

2021 SENATE HUMAN SERVICES

SB 2256

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee Sakakawea Room, State Capitol

SB 2256
1/26/2021

A BILL for an Act to provide for a legislative management study of the state's home and community-based services waiver for individuals with intellectual disabilities and developmental disabilities.

Madam Chair Lee opened the hearing on SB 2256 at 11:15 a.m. All members present: Senator Lee, Senator K. Roers, Senator Hogan, Senator Clemens, Senator Anderson, Senator O. Larsen.

Discussion Topics:

- Administrative rule change
- Renegotiation of services
- Administrative rule V.S. state and federal law
- Eligibility and service delivery
- Intellectual disability

[11:16] Senator Dick Dever, District 32. Introduced SB 2256.

[11:22] Pam Mack, Director, Program Services, Protection & Advocacy Project (P&A). Provided testimony #3232 in favor.

[11:30] Kirsten Dvorak, Executive Director, The Arc of North Dakota. Provided testimony #3248 in favor.

[11:34] Donene Feist, Director, Family Voices of North Dakota. Provided testimony #3260 in favor.

[11:44] Carl Young, Executive Director, Family Services Network Inc. Provided testimony #3263 in favor.

[11:51] Jonathan Alm, Attorney, DHS. Provided testimony #5916 in opposition.

Additional written testimony: (4)

Dr. Larry Burd, Professor, Department of Pediatrics, UND of Medicine and Health Sciences. Provided written testimony #3278 in favor.

Roxane Romanick, Executive Director, Designer Genes. Provided written testimony #3279 in favor.

Vicki Peterson, Family Voices of North Dakota. Provided written testimony #3292 in favor.

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Samantha Peterson, Lincoln, North Dakota Citizen. Provided written testimony #3307 in favor.

Madam Chair Lee closed the hearing on SB 2256 at 12:04 a.m.

Justin Velez, Committee Clerk

Senate Education

Sixty-seventh Legislative Assembly of North Dakota

Senate Bill No. 2256

January 26, 2021

Good morning, Chairman Lee, and Members of the Senate Human Services Committee. I am Pam Mack, Director of Program Services for the Protection & Advocacy Project (P&A).

P&A is here today to support SB 2256 - a legislative management study of home and community-based waived services for individuals with Developmental Disabilities. NDCC § 25-01.2-01 and 42 U.S.C 15002(8) provide definitions for the term "developmental disability". NDCC § 25-01.2-02 further provides that "all individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting". While these services may be provided by a public or private agency or organization, funding for services is not intended to be a payor of last resort.

Moving to the administrative rules (NDAC § 75-04-06), there is a narrowing of the scope of individuals to be served through the "Intellectual Disabilities – Developmental Disabilities Program Management Services" system to include, in some places, replacement of the term "developmental disabilities" with "intellectual disabilities". To be eligible for DD Program Management AND DD services, an individual must, amongst other things, be: 1) eligible for ND Medicaid; and 2) meet the Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care.

Currently, some individuals determined by DHS to have a developmental disability, but who are not able to be screened for ICF/IID, receive Program Management Services only (using State General Funds). DHS' proposed budget for the 21-23 biennium removes the State funds, and therefore Program Management, for these individuals. I refer you to the attached hand-out from DHS, dated July 2019, which shows the process as a flow chart.

Moving on to the HCBS waiver, eligibility is based on screening with the ICF/IID level of care. Any waiver requires screening some type of institution (e.g., hospital, nursing home). The following is also included:

The State additionally limits the waiver to individuals with intellectual disabilities or individuals with related conditions (as defined in 42 CFR §435.1009) and cognitive impairment who meet the ICF/IID level of care (as defined in 42 CFR §440.150(a)(2)). Cognitive impairment means that a person performs significantly below appropriate age level in brain function (perception, attention, memory, motor, language, executive functioning), and the impairments are not severe enough to qualify as an intellectual disability.

Back to State law, which gives DHS the authority to adopt rules (NDCC § 25-01.2-18). It specifically states, "the rules adopted may not restrict or limit the rights guaranteed by this chapter". What we have today is not congruent with NDCC § 25-01.2-02, which states that "all individuals with developmental disabilities have a right to appropriate treatment, services and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting". A Legislative study could help sort this out.

If you have any questions or would like to contact me, you can reach me by e-mail at pmack@nd.gov or by phone at (701) 328-3975. Thank you for your consideration.

Process to Obtain Developmental Disabilities Program Management (DDPM) and DD Services

Step 1:

Contact your local Human Service Center: <http://www.nd.gov/dhs/locations/regionalhsc/>

Your inquiry will be provided to the DD Unit and they will arrange for an in-person meeting to gather information.

Step 2:

During the in-person meeting, the following will be addressed:

- Information about you and your needs
- Explanation of the eligibility criteria/process for both DDPM and DD services, Medicaid eligibility, role of the DDPM, and overview of DD services
- Complete an application, releases of information, and other necessary paperwork.
- Assist in obtaining or completing any necessary evaluations or information such as adaptive functioning, psychological testing, school records, speech, etc.
- Complete a screening assessment identifying current levels of functioning to determine level of care
 - If eligible, this assessment must be completed each year if you wish to continue to receive services

Step 3:

After all the necessary information is obtained, the Human Service Center will determine if you are eligible for DDPM and/or DD services using the information collected and screening assessment. A notice will be sent to you to let you know the results of the eligibility determination. If you are determined not eligible, you can request an appeal to have the decision reviewed.

- Eligibility for DDPM and DD services are 2 separate processes and you may be eligible for only DDPM **or** both DDPM and DD services. (see page 2)
- Eligibility may take up to 45 days, or longer if all the information is not available.
- **What is a DDPM?**

The DDPM is an employee of the State of North Dakota Department of Human Services located at one of the eight regional human service centers. The DDPM will help you locate, coordinate, provide information, and monitor supports and services with you, including natural and community supports.

Step 4:

If you are determined eligible for DDPM and/or DD services, you will choose among available DD services, will be referred to available DD providers of your choice, and can meet with any providers. Once an available provider(s) accepts your referral, you will choose the provider(s) to provide the service(s).

- Self-directed services are available and may be an option depending on your service needs.

Step 5:

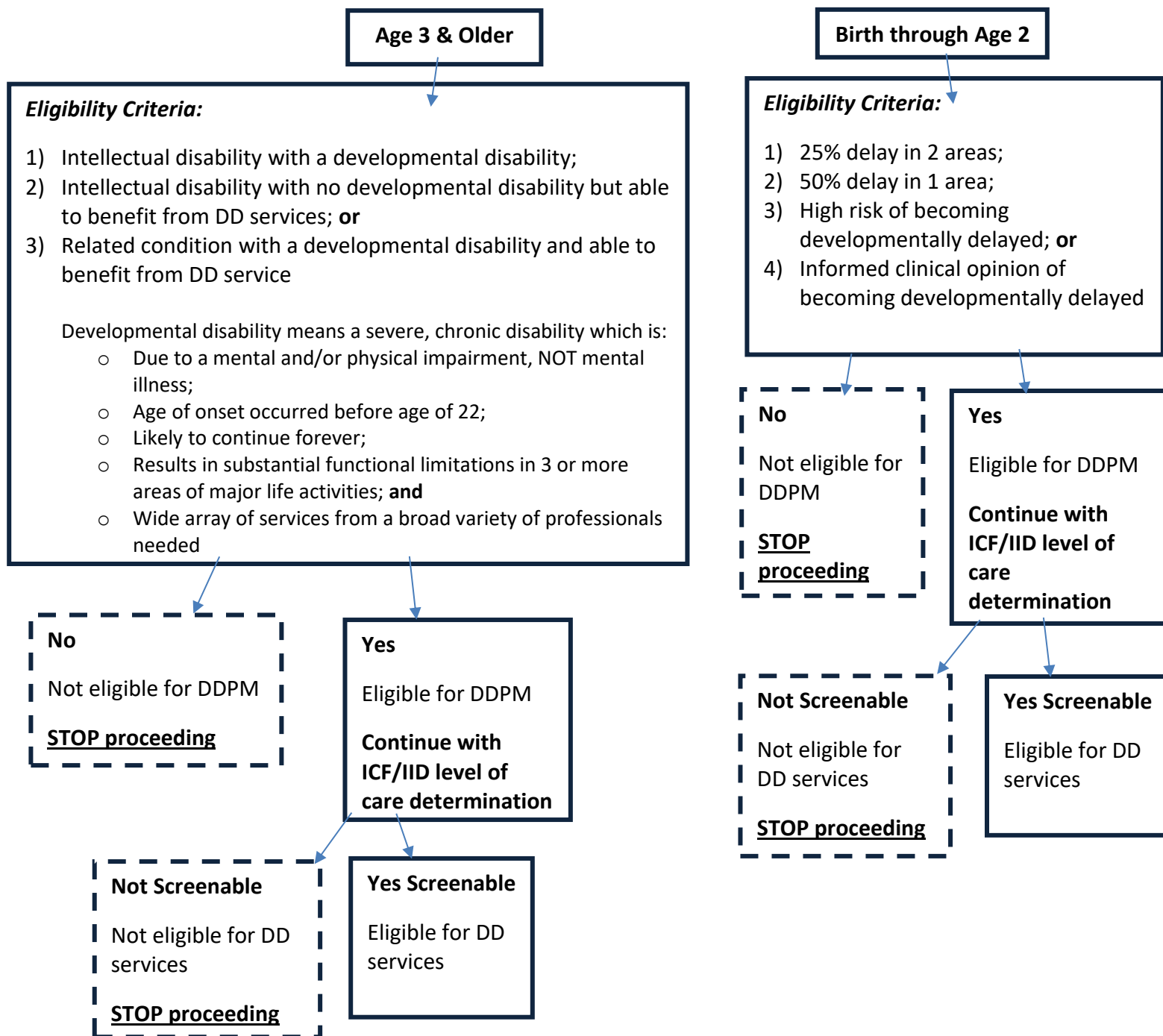
The provider and the DDPM will help you identify family and/or other individuals who are important to you to be part of the planning team. You and your planning team will work together to evaluate your needs, goals, and develop a person-centered service plan (PCSP). The DDPM will review your plan to make sure it meets your needs.

- The PCSP must be updated each year or as needs change. You may request an update to your plan anytime by contacting your DDPM or provider.

Eligibility Determination Process for DDPM and DD Services

In order to be eligible for supports and services from the ND Department of Human Services Developmental Disabilities Division (DD Division) a person must:

- Be a resident of ND and meet Medicaid U.S. citizenship and alienage
- Be eligible for ND Medicaid (Determined by the local County Social Service office)
- Meet the criteria defined in law per North Dakota Administrative Code (NDAC) 75-04-06
<https://www.legis.nd.gov/information/acdata/pdf/75-04-06.pdf>
- Meet the Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care





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#3248

Testimony of Support Senate Bill 2256
Senate Human Services
January 12, 2021

Chairman Lee and members of the Senate Human Services Committee, my name is Kirsten Dvorak. I am the executive director of The Arc of North Dakota, which includes all six Arc chapters in North Dakota: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve people's quality of life with intellectual and developmental disabilities and actively support their full inclusion and community participation.

I am also a parent of a 21-year-old with autism, Radek, who is non-screenable for the waiver; what services he has received is through the state plan, which he only received for three years as autism services stop at the 21. Because of Radek's autism, he needs help with executive functions such as time management, keeping his living space clean, ensuring that hygiene is done, and doing laundry regularly. He also uses job supports to help him stay on task at his job. Today the ABA therapy he receives is through private pay, which we are fortunate to pay. He is successfully attending ASTEP at Minot State University because of the ABA therapies and the ASTEP program's support, all of which are covered through student loans and private pay.

If he were not at ASTEP, he would be living in my basement because he doesn't qualify for services at this time. To receive those services, he would need to move out of our house, which puts him at risk of being homeless.

So, Chairman Lee, I ask that you pass 2256 to ensure that individuals are appropriately screened for DD services and that they are not falling through the cracks.

In the word of Temple Grandon, it's time to get them out of the basement.

Kristen Dvorak
Executive Director

SB2256
Senate Human Services Committee
Senator Lee Chair

Senator Lee and Members of the Committee,

My name is Donene Feist and I am the Director for Family Voices of North Dakota. Our work as you know, includes working with families who have children and youth with disabilities and chronic health conditions.

I rise to support SB2256. Over the years, many of us have stood before you to express our concerns over the wide array of gaps in our already complex system of care. Many families we assist have none too few options for assistance for their child and youth with special health care needs. Many possibly could be served if we broadened the ND Definition of Developmental Disabilities.

Digging through my old files found as far back as 2005 during and interim committee led by Senator Dever asking to review waivers, criteria and how all worked together. I believe at that time, Children's Special Health Services, now called Special Health Services was reviewed but the Developmental Disabilities Division, Medicaid and other programs that families utilize were not reviewed.

In 2013, Senator Kaiser requested a study to be done. The department of human services, during the 2013-2014 interim, shall identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver. In preparing the estimate, the department shall secure input from stakeholders, including families, providers, and advocates. The department of human services shall report its findings to the sixty-fourth legislative assembly. The report shall include the estimated number of children eligible, criteria for the provision of services under the waiver, the services to be offered, and a timeline for implementation of the waiver.

<https://www.legis.nd.gov/assembly/63-2013/documents/13-0778-01000.pdf>

This was done, over the course of 2 years family groups met with administration to identify gaps. I do not recall a report being given on what was discovered and what we were going to continue to do to monitor.

We also know some study work has been done and am sure others testifying will be commenting on this.

Somewhere in those years the Medically Fragile waiver and Hospice waiver were initiated to address some of the gaps. Both currently well utilized, however, the MF waiver could be broadened to encompass more people. Many of the parents that we brought in for input did not qualify under the medically fragile waiver as was too restrictive.

The DD waiver narrowly defined for those with an intellectual disability, when we know many who do have a developmental disability but not the ID diagnosis are often going unassisted.

All of the current data indicates the needs for families growing and the increase of children identified with a developmental disability is increasing.

The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) found that 17% of children aged 3–17 years had a developmental disability. I could not locate information beyond that to identify fully who those children are beyond 2017. About 1 in 6 (17%) children aged 3–17 years were diagnosed with a developmental disability, as reported by parents.

Family Voices of ND has always followed the HRSA Maternal and Child Health Bureau of children with special health care needs which is: Children and youth with special health care needs (CYSHCN) are those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.

An estimated 13.5 million children in this country, or approximately 20% of U.S. children under age 18 years of age, have a special health care need. CYSHCN and their families often need services from multiple systems - health care, public health, education, mental health, and social services.

Included below is data from the National Data Resource Center.

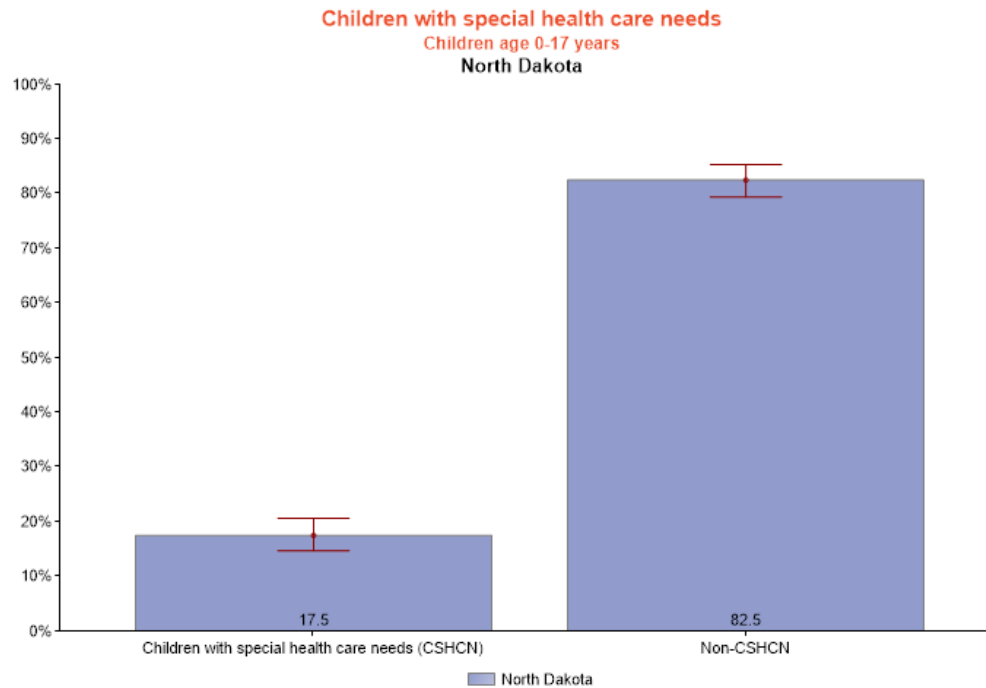
The Data Resource Center is a national center assisting in the design, development, documentation and public dissemination of user friendly information about, data findings on and datasets and codebooks for the National Survey of Children's Health (NSCH). Since its initial design in 2001, the NSCH (first fielding in 2003) has been supported and led by the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA/MCHB). <https://www.childhealthdata.org/>

According to the Data Resource Center we have 30,244 children and youth with special health care needs in ND.

Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



	Children with special health care needs (CSHCN)	Non-CSHCN	Total %
%	17.5	82.5	100.0
C.I.	14.7 - 20.6	79.4 - 85.3	
Sample Count	245	932	
Pop. Est.	30,244	142,966	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.			



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

I fully support a study that would look at all of the options that families have currently. What happens to those families who may have a child with cerebral palsy, spina bifida, Down Syndrome who have significant challenges but do not have the level of ID to receive services. Families are struggling and have few options. Nor is the system so well built that families know where to go, whom to ask and where are services provided.

It would be helpful to review the federal definition of developmental disabilities and the state definition through century code. Can we create a system without putting a child in a box, one that meets the needs of the child? After a child in early intervention turns 3, do we know how many 3-21 utilize the DD waiver?

By and large what families need is the access to Medicaid. Medicaid is an essential program for children and youth with special health care needs. Its benefits should serve as a model for all children and youth needing specialized health care services, whether publicly or privately funded.

Children and youth with special health care needs are a small but significant part of our state's population of children. Though not well understood by many health plans, nevertheless their experiences are reflections of how well our health systems are performing, and should be monitored carefully.

For some children and youth whose primary health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential. Additionally, children and youth with special health care needs require flexibility in health care plans such as streamlined procedures for getting specialty care and care coordination or case management.

Parents want and need clear information from private and public health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child's needs. Who is explaining this to families?

Families face a very confusing maze of services from health plans, school systems, state agencies and private agencies that are not well coordinated. This leaves families with an overwhelming roller coaster of emotions. It is much too often left to families to figure out who will provide and pay for services such as physical, occupational, speech, and mental health therapies. Payment responsibility needs to be clarified among all the multiple possible payers so that children are not left un-served while agencies and programs try to decide who will pay for what. Additionally families need and require complete unbiased information to make informed decisions.

Many families provide large amounts of complicated health care for their children at home, and need more support than they now receive. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts. Children with health conditions that are unstable and severe, have needs that are not well met by the present approaches of health plans, government programs, and community agencies.

Equally important for a study is the families' voice. This needs to be assured as an equal team player at advisory meetings, committees, policy making etc. in order to build a comprehensive system of care for children and youth with special health care needs.

The only way to assure that we are looking at all services to families is to complete a full study. Prevalence data is showing us that the needs and numbers diagnosed continues to rise. Let's be proactive and address the needs of the most vulnerable families in the state.

Please pass SB2256

Below I have pulled some data, which I hope you review. I believe it gives a better understanding of needs for our most vulnerable families.

Thank you for your consideration.

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


Of the 32,000 children and youth above we know that nearly 24,000 have one or more functional difficulties.

Indicator 1.10: Does this child have one or more functional difficulties from a list of 12 difficulties? 

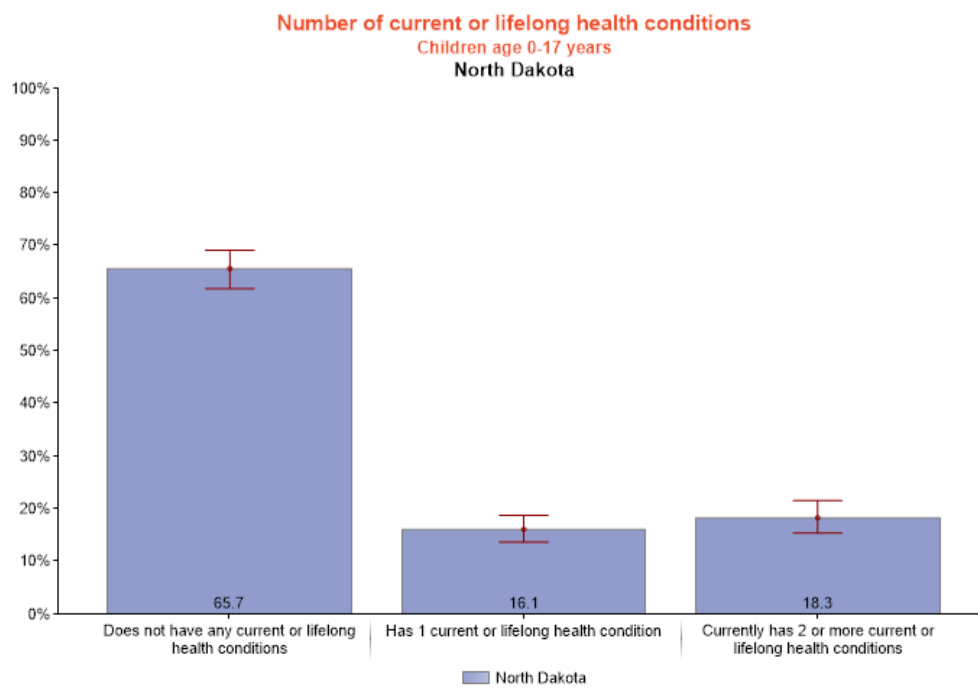
		Does not have any difficulties	One functional difficulty	Two or more functional difficulties	Total %
Children with special health care needs (CSHCN)	%	38.5	32.8	28.7	100.0
	C.I.	30.2 - 47.6	24.8 - 41.9	21.0 - 37.9	
	Sample Count	96	78	71	
	Pop. Est.	11,650	9,915	8,680	
Non-CSHCN	%	83.3	10.4	6.3	100.0
	C.I.	79.6 - 86.4	8.1 - 13.3	4.2 - 9.2	
	Sample Count	793	101	37	
	Pop. Est.	118,932	14,894	8,944	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.					

DATA ALERT: CSHCN status is determined using a validated instrument for identification of children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer. For more information, email info@cahmi.org.

That 27,838 have one lifelong health condition and 31,648 have 2 or more lifelong conditions.

Indicator 1.9: Does this child have current or lifelong health conditions from a list of 27 (2018) or 26 (2019) conditions? 

	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Currently has 2 or more current or lifelong health conditions	Total %
%	65.7	16.1	18.3	100.0
C.I.	61.9 - 69.2	13.7 - 18.8	15.4 - 21.6	
Sample Count	732	214	231	
Pop. Est.	113,724	27,838	31,648	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.				



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

The number of children with special health care needs by FPL


Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
Household income 0-99% FPL	%	22.4	77.6	100.0
	C.I.	13.6 - 34.8	65.2 - 86.4	
	Sample Count	24	64	
	Pop. Est.	4,982	17,213	
Household income 100-199% FPL	%	18.1	81.9	100.0
	C.I.	11.5 - 27.2	72.8 - 88.5	
	Sample Count	35	114	
	Pop. Est.	6,006	27,181	
Household income 200-399% FPL	%	19.6	80.4	100.0
	C.I.	14.9 - 25.2	74.8 - 85.1	
	Sample Count	91	339	
	Pop. Est.	11,528	47,404	
Household income 400% FPL or greater	%	13.1	86.9	100.0
	C.I.	10.2 - 16.8	83.2 - 89.8	
	Sample Count	95	415	
	Pop. Est.	7,728	51,168	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

 Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable. For more information about the data suppression and display criteria [click here](#).

Number of families served through both public and private means.

Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



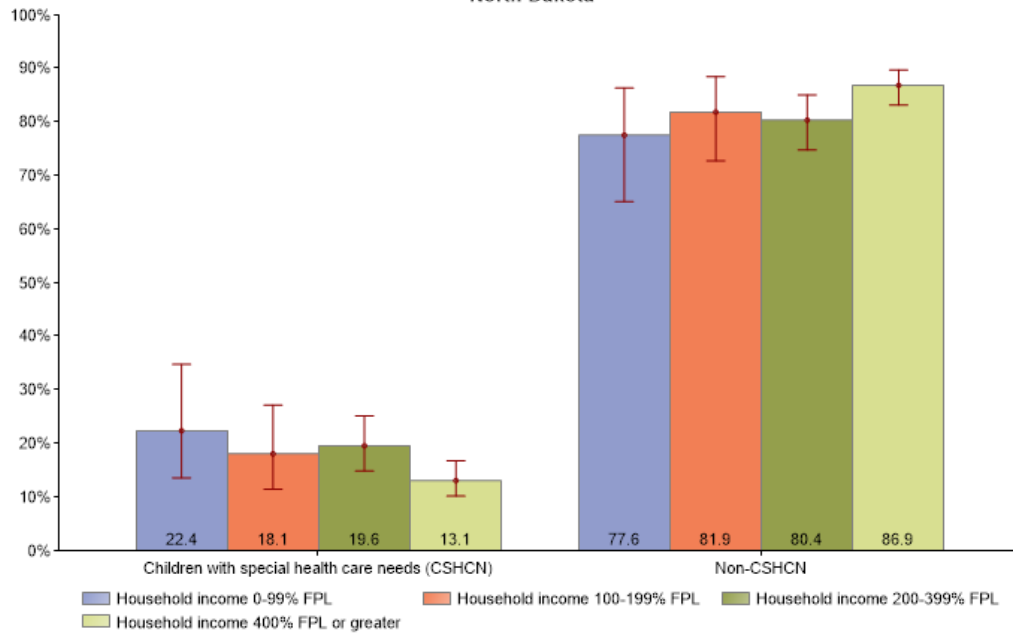
		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
Public health insurance only	%	32.4	67.6	100.0
	C.I.	20.8 - 46.6	53.4 - 79.2	
	Sample Count	31	49	
	Pop. Est.	7,492	15,640	
Private health insurance only	%	12.6	87.4	100.0
	C.I.	10.4 - 15.3	84.7 - 89.6	
	Sample Count	171	807	
	Pop. Est.	16,287	112,510	
Public and private insurance	%	52.4	47.6	100.0
	C.I.	33.5 - 70.6	29.4 - 66.5	
	Sample Count	31	20	
	Pop. Est.	3,956	3,595	
Currently uninsured	%	21.7	78.3	100.0
	C.I.	9.8 - 41.2	58.8 - 90.2	
	Sample Count	11	44	
	Pop. Est.	2,466	8,918	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable. For more information about the data suppression and display criteria [click here](#).

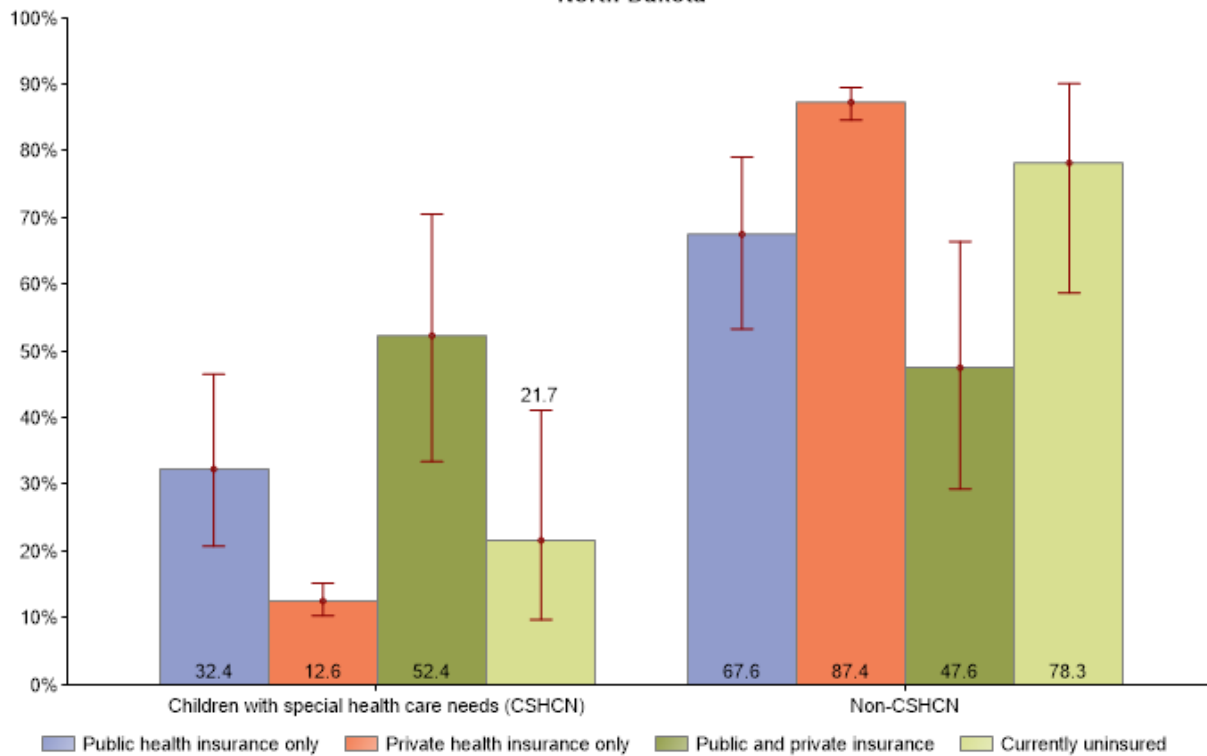
Children with special health care needs
 Children age 0-17 years
 North Dakota



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

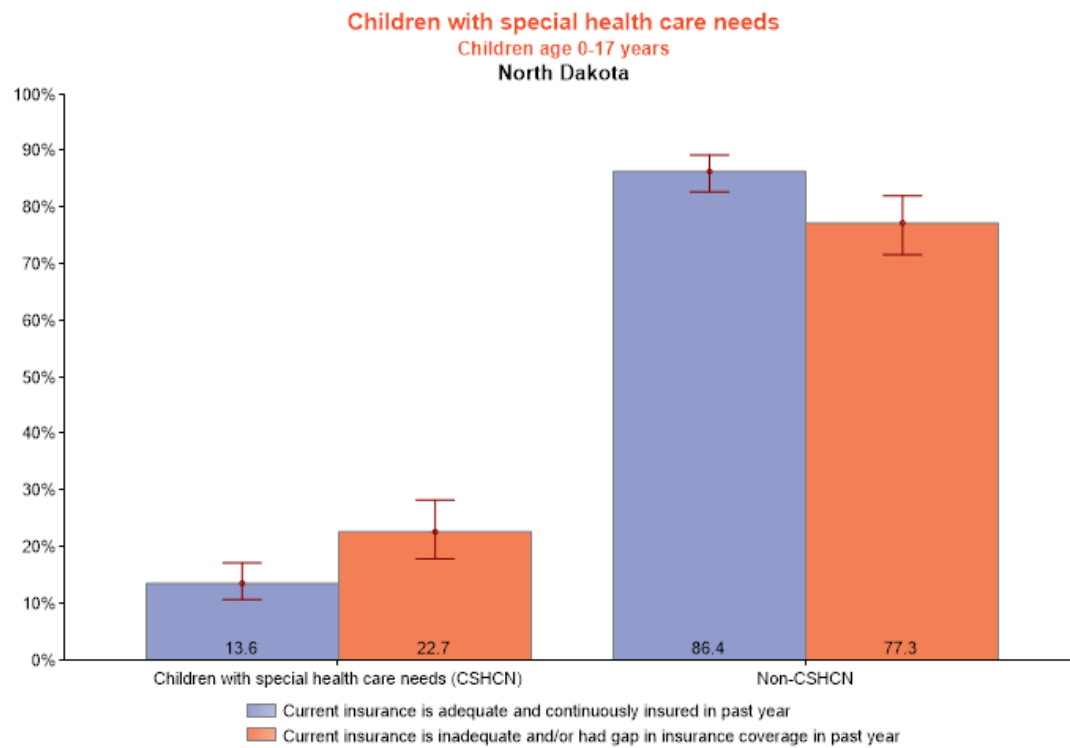
Children with special health care needs
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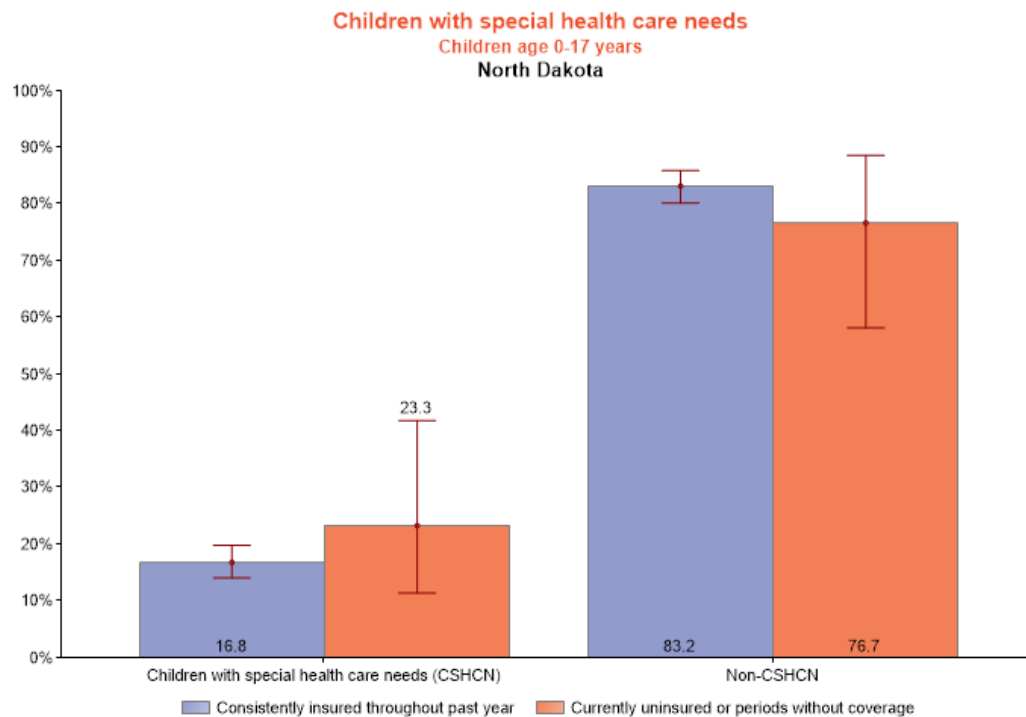
Percent of children served who's had adequate and inadequate coverage.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

Number of children with special health care needs continuously covered. I find this diagram a bit alarming.

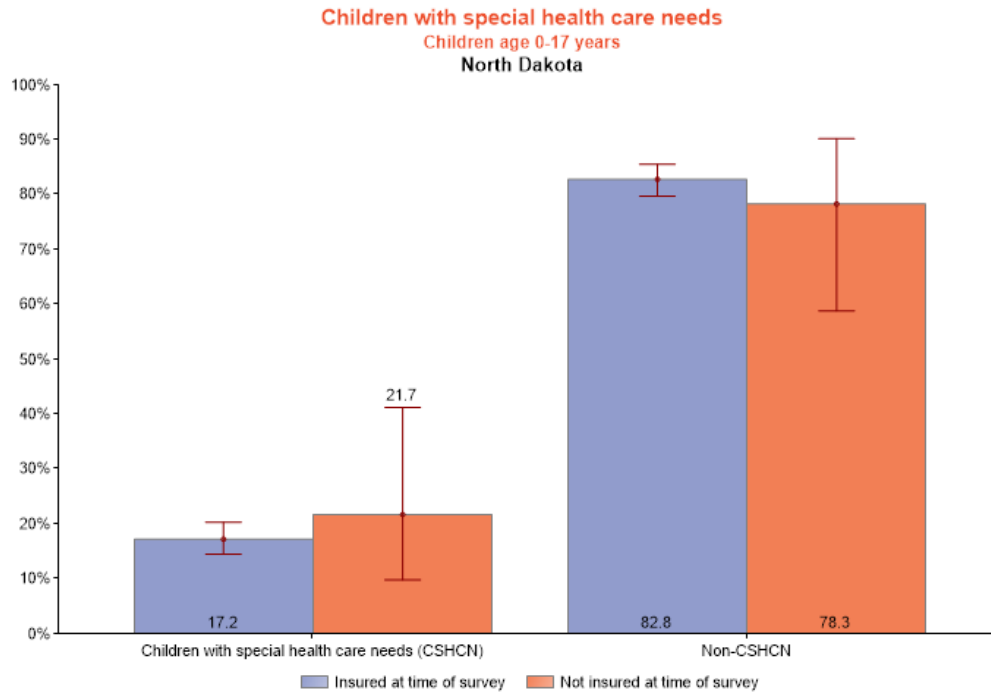


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Those children with a special health care need insured and uninsured

DATA ALERT: Children who are covered only by the Indian Health Service or a health care sharing ministry are considered as "not insured at time of survey".

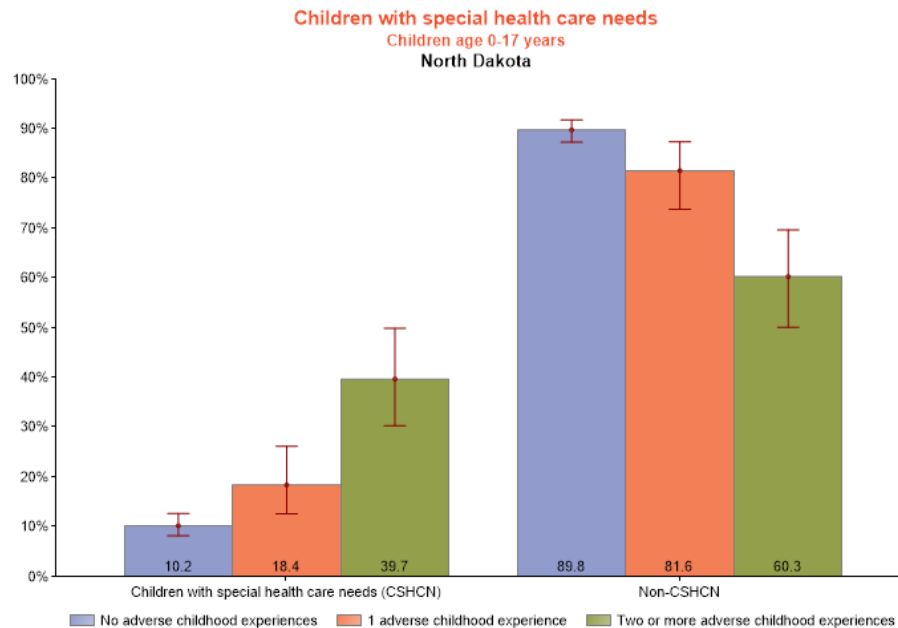


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The number of ND children affected by ACE's. I present this data simply because we know that many of our children with special health care needs experience significant trauma. Every time they go to a medical procedure they may feel the affect of trauma which may result in co-occurring conditions with health and behaviroal health.

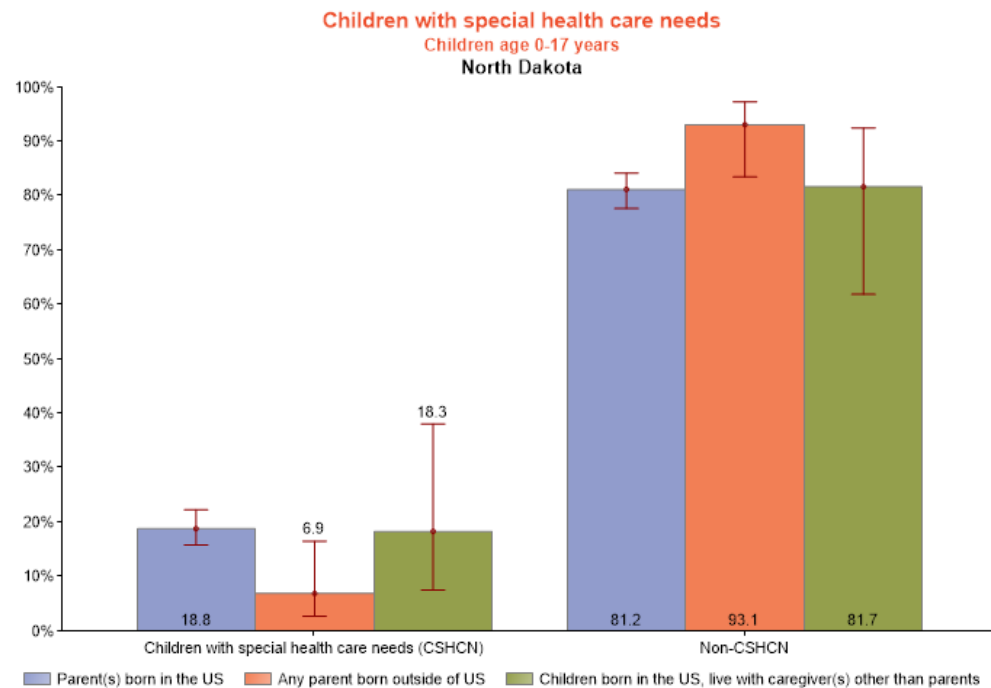
DATA ALERT: This ACEs subgroup includes 9 ACEs items: hard to cover basics on family's income; parent/guardian divorced or separated; parent/guardian died; parent/guardian served time in jail; saw or heard parents/adults slap, hit, kick, punch one another in the home; was a victim of or witnessed violence in neighborhood; lived with anyone who was mentally ill, suicidal, or severely depressed; lived with anyone who had a problem with alcohol/drugs; and treated or judged unfairly due to race/ethnicity.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

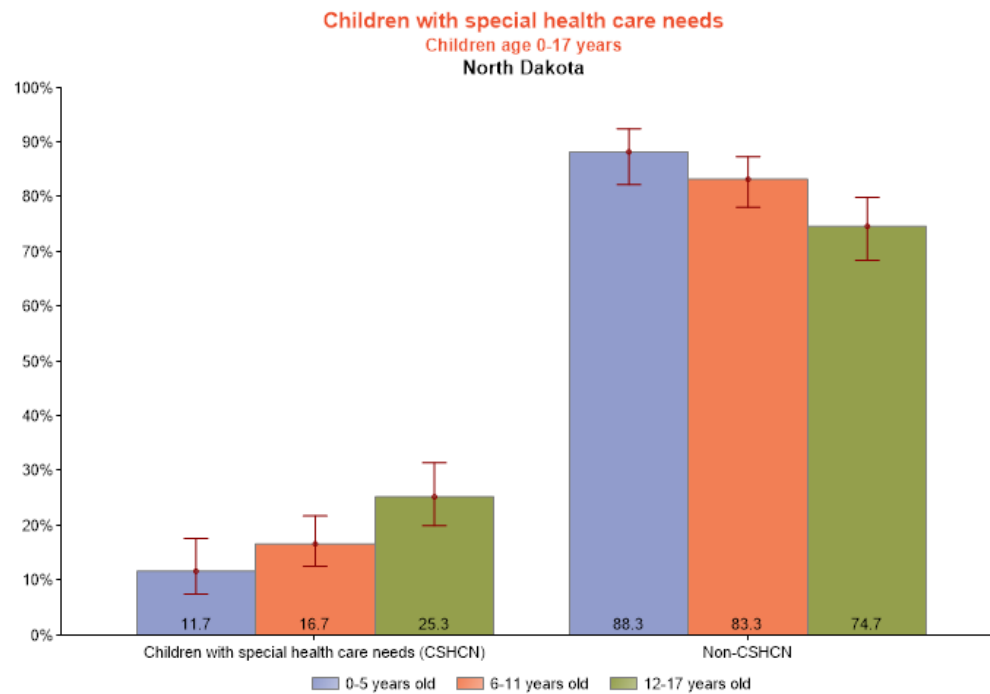
ND demographics. Of concern here is the increasing number of children being raised by someone other than their parent is alarming. That may mean a grandparent, sibling, foster care, who may or may not have the means if the child does not have access to services.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [\[www.childhealthdata.org\]](http://www.childhealthdata.org).

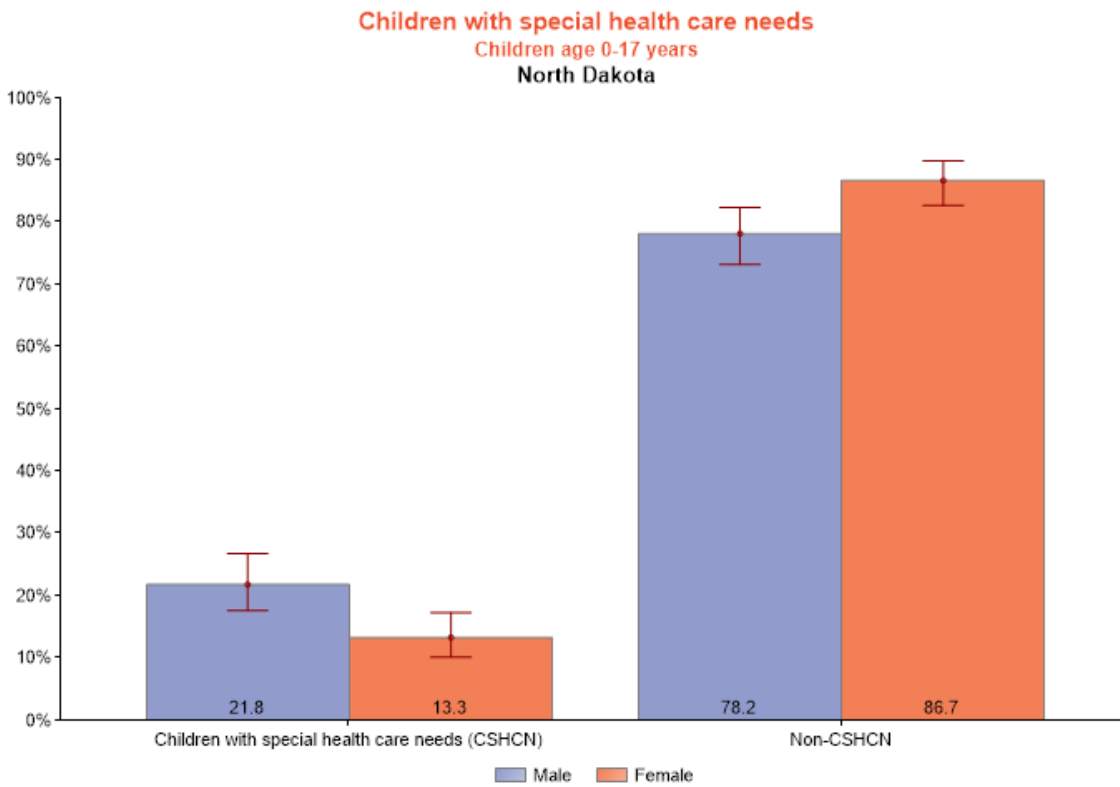
Breakdown by age of the percent of children in each age category



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

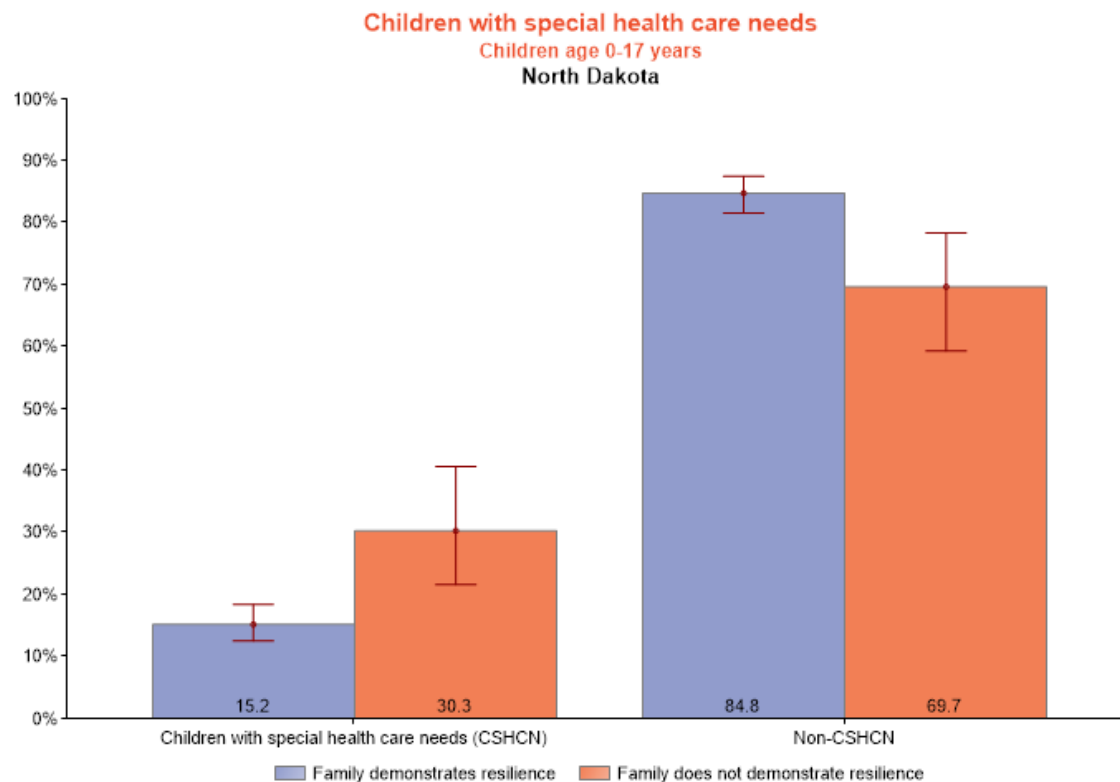
Number of children by male/female



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

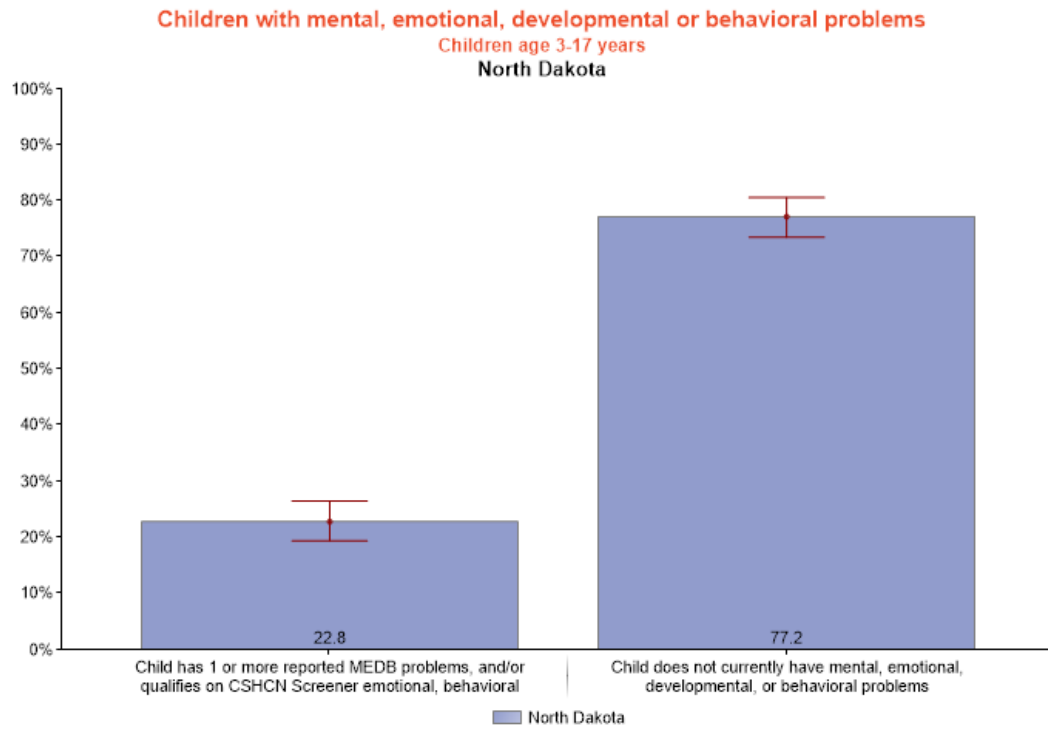
Percent of families who are able to demonstrate resilience. This is also a concerning number and we are seeing this with many of the families we serve. The needs are so vast for families and given the pandemic, that has also increased.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

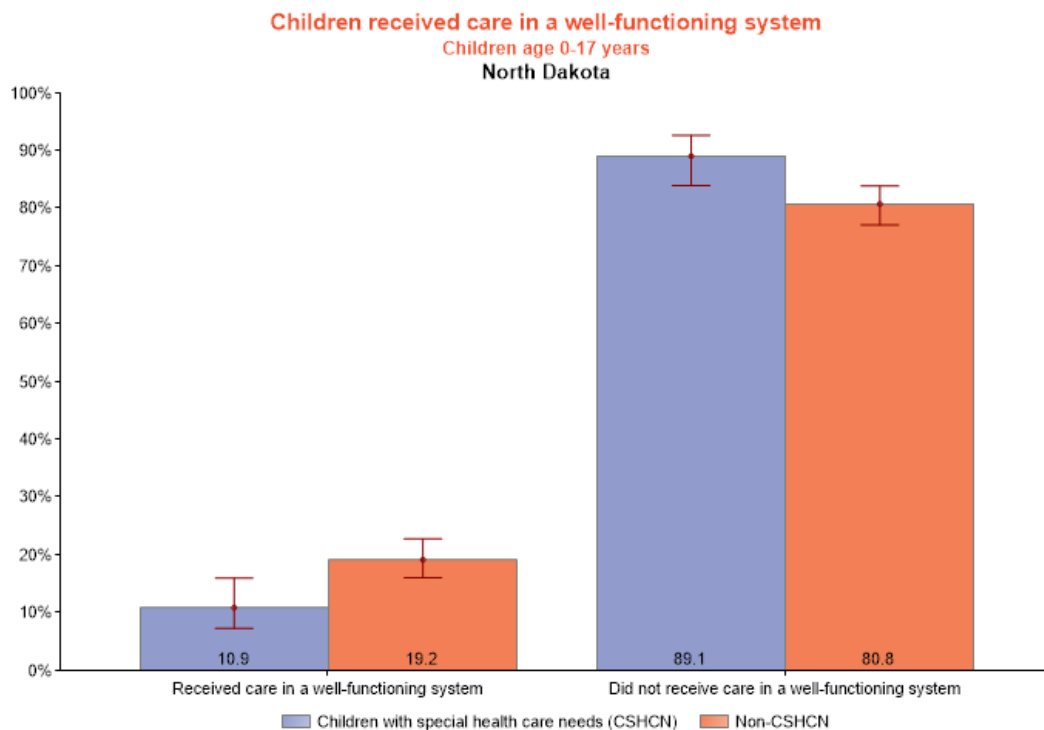
Percent of children with emotional, developmental or behavior problems.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

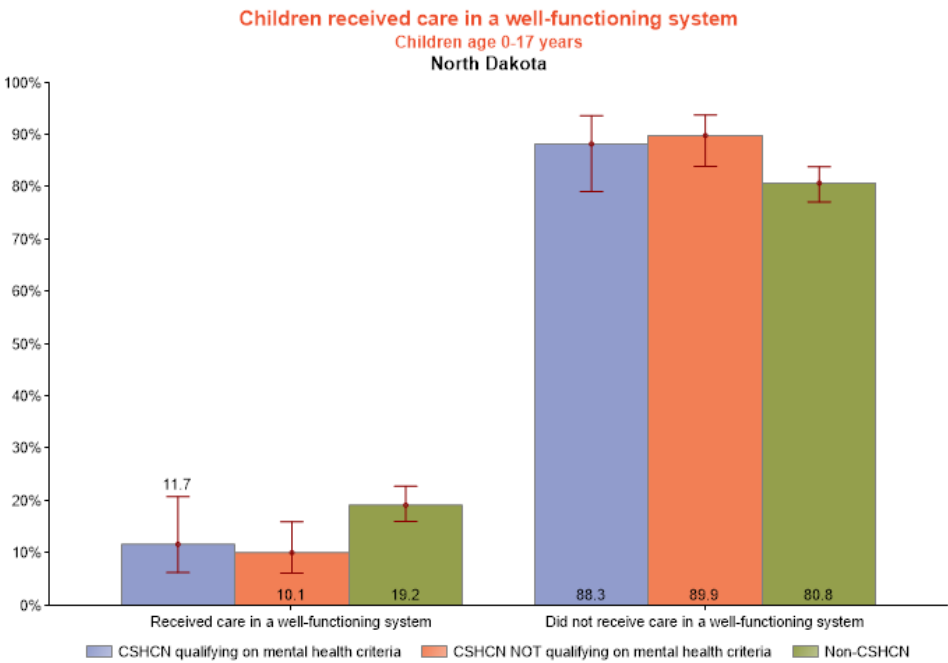
The next 3 slides are the percent of children who receive care in a well-functioning system. To me this is also some troublesome data.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

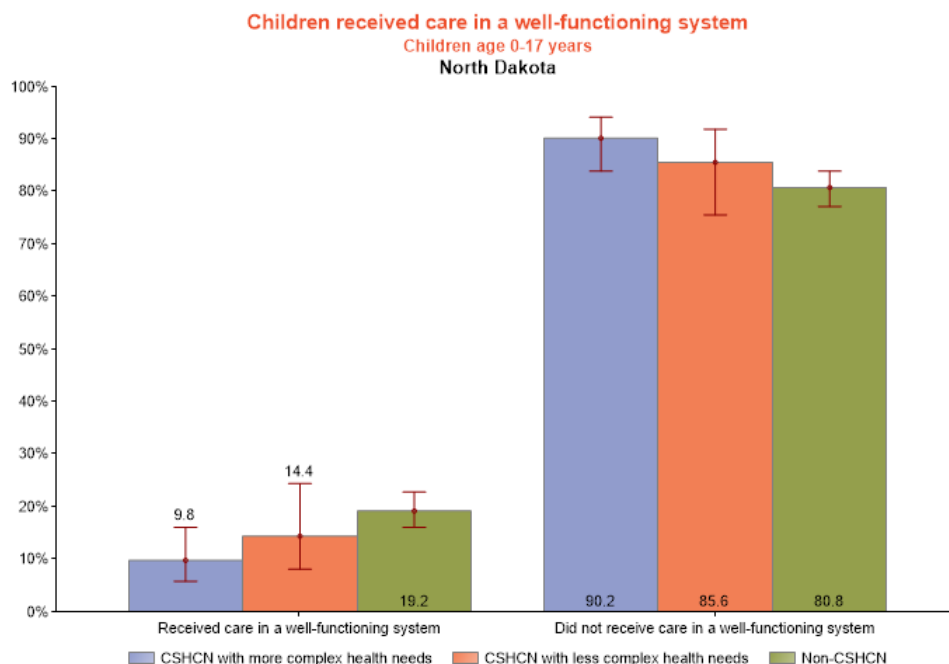
DATA ALERT: Children with ongoing emotional, behavioral or developmental problems for which treatment or counseling is needed are identified by the answers to two questions on the validated CSHCN Screener. For more information, email info@cahmi.org.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

DATA ALERT: CSHCN status is determined using a validated instrument for identification of children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer. For more information, email info@cahmi.org.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

National Performance Measure 12: Percent of adolescents with special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care i

	Received services necessary for transition to adult health care	Did not receive services necessary for transition to adult health care	Total %
%	26.1	73.9	100.0
C.I.	17.5 - 37.2	62.8 - 82.5	
Sample Count	39	88	
Pop. Est.	3,271	9,241	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Carl Young
Family Services Network Inc.
Executive Director
Lobbyist Badge Number 136
Bismarck, ND 58504
7012143152
carl@ndctn.org

January 26, 2021

Senators,

|

I would like to urge you to approve SB 2256.

My name is Carl Young, I am the executive director of Family Services Network, Inc., an organization that supports families of children born substance exposed to drugs or alcohol. All of the families that we currently work with are foster adopt. Meaning that the children were in some type of foster living situation at one point in their lives.

Currently, at the national level, according to the National Organization on Fetal Alcohol Syndrome, approximately 1 in 20 children are living with Fetal Alcohol Syndrome. Most of those are undiagnosed. However, the number may not be accurate due to shame the birth parent might feel for causing their child's condition through substance abuse or alcohol intake.

This study gets to the heart of the matter, of the families that I work with, three have applied to the Department of Human Services and been denied because the child's intellect quotient is too high.

The family in Watford City that wants their little boy to just be able to attend school with the supports that he needs.

The family in Pembina that wants their daughter to be able to have supports so that she can be successful in her school and after-school activities.

The family in Fargo that wants their daughter to get the services and supports that she needs to make proper decisions that aren't destructive.

The family in Bismarck whose now adult son is currently in jail owing in part to the fact that he was denied the support that he needed to make decisions.

I'd like to talk more about the Bismarck family. The son came to his family when he was 18 months old. From the age of 7, the family sought care, both in state and out of state for their son. Diagnoses ranged from oppositional defiant disorder, to obsessive compulsive disorder. From Autism to pediatric Bipolar. From Reactive Attachment Disorder to Fetal Alcohol and Neonatal Abstinence Syndrome.

At present he has the following diagnoses: Oppositional Defiant Disorder, Reactive Attachment Disorder, Fetal Alcohol Spectrum Disorder and Autism Spectrum Disorders.

When he was 15 the family took him to see Dr. Larry Burd at the University of North Dakota's Fetal Alcohol Clinic. Armed with medical records, facility records and police reports, they sought answers. This is where and when they received the diagnosis of Fetal Alcohol.

Fetal Alcohol Spectrum Disorders are caused by as little as one ounce of alcohol in the first trimester, though it can affect brain development at any stage of the pregnancy. Specifically touching those sections of the brain that control cognition. It does this by immediately crossing the placenta upon introduction to the blood stream.

Though all areas of the brain are important we will focus on one. The Frontal Lobe. Here is where executive function takes place. The ability to apply logic and reason. Self-control lives here. Inhibition lives here.

One example of how executive function works likened it to Air Traffic Control. The tower (executive function) tells the person that what they are about to do might not be a good idea.

Without the tower, the right things can still happen, but they are less likely to be successful.

How does this apply to the family from Bismarck?

In 2016 they applied for Developmental Disability Services at WCHSC. They were approved and then a week later denied. The claim for denial was that the intellect quotient was too high.

The decision was appealed to Administrative Law where it was upheld.

During this period the family learned how the decision is made. The son met all of the criteria for services except one, which was a Progress Assessment Review done in a program called Therap. The decision that can be returned here is Y. N. or P. Yes, No, or Professional Judgement.

The son came back as a P. The decision to deny was based on testing that the family didn't know about and never authorized. His intellect quotient was 85.

He qualified in all other areas mandated by state and federal law.

During the administrative hearing, the social worker for the state had to explain why they use the process that they do. Their repeated response to questioning? "That's the way we have always done it."

State and Federal Law do not use intellect quotient as a determining factor in developmental disability cases.

The son, as I stated, is now in jail awaiting trial for Criminal Conspiracy, Criminal Mischief, minor in consumption, minor in possession. He has had charges of unlawful use of a vehicle, breaking and entering, theft, minor in possession with intent, criminal trespass, and a host of other crimes. He has been involved with the justice system both as a juvenile and as an adult.

He has been homeless.

We have been told that he now qualifies for developmental disability services, though with Covid-19 and his criminal record he has been unable to get the services he needs.

His story is one of many I could share, in the interest of time, I will share one more fact about his life.

He is my son.

Please support this study so that we can ensure that the department is following state and federal law when determining DD eligibility.

Thank you and I'd be happy to answer any questions.

Carl Young

Testimony
Senate Bill 2256 - Department of Human Services
Senate Human Services Committee
Senator Judy Lee, Chairman
January 26, 2021

Chairman Lee, and members of the Senate Human Services Committee, I am Jonathan Alm, an attorney with the Department of Human Services (Department). I appear before you in opposition of Senate Bill 2256.

Senate Bill 2256 instructs Legislative Management to identify changes that need to be made to the Department's Administrative Code and internal policies and protocols regarding section 1915(c) home and community-based services waiver for individuals with intellectual disabilities and developmental disabilities. The Department complies with the administrative rulemaking process outlined in chapter 28-32 of the North Dakota Century Code, receives a review from the Attorney General's Office as to the legality before final adoption, and the Department appears before the Administrative Rules Committee. The administrative rulemaking process requires the Department to provide notice, hold a public hearing, and consider comments on the rules. This statutory process allows anyone to participate in the Department's rulemaking process.

The legislative body has delegated the authority, pursuant to section 28-32-02 of the North Dakota Century Code, to an administrative agency to adopt rules. In addition, the Department has statutory authority to create rules as set forth in section 25-01.2-18 of the North Dakota Century Code. Section 28-32-02 of the North Dakota Century Code also sets forth that the legislative assembly reserves to itself the authority to determine when and if rules of administrative agencies are effective. The Administrative Rules Committee has the authority to object, void, or amend a rule following the process outlined in chapter 28-32 of the North Dakota Century Code. Senate Bill 2256 does not follow the process set forth in chapter 28-32 of the North Dakota Century Code regarding an agency's administrative rules.

In addition, an individual that has been denied or revoked a service or benefit has a right to appeal the Department's decision. The appeal is heard by the Office of Administrative Hearings and an administrative law judge issues a recommended findings and proposed order. If the individual still disagrees with the Department's decision, the individual can appeal the decision to the district court.

Finally, any changes to the administrative rules, policies, and protocols must comply with federal and state laws and regulations, and the Department must have the appropriate appropriation for such changes.

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

Chairmen Senator Judy Lee and Committee Members,

Thank you for the opportunity to present written testimony in support of Senate Bill 2256. 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. I am also the Director of the North Dakota Fetal Alcohol Syndrome Center. We provide diagnostic and management services for people with Fetal Alcohol Spectrum Disorder (FASD) from North Dakota.

I am in support of classifying FASD as a developmental disability. Alcohol exposure results in highly variable outcomes and only some people who are exposed will meet criteria for FASD. The most common problem from prenatal alcohol exposure is damage to the developing brain of the fetus.

People with FASD are born with a developmental disability. The condition will impact them over the course of their life. People with FASD require services similar to other developmental disabilities such as autism, cerebral palsy, intellectual disability, and traumatic brain injury. People with FASD have many similar needs over their life and respond favorably to services from developmental disability services. In my opinion, the services provided by developmental disabilities is the optimal mix of services for people with FASD.

Developmental disabilities are certainly not the only service required by people with FASD. They also need early intervention, special education, and mental health services. They have multiple chronic health conditions which require ongoing management. These include a fourfold increase in mortality over their lifespan, a 24 fold increase in risk for intellectual disability, and extremely high rates of placement in foster care (often in multiple foster homes). They are also 19 times more likely to be involved in the juvenile corrections system.

Currently, it is very difficult for people with FASD to obtain services from developmental disabilities. Their IQ is often too high to meet the requirements of the current developmental disability's eligibility requirements. While their IQ may exceed the levels currently used in evaluating people for developmental disabilities, their adaptive behavior scores are frequently far more impaired than their IQ. We have found that adaptive behavior testing is a more useful measure of their potential for achievement, capacity for independent living and employment, than IQ.

Without appropriate services they are more likely to develop problems which involve them in the legal system which typically results in a spiral of problems that make them especially susceptible to additional contact with the legal system. People with FASD are especially vulnerable to victimization, exploitation, and development of substance use disorders.

My experience over the past 40 years has demonstrated that when people with FASD receive services from developmental disabilities, their annual cost of care is reduced and they have very low rates of incarceration and decreased rates of development of substance use disorders.

In my opinion, developmental disabilities services are the optimal service provider for people with FASD. Several other states including Alaska, Minnesota, and Colorado are increasing access to developmental disabilities services for people with FASD. I would like to encourage passage of this legislation to allow optimal planning for how to best serve the people of North Dakota with FASD across their lifespan.

Thank you for consideration of my comments.



SB 2256
Senate Human Services
Tuesday, January 26, 2021

Chairman Lee and Members of the Senate Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 260 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

We are keenly aware that public supports for our individuals living with Down syndrome and their families are key to their ability to live with dignity and quality in our schools, homes, and communities. Needing public supports is never easy and our individuals and families are grateful for the assistance they get. One of the many questions I'm asked when I meet a family who is expecting a new baby with Down syndrome is "How will I be able to afford this?" Understanding that they have partners both publicly and privately gives them confidence that they will be able to move forward in raising a child with Down syndrome. My husband and I faced the same news 22 years ago as we found ourselves expecting our daughter, Elizabeth. It brought us great peace to know that we would not be facing someone at delivery telling us her only option was placement in the institution and that, in fact, we were confident that there were great supports waiting for her in the ND Part C Early Intervention system, Bismarck Public Schools and along the rest of her journey.

I am here today to ask your assistance to make the path even smoother for families that find themselves caring for a loved one with a special health care need or a disability like Down syndrome. We have some solid public services in ND and we have some gaps. I see them when I'm trying to assist families with navigating our system of supports.

In the past, you, the Legislature, have heard from parents who have children with Down syndrome, cerebral palsy, and other special health care needs that had amazing wrap-around services until age 3. As eligibility criteria changes, they were deemed no longer eligible for DD Program

Management, de-screened from the IID/DD 1915 (c) waiver and then had no way to access Medicaid, In-home supports, additional therapies, equipment or supplies, or behavioral health support.

I'm asking you to give SB 2256 a "do pass". The gap between our working eligibility processes for Developmental Disability services and our state definition of developmental disability is real. And it starts with children, the youngest of them being just shy of three years old.

I have stood before this committee and Appropriations to ask you for help in addressing the gaps in services for children that have Down syndrome and complex health conditions and find themselves falling off the Intellectual Disability/Developmental Disability (IID/DD) Waiver when they turn 3 years old. Advocates have gotten studies passed but the studies have not resulted in changes that address the issue. In the 65th session, \$500,000 was included in the Department's budget to partially address this issue, but as far as I know, the money was not used to address the gap.

In 2017, the National Association of State Directors of Developmental Disability Services (NASDDDS) was contracted to conduct a study. (<http://nd.gov/dhs/info/testimony/2017-2018-interim/human-services/2018-1-4-handout-nasddds-ta-recommendations-opportunities.pdf>) Entitled "Report to North Dakota: Eligibility, Service Array, and Person-Centered Practices: Observations and Recommendations for Consideration this report outlined recommendations for the state to consider. While there was legislative intent for the NASDDDS study to address eligibility for children, the report did little to further that effort. Very young children (under 3) continue to be subjected to standardized intelligence testing that can result in either false positive or false negative results and thus affecting the eligibility determination. No changes have occurred to address this.

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

Thank you for your time and I would take any questions.

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

SB2256
Senate Human Services Committee
January 26th, 2021

Senator Chairwoman Lee and Vice Chair Senator Roers and Members of the Senate Human Service Committee.

My name is Vicki Peterson, and I am here to testify in favor of Senate Bill 2256 for a study of the home and community-based services for individuals with intellectual disabilities and developmental disabilities.

I am a Family Consultant for Family Voices of ND and I work with families who have children and youth with disabilities and special health care needs. A big part of my job is to help families navigate systems of care. Currently in ND, the term of Intellectual Disability is a very narrowly defined and for many who have been found eligible as having a Developmental Disability, are not found eligible for the Developmental Disability Waiver on the fact that an Intellectual Disability does not present as clearly as it may for others. These same people, many, the federal programs, such as SSA, do define as having a Developmental Disability. There seems to be a discrepancy in defining the term Developmental Disability.

Over the years that I have helped families navigate systems, I have supported families who have children that have had diagnosis of Developmental Disability but do not meet the eligibility criteria for the DD wavier in this state. We have a system of silos and the silos are not meeting the needs of children and our state. I believe a study will help lawmakers make better options for families, increase the productivity in our young children and youth to succeed and families have access to support. I believe ND can do a better job; I believe in ND we can find the ways to do so.

Some of the hardest conversations I have had with parents is *"I was told my child has a developmental disability, but my child is too smart"*. Those are times I do not have much in my toolbox to say.

I support the study so that we can support all children with disabilities in a system of care that looks at the child as a whole and the needs not just what a child my score for an intellectual disability.

Thank you for your time and consideration.

Vicki L Peterson
Family Voices of ND
vickiasdc@bis.midco.net
701-258-2237
701-527-2889

Senate Bill 2256

Senate Human Services

January 26, 2021

Madam Chair and members of the Senate Human Services,

I am Sammantha Peterson, a North Dakota parent of a child with cerebral palsy. I am giving testimony today, to ask you to recommend a do pass on Senate Bill 2256.

My daughter is among many others in the state who has a significant physical disability and does not qualify for any of the existing waivers. My daughter is beautiful, sweet, and smart. She is also a wheelchair user and needs assistance with the most basic of care. Without access to the Developmental Delay (DD) waiver, our family goes without much needed services. My daughter does not have an intellectual disability severe enough to qualify for the waiver based on its current verbiage. Yet she spends 4 or more hours in physical and occupational therapy each week. She sees a team of specialists too long to list. She has undergone complex surgeries that have hospitalized her for weeks at a time and intense rehab afterwards. During her hip and foot surgery at the end of 2017, I spent 22 straight days in my home caring for her full time.

Like any other disability or chronic health condition, a child with cerebral palsy needs access to safe and reliable care. She needs expensive home modifications, assistive technology, vehicle modifications, and so forth. Without access to the waiver, our family struggles to afford these things out of pocket. I truly feel that this holds my daughter back. She could do so much more if she just had the accessibility to do so. This also hinders my ability to have full time employment. As much as I love my daughter and will always take care of her, surviving on one income in our current economy is difficult. These children deserve not only a study, but a true evaluation and action. It is long overdue, and our families need your help.

Thank you so much for your time,

Sammantha Peterson

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Lincoln, ND 58504

605-490-0975

sammanthapeterson@hotmail.com

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee Sakakawea Room, State Capitol

SB 2256
2/1/2021

A BILL for an Act to provide for a legislative management study of the state's home and community-based services waiver for individuals with intellectual disabilities and developmental disabilities.

Madam Chair Lee opened the discussion on SB 2256 at 3:03 p.m. Members present: Lee, K. Roers, Hogan, Anderson, Clemens. Absent: O. Larsen.

Discussion Topics:

- Autism waiver and voucher

[3:03] Jonathan Alm, Attorney, Department of Human Services. Provided committee with proposed amendment (testimony #5922) to provide for a study.

Senator Hogan moves to **ADOPT AMENDMENT** proposed by Jonathan Alm.

Senator Anderson seconded

Voice Vote – motion passed

Senator K. Roers moves **DO PASS, AS AMENDED, REREFFER TO APPROPRIATIONS.**

Senator Hogan seconded.

Senators	Vote
Senator Judy Lee	Y
Senator Kristin Roers	Y
Senator Howard C. Anderson, Jr.	Y
Senator David A. Clemens	Y
Senator Kathy Hogan	Y
Senator Oley Larsen	N

The motion passed 5-0-1

Senator Lee will carry SB 2256.

Additional written testimony: N/A

Madam Chair Lee closed the discussion on SB 2256 at 3:09 p.m.

Justin Velez, Committee Clerk

February 1, 2021

CS
211
1 of 1

PROPOSED AMENDMENTS TO SENATE BILL NO. 2256

Page 1, line 1, remove "home and"

Page 1, line 2, remove "community-based services waiver for individuals with intellectual disabilities and"

Page 1, line 3, replace "disabilities" with "services; and to provide an appropriation"

Page 1, line 5, remove "**HOME AND COMMUNITY-BASED SERVICES WAIVERS -**"

Page 1, line 6, after "**STUDY**" insert "**- DEVELOPMENTAL DISABILITIES SERVICES**"

Page 1, line 6, remove "identify"

Page 1, replace lines 7 through 13 with:

"study state and federal laws and regulations relating to the care and treatment of individuals with developmental disabilities.

1. The study must include a review of the following:
 - a. The state's existing programs to identify potential pathways for individuals who have a developmental disability but do not meet the eligibility criteria for existing programs;
 - b. Gap identification with programmatic recommendations identifying potential strategies to address the gaps, and potential federal and state funding sources;
 - c. Efforts and services offered by other states, including the planning and implementation process for any new programs; and
 - d. The impact of implementation and expanding of programs to address service gaps, including the number of individuals impacted, cost, and timeline for implementation.
2. The legislative management shall report its findings and recommendations, together with any legislation necessary to implement those recommendations, to the sixty-eighth legislative assembly.

SECTION 2. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$150,000, or so much of the sum as may be necessary, to the department of human services for the purpose of selecting a consultant to assist legislative management in the study related to the state's developmental services, for the biennium beginning July 1, 2021, and ending June 30, 2023."

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2256: Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (5 YEAS, 0 NAYS, 1 ABSENT AND NOT VOTING). SB 2256 was placed on the Sixth order on the calendar.

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Page 1, line 5, remove "**HOME AND COMMUNITY-BASED SERVICES WAIVERS -**"

Page 1, line 6, after "**STUDY**" insert "**- DEVELOPMENTAL DISABILITIES SERVICES**"

Page 1, line 6, remove "identify"

Page 1, replace lines 7 through 13 with:

"study state and federal laws and regulations relating to the care and treatment of individuals with developmental disabilities.

1. The study must include a review of the following:
 - a. North Dakota's existing programs to identify potential pathways for individuals who have a developmental disability but do not meet the eligibility criteria for existing programs;
 - b. Gap identification with programmatic recommendations, identifying potential strategies to address these gaps, and potential federal and state funding sources;
 - c. Efforts and services offered by other states, including the planning and implementation process for any new programs; and
 - d. The impact of implementation and expanding of programs to address service gaps, including the number of individuals impacted, cost, and timeline for implementation.
2. The legislative management shall report its findings and recommendations, together with any legislation necessary to implement those recommendations, to the sixty-eighth legislative assembly.
3. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriate, the sum of \$150,000, or so much of the sum as may be necessary, to the department of human services for the purpose of selecting a consultant to assist legislative

management in its study, for the biennium beginning July 1, 2021,
and ending June 30, 2023."

Renumber accordingly

2021 SENATE APPROPRIATIONS

SB 2256

2021 SENATE STANDING COMMITTEE MINUTES

Appropriations Committee Roughrider Room, State Capitol

SB 2256
2/8/2021
Senate Appropriations Committee

A BILL for an Act to provide for a legislative management study of the state's developmental services; and to provide an appropriation.

Chairman Holmberg opened the hearing at 9:30 a.m.

Senators present: **Holmberg, Krebsbach, Wanzek, Bekkedahl, Poolman, Erbele, Dever, Oehlke, Rust, Davison, Hogue, Sorvaag, Mathern, and Heckaman.** Senator Poolman was absent.

Discussion Topics:

- Concerns about the Amendments

Senator Dever, District 32, introduced the bill.

Roxane Romanick, Executive Director, North Dakota Designer Genes, testified neutrally.

Jonathan Alm, Attorney, Department of Human Services, testified in favor.

Senator Dever made a motion to DO PASS.

Senator Mathern seconded the motion.

<i>Senators</i>		<i>Senators</i>	
<i>Senator Holmberg</i>	N	<i>Senator Hogue</i>	Y
<i>Senator Krebsbach</i>	Y	<i>Senator Oehlke</i>	Y
<i>Senator Wanzek</i>	Y	<i>Senator Poolman</i>	A
<i>Senator Bekkedahl</i>	N	<i>Senator Rust</i>	Y
<i>Senator Davison</i>	Y	<i>Senator Sorvaag</i>	Y
<i>Senator Dever</i>	Y	<i>Senator Heckaman</i>	Y
<i>Senator Erbele</i>	N	<i>Senator Mathern</i>	Y

Motion Passes 10-3-1

Chairman Holmberg closed the hearing at 10:02 a.m.

Skyler Strand, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2256, as engrossed: Appropriations Committee (Sen. Holmberg, Chairman)
recommends **DO PASS** (10 YEAS, 3 NAYS, 1 ABSENT AND NOT VOTING).
Engrossed SB 2256 was placed on the Eleventh order on the calendar.

2021 HOUSE HUMAN SERVICES

SB 2256

2021 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee Pioneer Room, State Capitol

SB 2256
3/9/2021

To provide for a legislative management study of the state's developmental services; and to provide an appropriation

Chairman Weisz opened the committee hearing at 3:12 p.m.

Representatives	Attendance
Representative Robin Weisz	P
Representative Karen M. Rohr	P
Representative Mike Beltz	P
Representative Chuck Damschen	P
Representative Bill Devlin	P
Representative Gretchen Dobervich	P
Representative Clayton Fegley	P
Representative Dwight Kiefert	P
Representative Todd Porter	P
Representative Matthew Ruby	A
Representative Mary Schneider	P
Representative Kathy Skroch	P
Representative Bill Tveit	P
Representative Greg Westlind	P

Discussion Topics:

- Intellectual disabilities
- Cognitive impairments
- Developmental disability services

David Boeck, State Employee & Lawyer for Protection & Advocacy Project (3:15) testified in favor and submitted testimony #8369 & #9472.

Grace Peterson, Lincoln (3:21) testified in favor and submitted testimony #8155.

Sammantha Peterson, Lincoln (3:23) testified in favor and submitted testimony #8154.

Pamela Mack, Director Program Services Protection & Advocacy Project (3:27) testified in favor and submitted testimony #8308.

Roxane Romanick, Executive Director Designer Genes of North Dakota, Inc. (3:34) testified in favor and submitted testimony #8208.

Kirsten Dvorak, Executive Director The Arc of North Dakota (3:40) testified in favor and submitted testimony #8152.

Bruce Murry, Executive Director North Dakota Association Community Providers (3:42) testified in favor and submitted testimony #8311.

Sen. Dick Dever, District 32 (3:45) testified in favor and supported proposed amendments (bill sponsor).

Tina Bay, Division Director Human Services (3:49) testified in favor and submitted testimony #8094.

Donene Feist, Director Family Voices of North Dakota (3:50) testified in favor and submitted testimony #7661.

Additional written testimony: #8233

Chairman Weisz adjourned at 3:59 p.m.

Tamara Krause, Committee Clerk

House Human Services Committee
Sixty-Seventh Legislative Assembly of North Dakota
Senate Bill No. 2256
March 9, 2021

Good afternoon, Chairman Weisz and Members of the House Human Services Committee. I am David Boeck, a State employee and a lawyer for the Protection & Advocacy Project. The Protection & Advocacy Project is an independent state agency that acts to protect people with disabilities from abuse, neglect, and exploitation, and advocates for the disability-related rights of people with disabilities.

The original Senate Bill 2256 arose from concerns shared by numerous individuals with disabilities and members of several disability-related groups. After the Senate hearing, it was apparent that the original Senate Bill 2256 had not been worded to accurately express the intent of the involved individuals and disability-related groups.

The First Engrossment looks quite different from what had been intended. The Department of Human Services testified critically on the original bill. After inquiry, the Senate Human Services Committee invited the Department of Human Services to suggest amendments that would convert the bill to one the Department could support.

As more clearly stated in amendments being proposed, the study should focus on individuals with developmental disabilities, who do not have intellectual disabilities or cognitive impairments. These are

Exhibit A to Testimony of David Boeck, Protection & Advocacy Project

SB 2256 as it would look if the House accepts all amendments proposed by the Protection & Advocacy Project on behalf of the individuals and disability-related groups behind the original SB 2256

A BILL for an Act to provide for a legislative management study of the state's responsibility to ensure adequate treatment, services, and habilitation in the least restrictive settings for individuals who have developmental disabilities but who do not have cognitive impairments or intellectual disabilities; and to provide an appropriation.

BE IT ENACTED BY THE LEGISLATIVE ASSEMBLY OF NORTH DAKOTA
SECTION 1. LEGISLATIVE MANAGEMENT STUDY - DEVELOPMENTAL
DISABILITIES SERVICES.

During the 2021-22 interim, the legislative management shall study the state's responsibility to enable all individuals with developmental disabilities to receive appropriate treatment, services, and habilitation for those disabilities in the least restrictive appropriate settings, consistent with the legislative purpose in enacting section 2 of chapter 294 of the 1981 session laws, "rights of the

developmentally disabled," now codified at section 25-01.2-02 of the century code.

1. The study must include
 - a. The state's programs for individuals who have a developmental disability and developmental disability-related needs for treatment, services, or habilitation but who do not have a cognitive impairment or intellectual disability;
 - b. Recommendations for modifications to existing programs and development of any new programs to enable individuals with developmental disabilities who do not have cognitive impairments or intellectual disabilities to obtain appropriate treatment, services, and habilitation in the least restrictive settings;
 - c. Efforts undertaken and services offered by other states, for similar populations, including the planning and implementation process for modifications of current programs and any new programs;
 - d. The impact of providing appropriate treatment, services, and habilitation in the least restrictive

appropriate setting, arising from a well-designed expansion of current and development of new human services programs; including the number of individuals impacted, associated costs and timelines for implementation; and

2. The legislative management shall report its findings and recommendations, together with any legislation necessary to implement those recommendations, to the sixty-eighth legislative assembly.

SECTION 2. APPROPRIATION. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$100,000, or so much of the sum as may be necessary, to legislative management for the purpose of selecting a consultant to assist legislative management in the study related to the state's developmental services, for the biennium beginning July 1, 2021, and ending June 30, 2023.

Supplement to Testimony of David Boeck
Protection & Advocacy Project

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2256

Page 1, line 1: remove "developmental"

Page 1, line 2: replace "services" with "responsibility to ensure appropriate treatment, services, and habilitation in the least restrictive appropriate settings for individuals who have developmental disabilities but who do not have cognitive impairments or intellectual disabilities"

Page 1, line 5: remove "state and"

Page 1, line 6: replace "federal laws and regulations relating to the care and treatment of" with "the state's responsibility to enable all"

Page 1, line 7: after "disabilities" insert "to receive appropriate treatment, services, and habilitation for those disabilities in the least restrictive appropriate settings, consistent with the legislative intent in enacting section 2 of chapter 294 of the 1981 session laws, "rights of the developmentally disabled," now codified at section 25-01.2-02 of the century code"

Page 1, line 8: remove "a review of the following"

Page 1, line 9: remove "existing" and "to identify potential pathways"

Page 1, line 10: remove "a"

Page 1, line 10: replace "disability but" with "disabilities,"

Page 1, line 10: remove "meet the eligibility criteria for existing"

Page 1, line 11: replace "programs" with "have cognitive impairments or intellectual disabilities, and have developmental disability-related needs for appropriate treatment, services, or habilitation"

Page 1, line 12: remove "Gap identification with programmatic recommendations identifying potential"

Page 1, line 13: Replace "strategies to address the gaps" with "Recommendations for modifications to existing programs and development of any new programs to enable individuals with developmental disabilities who do not have cognitive impairments or intellectual disabilities to obtain appropriate treatment, services, and habilitation in the least restrictive appropriate settings"

Page 1, line 14: after "Efforts" insert "undertaken"

Supplement to Testimony of David Boeck
Protection & Advocacy Project

Page, line 14: after "states" insert "for similar populations"

Page 1, line 15: after "for", insert "modifications of current programs and"

Page 1, line 16: remove "implementation and expanding of programs to address service"

Page 1, line 17: replace "gaps" with "providing appropriate treatment, services, and habilitation in the least restrictive appropriate settings for individuals with developmental disabilities who do not have cognitive impairments or intellectual disabilities, through a well-designed expansion of current and development of new human services programs"

Page 1, line 23: replace "\$150,000" with "\$100,000"

Page 1, line 24: replace "the department of human services" with "the legislative management"

Page 2, line 1: remove "related to the state's developmental"

Page 2, line 2: before "services" insert "of the provision of appropriate treatment,

Page 2, line 11: after "services," insert "and habilitation in the least restrictive appropriate settings for individuals who have developmental disabilities and do not have cognitive impairments or intellectual disabilities"

My name is Grace Peterson. I am 10 ½ years old. I love to ride horses, swim, bake cupcakes, and play with slime. I have CP. I am going to be honest. CP sucks. It makes me sad because I can't do all of the things that my friends can do. It can be painful, and I sometimes I get really tired. I am standing here today with help to ask you for your help. Please vote do pass for kids like me.

Senate Bill 2256

House Human Services

March 9, 2021

Chairman Weisz and Members of the Committee,

I am Sammantha Peterson, a North Dakota parent of a child with cerebral palsy. I am giving testimony today, to ask you to recommend a do pass on Senate Bill 2256 with the amendments proposed today. My daughter is among many others in the state who has a significant physical disability and does not qualify for any of the existing waivers. My daughter is beautiful, sweet, and smart. She is also a wheelchair user and needs assistance with basic care. Without access to the Developmental Delay (DD) waiver, our family goes without much needed services. My daughter does not have an intellectual disability severe enough to qualify for the waiver based on its current verbiage. Yet she spends 4 or more hours in physical and occupational therapy each week. She sees a team of specialists too long to list. She has undergone complex surgeries that have hospitalized her for weeks at a time and intense rehab afterwards. For example, during her hip and foot surgery at the end of 2017, I spent 22 straight days in my home caring for her full time. Due to the casts on her legs and the weight of her body with the casts, we were unable to get her out of the home.

Like any other disability or chronic health condition, a child with cerebral palsy needs access to safe and reliable care. She needs expensive home modifications, assistive technology, vehicle modifications, and more. She could do so much more if she just had the accessibility to do so. This also hinders my own ability to have full time employment. As much as I love my daughter and will always take care of her, surviving on one income in our current economy is difficult. These children deserve not only a study, but a true evaluation and action. It is long overdue, and our families need your help.

Thank you so much for your time,

Sammantha Peterson

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House Human Services

Sixty-seventh Legislative Assembly of North Dakota

Senate Bill No. 2256

March 9, 2021

Good morning, Chairman Wiesz, and Members of the House Human Services Committee. I am Pam Mack, Director of Program Services for the Protection & Advocacy Project (P&A).

P&A is here today to support SB 2256 - a legislative management study of home and community-based waived services for individuals with Developmental Disabilities. NDCC § 25-01.2-01 and 42 U.S.C 15002(8) provide definitions for the term "developmental disability". NDCC § 25-01.2-02 further provides that "all individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting".

Currently, within our service delivery system and our current administrative rules (NDAC § 75-04-06), there is a narrowing of the scope of individuals to be served through the "Intellectual Disabilities – Developmental Disabilities Program Management Services" system to include, in some places, replacement of the term "developmental disabilities" with "intellectual disabilities". To be eligible for DD Program Management AND DD services, an individual must, amongst other things, be: 1) eligible for ND Medicaid; and 2) meet the Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care.

Currently, some individuals determined by DHS to have a developmental disability, but who are not able to be screened for ICF/IID,

receive Program Management Services only (using State General Funds). DHS' proposed budget for the 21-23 biennium removes the State funds, and therefore Program Management, for these individuals. I refer you to the attached hand-out from DHS, dated July 2019, which shows the process as a flow chart.

Moving on to the HCBS waiver, eligibility is based on screening with the ICF/IID level of care. Any waiver requires screening some type of institution (e.g., hospital, nursing home). The following is also included:

The State additionally limits the waiver to individuals with intellectual disabilities or individuals with related conditions (as defined in 42 CFR §435.1009) and cognitive impairment who meet the ICF/IID level of care (as defined in 42 CFR §440.150(a)(2)). Cognitive impairment means that a person performs significantly below appropriate age level in brain function (perception, attention, memory, motor, language, executive functioning), and the impairments are not severe enough to qualify as an intellectual disability.

State law gives DHS the authority to adopt rules (NDCC § 25-01.2-18). It specifically states, "the rules adopted may not restrict or limit the rights guaranteed by this chapter". What we have today is not congruent with NDCC § 25-01.2-02, which states that "all individuals with developmental disabilities have a right to appropriate treatment, services and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting".

Therefore, P&A supports a legislative management study to help sort this out.

If you have any questions or would like to contact me, you can reach me by e-mail at [**pmack@nd.gov**](mailto:pmack@nd.gov) or by phone at (701) 328-3975. Thank you for your consideration.

Process to Obtain Developmental Disabilities Program Management (DDPM) and DD Services

Step 1:

Contact your local Human Service Center: <http://www.nd.gov/dhs/locations/regionalhsc/>

Your inquiry will be provided to the DD Unit and they will arrange for an in-person meeting to gather information.

Step 2:

During the in-person meeting, the following will be addressed:

- Information about you and your needs
- Explanation of the eligibility criteria/process for both DDPM and DD services, Medicaid eligibility, role of the DDPM, and overview of DD services
- Complete an application, releases of information, and other necessary paperwork.
- Assist in obtaining or completing any necessary evaluations or information such as adaptive functioning, psychological testing, school records, speech, etc.
- Complete a screening assessment identifying current levels of functioning to determine level of care
 - If eligible, this assessment must be completed each year if you wish to continue to receive services

Step 3:

After all the necessary information is obtained, the Human Service Center will determine if you are eligible for DDPM and/or DD services using the information collected and screening assessment. A notice will be sent to you to let you know the results of the eligibility determination. If you are determined not eligible, you can request an appeal to have the decision reviewed.

- Eligibility for DDPM and DD services are 2 separate processes and you may be eligible for only DDPM or both DDPM and DD services. (see page 2)
- Eligibility may take up to 45 days, or longer if all the information is not available.
- **What is a DDPM?**

The DDPM is an employee of the State of North Dakota Department of Human Services located at one of the eight regional human service centers. The DDPM will help you locate, coordinate, provide information, and monitor supports and services with you, including natural and community supports.

Step 4:

If you are determined eligible for DDPM and/or DD services, you will choose among available DD services, will be referred to available DD providers of your choice, and can meet with any providers. Once an available provider(s) accepts your referral, you will choose the provider(s) to provide the service(s).

- Self-directed services are available and may be an option depending on your service needs.

Step 5:

The provider and the DDPM will help you identify family and/or other individuals who are important to you to be part of the planning team. You and your planning team will work together to evaluate your needs, goals, and develop a person-centered service plan (PCSP). The DDPM will review your plan to make sure it meets your needs.

- The PCSP must be updated each year or as needs change. You may request an update to your plan anytime by contacting your DDPM or provider.

Eligibility Determination Process for DDPM and DD Services

In order to be eligible for supports and services from the ND Department of Human Services Developmental Disabilities Division (DD Division) a person must:

- Be a resident of ND and meet Medicaid U.S. citizenship and alienage
- Be eligible for ND Medicaid (Determined by the local County Social Service office)
- Meet the criteria defined in law per North Dakota Administrative Code (NDAC) 75-04-06
<https://www.legis.nd.gov/information/acdata/pdf/75-04-06.pdf>
- Meet the Intermediate Care Facility for Individuals with Intellectual Disability (ICF/IID) level of care

Age 3 & Older

Eligibility Criteria:

- 1) Intellectual disability with a developmental disability;
- 2) Intellectual disability with no developmental disability but able to benefit from DD services; or
- 3) Related condition with a developmental disability and able to benefit from DD service

Developmental disability means a severe, chronic disability which is:

- Due to a mental and/or physical impairment, NOT mental illness;
- Age of onset occurred before age of 22;
- Likely to continue forever;
- Results in substantial functional limitations in 3 or more areas of major life activities; and
- Wide array of services from a broad variety of professionals needed

No

Not eligible for DDPM

STOP proceeding

Yes

Eligible for DDPM

Continue with
ICF/IID level of
care determination

Not Screenable

Not eligible for DD
services

STOP proceeding

Yes Screenable

Eligible for DD
services

Birth through Age 2

Eligibility Criteria:

- 1) 25% delay in 2 areas;
- 2) 50% delay in 1 area;
- 3) High risk of becoming developmentally delayed; or
- 4) Informed clinical opinion of becoming developmentally delayed

No

Not eligible for
DDPM

STOP
proceeding

Yes

Eligible for DDPM

Continue with
ICF/IID level of
care
determination

Not Screenable

Not eligible for
DD services

STOP proceeding

Yes Screenable

Eligible for DD
services

**SB 2256****House Human Services****Tuesday, March 9, 2021****Rep. Robin Weisz, Chairman**

Chairman Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I'm representing Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 260 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

We are keenly aware that public supports for our individuals living with Down syndrome and their families are key to their ability to live with dignity and quality in our schools, homes, and communities. Needing public supports is never easy and our individuals and families are grateful for the assistance they receive. One of the many questions I'm asked when I meet a family who is expecting a new baby with Down syndrome is "How will I be able to afford this?" Understanding that they have partners both publicly and privately gives them confidence that they will be able to move forward in raising a child with Down syndrome. My husband and I faced the same news 22 years ago as we found ourselves expecting our daughter, Elizabeth. It brought us great peace to know that we would not be facing someone at delivery telling us her only option was placement in an institution and that there were great supports waiting for her in the ND Part C Early Intervention system, Bismarck Public Schools and along the rest of her journey.

I am here today to ask your assistance to make the path even smoother for families that find themselves caring for a loved one with a special health care need or a disability like Down syndrome. We have some solid public services in ND but there are cracks where children and adults fall through because they don't meet the eligibility criteria that our state has designed. I see these cracks in my family support when I'm assisting families to navigate our system of supports.

In the past, you, the Legislature, have heard from parents who have children with Down syndrome, cerebral palsy, and other special health care needs that had a robust system of wrap-around

services until age 3. Annually, North Dakota serves roughly 3000 children and their families in our Part C Early Intervention program for infants and toddlers with delays and disabilities. We have maximized the use of the federal Medicaid match for this program, so close to 100% of the children can be eligible for state plan Medicaid as well as being screened to our Individuals with Intellectual Disabilities/Developmental Disabilities (IID/DD) 1915(c) Medicaid waiver. Children with conditions like Down syndrome are essentially automatically eligible for this program based on their diagnosis. At age 3 however, all of the children face more stringent eligibility criteria both for school-based special education services as well as continued support under the IID/DD waiver. While it is very appropriate for many of these children to find their delays mitigated, we have children whose special health care conditions continue and their needs don't stop. As eligibility criteria changes, they face being no longer eligible for Developmental Disabilities Program Management, de-screened from the IID/DD waiver and then have no way to access Medicaid, In-home supports, additional therapies, equipment or supplies, or behavioral health support. In the past, I have testified that this includes toddlers with Down syndrome.

I'm asking you to give SB 2256 a "do pass" with the proposed amendments. One example of why this study is needed is the stark differences between our working eligibility processes for Developmental Disability services and our state definition of developmental disability as found in NDCC 25-01.2-02. As I noted earlier, these differences leave young children at the age of 3 with physical disabilities, significant health issues, undiagnosable intellectual disabilities, and developmental delays without the supports that they were receiving the day before their third birthday.

In the past, advocates have gotten studies passed but the studies have not resulted in changes that address the issue. In the 65th session, \$500,000 was included in the Department's budget to partially address this issue, but as far as I know, the money was not used to address the gap. In 2017, the National Association of State Directors of Developmental Disability Services (NASDDDS) was contracted to conduct a study. (<http://nd.gov/dhs/info/testimony/2017-2018-interim/human-services/2018-1-4-handout-nasddds-ta-recommendations-opportunities.pdf>) Entitled "Report to North Dakota: Eligibility, Service Array, and Person-Centered Practices: Observations and Recommendations for Consideration", this report outlined recommendations for the state to consider. While there was legislative intent for the NASDDDS study to address eligibility for children, the report did little to further that effort. Very young children (under 3) continue to be subjected to standardized intelligence testing that can result in either false positive or false negative results and thus affecting the eligibility determination. No changes have occurred to address this. This bill is different from previous studies, because it directs our attentions to

our North Dakota's century code and the language of "appropriate treatment, services, and habilitation for those disabilities in the least restrictive appropriate settings".

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

Thank you for your time and I would take any questions.

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



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#8152

**Testimony of Support Senate Bill 2256
House Human Services
March 9th, 2021**

Chairman Weisz and members of the Human Services Committee, my name is Kirsten Dvorak. I am the executive director of The Arc of North Dakota, which includes all six Arc chapters in North Dakota: Bismarck, Bowman, Dickinson, Fargo, Grand Forks, and Valley City. Our mission is to improve people's quality of life with intellectual and developmental disabilities and actively support their full inclusion and community participation.

The Arc of North Dakota asks for a due pass with proposed amendments.

I am also a parent of a 21-year-old with autism, Radek, who is non-screenable for the waiver; what services he has received is through the state plan, which he only received for three years as autism services stop at 21. Because of Radek's autism, he needs help with executive functions such as time management, keeping his living space clean, ensuring that hygiene is done, and doing laundry regularly. He also uses job supports to help him stay on task at his job. The applied behavior analysis (ABA) therapy he receives is through private pay, which we are fortunate to pay. He is successfully attending ASTEP at Minot State University because of the ABA therapies and the ASTEP program's support, all of which are covered through student loans and private pay.

If he were not at ASTEP, he would be living in my basement because he doesn't qualify for services at this time. To receive those services, he would need to move out of our house, which puts him at risk of being homeless.

I ask that you pass 2256 to ensure that individuals are appropriately screened for DD services and are not falling through the cracks.

Kristen Dvorak
Executive Director

Senate Bill 2256
NDACP Testimony
House Human Services Committee
Hon. Robin Weisz, Chairman
March 9, 2021

Chairman Weisz and members of the House Human Services Committee, good afternoon, and thank you for this opportunity. I am Bruce Murry, Executive Director of the North Dakota Association of Community Providers (NDACP.org). NDACP is the membership organization of 30 licensed providers of services to North Dakotans with developmental disabilities (DD). NDACP supports SB 2256 with additional amendments.

The North Dakota Century Code Section provides the State's duty of care to people with developmental disabilities:

25-01.2-02. Appropriate treatment, services, and habilitation - Treatment in least restrictive appropriate setting.

All individuals with developmental disabilities have a right to appropriate treatment, services, and habilitation for those disabilities. Treatment, services, and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting.

A significant number of North Dakotans with developmental disabilities do not qualify for what we commonly call the "DD Waiver." Some of these people receive services from a state funded program called Section 11, with about \$7 per day in supports for residential or vocational needs. However, the Governor's budget as introduced in the House proposed to eliminate Section 11 to "reinvest" the money in addiction services. The Governor's budget offered no plan to help the people whose services were eliminated.

Others with DD, who qualify for neither the DD Waiver nor Section 11, receive only case management. This means the DD Division will help them look for services, but can't pay for them. Still others who meet the federal definition of having DD, because of childhood disabilities, receive services from Aging Services Division through its QSP programs or from Behavioral Health Division or none at all. To be clear, receiving no services is the ultimate success for some people with disabilities, but only when they have the ability maintain their overall wellbeing.

State employees are generally required to support the Governor's budget. So they might not be able to tell you these people on the edge of the DD system are at risk and often deteriorating once they are independent of their parents.

When this bill was proposed the Department offered hog-house amendments to bring the study in house. NDACP was not involved in the Senate as this was an organic movement from non-service-provider advocates. NDACP did not want to presume that they wanted our members to define any new services. One of the amendments allows the Department to choose its own consultant to study the situation. That creates a tendency for the consultant to report what they think the paying body wants to hear. For example, when the Department hired a consultant to study the first year of the DD Payment system, the consultant was ill informed and hostile, and made unfounded accusations NDACP has refuted over the last year and a half with real data.

I recommend that Legislative Management retain the authority to choose and hire the consultant in consultation with the Department and key stakeholders like The Arc of North Dakota and the Protection and Advocacy Project. This will change the tenor of the relationship with the consultant, and prevent confusion about the need for an independent review by a third party.

My colleague, Angela Dinius, and I are both happy to answer any questions that may arise about SB 2256, NDACP, its members' services to people, and our priorities. Our contact information is below.

Thank you for your time and attention today.



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Executive Director

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North Dakota Association of Community Providers

North Dakota Association of Community Providers

Testimony
Engrossed Senate Bill 2256 - Department of Human Services
House Human Services Committee
Representative Robin Weisz, Chairman
March 9, 2021

Chairman Weisz, and members of the House Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Division for the Department of Human Services (Department). I am here today in support of Engrossed Senate Bill 2256.

North Dakota Century Code chapter 25-01.2 defines developmental disability using the federal definition of developmental disability with the addition of specifically citing Down Syndrome as a developmental disability.

North Dakota Century Code section 25-01.2-02 states “all individuals with developmental disabilities have a right to appropriate treatment, services and habilitation for those disabilities. Treatment, services and habilitation for individuals with a developmental disability must be provided in the least restrictive appropriate setting”. This section of Century Code does not identify one agency or program solely responsible for this section of law.

The Department has a variety of services that individuals with developmental disabilities may utilize. Examples of these services include six Medicaid 1915(c) waivers; Vocational Rehabilitation; Medicaid; Children’s Health Insurance Program; Children with Disabilities Medicaid Buy-In; Early and Periodic Screening, Diagnostic and Treatment; 1915(i) services; home health; and personal care. In addition, other state agencies such as the Department of Health and Department of Public Instruction have service options available to individuals with developmental disabilities.

In 2017, the Department requested technical assistance through a grant offered by the Centers for Medicare and Medicaid Services. There were five tasks included in the technical assistance request, one of which was to conduct a comprehensive review of the state's Medicaid waiver programs to identify potential paths for eligibility for non-intellectually or developmentally disabled individuals and provide program recommendations.

As noted in the final report, states can determine eligibility criteria, target groups, definitions, etc. and eligibility in one state does not equate to eligibility in all states. The Department has made several changes to the waiver and state plan programs since the issuance of the report. Examples include enhanced funding for individuals with complex medical conditions in the Traditional Individuals with Intellectual/Developmental Disability (IID/DD) waiver, changes to the capacity for the Medically Fragile waiver, added 24-hour residential habilitation to the Home and Community Based Services Aged and Disabled waiver, and the implementation of the 1915(i) state plan amendment for individuals with behavioral health needs.

As previously noted, services must be provided in the least restrictive appropriate setting. The purpose of a 1915(c) waiver is to assist Medicaid beneficiaries to live in the community and avoid institutionalization. For any waived service, a state must choose a level of care (intermediate care facility, nursing or hospital) and then design the waiver program to address the needs of the waivers' target population, in keeping with federal requirements related to the purpose of Medicaid waived services. The guiding principle for the development of a waived service is as follows: but for the availability of the services made available by the waiver, the individual being served would need institutional care.

Although the Department received technical assistance in 2017, Engrossed Senate Bill 2256 is not a duplication and would include a study that examines eligibility considerations for a broader swath of the state's existing programs, going beyond the six Medicaid waivers. Additionally, the study would analyze efforts and services

offered by other states; identify necessary planning and implementation processes; and define the number of individuals who may be affected by a change in state eligibility guidelines, as well as a cost and timeline for implementation of those changes. Engrossed Senate Bill 2256 recognizes that waived services are an important part of our state's continuum of care, but they are not the only service option available to people with developmental disabilities. This study has the potential to identify intersections between service options to help the State better understand how eligibility guidelines shape availability of services in North Dakota.

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

SB2256
House Human Services Committee
Chairman Weisz

Chairman Weisz and Members of the Committee,

My name is Donene Feist and I am the Director for Family Voices of North Dakota. Our work as you know, includes working with families who have children and youth with disabilities and chronic health conditions.

I rise to support SB2256. Over the years, many of us have stood before you to express our concerns over the wide array of gaps in our already complex system of care. Many families we assist have none too few options for assistance for their child and youth with special health care needs. Many possibly could be served if we broadened the ND Definition of Developmental Disabilities.

Digging through my old files found as far back as 2005 during an interim committee led by Senator Dever asking to review waivers, criteria and how all worked together. I believe at that time, Children's Special Health Services, now called Special Health Services was reviewed but the Developmental Disabilities Division, Medicaid and other programs that families utilize were not reviewed.

In 2013, Senator Kaiser requested a study to be done. The department of human services, during the 2013-2014 interim, shall identify the estimated cost to implement a Medicaid waiver or amend an existing Medicaid waiver, to provide coverage for children who have continued and substantial medical and support needs, but who, at the age of three years, no longer qualify for services under the developmental disabilities waiver. In preparing the estimate, the department shall secure input from stakeholders, including families, providers, and advocates. The department of human services shall report its findings to the sixty-fourth legislative assembly. The report shall include the estimated number of children eligible, criteria for the provision of services under the waiver, the services to be offered, and a timeline for implementation of the waiver.

<https://www.legis.nd.gov/assembly/63-2013/documents/13-0778-01000.pdf>

This was done, over the course of 2 years family groups met with administration to identify gaps. I do not recall a report being given on what was discovered and what we were going to continue to do to monitor.

We also know some study work has been done and am sure others testifying will be commenting on this.

Somewhere in those years the Medically Fragile waiver and Hospice waiver were initiated to address some of the gaps. Both currently well utilized, however, the MF waiver could be broadened to encompass more people. Many of the parents that we brought in for input did not qualify under the medically fragile waiver as was too restrictive.

The DD waiver narrowly defined for those with an intellectual disability, when we know many who do have a developmental disability but not the ID diagnosis are often going unassisted.

All of the current data indicates the needs for families growing and the increase of children identified with a developmental disability is increasing.

The Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) found that 17% of children aged 3–17 years had a developmental disability. I could not locate information beyond that to identify fully who those children are beyond 2017. About 1 in 6 (17%) children aged 3–17 years were diagnosed with a developmental disability, as reported by parents.

Family Voices of ND has always followed the HRSA Maternal and Child Health Bureau of children with special health care needs which is: Children and youth with special health care needs (CYSHCN) are those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.

An estimated 13.5 million children in this country, or approximately 20% of U.S. children under age 18 years of age, have a special health care need. CYSHCN and their families often need services from multiple systems - health care, public health, education, mental health, and social services.

Included below is data from the National Data Resource Center.

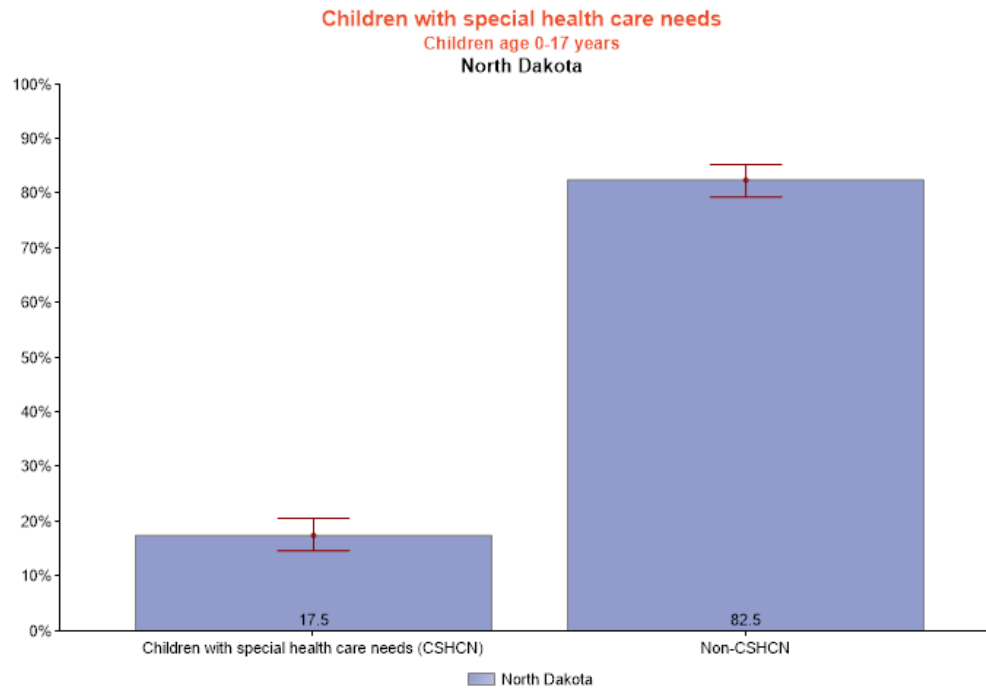
The Data Resource Center is a national center assisting in the design, development, documentation and public dissemination of user friendly information about, data findings on and datasets and codebooks for the National Survey of Children's Health (NSCH). Since its initial design in 2001, the NSCH (first fielding in 2003) has been supported and led by the Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA/MCHB). <https://www.childhealthdata.org/>

According to the Data Resource Center we have 30,244 children and youth with special health care needs in ND.

Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



	Children with special health care needs (CSHCN)	Non-CSHCN	Total %
%	17.5	82.5	100.0
C.I.	14.7 - 20.6	79.4 - 85.3	
Sample Count	245	932	
Pop. Est.	30,244	142,966	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.			



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

I fully support a study that would look at all of the options that families have currently. What happens to those families who may have a child with cerebral palsy, spina bifida, Down Syndrome who have significant challenges but do not have the level of ID to receive services. Families are struggling and have few options. Nor is the system so well built that families know where to go, whom to ask and where are services provided.

It would be helpful to review the federal definition of developmental disabilities and the state definition through century code. Can we create a system without putting a child in a box, one that meets the needs of the child? After a child in early intervention turns 3, do we know how many 3-21 utilize the DD waiver?

By and large what families need is the access to Medicaid. Medicaid is an essential program for children and youth with special health care needs. Its benefits should serve as a model for all children and youth needing specialized health care services, whether publicly or privately funded.

Children and youth with special health care needs are a small but significant part of our state's population of children. Though not well understood by many health plans, nevertheless their experiences are reflections of how well our health systems are performing, and should be monitored carefully.

For some children and youth whose primary health coverage benefits are limited, secondary health care coverage, like Medicaid, is essential. Additionally, children and youth with special health care needs require flexibility in health care plans such as streamlined procedures for getting specialty care and care coordination or case management.

Parents want and need clear information from private and public health plans about health plan benefits and how to get the covered services for their child, where to go with complaints and appeals, and about other available resources that will help them meet their child's needs. Who is explaining this to families?

Families face a very confusing maze of services from health plans, school systems, state agencies and private agencies that are not well coordinated. This leaves families with an overwhelming roller coaster of emotions. It is much too often left to families to figure out who will provide and pay for services such as physical, occupational, speech, and mental health therapies. Payment responsibility needs to be clarified among all the multiple possible payers so that children are not left un-served while agencies and programs try to decide who will pay for what. Additionally families need and require complete unbiased information to make informed decisions.

Many families provide large amounts of complicated health care for their children at home, and need more support than they now receive. The impacts of a child with special health care needs on a parent's job, finances and time must be recognized and public policies must address these impacts. Children with health conditions that are unstable and severe, have needs that are not well met by the present approaches of health plans, government programs, and community agencies.

Equally important for a study is the families' voice. This needs to be assured as an equal team player at advisory meetings, committees, policy making etc. in order to build a comprehensive system of care for children and youth with special health care needs.

The only way to assure that we are looking at all services to families is to complete a full study. Prevalence data is showing us that the needs and numbers diagnosed continues to rise. Let's be proactive and address the needs of the most vulnerable families in the state.


Please pass SB2256

Below I have pulled some data, which I hope you review. I believe it gives a better understanding of needs for our most vulnerable families.

Thank you for your consideration.

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Of the 32,000 children and youth above we know that nearly 24,000 have one or more functional difficulties.

Indicator 1.10: Does this child have one or more functional difficulties from a list of 12 difficulties? 

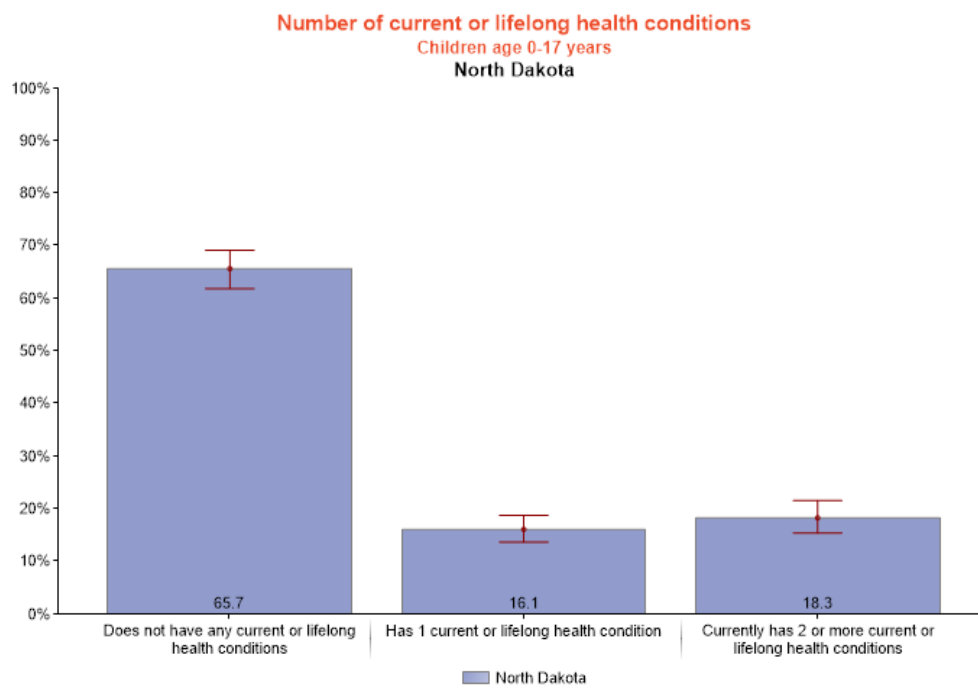
		Does not have any difficulties	One functional difficulty	Two or more functional difficulties	Total %
Children with special health care needs (CSHCN)	%	38.5	32.8	28.7	100.0
	C.I.	30.2 - 47.6	24.8 - 41.9	21.0 - 37.9	
	Sample Count	96	78	71	
	Pop. Est.	11,650	9,915	8,680	
Non-CSHCN	%	83.3	10.4	6.3	100.0
	C.I.	79.6 - 86.4	8.1 - 13.3	4.2 - 9.2	
	Sample Count	793	101	37	
	Pop. Est.	118,932	14,894	8,944	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.					

DATA ALERT: CSHCN status is determined using a validated instrument for identification of children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer. For more information, email info@cahmi.org.

That 27,838 have one lifelong health condition and 31,648 have 2 or more lifelong conditions.

Indicator 1.9: Does this child have current or lifelong health conditions from a list of 27 (2018) or 26 (2019) conditions? 

	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Currently has 2 or more current or lifelong health conditions	Total %
%	65.7	16.1	18.3	100.0
C.I.	61.9 - 69.2	13.7 - 18.8	15.4 - 21.6	
Sample Count	732	214	231	
Pop. Est.	113,724	27,838	31,648	
C.I. = 95% Confidence Interval. Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.				



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

The number of children with special health care needs by FPL


Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
Household income 0-99% FPL	%	22.4	77.6	100.0
	C.I.	13.6 - 34.8	65.2 - 86.4	
	Sample Count	24	64	
	Pop. Est.	4,982	17,213	
Household income 100-199% FPL	%	18.1	81.9	100.0
	C.I.	11.5 - 27.2	72.8 - 88.5	
	Sample Count	35	114	
	Pop. Est.	6,006	27,181	
Household income 200-399% FPL	%	19.6	80.4	100.0
	C.I.	14.9 - 25.2	74.8 - 85.1	
	Sample Count	91	339	
	Pop. Est.	11,528	47,404	
Household income 400% FPL or greater	%	13.1	86.9	100.0
	C.I.	10.2 - 16.8	83.2 - 89.8	
	Sample Count	95	415	
	Pop. Est.	7,728	51,168	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

 Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable. For more information about the data suppression and display criteria [click here](#).

Number of families served through both public and private means.

Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



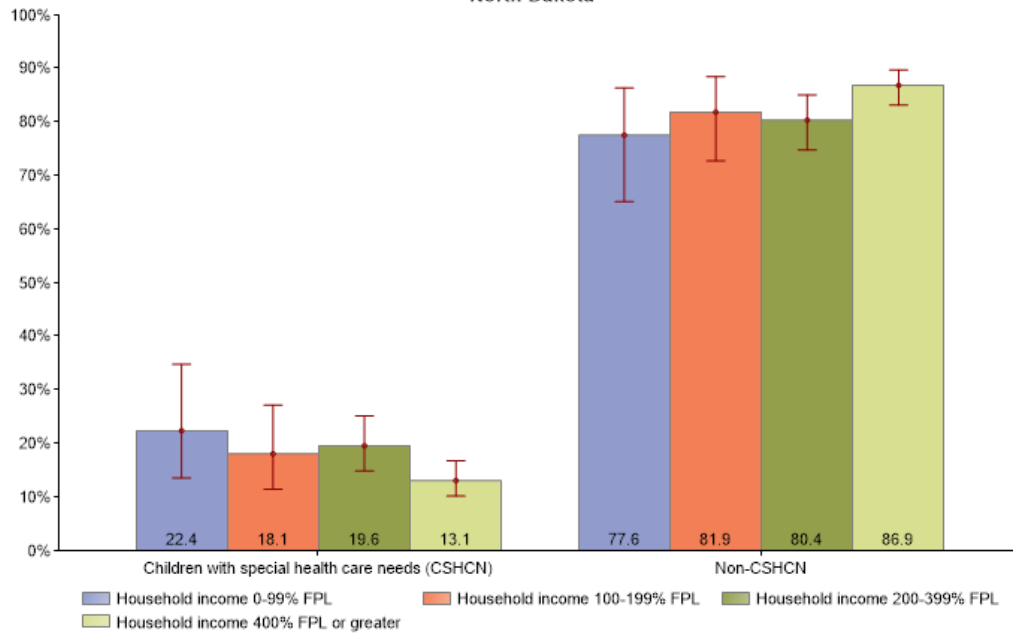
		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
Public health insurance only	%	32.4	67.6	100.0
	C.I.	20.8 - 46.6	53.4 - 79.2	
	Sample Count	31	49	
	Pop. Est.	7,492	15,640	
Private health insurance only	%	12.6	87.4	100.0
	C.I.	10.4 - 15.3	84.7 - 89.6	
	Sample Count	171	807	
	Pop. Est.	16,287	112,510	
Public and private insurance	%	52.4	47.6	100.0
	C.I.	33.5 - 70.6	29.4 - 66.5	
	Sample Count	31	20	
	Pop. Est.	3,956	3,595	
Currently uninsured	%	21.7	78.3	100.0
	C.I.	9.8 - 41.2	58.8 - 90.2	
	Sample Count	11	44	
	Pop. Est.	2,466	8,918	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.

Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable. For more information about the data suppression and display criteria [click here](#).

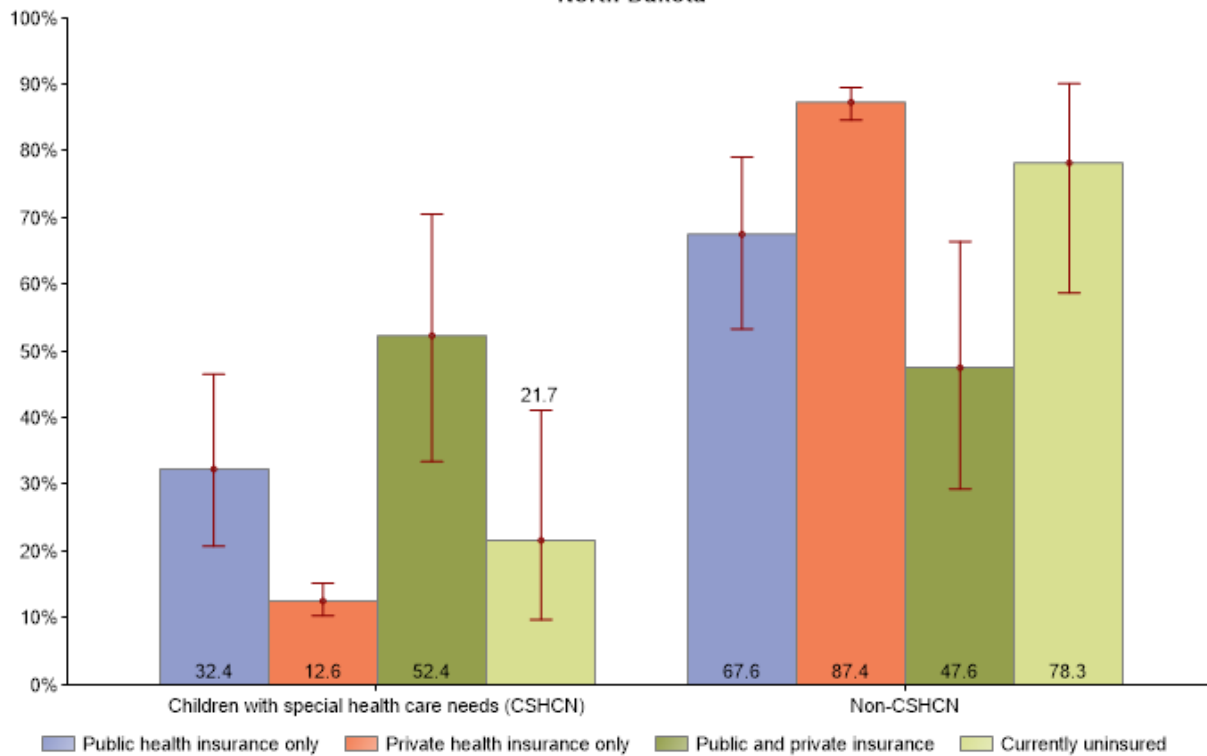
Children with special health care needs
 Children age 0-17 years
 North Dakota



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

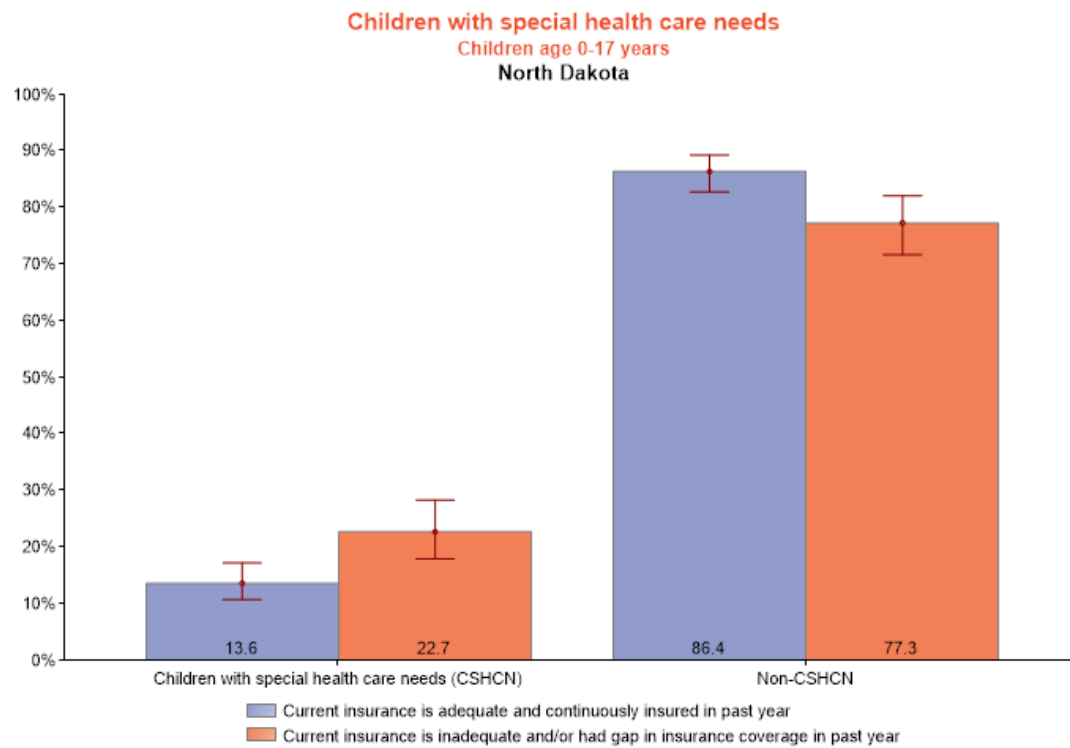
Children with special health care needs
 Children age 0-17 years
 North Dakota



Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.surveys>

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource C Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

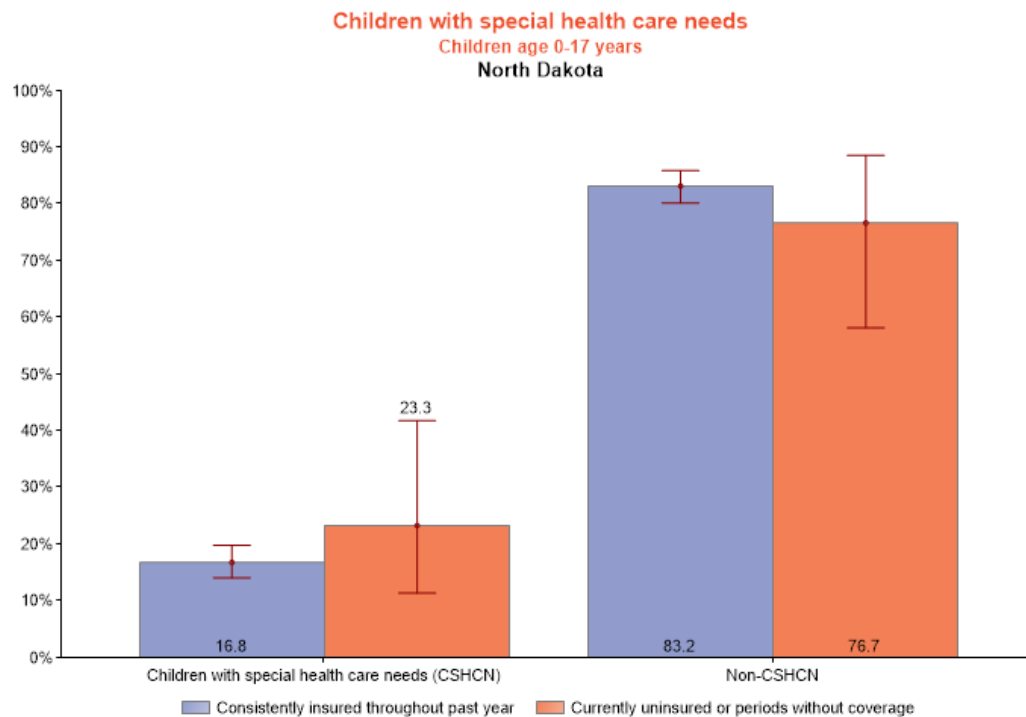
Percent of children served who's had adequate and inadequate coverage.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

Number of children with special health care needs continuously covered. I find this diagram a bit alarming.

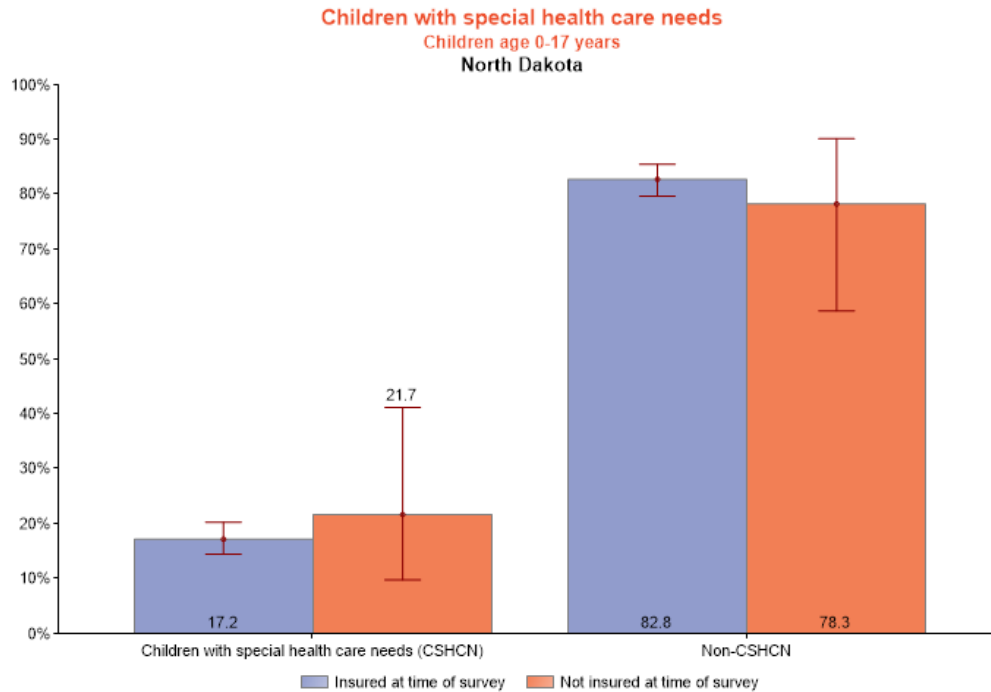


Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.hrsa.gov/data/national-surveys>

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [www.childhealthdata.org].

Those children with a special health care need insured and uninsured

DATA ALERT: Children who are covered only by the Indian Health Service or a health care sharing ministry are considered as "not insured at time of survey".

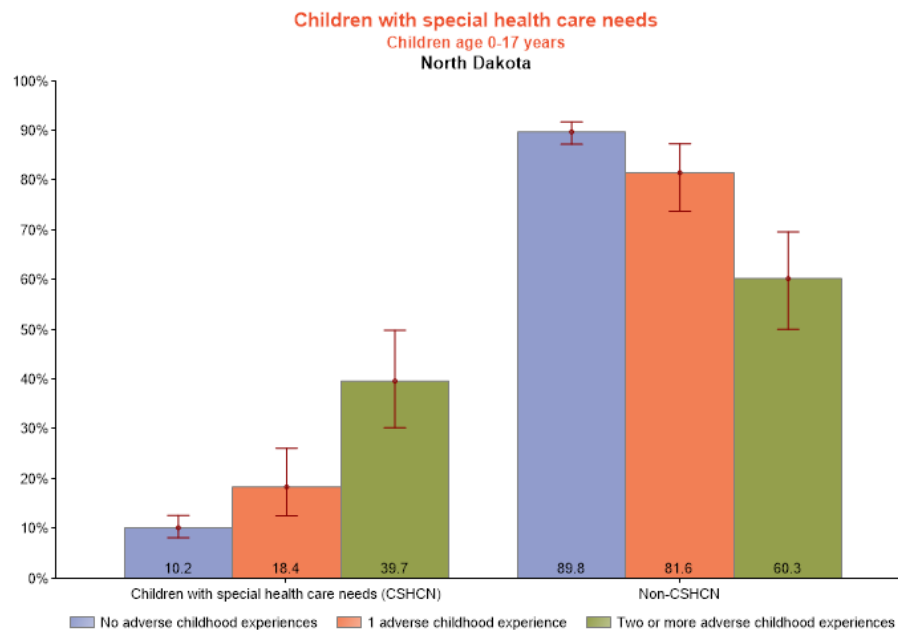


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The number of ND children affected by ACE's. I present this data simply because we know that many of our children with special health care needs experience significant trauma. Every time they go to a medical procedure they may feel the affect of trauma which may result in co-occurring conditions with health and behaviroal health.

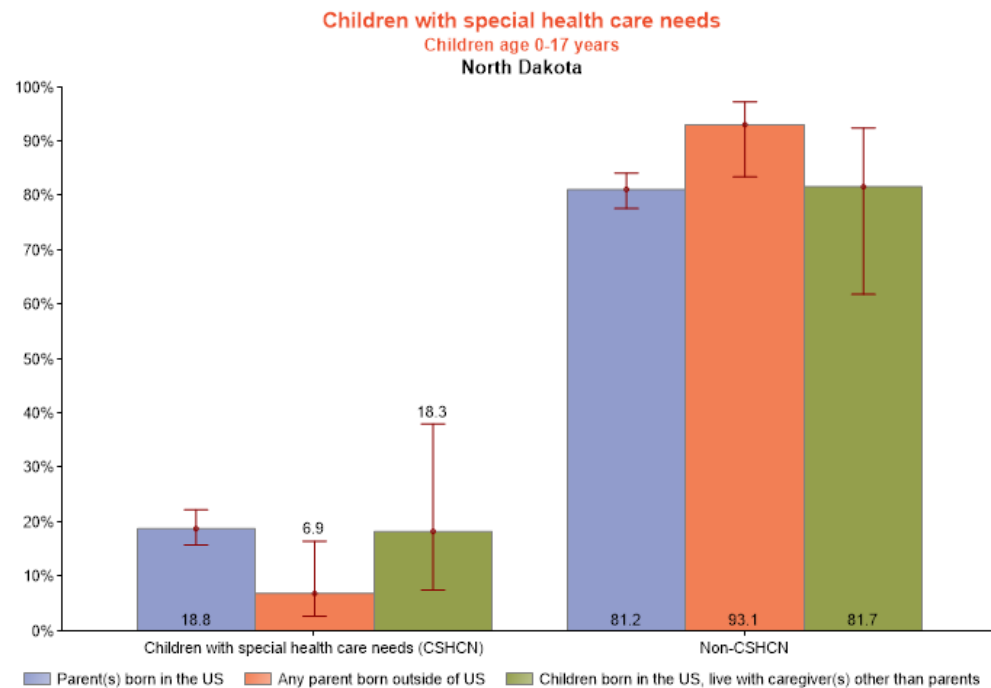
DATA ALERT: This ACEs subgroup includes 9 ACEs items: hard to cover basics on family's income; parent/guardian divorced or separated; parent/guardian died; parent/guardian served time in jail; saw or heard parents/adults slap, hit, kick, punch one another in the home; was a victim of or witnessed violence in neighborhood; lived with anyone who was mentally ill, suicidal, or severely depressed; lived with anyone who had a problem with alcohol/drugs; and treated or judged unfairly due to race/ethnicity.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

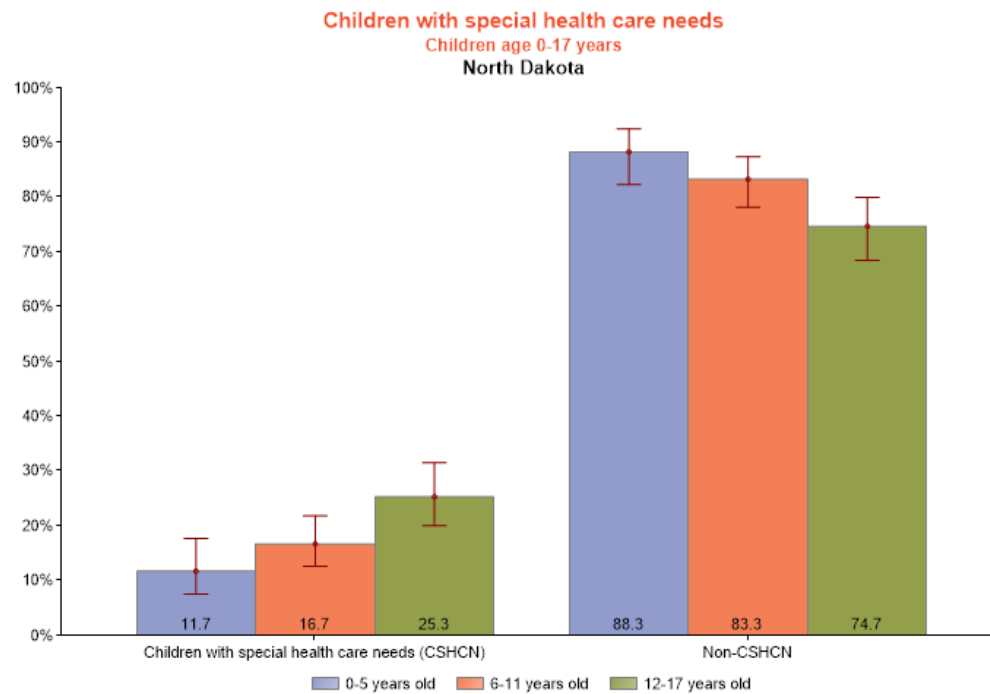
ND demographics. Of concern here is the increasing number of children being raised by someone other than their parent is alarming. That may mean a grandparent, sibling, foster care, who may or may not have the means if the child does not have access to services.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from [\[www.childhealthdata.org\]](http://www.childhealthdata.org).

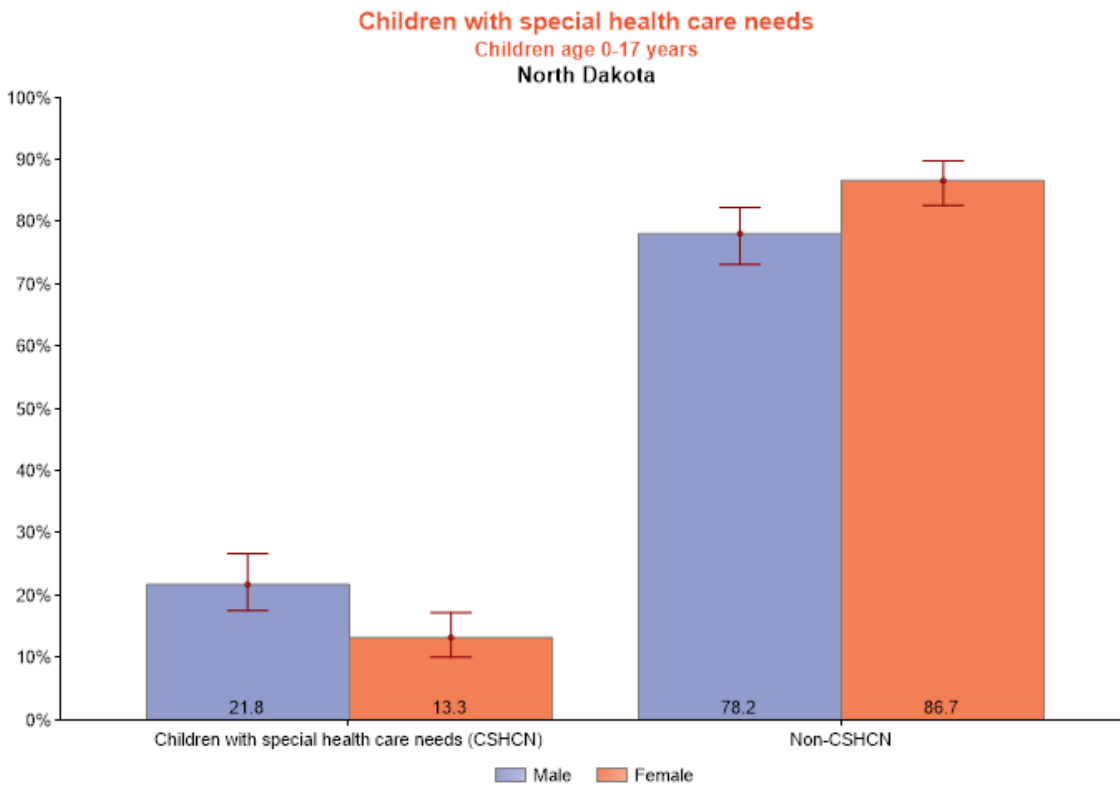
Breakdown by age of the percent of children in each age category



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

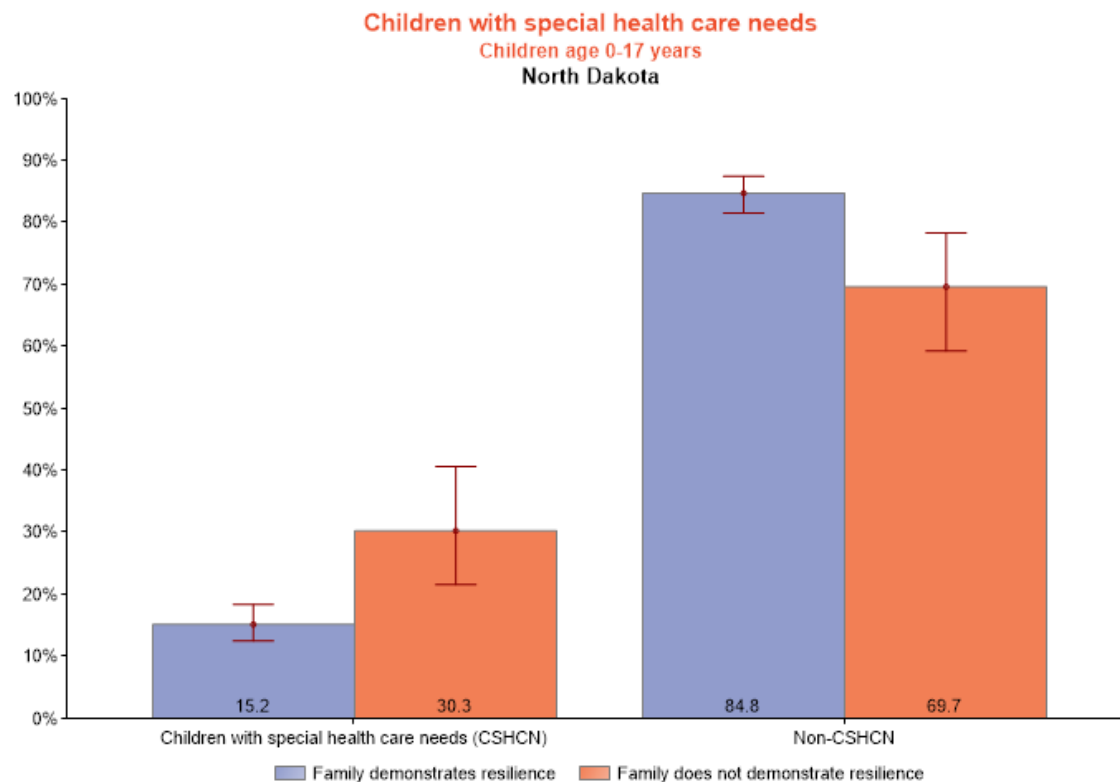
Number of children by male/female



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

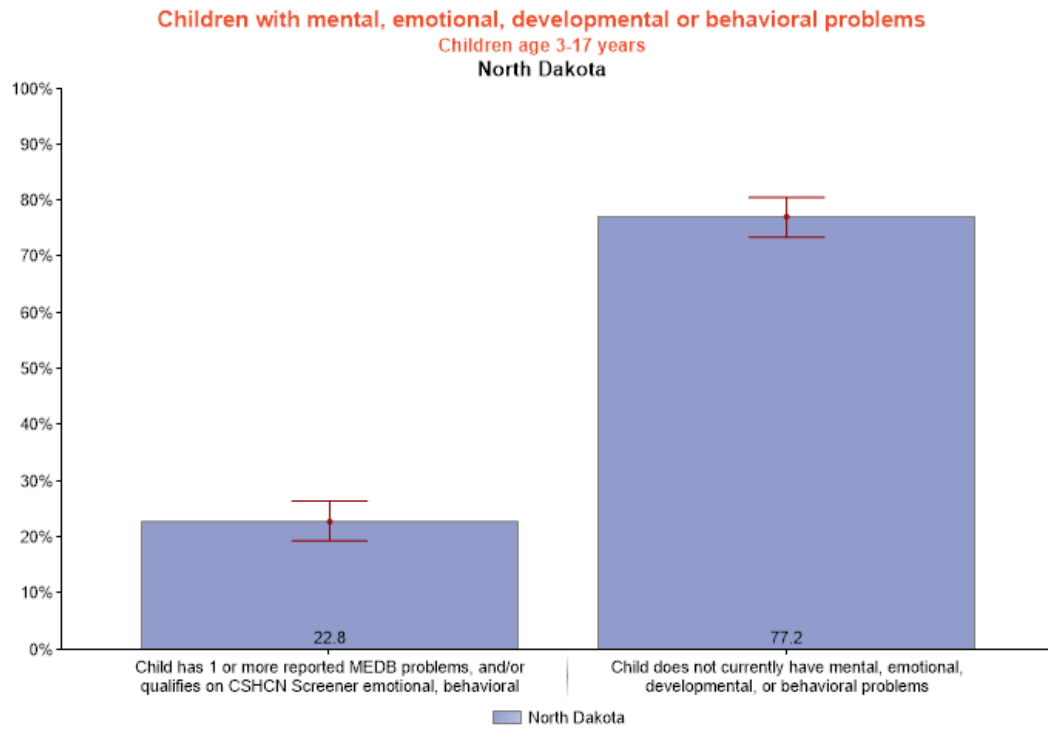
Percent of families who are able to demonstrate resilience. This is also a concerning number and we are seeing this with many of the families we serve. The needs are so vast for families and given the pandemic, that has also increased.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

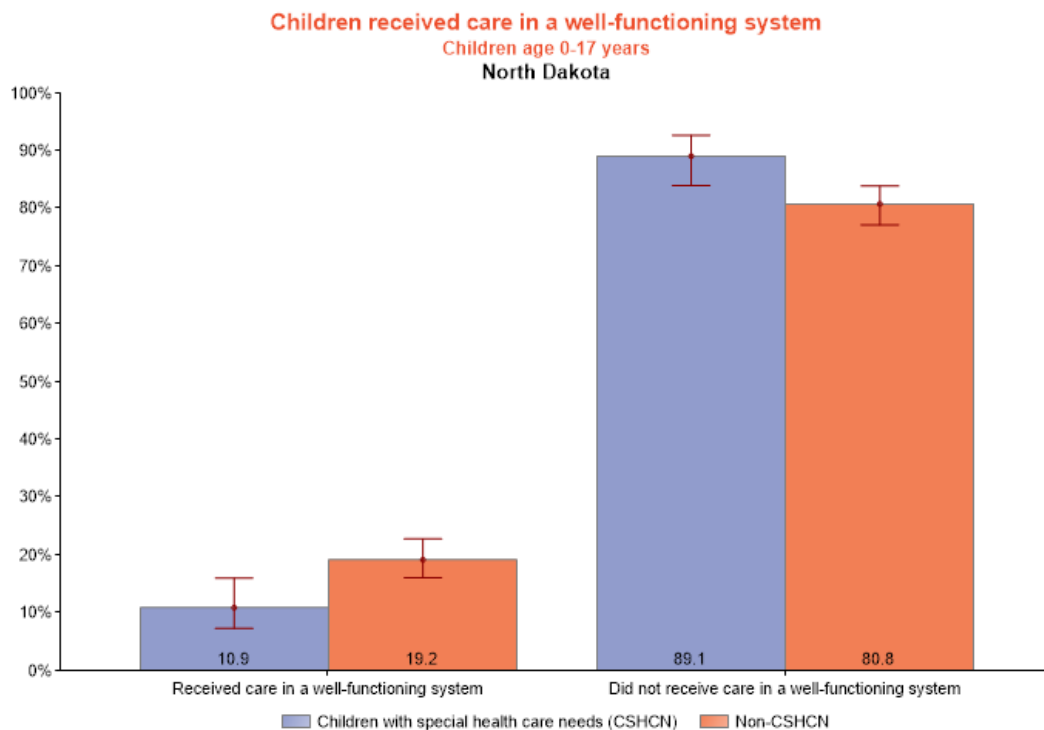
Percent of children with emotional, developmental or behavior problems.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

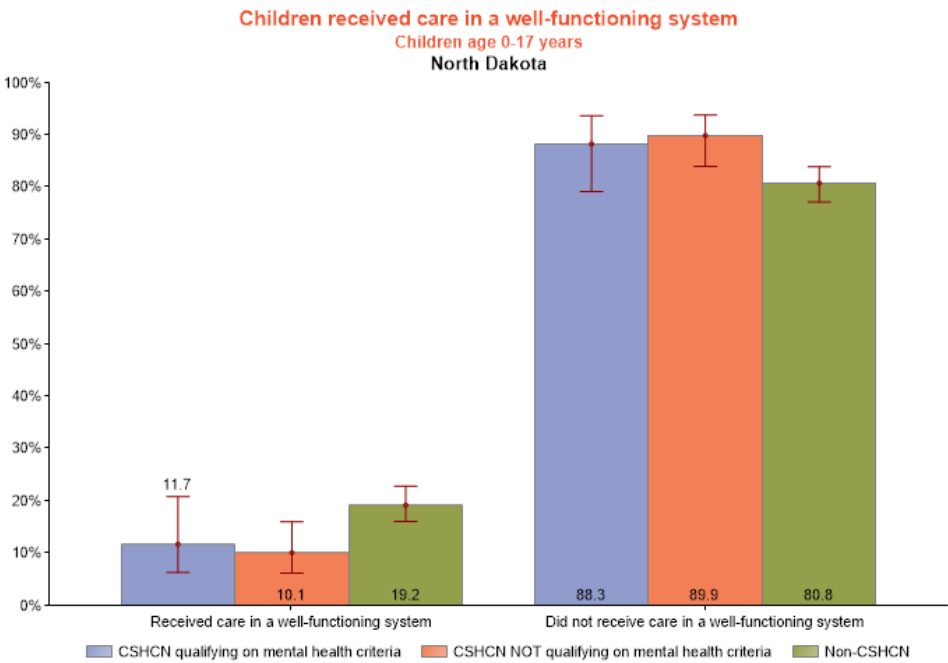
The next 3 slides are the percent of children who receive care in a well-functioning system. To me this is also some troublesome data.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

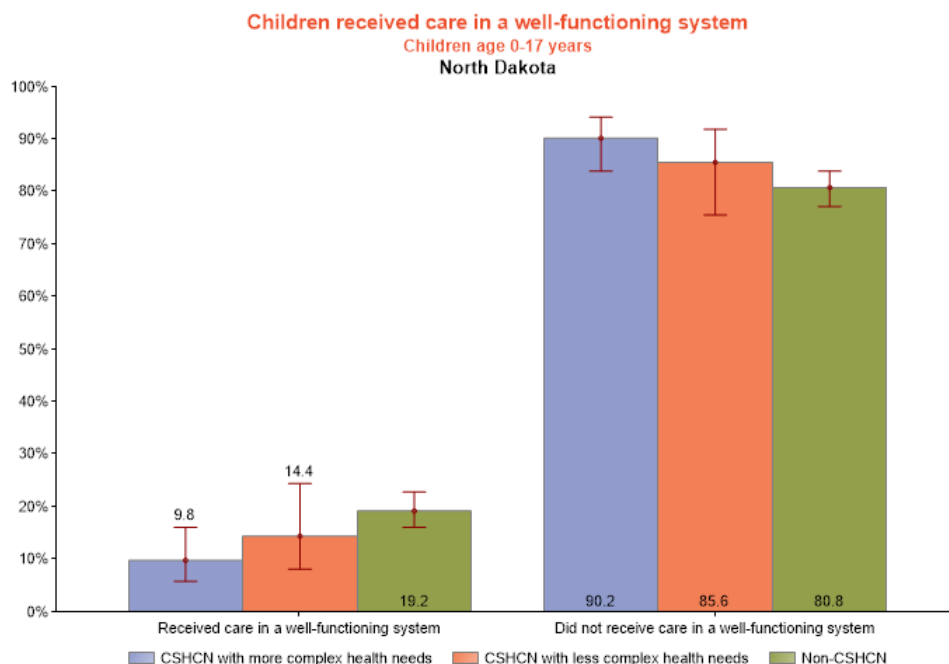
DATA ALERT: Children with ongoing emotional, behavioral or developmental problems for which treatment or counseling is needed are identified by the answers to two questions on the validated CSHCN Screener. For more information, email info@cahmi.org.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

DATA ALERT: CSHCN status is determined using a validated instrument for identification of children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer. For more information, email info@cahmi.org.



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

Citation: Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [mm/dd/yy] from www.childhealthdata.org.

National Performance Measure 12: Percent of adolescents with special health care needs, ages 12 through 17, who received services necessary to make transitions to adult health care i

	Received services necessary for transition to adult health care	Did not receive services necessary for transition to adult health care	Total %
%	26.1	73.9	100.0
C.I.	17.5 - 37.2	62.8 - 82.5	
Sample Count	39	88	
Pop. Est.	3,271	9,241	

C.I. = 95% Confidence Interval.

Percentages and population estimates (Pop.Est.) are weighted to represent child population in US.



SB 2256
House Human Services Committee
Tuesday, March 9th, 2021

Chairman Weisz and the members of the House Human Services Committee, my name is Tim Eissinger and I serve as CEO of the Anne Carlsen Center. I am providing written testimony today in support of SB 2256. I believe there is a need for a 2021-2022 interim study examining the ability of providers and regulating agencies to adapt to the unique and changing needs of the persons we serve and the environments we operate in. Gap identification is always a critical step in making sure we meet the needs of everyone benefitting from this type of support, and not allowing anyone to fall through the cracks. It is important that Legislators examine recently enacted policy and rule and make sure it is having its intended effect and effectively using the funding available for these programs. It is also a great opportunity to hear directly from those affected by these changes, or from those advocates serving as their voice to assist in making the persons we serve as independent as possible. Thank you for your consideration of my written testimony.

A handwritten signature in blue ink that reads 'Tim Eissinger'. The signature is fluid and cursive, with the first name 'Tim' and last name 'Eissinger' clearly legible.

Tim Eissinger, CEO
Anne Carlsen Center
Email: tim.eissinger@annecenter.org
Work cell: 701-269-7355

2021 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee Pioneer Room, State Capitol

SB 2256
3/17/2021

To provide for a legislative management study of the state's developmental services; and to provide an appropriation

Chairman Weisz opened the committee meeting at 2:58 p.m.

Representatives	Attendance
Representative Robin Weisz	P
Representative Karen M. Rohr	P
Representative Mike Beltz	P
Representative Chuck Damschen	P
Representative Bill Devlin	P
Representative Gretchen Dobervich	P
Representative Clayton Fegley	P
Representative Dwight Kiefert	P
Representative Todd Porter	P
Representative Matthew Ruby	P
Representative Mary Schneider	P
Representative Kathy Skroch	P
Representative Bill Tveit	P
Representative Greg Westlind	P

Discussion Topics:

- Legislative management study budget
- Department consultant

Rep. Todd Porter (3:02) made a motion to amend line 23 instead of \$150,000 to state \$100,000. After discussion motion was withdrawn.

Rep. Todd Porter (3:03) moved **Do Pass Rerefer to Appropriations**

Rep. Mary Schneider (3:03) second

Representatives	Vote
Representative Robin Weisz	N
Representative Karen M. Rohr	Y
Representative Mike Beltz	Y
Representative Chuck Damschen	Y
Representative Bill Devlin	Y
Representative Gretchen Dobervich	Y
Representative Clayton Fegley	Y
Representative Dwight Kiefert	Y
Representative Todd Porter	Y

Representative Matthew Ruby	Y
Representative Mary Schneider	Y
Representative Kathy Skroch	Y
Representative Bill Tveit	N
Representative Greg Westlind	Y

Motion Carried Do Pass Rerefer to Appropriations 12-2-0

Bill Carrier: Rep. Mary Schneider

Chairman Weisz adjourned at 3:06 p.m.

Tamara Krause, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2256, as engrossed: **Human Services Committee** (Rep. Weisz, Chairman) recommends **DO PASS** and **BE REREFERRED** to the **Appropriations Committee** (12 YEAS, 2 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2256 was rereferred to the **Appropriations Committee**.

2021 HOUSE APPROPRIATIONS

SB 2256

2021 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee Brynhild Haugland Room, State Capitol

SB 2256
4/1/2021

BILL for an Act to provide for a legislative management study of the state's developmental disability services

8:45 Chairman Delzer- Opened the meeting for SB 2256;

Attendance	P/A
Representative Jeff Delzer	P
Representative Keith Kempenich	P
Representative Bert Anderson	P
Representative Larry Bellew	P
Representative Tracy Boe	P
Representative Mike Brandenburg	P
Representative Michael Howe	P
Representative Gary Kreidt	P
Representative Bob Martinson	P
Representative Lisa Meier	P
Representative Alisa Mitskog	P
Representative Corey Mock	P
Representative David Monson	P
Representative Mike Nathe	P
Representative Jon O. Nelson	P
Representative Mark Sanford	P
Representative Mike Schatz	A
Representative Jim Schmidt	P
Representative Randy A. Schobinger	P
Representative Michelle Strinden	P
Representative Don Vigesaa	P

Discussion Topics:

- Study
- Developmental Disabilities
- Human Services General Fund Appropriation
- Olmstead Act

Representative Weisz – Introduces the bill.

8:47 Committee Discussion

9:00 Chairman Delzer- Closes the meeting for SB 2256

*Risa Berube,
House Appropriations Committee Clerk*

2021 HOUSE STANDING COMMITTEE MINUTES

Appropriations Committee Brynhild Haugland Room, State Capitol

SB 2256
4/1/2021

BILL for an Act to provide for a legislative management study of the state's developmental services; and to provide an appropriation.

3:38 Chairman Delzer- Opened the meeting for SB 2256

Attendance	P/A
Representative Jeff Delzer	P
Representative Keith Kempenich	P
Representative Bert Anderson	P
Representative Larry Bellew	P
Representative Tracy Boe	P
Representative Mike Brandenburg	P
Representative Michael Howe	P
Representative Gary Kreidt	P
Representative Bob Martinson	P
Representative Lisa Meier	P
Representative Alisa Mitskog	P
Representative Corey Mock	P
Representative David Monson	P
Representative Mike Nathe	P
Representative Jon O. Nelson	P
Representative Mark Sanford	P
Representative Mike Schatz	A
Representative Jim Schmidt	P
Representative Randy A. Schobinger	P
Representative Michelle Strinden	P
Representative Don Vigesaa	P

Discussion Topics:

- Amendment
- Shall Study

3:38 Chairman Delzer – Introduces the budget and the amendment 21.0957.02002

3:47 Representative Kempenich - Makes a motion to adopt the amendment

Representative Meier Second

Further discussion

3:48 Voice Vote- Motion Carries

Representative Kempenich Makes a motion for a Do Pass as Amended

Representative Meier Second

Further discussion

3:49 Roll Call Vote was Taken;

Representatives	Vote
Representative Jeff Delzer	Y
Representative Keith Kempenich	Y
Representative Bert Anderson	Y
Representative Larry Bellew	Y
Representative Tracy Boe	Y
Representative Mike Brandenburg	Y
Representative Michael Howe	Y
Representative Gary Kreidt	Y
Representative Bob Martinson	Y
Representative Lisa Meier	Y
Representative Alisa Mitskog	Y
Representative Corey Mock	Y
Representative David Monson	Y
Representative Mike Nathe	Y
Representative Jon O. Nelson	Y
Representative Mark Sanford	Y
Representative Mike Schatz	Y
Representative Jim Schmidt	Y
Representative Randy A. Schobinger	Y
Representative Michelle Strinden	Y
Representative Don Vigesaa	Y

Motion Carries 21-0-0 Representative Meier will carry the bill

Additional written testimony: No Additional Testimony

3:50 Chairman Delzer- Closes the meeting for SB 2256

Risa Berube,

House Appropriations Committee Clerk

21.0957.02002
Title.03000

Prepared by the Legislative Council staff for
House Appropriations Committee
April 1, 2021

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2256

Page 1, line 1, after "developmental" insert "disability"

Page 1, line 2, remove "; and to provide an appropriation"

Page 1, line 13, after "sources" insert "including the federal Medicaid 1915(i) waiver"

Page 1, remove lines 22 through 24

Page 2, remove lines 1 and 2

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2256, as engrossed: Appropriations Committee (Rep. Delzer, Chairman)
recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends
DO PASS (21 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). Engrossed SB 2256
was placed on the Sixth order on the calendar.

Page 1, line 1, after "developmental" insert "disability"

Page 1, line 2, remove "; and to provide an appropriation"

Page 1, line 13, after "sources" insert "including the federal Medicaid 1915(i) waiver"

Page 1, remove lines 22 through 24

Page 2, remove lines 1 and 2

Renumber accordingly

2021 CONFERENCE COMMITTEE

SB 2256

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2256
4/21/2021
Conference Committee

A BILL for an Act to provide for a legislative management study of the state's developmental disability services.

Madam Chair Lee opened the conference committee on SB 2256 at 9:27 a.m. Members present: Senator Lee, Clemens, Hogan, Representative Rohr, Tveit, Schneider.

Discussion Topics:

- House actions
- 1915i waiver funding
- Funding of study
- 1915i state plan amendment language
- Stakeholder group consultant

[9:34] Chris Jones, Director, DHS. Provided additional information on budget and funding.

Additional written testimony: N/A

Madam Chair Lee closed the conference committee on SB 2256 at 9:56 a.m.

Justin Velez, Committee Clerk

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2256
4/22/2021
Conference Committee

A BILL for an Act to provide for a legislative management study of the state's developmental disability services.

Madam Chair Lee opened the conference committee on SB 2256 at 10:30 a.m. Members present: Senator Lee, Clemens, Hogan, Representative Rohr, Tveit, Schneider.

Discussion Topics:

- Proposed amendment
- 1915i waiver V.S. state plan amendment language change

Senator Hogan moves the **HOUSE RECEDE FROM HOUSE AMENDMENTS AND AMEND AS FOLLOWS** 21.0957.02003.

Representative Rohr seconded.

Motion passed 6-0-0.

Senator Lee and **Representative Rohr** will carry SB 2256.

Additional written testimony: N/A

Madam Chair Lee closed the conference committee on SB 2256 at 10:46 a.m.

Committee action reconsidered on 4/26

Justin Velez, Committee Clerk

April 22, 2021

CJ
4/22
1 of 1

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2256

That the House recede from its amendments as printed on page 1313 of the Senate Journal and pages 1437 and 1438 of the House Journal and that Engrossed Senate Bill No. 2256 be amended as follows:

Page 1, line 1, after "developmental" insert "disability"

Page 1, line 2, replace "an appropriation" with "a statement of legislative intent"

Page 1, line 13, after "sources" insert "including the federal Medicaid 1915(i) state plan amendment"

Page 1, remove lines 22 through 24

Page 2, replace lines 1 and 2 with:

"SECTION 2. LEGISLATIVE INTENT - STATE FISCAL RECOVERY FUND. It is the intent of the sixty-seventh legislative assembly that the department of human services seek an appropriation during any special session of the sixty-seventh legislative assembly from, or subsequent to, the state fiscal recovery fund received through H.R. 1319 of the 117th Congress, also known as the federal American Rescue Plan Act, for the purpose of selecting a consultant to assist the legislative management in the study related to the state's services to individuals with developmental disabilities."

Renumber accordingly

**2021 SENATE CONFERENCE COMMITTEE
ROLL CALL VOTES**

BILL/RESOLUTION NO. SB 2256 as (re) engrossed

Senate Human Services Committee

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

Motion Made by: Senator Hogan Seconded by: Representative Rohr

Senators				Yes	No		Representatives				Yes	No
Senator Lee				X			Representative Rohr				X	
Senator Clemens				X			Representative Tveit				X	
Senator Hogan				X			Representative Schneider				X	
Total Senate Vote							Total Rep. Vote					

Vote Count Yes: 6 No: 0 Absent: 0

Senate Carrier Senator Lee House Carrier Representative Rohr

LC Number 21.0957 . 02003 of amendment

LC Number 21.0957 . 04000 of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

Change "waiver" on line 14 to "state plan amendment" and add a new section 2 for state fiscal recovery fund – " It is the intent of the sixty-seventh legislative assembly that the department of Human Services seek an appropriation during any special session of the sixty-seventh legislative assembly from, or subsequent to, the state fiscal recovery fund received through H.R. 1319 of the 117th Congress, also known as the federal American Rescue Plan Act, for the purpose of selecting a consultant to assist the legislative management in the study related to the state's services to individuals with developmental disabilities.

2021 SENATE STANDING COMMITTEE MINUTES

Human Services Committee
Sakakawea Room, State Capitol

SB 2256
4/26/2021
Conference Committee

A BILL for an Act to provide for a legislative management study of the state's developmental disability services.

Madam Chair Lee opened the conference committee on SB 2256 at 1:39 p.m. Members present: Senator Lee, Clemens, Hogan, Representative Rohr, Tveit, Schneider.

Discussion Topics:

- Proposed amendment
- Autism spectrum disorder addition language
- Viable funding of study
- Third party consultant

[1:40] Senator Judy Lee, District 13. Provided the committee with proposed amendment 21.0957.02004 (testimony #11647).

Senator Hogan moves to **RECONSIDER COMMITTEE ACTION.**
Representative Schneider seconded.

Voice vote – Motion passed.

Senator Hogan moves the **HOUSE RECEDE FROM HOUSE AMENDMENTS AND AMENDS AS FOLLOWS:** 21.0957.02004.
Representative Rohr seconded.

Motion passed 6-0-0.

Senator Lee and **Representative Rohr** will carry SB 2256.

Additional written testimony: N/A

Madam Chair Lee closed the conference committee on SB 2256 at 1:53 p.m.

Justin Velez, Committee Clerk

CS
4/26
10:41

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2256

That the House recede from its amendments as printed on page 1313 of the Senate Journal and pages 1437 and 1438 of the House Journal and that Engrossed Senate Bill No. 2256 be amended as follows:

Page 1, line 1, after "developmental" insert "disability"

Page 1, line 2, replace "; and to provide an appropriation" with "and autism spectrum disorder waiver and voucher programs"

Page 1, line 5, after "**SERVICES**" insert "**- AUTISM SPECTRUM DISORDER WAIVER AND VOUCHER PROGRAMS**"

Page 1, line 6, after "regulations" insert "and services"

Page 1, line 7, after "disabilities" insert "and individuals with autism spectrum disorder"

Page 1, line 10, after "disability" insert "and individuals who have an autism spectrum disorder"

Page 1, line 13, after "sources" insert ", including the federal Medicaid 1915(i) state plan amendment"

Page 1, line 15, after "new" insert "or modified"

Page 1, line 15, remove "and"

Page 1, line 18, after "implementation" insert "; and

- e. The elimination of the autism spectrum disorder task force, including contracting with a private, nonprofit entity that does not provide autism spectrum disorder services to facilitate and provide support services to the autism spectrum disorder task force"

Page 1, line 19, after "2." insert "In conducting the study, the legislative management shall contract with a third party.

3."

Page 1, remove lines 22 through 24

Page 2, remove lines 1 and 2

Renumber accordingly

**2021 SENATE CONFERENCE COMMITTEE
ROLL CALL VOTES**

BILL/RESOLUTION NO. SB 2256 as (re) engrossed

Senate Human Services Committee

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

Motion Made by: Senator Hogan Seconded by: Representative Rohr

Senators				Yes	No		Representatives				Yes	No
Senator Lee				X			Representative Rohr				X	
Senator Clemens				X			Representative Tveit				X	
Senator Hogan				X			Representative Schneider				X	
Total Senate Vote				3	0		Total Rep. Vote				3	0

Vote Count Yes: 6 No: 0 Absent: 0

Senate Carrier Senator Lee House Carrier Representative Rohr

LC Number 21.0957 . 02004 of amendment

LC Number 21.0957 . 05000 of engrossment

Emergency clause added or deleted

Statement of purpose of amendment

Autism spectrum disorder waiver and voucher programs addition.

Insert LC: 21.0957.02004
Senate Carrier: Lee
House Carrier: Rohr

REPORT OF CONFERENCE COMMITTEE

SB 2256, as engrossed: Your conference committee (Sens. Lee, Clemens, Hogan and Reps. Rohr, Tveit, Schneider) recommends that the **HOUSE RECEDE** from the House amendments as printed on SJ pages 1313-1314, adopt amendments as follows, and place SB 2256 on the Seventh order:

That the House recede from its amendments as printed on page 1313 of the Senate Journal and pages 1437 and 1438 of the House Journal and that Engrossed Senate Bill No. 2256 be amended as follows:

Page 1, line 1, after "developmental" insert "disability"

Page 1, line 2, replace "; and to provide an appropriation" with "and autism spectrum disorder waiver and voucher programs"

Page 1, line 5, after "**SERVICES**" insert "**- AUTISM SPECTRUM DISORDER WAIVER AND VOUCHER PROGRAMS**"

Page 1, line 6, after "regulations" insert "and services"

Page 1, line 7, after "disabilities" insert "and individuals with autism spectrum disorder"

Page 1, line 10, after "disability" insert "and individuals who have an autism spectrum disorder"

Page 1, line 13, after "sources" insert ", including the federal Medicaid 1915(i) state plan amendment"

Page 1, line 15, after "new" insert "or modified"

Page 1, line 15, remove "and"

Page 1, line 18, after "implementation" insert "; and

- e. The elimination of the autism spectrum disorder task force, including contracting with a private, nonprofit entity that does not provide autism spectrum disorder services to facilitate and provide support services to the autism spectrum disorder task force"

Page 1, line 19, after "2." insert "In conducting the study, the legislative management shall contract with a third party.

3."

Page 1, remove lines 22 through 24

Page 2, remove lines 1 and 2

Renumber accordingly

Engrossed SB 2256 was placed on the Seventh order of business on the calendar.

21.0957.02004

FIRST ENGROSSMENT

Sixty-seventh
Legislative Assembly
of North Dakota

ENGROSSED SENATE BILL NO. 2256

Introduced by

Senators Dever, Hogan, Lee, Mathern

Representatives Meier, J. Nelson

1 A BILL for an Act to provide for a legislative management study of the state's developmental
2 disability services; ~~and to provide an appropriation~~ and autism spectrum disorder waiver and
3 voucher programs.

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

5 **SECTION 1. LEGISLATIVE MANAGEMENT STUDY - DEVELOPMENTAL DISABILITIES**
6 **SERVICES - AUTISM SPECTRUM DISORDER WAIVER AND VOUCHER PROGRAMS.**

7 During the 2021-22 interim, the legislative management shall study state and federal laws and
8 regulations and services relating to the care and treatment of individuals with developmental
9 disabilities and individuals with autism spectrum disorder.

10 1. The study must include a review of the following:

- 11 a. The state's existing programs to identify potential pathways for individuals who
12 have a developmental disability and individuals who have an autism spectrum
13 disorder but do not meet the eligibility criteria for existing programs;
- 14 b. Gap identification with programmatic recommendations identifying potential
15 strategies to address the gaps, and potential federal and state funding sources,
16 including the federal Medicaid 1915(i) state plan amendment;
- 17 c. Efforts and services offered by other states, including the planning and
18 implementation process for any new or modified programs; ~~and~~
- 19 d. The impact of implementation and expanding of programs to address service
20 gaps, including the number of individuals impacted, cost, and timeline for
21 implementation; and
- 22 e. The elimination of the autism spectrum disorder task force, including contracting
23 with a private, nonprofit entity that does not provide autism spectrum disorder

1 services to facilitate and provide support services to the autism spectrum
2 disorder task force.

3 2. In conducting the study, the legislative management shall contract with a third party.

4 3. The legislative management shall report its findings and recommendations, together
5 with any legislation necessary to implement those recommendations, to the
6 sixty-eighth legislative assembly.

7 ~~— **SECTION 2. APPROPRIATION.** There is appropriated out of any moneys in the general~~
8 ~~fund in the state treasury, not otherwise appropriated, the sum of \$150,000, or so much of the~~
9 ~~sum as may be necessary, to the department of human services for the purpose of selecting a~~
10 ~~consultant to assist legislative management in the study related to the state's developmental~~
11 ~~services, for the biennium beginning July 1, 2021, and ending June 30, 2023.~~