlr77.pdf)

such as medical and housing issues, and directly discuss petitioning for guardianship with the young adult's parents. In less direct situations, professionals may refuse to act on decisions made by people with disabilities.<sup>251</sup> A viable option to guardianship is the "Supported Decision-Making" process. This model's goal is to avoid unnecessary guardianships. The model uses "supporters" who assist the person with disabilities in understanding options, responsibilities, and potential consequences of their decisions. The supporter helps them obtain and interpret information relevant to their choices and to communicate their preferences to the appropriate people. Information on this model indicates that the majority of people with IDD/DD can manage their affairs with informal assistance and guidance from trusted family members and friends. In ND, the supported decision-making model gained support in the 2019 legislative session with the passage of House Bill 1378. This bill approves a Supported Decision-Making process in ND.<sup>252</sup> The bill details the process for making well-informed, voluntary decisions by methods less restrictive than guardianship. According to the Protection and Advocacy Project in ND (P&A), a supported decision-making agreement between the individual and the supporter is signed, dated, and requires witnesses or a notary public. The agreement defines what type of assistance the individual is requesting and what the supporter has permission to do. Educational materials and information sessions are being developed.<sup>253</sup>

## **Aging Services**

DHS- Aging Services Division administers home and community-based services that allow older adults and individuals with physical disabilities to remain in their own homes and communities. The goal of the programs is to protect the health, safety, welfare, and rights of residents of long-term care settings and vulnerable adults in the community.<sup>254</sup> The Aging and Disability Resource LINK (ADRL) provides information and assistance through the Care Choice website and the toll-free telephone line. In 2017, the website received 6,860 hits, and 2,790 individuals received support over the phone. Eighty-five people received options counseling, which helps guide individuals and their family members through choices in care services and supports.<sup>255</sup>

According to the DHS-Aging Services 2019 Legislative testimony, the top five information requests on the ADRL are: <sup>256</sup>

1. In-home assistance
2. Medicaid Information
3. Adult protective services
4. Ombudsman referral
5. Options counseling

In 1989, the vulnerable adult protection services (VAPS) law was passed and authorized by the DHS to develop, administer, and implement a program of protective services for vulnerable adults. A vulnerable adult is any person older than age 18 that has a substantial mental or

<sup>251</sup> Special Needs Alliance. Retrieved from: <https://www.specialneedsalliance.org/blog/how-you-can-promote-supported-decision-making-for-people-with-intellectual-and-developmental-disabilities/>

<sup>252</sup> ND Legislative Management. Retrieved from: <https://www.legis.nd.gov/assembly/66-2019/documents/19-0884-04000.pdf>

<sup>253</sup> ND Protection and Advocacy Project. Retrieved from: <http://www.ndpanda.org/decide/supportedDecisionMaking.html>

<sup>254</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019/house-approp-hr/sb2012-overview-aging-2019-3-7.pdf>

<sup>255</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/news/2012/5-22-options-counseling.pdf>

<sup>256</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019/house-approp-hr/sb2012-overview-aging-2019-3-7.pdf>

functional impairment. In 2013, the mandated reporting law passed, which "requires any person who reasonably believes that a vulnerable adult has been subjected to abuse or neglect or observes conditions or circumstances that reasonably would result in abuse or neglect may report the information to the department or an appropriate law enforcement agency."<sup>257</sup> In 2018, the VAPS program received 2,276 reports with 1,405 allegations, and 1,305 were investigated. Seven hundred seventy-nine of those investigated were substantiated (55%). Self-neglect was the most common allegation. The 2018 substantiated number is a 58 percent increase since the mandatory reporting law passed.

The State Long Term Care Ombudsman Program, required by the Older Americans Act, investigates and resolves complaints by residents of nursing facilities, board and care facilities, and other adult care homes.<sup>258</sup> In ND, there are 5,953 nursing facility beds, 2,040 basic care beds, 3,143 assisted living beds, 255 facilities in 70 communities.<sup>259</sup>

### **Child Welfare**

ND began a social service system redesign with the passage of Senate Bill 2206 (2017) and continues with the passage of Senate Bill 2124 (2019). The ND DHS, the ND Association of Counties, and local social services leaders are working together to redesign social services to serve citizens better and deliver services more efficiently.<sup>260</sup> On January 1, 2020, the administration of human services at the local county level shifted from 50 or more individual and multi-county social service offices, each with their director, to 19 Human Service Zones led by 19 interim directors.<sup>261</sup>

Existing literature suggests that youth with disabilities at an increased risk of abuse or neglect.<sup>262</sup> Nationally, youth with disabilities constituted 31.8% of the entire foster care population.<sup>263</sup> An important note is that while reunification with family is the ideal goal for most youth in foster care, youth with disabilities are 37% less likely to be placed with a family in a trial home visit. While kinship (blood relationship) foster care is often regarded as the best alternative home, youth with disabilities are 40% less likely to live in this type of setting.<sup>265</sup> Nationally, parents with IDD are over-represented in the child protective services system.<sup>266</sup> In ND, in FFY 2017, 42 percent of children removed from their homes was due to parental substance abuse, and 22

<sup>257</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/adultsaging/vulnerable.html>

<sup>258</sup> Find Law. Retrieved from: <https://elder.findlaw.com/elder-care-law/what-is-the-long-term-care-ombudsman-program.html>

<sup>259</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019/house-approp-hr/sb2012-overview-aging-2019-3-7.pdf>

<sup>260</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/redesign-sb2124/index.html>

<sup>261</sup> ND Department of Human Services. Retrieved from: <http://www.nd.gov/dhs/info/redesign-sb2124/2020-01-update-fact-sheet.pdf>

<sup>262</sup> Slayter, Elspeth. (2016). Youth with Disabilities in the United States Child Welfare System. Children and Youth Services Review. 64. Retrieved from:

[https://www.researchgate.net/publication/298215479\\_Youth\\_with\\_Disabilities\\_in\\_the\\_United\\_States\\_Child\\_Welfare\\_System](https://www.researchgate.net/publication/298215479_Youth_with_Disabilities_in_the_United_States_Child_Welfare_System)

<sup>264</sup> Administration for Children and Families-Childrens Bureau. Retrieved from: <https://www.acf.hhs.gov/cb/research-data-technology/reporting-systems>

<sup>265</sup> Slayter, Elspeth. (2016). Youth with Disabilities in the United States Child Welfare System. Children and Youth Services Review. 64. Retrieved from:

[https://www.researchgate.net/publication/298215479\\_Youth\\_with\\_Disabilities\\_in\\_the\\_United\\_States\\_Child\\_Welfare\\_System](https://www.researchgate.net/publication/298215479_Youth_with_Disabilities_in_the_United_States_Child_Welfare_System)

<sup>266</sup> Journal of Mental Health Research in Intellectual Disabilities. (2012). Apr 1; 5(2): 94–129.

Published online 2012 Apr 10. doi: [10.1080/19315864.2011.615460](https://doi.org/10.1080/19315864.2011.615460)

percent were removed due to neglect.<sup>267</sup> For the same fiscal year, there were 15,646 reports suspecting abuse or neglect with 2064 victims of abuse or neglect. Neglect or Abuse reports have increased by 64 percent since 2010. Child victims have increased by 82 percent since 2010; 919 of the victims were under the age of 5. Due to a significant effort to reunify children with their parents, blood relatives, or foster homes, congregate care placements in child welfare have decreased by 39 percent since 2012. In ND, there were 327 children in congregate care in 2012, whereas, in FFY 2018, there were 201.

## **Independent Living**

Independent living means that a person lives in his or her apartment or house and needs limited or no help from outside agencies.<sup>268</sup> The purpose of Independent Living (IL) services is to eliminate barriers and provide assistance to individuals with disabilities so they can live and work more independently in their homes and communities. ND has four Centers for Independent Living (CIL's) that provide IL services to individuals with disabilities of all ages.

All of CIL's offer the following core services:

- independent living skills training
- peer support
- individual and systems advocacy
- information and referral
- youth and institutional transition

CIL's also provide additional services as determined by consumer identified needs in their service area. The services may include;

- personal assistance services,
- housing assistance,
- transportation assistance,
- social and recreational activities,
- community awareness and education, and
- technical support to businesses and local governments.<sup>269</sup>

## **Day Supports**

Day supports is a service provided through the traditional IDD waiver. A day program assists individuals in acquiring, retaining, and improving skills necessary to reside in a community setting successfully. "Services may include assistance with self-help, socialization, and adaptive skills; provision of social, recreational, and therapeutic activities to maintain physical, recreational, personal care, and community integration skills; and development of prevocational skills such as compliance, attendance, task completion, problem-solving, and safety; and supervision for health and safety."<sup>270</sup>

<sup>267</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/info/testimony/2019/house-approp-hr/sb2012-overview-cfs-2019-3-5.pdf>

<sup>268</sup> Centers for Disease Control and Prevention. Retrieved from: <https://www.cdc.gov/ncbddd/disabilityandhealth/people.html>

<sup>269</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/dvr/individual/independent.html>

<sup>270</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/services/disabilities/dd-overview.html>

## Peer Support

Peer Support, as it relates to individuals with IDD, empowers those who live in institutions to understand, learn, and lead. The goal is to increase understanding of rights, learn about community opportunities, and actively participate in their planning process.<sup>271</sup> The Bridge-Pathways to Employment Workshop is available for agencies through the DHS-DVR website that assists individuals with IDD/DD to attain employment.<sup>272</sup> However, no specific ND IDD peer support effort was found.

## Family Support

The following agencies provide support to families of individuals with disabilities.

1. **Family Voice of North Dakota** has been assisting families since 1997. They have several programs designed to support families.<sup>273</sup>
  - a. The **Health Information and Education Center** program assists families in navigating public and private systems to access services and resources for their children. They work to promote family-centered care and medical homes for children with special health care needs.<sup>274</sup>
  - b. **ND Parent to Parent** is a statewide network of parents supporting families of children with developmental delays, disabilities, and special health needs.<sup>275</sup>
2. **Federation of Families**

The ND Federation of Families for children's mental health is a parent-run advocacy organization focused on the needs of children and youth with emotional, behavioral, and mental disorders and their families.<sup>276</sup> The Youth Move Beyond organization, which is a youth-based organization that advocates for youth rights and voice in mental health and other systems that serve youth, was formed by the Federation of Families to increase youth involvement.<sup>277</sup>
3. **Pathfinders** is a statewide non-profit organization founded in November 1987, by a small group of parents with a strong desire to help other families understand the special education laws and systems. They offer resources to parents & families, youth and young adults, professionals, and the community focusing on individuals ages birth through 26 with learning differences or challenges.<sup>278</sup>
4. The **North Dakota Association for the Disabled** (NDAD) was founded more than 40 years ago by concerned citizens to assist people with disabilities and health challenges in the state of North Dakota, many of whom were ineligible for services from other agencies.<sup>279</sup> They offer financial assistance, equipment for loan, and information, referral, and advocacy.<sup>280</sup>

<sup>271</sup> Peer support specialist network. Retrieved from: <https://www.projectamistad.org/pssn>

<sup>272</sup> ND Department of Human Services. Retrieved from: <https://www.nd.gov/dhs/dvr/individual/student.html>

<sup>273</sup> Family Voices of North Dakota. Retrieved from: <http://fvnd.org/site/index.php/about-us/our-mission/>

<sup>274</sup> Family Voices of North Dakota. Retrieved from: <http://fvnd.org/site/index.php/education/health-information-center/>

<sup>275</sup> Family Voices of North Dakota. Retrieved from: <http://fvnd.org/site/index.php/nd-parent-to-parent/>

<sup>276</sup> ND Federation of Families for Children's Mental Health. Retrieved from: [http://www.ndffcmh.org/about\\_us](http://www.ndffcmh.org/about_us)

<sup>277</sup> ND Federation of Families for Children's Mental Health. Retrieved from: [http://www.ndffcmh.org/youth\\_move\\_beyond](http://www.ndffcmh.org/youth_move_beyond)

<sup>278</sup> Pathfinder Services of North Dakota. Retrieved from: [http://pathfinder-nd.org/index.php?option=com\\_k2&view=item&layout=item&id=70&Itemid=141](http://pathfinder-nd.org/index.php?option=com_k2&view=item&layout=item&id=70&Itemid=141)

<sup>279</sup> ND Association for the Disabled. Retrieved from: <https://ndad.org>

<sup>280</sup> ND Association for the Disabled. Retrieved from: <https://ndad.org/services/>

5. The **ND Center for Person with Disabilities** (NDCPD) provides community services in the form of training, research, preservice, and information dissemination.<sup>281</sup> Their 2017-2022 plan goals focus on improving employment, healthy aging, education, and the overall health of people with IDD.<sup>282</sup>
6. **The ARC's** mission is to fight for the civil rights and inclusion of people with IDD and their families. The ARC has played a lead role in significant victories in civil rights, community living, education, income security, and other vital issues. There are six chapters in ND. <sup>283</sup>

<sup>281</sup> ND Center for Persons with Disabilities. Retrieved from: <http://ndcpd.org/core.html>

<sup>282</sup> ND Center for Persons with Disabilities. Retrieved from: <http://ndcpd.org/index.html>

<sup>283</sup> The ARC. Retrieved from: <https://thearc.org/chapter/the-arc-of-north-dakota-inc/>

## Recreation

Recreation and socialization add meaning and richness to everyone's life. For individuals with physical and developmental disabilities, it is especially important to find safe, comfortable, and fun activities in the community.<sup>284</sup> Unfortunately, there is a higher prevalence of sedentary behavior among adults with IDD compared to the general population.<sup>285</sup> ND is fortunate to have a variety of recreation options for people with disabilities. There are opportunities available to people statewide and city-specific. The information was retrieved via the internet and may not be a complete listing of recreation opportunities across the state.

### Recreation Opportunities Available to Individuals statewide:

- 1) **Camp ReCreation** is a Christian summer camp for people with IDD. The Camp aims to pair young adult counselors with campers who have special needs on a one-to-one basis. As they participate in each day's activities, the pairing builds bridges of understanding and friendship. Camp ReCreation promotes respect, community involvement, and volunteerism. The camp takes place at the Richardton-Taylor High School. Camp activities include, but are not limited to, crafts, music, games, and faith formation, as well as special events such as bowling, swimming, a dance, carnival, picnics, and live entertainment.<sup>286</sup>
- 2) **ND Assistive** provides has items that may help individuals with IDD participate in recreation, sports, and leisure. Assistive technology devices and services that can help with this may include:
  - Large print playing cards and playing cardholders
  - Adaptive video game consoles
  - Voice-activated home automation for entertainment
  - Referrals to other organizations in the state that specialize in adaptive activities for recreation<sup>287</sup>
- 3) **Tewaukon National Wildlife Refuge**-The 8,363-acre Tewaukon refuge established in 1945 is located in southeast ND. People can enjoy fishing, hunting for deer and pheasants, and bird watching on the Refuge. The refuge has accessible bathrooms, boat docks, fishing locations, and a nature center. <sup>288</sup>
- 4) The **National Center on Health, Physical Activity, and Disability website** lists several youth programs available for people with disabilities and health conditions in ND. NCHPAD's overall mission is to help people with disabilities find accessible programs.<sup>289</sup>
- 5) **Escape to the Lake** is NDAD's annual adaptive water recreation event, which provides adults and children with physical disabilities the opportunity to water-ski, or take a pontoon

<sup>284</sup> Senior Link. Retrieved from: <https://www.seniorlink.com/blog/the-importance-of-recreation-for-individuals-with-disabilities>

<sup>285</sup> American Association of Health and Disability. Retrieved from: <https://www.aahd.us/abstract/a-review-of-social-and-environmental-barriers-to-physical-activity-for-adults-with-intellectual-disabilities/>

<sup>286</sup> Camp Recreation. Retrieved from: <https://www.camprecreationnd.com/>

<sup>287</sup> ND Assistive. Retrieved from: <https://ndassistive.org/services-for-individuals/recreation-sports-leisure/>

<sup>288</sup> National Center on Health, Physical Activity and Disability. Retrieved from: <https://www.nchpad.org/Directories/Parks/1069/Tewaukon~National~Wildlife~Refuge>

<sup>289</sup> National Center on Health, Physical Activity and Disability. Retrieved from: <https://www.nchpad.org/Directories/Youth/USA/North~Dakota>



ride.<sup>290</sup> NDAD also sponsors qualifying individuals with access to other adaptive recreation activities such as swimming lessons, sled hockey, bowling, and more.

- 6) **Annie's House** at the Bottineau Winter Park, managed by the Anne Carlsen Center, accommodates skiers with physical and cognitive disabilities. The park is evolving into an all-season recreation, education, and arts program.<sup>291</sup> This state-of-the-art facility and the surrounding area provide an array of life-changing opportunities for individuals and veterans with disabilities.<sup>292</sup> There is no charge for these activities
- 7) The **Art at Anne's** program offers classes statewide to allow creative expression and personal development for all students. Types of classes offered include visual art, sculpture/clay art, music, creative movement, drumming, theatre, writing, photography, and multi-media. The art classes and experiences are designed for all ages.<sup>293</sup>
- 8) **Can Shine** is a national charitable non-profit organization. Anne Carlsen has partnered with Can Shine to create a 5-day program to assist riders with disabilities to learn how to bike. Approximately 80 percent of the people who participate can ride a two-wheel bicycle independently (at least 75 feet with no assistance) by the end of the program.<sup>294</sup>
- 9) **Techno Camps** provide students of all abilities the opportunity to access new technologies and apply them in the real world. The focus of the camp is to assist individuals further develop skills with technology adaptations. The Techno Camps are held at the Elks Camp Grassick. Attendance at camp is limited, and participants must be age 13 – 21 and have a disability.<sup>295</sup>

## City Specific Recreational Opportunities

- 1) Fargo
  - Fargo parks have both adult and child adaptive programs, and their website also lists ADA fishing sites. <sup>296</sup> Examples of youth programs in Fargo include Adaptive Tae Kwon Do, Coed Softball League, camps, wheelchair sports.<sup>297</sup>
- 2) Grand Forks
  - The SMILE program is an adaptive recreational program for adolescents. This program assists in developing appropriate and healthy leisure and social skills. Participating in this program is by recommendation only. Program size is limited to thirty (30) participants.<sup>298</sup>
- 3) West Fargo
  - The Camp-A-Day Adaptive Recreation Program is for youth with developmental disabilities. Campers are provided with recreational activities, including crafts and field trips. All participants must have a current IEP. This camp occurs in June.<sup>299</sup>

<sup>290</sup> North Dakota Association for the Disabled. Retrieved from:

<https://ndad.org/services/RecreationalActivities/EscapetotheLake/>

<sup>291</sup> Anne Carlsen Center. Retrieved from: <https://annecarlsen.org/about/>

<sup>292</sup> Anne Carlsen Center. Retrieved from: <https://annecarlsen.org/recreation-and-leisure/annies-house/>

<sup>293</sup> Anne Carlsen Center. Retrieved from: <https://annecarlsen.org/events/art-at-annes/>

<sup>294</sup> Anne Carlsen Center. Retrieved from: <https://annecarlsen.org/events/ican-bike/>

<sup>295</sup> Anne Carlsen Center. Retrieved from: <https://annecarlsen.org/events/technocamp/>

<sup>296</sup> Fargo Parks and Recreation. Retrieved from: <https://www.fargoparks.com/>

<sup>297</sup> National Center on Health, Physical Activity and Disability. Retrieved from:

<https://www.nchpad.org/Directories/Youth/USA/North~Dakota/Fargo>

<sup>298</sup> National Center on Health, Physical Activity and Disability. Retrieved from:

<https://www.nchpad.org/Directories/Youth/173/SMILE~~Special~Needs>

<sup>299</sup> West Fargo Parks and Recreation. Retrieved from: <https://www.wfparks.org/activities/youth-activities/camps/>

4) Bismarck

- Meet it or Beat It Bowling is a program that is offered to individuals of all ages and abilities. This short program is designed for the individual bowler to meet or beat his/her previous week's scores. Emphasis is on participation.<sup>300</sup>
- The Triple Star Day Camp is offered to individuals ages ten and up with varying abilities. Emphasis is given to age-appropriate activities, as well as opportunities to participate in community activities and to swim.

5) Mandan

- Dreams in Motion provides competitive and recreational adaptive sports programs critical to the health and well-being of youth and adults with mobility challenges or visual impairments.<sup>301</sup>
- Universal Play Ground-The playground was designed considering people's physical, sensory, social, communication, and cognitive abilities. The universal playground has a rubberized poured-in-place surface. This surface allows people to use their senses to know 'safe zones' when referring to where playground equipment is located. The surface also allows people with wheelchairs to easily access the playground and provides a soft surface if anyone was to fall.<sup>302</sup>

6) Williston

- Williston parks hold a swim party for families and children who need a low stimulation environment who may have disabilities, anxiety, or need extra assistance<sup>303</sup>

<sup>300</sup> Bismarck Parks and Recreation. Retrieved from: <https://www.bisparks.org/programs/adult-programs/adaptive-recreation/>

<sup>301</sup> Dreams in Motion. Retrieved from: <https://www.dreamsinmotioninc.com/>

<sup>302</sup> Mandan Parks and Recreation. Retrieved from: <https://mandanparks.com/parks-shelters/shelter-rentals/universal-playground/>

<sup>303</sup> Williston Parks and Recreation. Retrieved from: <https://www.willistonparks.com/special-needs-events>

## Report Observations

Table 15 summarizes the positive items and challenges identified while drafting this report. The table provides the Council with a potential framework for future initiatives.

*Table 15: Positive Findings and Challenges Identified in the Comprehensive Review and Analysis Report*

Positive Findings	Challenges
Autism Waiver has an increased age limit	There are 4,509 people with disabilities in ND who are uninsured.
CHIP coverage matches Medicaid	Immunization targets for young children are not met.
ND HCBS waiver spending per capita outpaces the US average. \$281 versus \$124	Medicaid Child and CHIP participation rate is below the US average. (93.7% versus 83.2%)
No wait list for the IDD waiver	Regional disparities in behavioral health access (70/1000 people served versus 28/1000 people)
Additional mandatory reportable conditions implemented	Lack of affordable housing in ND
CARES team provides behavioral health services to those with IDD.	Low number of MFP transition for people with IDD (156 between 2007-2012)
There is an increased use of telehealth.	33% of people with a cognitive disability live in poverty in ND
ND leads in the # of people with IDD that are employed	48% of ND people with a cognitive disability are not in the labor force
New AEPS tool used in Infant Development to gain better data.	35% of ADA ND charges are due to lack of accommodation
Supported Decision-Making option in place.	Special Ed outcomes for students with IEPs and time spent in a regular classroom
Number of people is limited to 8 in the group employment service in the IDD Waiver	Graduation rate of students with IEPs ( 66.2-68.48% ND 4-year rate)
A full-time infant development coordinator was hired in 2018	Poor educational outcomes for students with IDD
	Child care options during non-traditional work hours
	Childcare capacity ( only 36% of potential demand met)
	Guardian Shortage (119 waitlist for Corporate Guardianships)
	Poor dental health of ND kindergartners and NA children

## Recommendations

The following recommendations are offered as a roadmap for system improvement and present a range of possible options for consideration.

1. FASD is 100% preventable. Consider contact with the UND FASD Center to determine opportunities to decrease new cases. (estimated to be 110-550 yearly in ND)
2. The missed immunization targets far exceed what would be expected given the rate of 3.14% of parents of kindergartners claiming an exemption. Consider contact with DOH to gain more information on barriers for children not receiving their immunizations.
3. Encourage an increase in the use of telehealth for people with IDD.
4. Make contact with MFP administrator to gain information on barriers for people with IDD using the MFP transition funds.
5. Advocate for more culturally appropriate services overall.
6. Monitor Infant Development data as a new data tool has been implemented.
7. Gain information on whether the HFA's rental support programs are being utilized fully.
8. Maximize the use of the Supported Decision-Making option.
9. Collaborate with DPI to gain information on barriers for students with IEPs and specifically students with an IDD to identify methods to address the poor outcomes.

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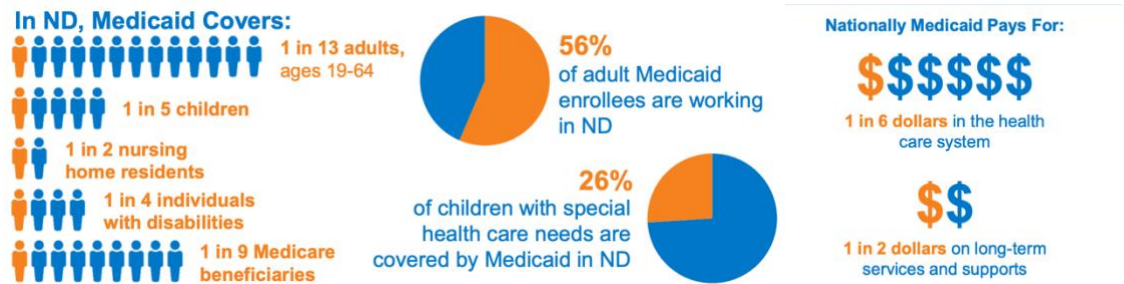


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## Appendix A

### ND Traditional Medicaid State Plan Covered Services

The services listed below are a general listing; some covered services have limitations or restrictions.

#### **Hospital**

**Inpatient:** Covers room and board, regular nursing services, supplies and equipment, operating and delivery room, X-rays, lab, and therapy.

**Outpatient:** Covers emergency room services and supplies, lab, X-ray, therapies, drugs and biologicals, and outpatient surgery.

#### **Nursing Facility**

Covers room and board, nursing care, therapies, general medical supplies, wheelchairs, and durable medical equipment.

#### **Clinics, Rural Health Clinics**

Covers outpatient medical services and supplies furnished under the direction of a doctor.

#### **Hospice**

Provides health care and support services to terminally ill individuals and their families.

#### **Physicians**

Covers medical and surgical services performed by a doctor; supplies and drugs given at the doctor's office; and X-rays and laboratory tests needed for diagnosis and treatment.

#### **Prescription Drugs**

Covers a wide range of, but not all, prescription drugs, insulin, family planning prescriptions, supplies, and devices. Requires a prescription from a doctor.

#### **Chiropractor**

Covers X-rays and manual manipulation of the spine for certain diagnoses.

#### **Health Tracks (EPDST)**

Covers screening and diagnostic services to determine physical and mental status, and treatment to correct or eliminate defects or chronic conditions and help prevent health problems from occurring for children under 21. It also covers medically necessary orthodontia and vaccinations.

#### **Home Health**

Covers nursing care, therapy, and medical supplies when provided in a recipient's home. A physician must order care.

#### **Durable Medical Equipment and Supplies**

Covers medical supplies such as oxygen and catheters and reusable equipment that is primarily medical in nature. Items must be medically necessary and do not include exercise equipment, personal comfort, or environmental control equipment.

#### **Dental**

Covers exams, X-rays, cleaning, fillings, surgery, extractions, crowns, root canals, dentures (partial and full), and anesthesia.

#### **Family Planning**

Covers diagnosis and treatment, drugs, supplies, devices, procedures, and counseling for persons of childbearing age.

### **Sterilization**

Covers sterilization procedures if: (1) The recipient is at least 21 years old; (2) The recipient is legally competent; (3) The recipient signs an informed consent form; and (4) At least 30 days but not more than 180 days have passed between the signing of the consent form and the sterilization.

### **Podiatry**

Covers office visits, supplies, X-rays, and surgery procedures.

### **Mental Health**

Covers psychiatric and psychological evaluations, inpatient services in a psychiatric unit of a hospital, individual-group-family psychotherapy, partial hospitalization services, and inpatient psychiatric and residential treatment centers services for individuals under 21 for the care and treatment of mental illness or disorders.

### **Ambulance**

Covers ground and air ambulance trips, attendant, oxygen, and mileage when medically necessary to transport a recipient to the closest health care facility meeting his needs. House Bill 1282 permits ambulance personnel to refuse transport to an individual where medical necessity cannot be demonstrated and recommend an alternative course of action for the individual. If the ambulance was not medically necessary, Medicaid will not pay for the service.

### **Transportation**

Covers non-emergency transportation services to and from the recipient's home to the closest medical provider capable of providing a medically necessary examination or treatment.

### **Vision**

Covers exam, glasses, frames, and some hard contact lenses for the correction of certain conditions. Replacement eyeglasses may only be provided after a minimum of 12 months for children under 21 or 24 months for adults if a lens change is medically necessary. An exception to the replacement limitation may be made if new eyeglasses are required for a significant change in correction and the eyeglasses are prior approved. Lost or broken glasses for individuals over 21 will not be replaced within the first two years.

### **Therapies**

Covers physical and occupational therapy and speech and language pathology.

### **Out-of-State Services**

Medically necessary covered services may be provided outside of North Dakota if the services are not available within North Dakota and have been prior approved by the department or if the services are provided in an emergency.

Source: ND DHS Medical Services Division

**23-0881.01000**

Sixty-eighth  
Legislative Assembly  
of North Dakota

**SENATE BILL NO. 2335**

Introduced by

Senators K. Roers, Dever, Lee

Representatives Beltz, Nelson

1 A BILL for an Act to create and enact a new section to chapter 50-06 and section 50-11-01.7 of  
2 the North Dakota Century Code, relating to training and screening for fetal alcohol spectrum  
3 disorder and creating a fetal ~~alcohol spectrum disorder council~~ cross-disability advisory  
4 council; and to amend and reenact ~~section 15.1-32-01~~, subsection 3 of section 25-01.2-01, ~~and~~  
5 ~~section 27-20.3-04~~ of the North Dakota Century Code, relating to fetal alcohol spectrum disorder;  
6 and to ~~provide a report~~ establish an annual day for awareness of fetal alcohol spectrum disorder.

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

8 ~~**SECTION 1. AMENDMENT.** Section 15.1-32-01 of the North Dakota Century Code is~~  
9 ~~amended and reenacted as follows:~~

9 ~~**15.1-32-01. Definitions.**~~

10 ~~As used in this chapter:~~

11 ~~1. "Related services" means transportation and developmental and corrective or~~  
12 ~~supportive services required to assist a student with disabilities to benefit from special~~  
13 ~~education.~~

14 ~~2. "Special education" means instruction designed to meet the needs of a student with~~  
15 ~~disabilities, transportation, and corrective and supporting services required to assist a~~  
16 ~~student with disabilities in taking advantage of, or responding to, educational programs~~  
17 ~~and opportunities.~~

18 ~~3. "Student who is gifted" means an individual who is identified by qualified professionals~~  
19 ~~as being capable of high performance and who needs educational programs and~~  
20 ~~services beyond those normally provided in a regular education program.~~

21 ~~4. a. "Student with a disability" means an individual who is at least three years of age~~  
22 ~~but who has not reached the age of twenty-one before August first of the year in~~  
23 ~~which the individual turns twenty-one and who requires special education and~~



24 — related services because of:

- 1                   (1)    An intellectual disability;
- 2                   (2)    A hearing impairment, including deafness;
- 3                   (3)    Deaf-blindness;
- 4                   (4)    A speech or language impairment;
- 5                   (5)    A visual impairment, including blindness;
- 6                   (6)    An emotional disturbance;
- 7                   (7)    An orthopedic impairment;
- 8                   (8)    ~~Fetal alcohol spectrum disorder;~~
- 9                   ~~(9)~~ (8)    Autism;
- 10                  ~~(9)~~ ~~(10)~~ (9)    A traumatic brain injury;
- 11                  ~~(10)~~ ~~(11)~~ ~~(10)~~    Other health impairment; or
- 12                  ~~(11)~~ ~~(12)~~ ~~(11)~~    A specific learning disability.
- 13                  b.    ~~"Student with a disability" includes a student age eighteen through twenty-one~~
- 14                  ~~who is incarcerated in an adult correctional facility and who, in the last~~
- 15                  ~~educational placement prior to incarceration, was identified as being a student~~
- 16                  ~~with a disability and did not have an individualized education program or was~~
- 17                  ~~identified as being a student with a disability and had an individualized education~~
- 18                  ~~program.~~

19                **SECTION 2.1. AMENDMENT.** Subsection 3 of section 25-01.2-01 of the North Dakota  
20 Century Code is amended and reenacted as follows:

- 21                3.    "Developmental disability" means a severe, chronic disability of an individual which:
  - 22                   a.    Is attributable to a mental or physical impairment or combination of mental and
  - 23                   physical impairments, including Down syndrome and fetal alcohol spectrum
  - 24                   disorders, including fetal alcohol syndrome, partial fetal alcohol syndrome, and
  - 25                   alcohol-related neurodevelopmental disorder;
  - 26                   b.    Is manifested before the individual attains age twenty-two;
  - 27                   c.    Is likely to continue indefinitely;
  - 28                   d.    Results in substantial functional limitations in three or more of the following areas
  - 29                   of major life activity:
    - 30                       (1)    Self-care;
    - 31                       (2)    Receptive and expressive language;

- 1                   (3) Learning;
- 2                   (4) Mobility;
- 3                   (5) Self-direction;
- 4                   (6) Capacity for independent living; and
- 5                   (7) Economic sufficiency; and
- 6                e. Reflects the individual's needs for a combination and sequence of special,
- 7                   interdisciplinary, or generic care, treatment, or other services which are of lifelong
- 8                   or extended duration and are individually planned and coordinated.

9                ~~SECTION 3. AMENDMENT. Section 27-20.3-04 of the North Dakota Century Code is~~  
10               ~~amended and reenacted as follows:~~

11               ~~27-20.3-04. Powers and duties of director of juvenile court.~~

- 12               ~~1. For the purpose of carrying out the objectives and purposes of this chapter and~~  
13               ~~subject to the limitations of this chapter or imposed by the court, a director shall:~~
  - 14               ~~a. Make investigations, reports, and recommendations to the juvenile court.~~
  - 15               ~~b. Receive and examine referrals of a child in need of services or child in need of~~  
16               ~~protection for the purpose of considering diversion of services.~~
  - 17               ~~c. Make a determination upon intake of referrals regarding the appropriate manner~~  
18               ~~to handle delinquent conduct, a child in need of services, or a child in need of~~  
19               ~~protection under this chapter.~~
  - 20               ~~d. Assess or screen each child in need of services or child in need of protection for~~  
21               ~~fetal alcohol spectrum disorder.~~
  - 22               ~~e. Make appropriate referrals to other private or public agencies of the community if~~  
23               ~~their assistance appears to be needed or desirable.~~
  - 24               ~~e.f. Issue a temporary custody order concerning a child who is referred to the~~  
25               ~~director's supervision or care as a child in need of services or a child in need of~~  
26               ~~protection. Except as provided by this chapter, a director does not have the~~  
27               ~~powers of a law enforcement officer.~~
  - 28               ~~f.g. Take acknowledgments of instruments for the purpose of this chapter.~~
  - 29               ~~g.h. Make such temporary order not to exceed ninety six hours for the custody and~~  
30               ~~control of a child alleged to be in need of services or protection as may be~~

1 ~~\_\_\_\_\_~~ deemed appropriate. The order must be reduced to writing within twenty-four  
2 ~~\_\_\_\_\_~~ hours, excluding holidays and weekends.

3 ~~\_\_\_\_\_~~ h.i. ~~\_\_\_\_\_~~ Perform all other functions designated by this chapter or under section 27-05-30  
4 ~~\_\_\_\_\_~~ or by order of the court, including, if qualified, those of a referee.

5 ~~\_\_\_\_\_~~ i.j. ~~\_\_\_\_\_~~ Issue an order to a law enforcement authority to transport a child to and from a  
6 ~~\_\_\_\_\_~~ specified location.

7 ~~\_\_\_\_\_~~ j.k. ~~\_\_\_\_\_~~ Receive and examine requests for review of a child's placement at a qualified  
8 ~~\_\_\_\_\_~~ residential treatment program under the Family First Prevention Services Act  
9 ~~\_\_\_\_\_~~ [Pub. L. 115-123; 132 Stat. 64; 42 U.S.C. 675].

10 ~~\_\_\_\_\_~~ 2. ~~\_\_\_\_\_~~ Any of the foregoing functions may be performed in another state if authorized by the  
11 ~~\_\_\_\_\_~~ court of this state and permitted by the laws of the other state.

12 ~~\_\_\_\_\_~~ **SECTION 4.** A new section to chapter 50-06 of the North Dakota Century Code is created  
13 ~~\_\_\_\_\_~~ and enacted as follows:

14 ~~\_\_\_\_\_~~ **Fetal alcohol spectrum disorder council – Appointment – Duties – Annual reports to**  
15 ~~\_\_\_\_\_~~ **governor and legislative management.**

16 ~~\_\_\_\_\_~~ 1. ~~\_\_\_\_\_~~ The fetal alcohol spectrum disorder council consists of:

17 ~~\_\_\_\_\_~~ a. ~~\_\_\_\_\_~~ The executive director of the department, or the executive director's designee;

18 ~~\_\_\_\_\_~~ b. ~~\_\_\_\_\_~~ The superintendent of public instruction, or the superintendent's designee;

19 ~~\_\_\_\_\_~~ c. ~~\_\_\_\_\_~~ The executive director of the North Dakota protection and advocacy project, or  
20 ~~\_\_\_\_\_~~ the director's designee;

21 ~~\_\_\_\_\_~~ d. ~~\_\_\_\_\_~~ The director of the fetal alcohol spectrum disorder clinic at the university of North  
22 ~~\_\_\_\_\_~~ Dakota, or the director's designee;

23 ~~\_\_\_\_\_~~ e. ~~\_\_\_\_\_~~ A member of the house of representatives from an even-numbered legislative  
24 ~~\_\_\_\_\_~~ district and a member of the house of representatives from an odd-numbered  
25 ~~\_\_\_\_\_~~ legislative district appointed by the majority leader of the house of  
26 ~~\_\_\_\_\_~~ representatives to serve two-year terms;

27 ~~\_\_\_\_\_~~ f. ~~\_\_\_\_\_~~ A member of the senate from an even-numbered legislative district and a  
28 ~~\_\_\_\_\_~~ member of the senate from an odd-numbered legislative district appointed by the  
29 ~~\_\_\_\_\_~~ majority leader of the senate to serve two-year terms;

Sixty-eighth  
Legislative Assembly

- 1 ~~g. The executive director of an organization that provides services and support to~~  
2 ~~the fetal alcohol spectrum disorder community, or the executive director's~~  
3 ~~designee;~~
- 4 ~~h. The director of the state council on developmental disabilities, or the director's~~  
5 ~~designee; and~~
- 6 ~~i. The following members appointed by the governor:~~
- 7 ~~(1) A pediatrician with expertise in the area of fetal alcohol spectrum disorder;~~  
8 ~~(2) A college of education faculty member with expertise in the area of fetal~~  
9 ~~alcohol spectrum disorder;~~
- 10 ~~(3) A behavioral specialist;~~
- 11 ~~(4) A representative of a licensed residential care facility providing care and~~  
12 ~~services to an individual with fetal alcohol spectrum disorder;~~
- 13 ~~(5) An enrolled member of a federally recognized Indian tribe;~~
- 14 ~~(6) An adult self-advocate with fetal alcohol spectrum disorder; and~~
- 15 ~~(7) Four parents of a child with fetal alcohol spectrum disorder.~~
- 16 ~~2. The council shall elect a chairman.~~
- 17 ~~3. The council shall meet at least quarterly at the call of the chairman.~~
- 18 ~~4. The council shall examine:~~
- 19 ~~a. Early intervention services;~~
- 20 ~~b. Family support services enabling an individual with fetal alcohol spectrum~~  
21 ~~disorder to remain in the least restrictive home-based or community setting;~~
- 22 ~~c. Programs transitioning an individual with fetal alcohol spectrum disorder from a~~  
23 ~~school-based setting to adult day programs;~~
- 24 ~~d. Workforce development programs;~~
- 25 ~~e. The cost of providing services; and~~
- 26 ~~f. Federal resources providing services for individuals with fetal alcohol syndrome~~  
27 ~~disorder.~~
- 28 ~~5. The council shall develop a state fetal alcohol spectrum disorder plan and present the~~  
29 ~~plan to the governor and a legislative interim committee designated by the chairman of~~  
30 ~~the legislative management before July 1, 2024. The council shall continue to review~~  
31 ~~and periodically update or amend the plan to best serve the needs of individuals with~~

~~1 fetal alcohol spectrum disorder and provide an annual report to the governor and a  
2 legislative interim committee designated by the chairman of the legislative  
3 management regarding the status of the plan.~~

4 **SECTION 2.** A new section to chapter 50-06 of the North Dakota Century Code is created  
5 and enacted as follows:

6 **Cross-disability advisory council – Appointment – Duties.**

7 1. The cross-disability advisory council shall participate with and provide feedback to the  
8 department regarding the implementation, planning, and design of the cross-disability  
9 children’s waiver and level of care reform for the comprehensive developmental disabilities  
10 Medicaid home and community-based waiver.

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

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

25 4. The cross-disability advisory council shall meet at least quarterly and may appoint  
26 subcommittees to address specific topics or disabilities, which may include autism, traumatic  
27 brain injury, and fetal alcohol spectrum disorder.

28 5. The cross-disability advisory council shall:

29 a. Discuss strategies to address gaps or needs regarding individuals with  
30 disabilities and

30 Medicaid home and community-based services;

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

33 c. Receive information from the department and its consultants.

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

37 **SECTION 5-3.** Section 50-11-01.7 of the North Dakota Century Code is created and enacted  
38 as follows:

39 **50-11-01.7. Fetal alcohol spectrum disorder training.**

40 ~~Before an initial licensure or licensure renewal under this chapter, each foster parent shall~~  
41 ~~complete a course of instruction related to fetal alcohol spectrum disorder.~~ The department shall  
42 ~~create the training or provide the training through a third party vendor.~~ integrate fetal alcohol  
43 spectrum disorder instruction into the training for all child welfare public and private providers  
44 and foster parents, and further shall integrate a formal fetal alcohol spectrum disorder screening  
45 into the early and periodic screening diagnostic and treatment.

46 **SECTION 4.** A new section to chapter 1-03 of the North Dakota Century Code is created  
47 and enacted as follows:

48 **Fetal Alcohol Spectrum Disorder Awareness Day.**

49 To celebrate the life of all affected by fetal alcohol spectrum disorder, reaffirm the dignity and  
50 value of every human being, and to create awareness of the number of people affected by this  
51 disorder, the ninth day of September of each year is designated and established as Fetal  
52 Alcohol Spectrum Disorder Awareness Day for the state of North Dakota.

53

Senate Human Services Committee  
Senate Bill 2335 – March 13, 2023

Representative Weisz and Committee Member,

My name is Donene Feist and I am the Director of Family Voices of North Dakota

We are providing favorable testimony in favor of SB2335.

We have heard from many families of children with FAS who fall into the gaps. Because of ND definition of developmental disabilities does not include FASD, many of these children have few to no resources.

Family Voices is very concerned about the continued gaps for families, lack of resources and economic impact for these families. The most we can do is provide 1:1 emotional support or connect them to others who are also facing the same issues or provide a referral to the North Dakota Fetal Alcohol Syndrome Center diagnostic and treatment center which provides wonderful services to families.

Families are struggling.

A council would be beneficial to understand and identify next steps, ongoing needs and impact. Having a council that focuses on the needs of all affected by FASD is vital.

Thank you for your time

Donene Feist  
Family Voices of ND  
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**Senate Human Services Committee**  
**Senate Bill 2335 – February 13, 2023**  
**Testimony of Rachel Sinness, P&A Legal Director**

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 provides testimony in favor of SB 2335 relating to changes in statute to accommodate fetal alcohol spectrum disorder. Approximately 1 in 20 North Dakotans have or will be diagnosed with a fetal alcohol spectrum disorder (FASD). FASD accounts for 1% of live births in North Dakota and is 2.5 times more prevalent than Autism. Despite its prevalence, North Dakota's definition of "developmental disability" currently does not include FASD. Exclusion from basic definitions, lack of training, and lack of screening and treatment result in an inability to receive developmental disability services, high rates of incarceration and recidivism among those who have FASD, and higher than average school exclusion rates.

Alaska, New York, and neighboring state Minnesota have already included FASD in their statutory definitions of "developmental disability." Individuals diagnosed with FASD are entitled to the same level of services as for any other developmental disability and have a basis to get those services provided immediately.<sup>1</sup> Minnesota has also implemented training on the prevention of FASD,<sup>2</sup> as well as prenatal alcohol exposure screening for children entering foster care,<sup>3</sup> much like the efforts put before the North

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<sup>1</sup> [FASD: Identification and Advocacy \(americanbar.org\)](https://www.americanbar.org/)

<sup>2</sup> [Sec. 245A.175 MN Statutes](#)

<sup>3</sup> [Sec. 260C.219 MN Statutes](#)

Dakota Legislature through this proposed legislation. While Minnesota’s legislation is relatively new, having been adopted in 2022, the state is seeing encouraging results in the identification of children with prenatal exposure to alcohol and FASD training,<sup>4</sup> and families are receiving much needed supports.<sup>5</sup>

On a national level, the FASD Respect Act has been introduced in Congress and has received wide bipartisan support. The bill seeks to “direct the Department of Health and Human Services, the National Institutes of Health, the National Center on Birth Defects and Developmental Disabilities, and the Health Resources and Services Administration to carry out and coordinate research, surveillance, and related activities to diagnose, prevent, and treat FASD.”<sup>6</sup> It also establishes grant programs to provide services for individuals affected by FASD, among other supports.<sup>7</sup> To keep up with national trends toward making FASD more visible and to provide services to individuals diagnosed with FASD, the legislation proposed in SB 2335 is a must to North Dakotans.

P&A further supports implementation of the path laid out in the Alvarez and Marsal study presented to the 2021-23 interim Human Services Committee, leading to a fully modern home and community-based waiver system. Like the Department of Health and Human Services (Department) and numerous advocacy groups, we view the cross-disability council as a key component of that project. P&A supports implementation of the path laid out in the Alvarez and Marsal study presented to the 2021-23 interim Human Services Committee, leading to a fully modern home and community-based

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<sup>4</sup> [Landmark Legislation: A Victory for the FASD Community - Proof Alliance](#)

<sup>5</sup> [Support - Proof Alliance](#)

<sup>6</sup> [H.R.4151 - 117th Congress \(2021-2022\): FASD Respect Act | Congress.gov | Library of Congress](#)

<sup>7</sup> [Id.](#)

waiver system. Like the Department of Health and Human Services (Department) and numerous advocacy groups, we view the cross-disability council as a key component of that project.

P&A would like to see vast improvements in this area in North Dakota; we are concerned about the prevalence of FASD, its economic impact on North Dakota and North Dakota families, and the lack of services available to those who are diagnosed with FASD. P&A supports any and all efforts to make FASD more visible in North Dakota and to make treatments available to individuals whom P&A serves. P&A urges a DO PASS on SB 2335.

Chairman Weisz,

My name is Dr. Larry Burd. I am a Professor in the Department of Pediatrics at the University of North Dakota School of Medicine and Health Sciences. Thank you for the opportunity to provide testimony today on SB 2335. My testimony provided today are my own opinions and are not on behalf of the University.

One out of twelve pregnant women in North Dakota drink throughout pregnancy. Based on four separate prevalence studies in North Dakota, the prevalence of fetal alcohol spectrum disorders (FASD) ranges from 1 to 5% of live births. In North Dakota, we have about 107 new cases of FASD each year. The mortality rate is over 5%. The recurrence risk within that family is increased by 77%. The annual cost of care for a child with fetal alcohol spectrum disorder (FASD) is increased by \$22,800 and for adults over \$24,300. As a point of comparison fetal alcohol spectrum disorders are twice as common as autism spectrum disorders and the annual cost of care is over 26% greater for FASD.

FASD is a lifelong condition increasing risk for learning impairments, mental health disorders, severe health problems, increased risk for placement in foster care, special education, and contact with juvenile and adult corrections systems. The peak severity of FASD in North Dakota typically occurs at between 22 and 30 years of age.

The North Dakota Fetal Alcohol Syndrome Center diagnostic and treatment center provides services for all of North Dakota. This program has provided services for families from every part of North Dakota. In my 43 years with the University of North Dakota School of Medicine and Health Sciences, I have evaluated and treated over 18,000 children and adults with developmental disorders and severe mental health disorders from every county in North Dakota. We have provided hundreds of training opportunities on FASD for social workers, physicians, nurses, teachers, substance use disorder treatment programs, and corrections and court personnel.

People with FASD require early intervention, appropriate treatment, and care from multiple service systems. After 40 plus years of working with people with FASD, I assure you it is not less expensive or

more efficient to utilize a poorly coordinated system of services for people with FASD and serve them occasionally or only when diagnosed with some other condition.

**Testimony  
Engrossed Senate Bill No. 2335  
House Human Services Committee  
Representative Weisz, Chairman  
March 14, 2023**

Chairman Weisz, and members of the House Human Services Committee, I am Cory Pedersen, Director of the Children and Family Services (CFS) Section with the Department of Health and Human Services (Department). I am here today to provide information on Engrossed Senate Bill 2335 for your consideration.

Our primary concerns relate to the training requirements outlined in Section 4 of the Bill. Lines 21-22 instruct the Department to “integrate fetal alcohol spectrum disorder instruction into the training programs for public and private child welfare providers and foster parents”.

The Department has contracts with the UND Training Center and the Native American Training Institute (NATI) to provide both child welfare certification training and training for foster parents. This training is both comprehensive and targeted in that it is structured to assure that participants receive training and resources that cover the variety of complex needs that children in their care may have.

Senate Bill 2335 would create the only diagnosis-specific training requirement in our system. In the past, FAS training has been offered to child welfare workers and stakeholders over the years at different times

and at statewide conferences. This effort will continue as we have staff turnover.

Additionally, the Department is unclear about who is included in the term “public and private child welfare providers” (line 22 page 3). The Department is also unsure how to enforce a training requirement on “private child welfare providers” and how to “integrate a formal fetal alcohol spectrum disorder screening into the early and periodic screening diagnostic and treatment services” through the foster care licensing chapter 50-11, as contemplated in the Bill as this section of law deals with the licensing of foster care.

The Department respectfully requests that the Committee remove Section 4 of Senate Bill 2335.

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



Testimony Prepared for the  
**House Human Services Committee**

March 14, 2023

By: Kim Jacobson, Agassiz Valley Human Service Zone Director

**RE: Senate Bill 2335 – Fetal Alcohol Spectrum Disorder Training and Screening**

Chair Weisz and members of the House Human Service Committee, my name is Kim Jacobson. I am the Agassiz Valley Human Service Zone Director, which includes the service area of Traill and Steele Counties. In addition, I serve as President of the North Dakota Human Service Zone Director Association. Please consider my testimony in support of SB 2335.

Fetal Alcohol Syndrome Disorder (FASD) is a condition that significantly impacts the development, behavior, and ability to learn of those who are impacted. Early detection, care, and treatment of those with FASD is known to result in better outcomes. As child welfare professionals, it is critical for our workforce to understand, refer, and support children that present with FASD symptoms. I support FASD-related training for new child welfare workers as well as ongoing training for child welfare workers and supervisors. However, I am uncertain if this training requirement needs to be in law. Rather, I suggest that the Department include this training requirement in Administrative Rule.

Furthermore, I support the addition of FASD screening during Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, which is commonly referred to as Health Tracks. This is a preventative health care program for newborns, children, and young adults through age 20 that are on Medicaid. In addition, all children who enter foster care are required to have a Health Tracks screening within the first 30 days in foster care and annually thereafter. Adding the FASD screen to the Health Tracks program would add an additional

safety net measure to ensure efforts for early detection and referral. Of note, the committee may want to consider linking this requirement to the health section of code to ensure clear communications of expectations.

Thank you for consideration of my testimony. I stand for questions from the committee.

**Senate Bill number 2335**  
**House Human Service Committee**  
**Testimony by Roger Loven**  
**March 14, 2023**

Chairman Weisz and Honorable Representatives of the Human Services Committee, I am appearing in opposition to Senate Bill 2335.

My name is Roger Loven. My wife and I have been foster parents in Burleigh County since 1991. Over the past 32 years we have been privileged to provide care for nearly 70 North Dakota children who have needed care outside of their home. I am a retired physician, having practiced anesthesiology in Bismarck for 35 years.

I am very much in favor of the State of North Dakota doing what it can to provide treatment and support to the victims of Fetal Alcohol Spectrum Disorder. This disorder can be very debilitating to the victim of FAS and challenging to family members.

I am not in favor of requiring training on a specific disorder or syndrome or disease for every foster parent to obtain licensure. Foster parents are required to have continuing education each year and there is a wide variety of opportunities for that training. Fetal Alcohol Syndrome has been part of the continuing education that my wife and I have attended. As far as I know, passage of this law would be the first time that training for foster parents regarding a specific disorder would be written into law. This could lead to a cumbersome list of required training.

I find that foster parents seek out education and training for the conditions of the children currently in their care.

I ask for your no vote on this bill.

Thank You for your service to the citizens of North Dakota

Carl Young

March 14, 2023

Page 1 of 3

Chair Weisz, members of the committee, my name is Carl Young. I am the Executive Director of FASD-North Dakota. FASD is an acronym for Fetal Alcohol Spectrum Disorder. I am also a lobbyist here in North Dakota, and my ID number is 136. I am here today in my capacity as Executive Director and as a parent of a child with FASD.

My son was born substance exposed. His chart refers to his early days as "Day of Life 1, Day of Life 2..." He spent his first weeks in neonatal intensive care here in Bismarck. Outside of the womb, he has never known his birth mom. He came to us when he was 18 months old, though in truth we knew him much earlier because my wife did daycare for his foster mom. The adoption was finalized at the age of two. We knew early on that something wasn't quite right for him. He could stay awake for 72 hours at a time. In fact, he was on adult doses of his mental health medication by the age of five, and we had to frequently rotate his meds because his body would metabolize them so quickly. Some years we would travel more than 15000 miles around North Dakota trying to find appropriate support for him.

He first tried to kill me when he was eight. Thus began the roller coaster ride that is getting residential care in North Dakota. We would spend the next ten years trying to get him appropriate care. Each time he was discharged from a facility the time home would be decreased before we had to find another placement for him. He thrived in the structure. A level of structure that we were unable to provide for him in our home.

We have been threatened by facilities with charges of abandonment because we questioned their practices. Questioned their "cure". Yes, we heard that word several times. "We cured him."

When he was 15, a careful review of all of his birth records and a lot of testing was completed at the FASD Center in Grand Forks. It was then that we learned about the FASD.

We applied for developmental disability services only to be denied those services because his IQ was too high.

At age 17, he made one last attempt on my life. Over the course of his life, he tried to take mine six times. It is not in us to make excuses for the things that he does. In fact, we have gone to considerable lengths to hold him accountable. To teach him to hold himself accountable. He knows that there is something not wired properly in his head. He knows he needs help.

Currently, my son is a convicted felon. He is serving the balance of a sentence in the Case County jail for stealing a car. He struggles to hold jobs, in fact struggles to even get jobs. He is frequently homeless and unmedicated for those mental health conditions that he has that are to an extent controllable by medicine.

There are a lot of reasons why he isn't being supported currently. According to him, most providers that he has tried are not able to staff him.

In the 1980's a lawsuit was brought against the state that resulted in the transfer of residents to home and community based settings from institutions in which they had been placed. Over time, society has begun to use prison and jail as an alternative.

All my son wants to do, is live in the community. To have the supports that he needs.

My wife and I created FASD- North Dakota in 2018. It was founded as Family Services Network. Our goal was to help families not have to struggle to get the support they need for their children. Initially we would get a call or referral every couple of months. Now, I get calls and referrals 3 to 5 times a week.

It is not our goal, nor is it the practice of any organization serving this population to shame the birth mom. Often, mom might not know that she is pregnant when she is drinking during that first trimester. There is no safe amount of alcohol that can be consumed during pregnancy.

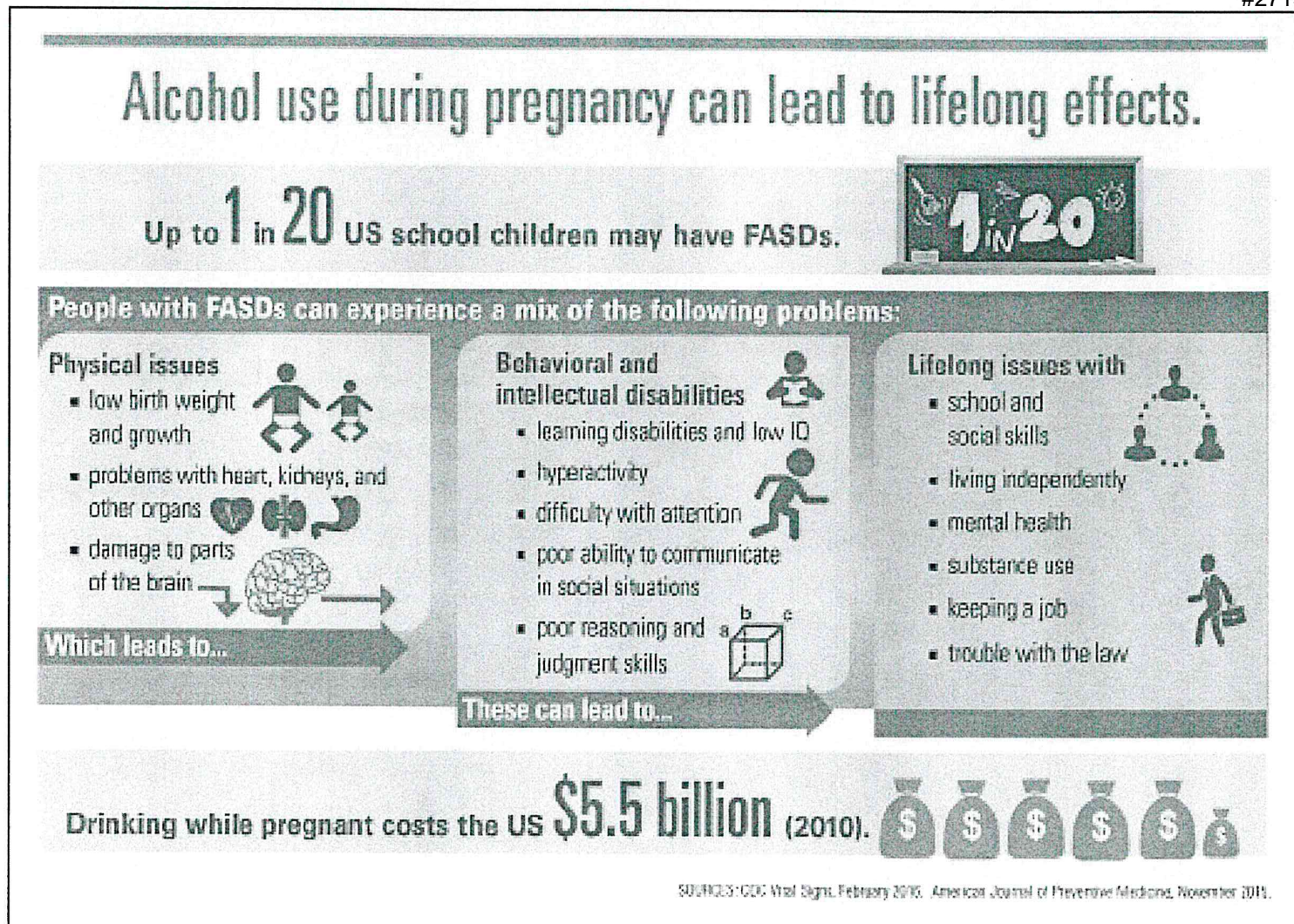
Conservative estimates are that 1 in 20 children may have an FASD. In our Tribal communities, that number is closer to 1 in 17. SB2335 is the start to helping these families that are affected by FASD. It is our hope that you will support SB2335 in its current form.

This legislation will have minimal impact on my son. It is our hope that future children will have better luck accessing care. That their families won't feel the pain, the anxiety of not being able to support their child.

Source:

Mitchell, Ann M. PhD, RN, AHN-BC, FIAAN, FAAN; Porter, Rebecca R. MS, LPC; Pierce-Bulger, Marilyn MN, FNP-BC, CNM; McKnight-Eily, Lela R. PhD, MEd. Addressing Alcohol Use in Pregnancy. *AJN, American Journal of Nursing* 120(7):p 22-24, July 2020. | DOI: 10.1097/01.NAJ.0000688188.28322.9c





Alcohol use during pregnancy can lead to lifelong effects in children exposed prenatally. Image courtesy of the Centers for Disease Control and Prevention.



**Testimony**  
**Engrossed Senate Bill No. 2335**  
**House Human Services Committee**  
**Representative Weisz, Chairman**  
**March 14, 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 2335 for your consideration as you review the Bill.

Section 2 of the Bill, page 1, lines 19 through 21, appears to communicate an intent to create automatic eligibility for Medicaid-funded DD services for individuals diagnosed with Fetal Alcohol Spectrum (FAS) disorders. The Department believes it is not necessary to add a specific diagnosis to this section of the North Dakota Century Code (NDCC) as FAS may be considered a developmental disability if the person meets all criteria identified in this section. It is important to note that the federal definition of developmental disability does not identify specific diagnoses.

If an individual wishes to access DD long term care services that are funded through the Centers for Medicare and Medicaid Services (CMS) the individual must meet the criteria that has been established for the Intermediate Care Facility for Individuals with an Intellectual Disability (ICF/IID) level of care. Under 42 CFR §435.1009 participants linked to the ICF/IID level of care must meet the "related condition" definition when they are not diagnosed as having an intellectual disability. The

definition of related conditions (42 CFR §435.1009) is functional; it is not tied to a fixed list of conditions therefore a change to NDCC will not change the eligibility process for people diagnosed with FAS. CMS does not allow states the option to establish automatic eligible by diagnosis; an individualized determination of eligibility is required.

People who qualify as having a "developmental disability" under the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 do not always meet an ICF/IID level of care. While "developmental disability" is a broad term that includes any mental/cognitive and/ or physical disability, it is often interchanged with intellectual disability. However, they are not equivalent as not all developmental disability conditions have the intellectual components closely related to intellectual disability.

Section 3 of the Bill, page 2, lines 15 through 31 and page 3, lines 1 through 17, creates a cross disability advisory council. This language aligned with Section 1 of House Bill 1035, which passed out of this committee but was defeated in the House. Included in HB 1035 was appropriations for a facilitator, consultants to provide expertise on the waiver design and level of care reform, and additional Department staff. The fiscal note for SB 2335 only includes reimbursement for committee members and a third-party facilitator. The Department's ability to move this work forward will depend both on legislation and resources the legislature will make available to support the effort.

Section 4 of the Bill, page 3, lines 22 through 24 directs the Department to integrate a formal FAS screening into the early and periodic screening

diagnostic and treatment (EPSDT) services. Screening for FAS and other developmental delays is currently a covered EPSDT service.

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