

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.

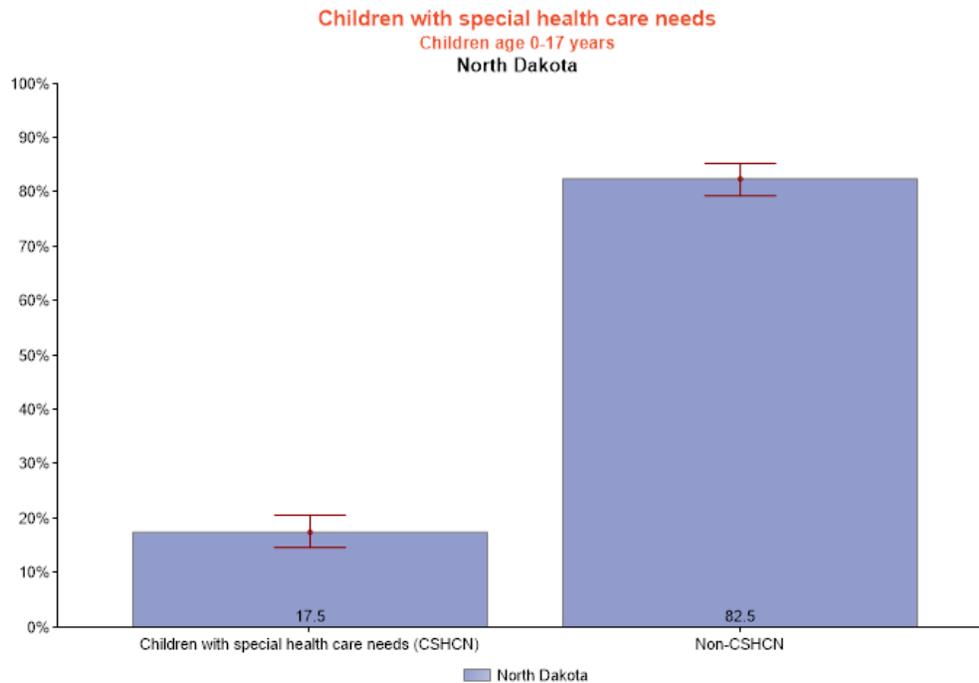
Indicator 1.11: Does this child have special health care needs (CSHCN) based on the CSHCN Screener?



	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.

Donene Feist  
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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](mailto:info@cahmi.org).

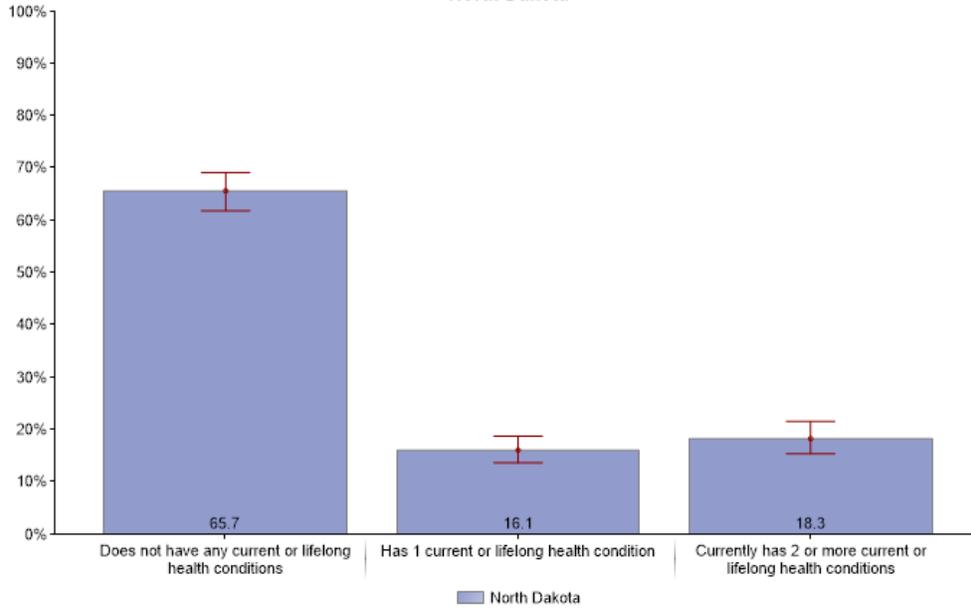
**That 27,838 have one lifelong health condition and 31,648 have 2 or more lifelong conditions.**

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.

**Number of current or lifelong health conditions**  
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](http://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?



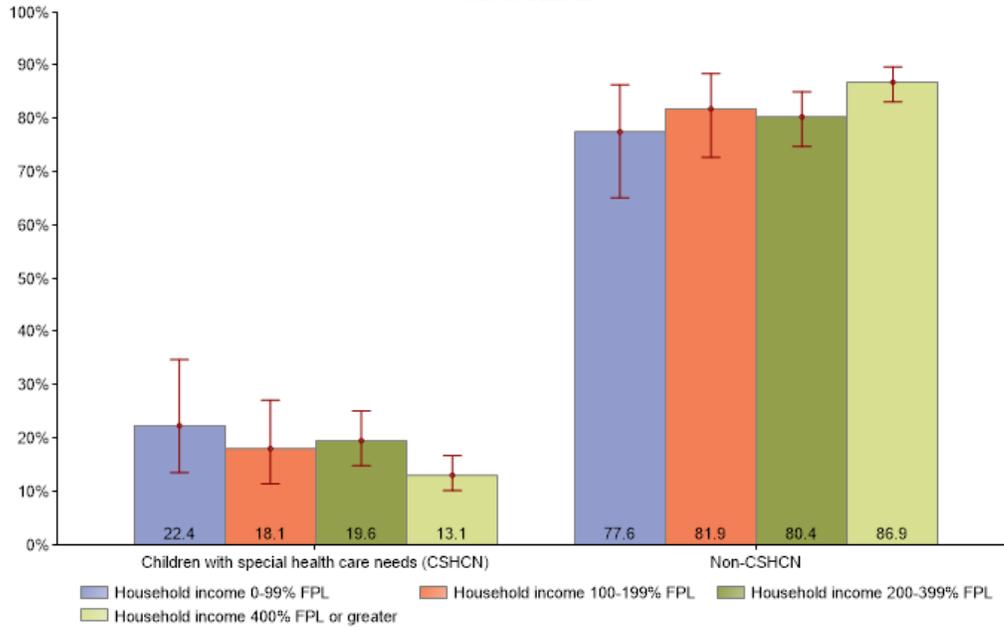
		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
<b>Public health insurance only</b>	%	32.4	67.6	100.0
	C.I.	20.8 - 46.6	53.4 - 79.2	
	Sample Count	31	49	
	Pop. Est.	7,492	15,640	
<b>Private health insurance only</b>	%	12.6	87.4	100.0
	C.I.	10.4 - 15.3	84.7 - 89.6	
	Sample Count	171	807	
	Pop. Est.	16,287	112,510	
<b>Public and private insurance</b>	%	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	
<b>Currently uninsured</b>	%	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.

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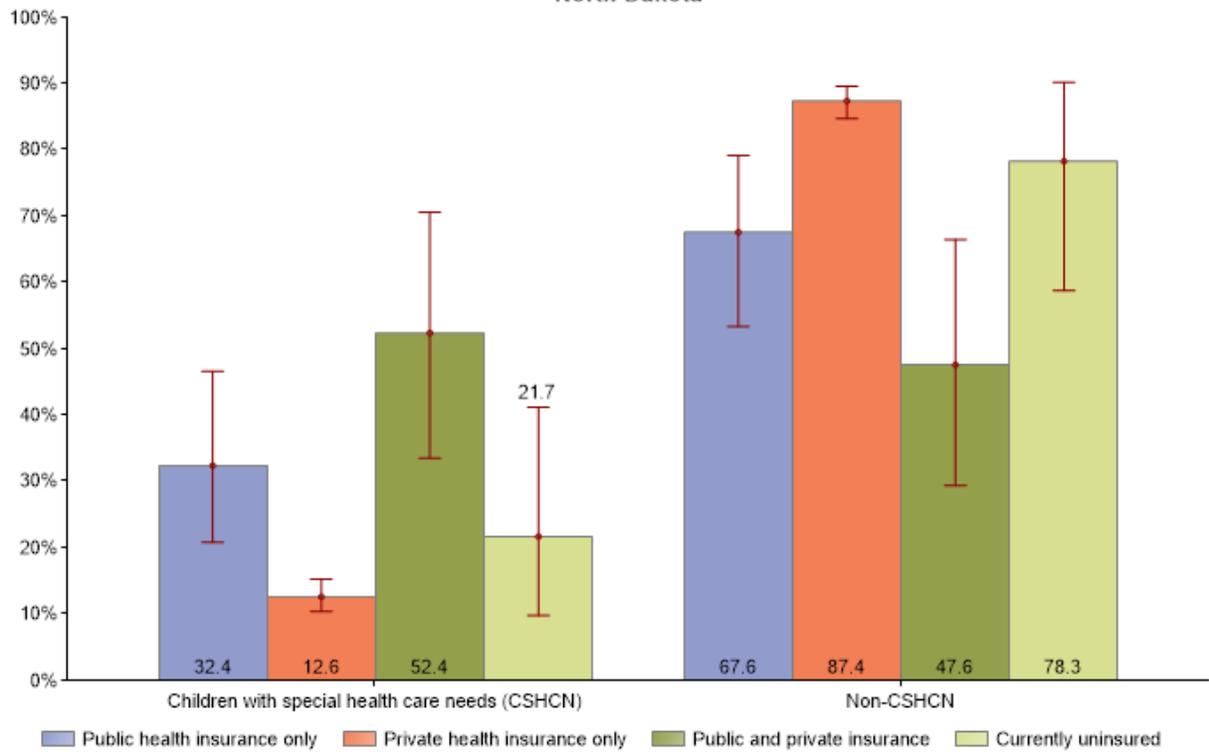
**Children with special health care needs**  
 Children age 0-17 years  
 North Dakota



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

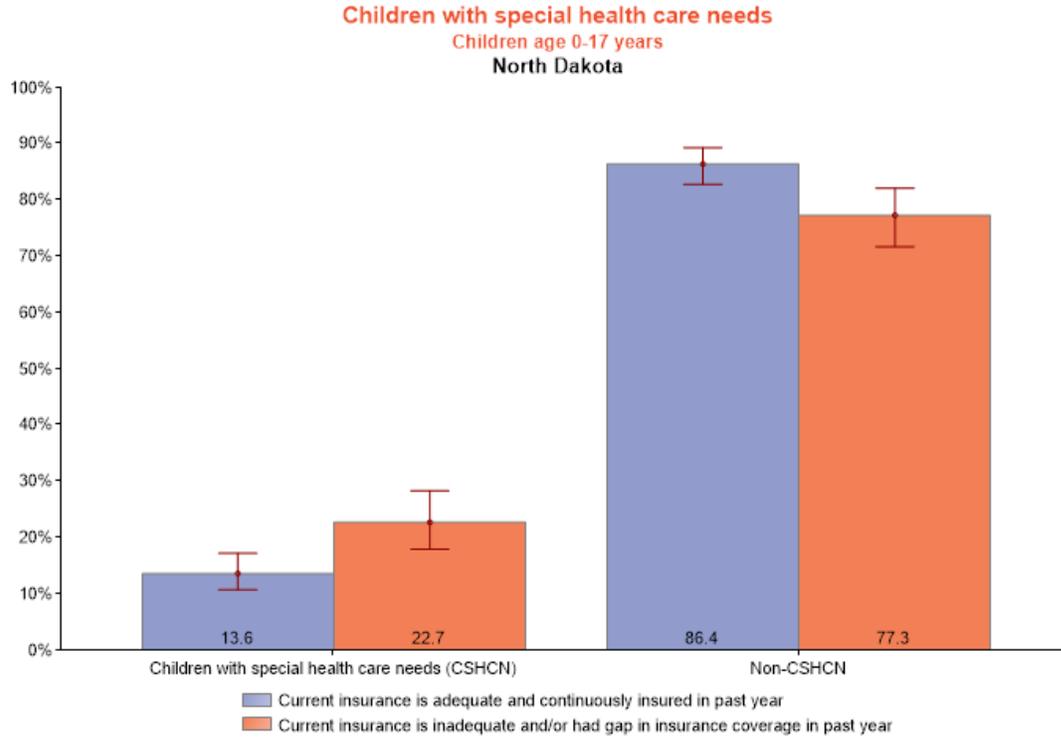
**Children with special health care needs**  
 Children age 0-17 years  
 North Dakota



**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](http://www.childhealthdata.org).

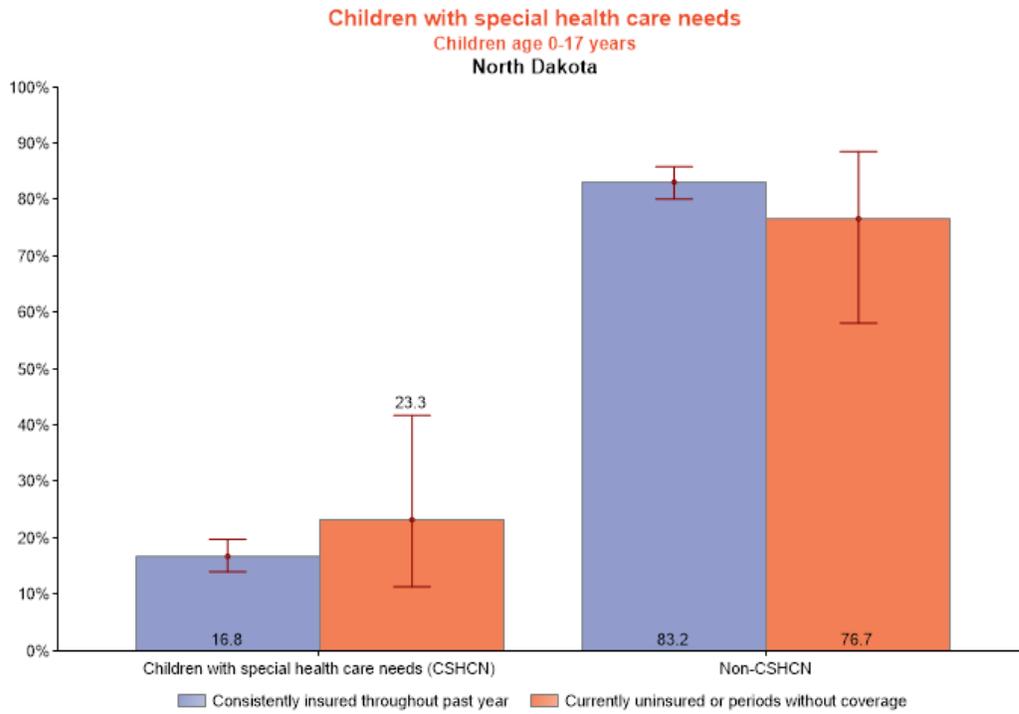
**Percent of children served who's had adequate and inadequate coverage.**



**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](http://www.childhealthdata.org).

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

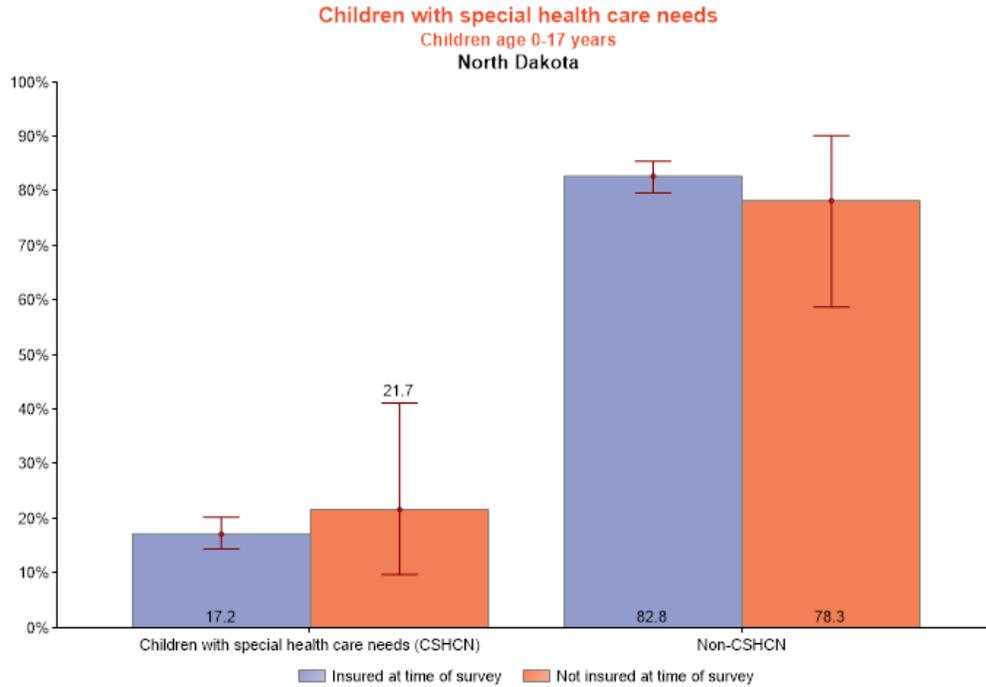


Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.hrsa.gov/data/national-surveys>

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](http://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".

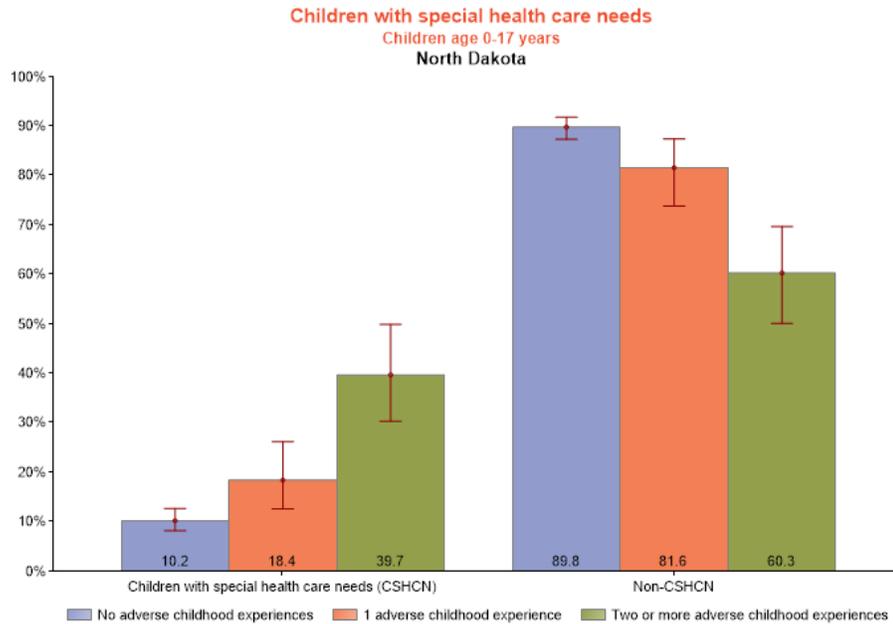


**Data Source:** National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.hrsa.gov/data/national-surveys>

**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).

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 behavioral health.

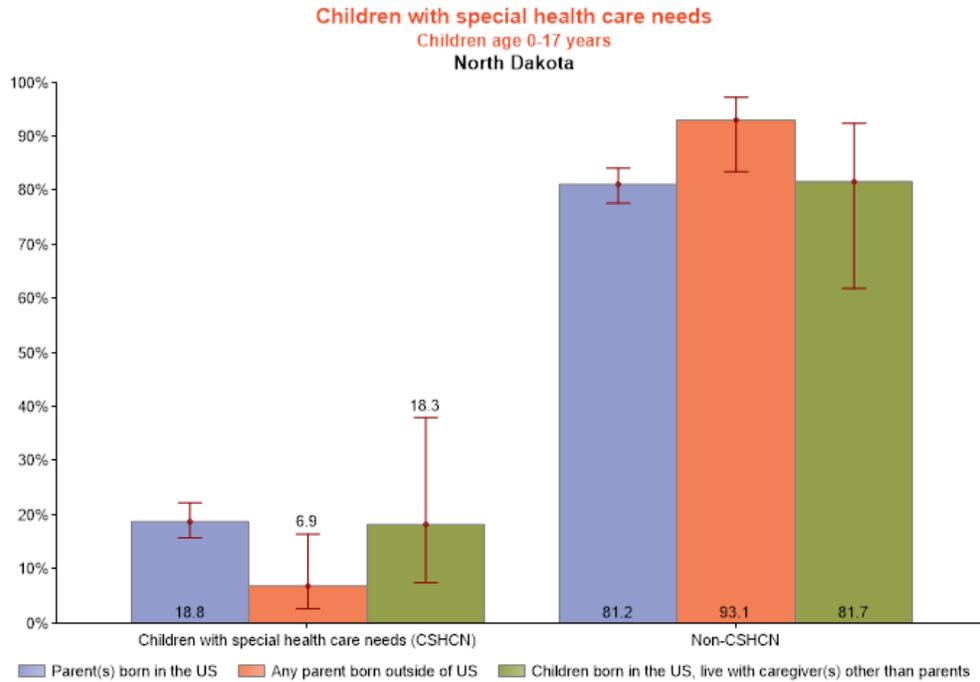
**DATA ALERT:** This ACEs subgroup includes 9 ACEs items: hard to cover basics on family's income; parent/guardian divorced or separated; parent/guardian died; parent/guardian served time in jail; saw or heard parents/adults slap, hit, kick, punch one another in the home; was a victim of or witnessed 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](http://www.childhealthdata.org).

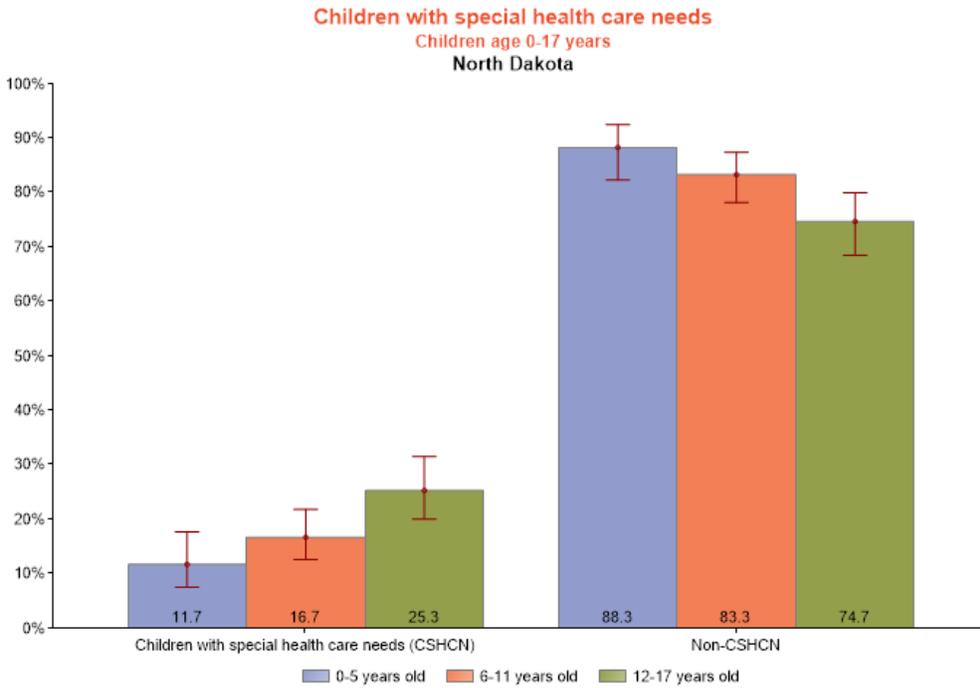
**ND demographics. Of concern here is the increasing number of children being raised by someone other than their parent is alarming. That may mean a grandparent, sibling, foster care, who may or may not have the means if the child does not have access to services.**



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).

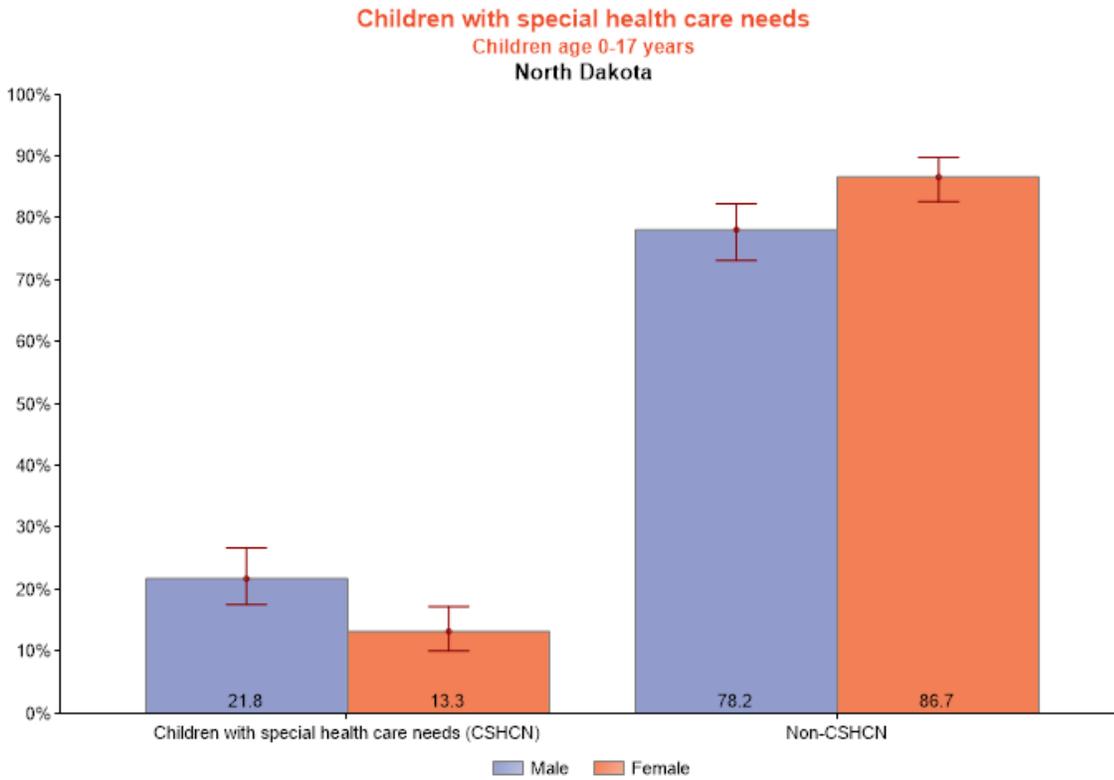
## Breakdown by age of the percent of children in each age category



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](http://www.childhealthdata.org)].

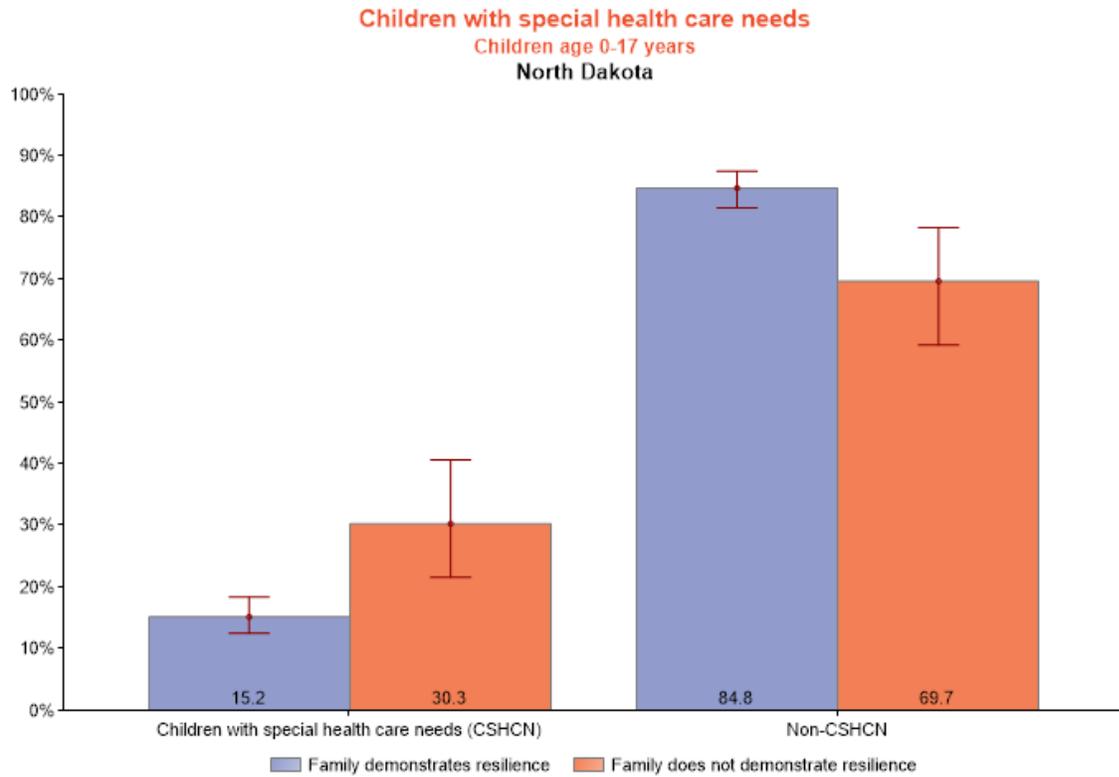
## Number of children by male/female



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](http://www.childhealthdata.org).

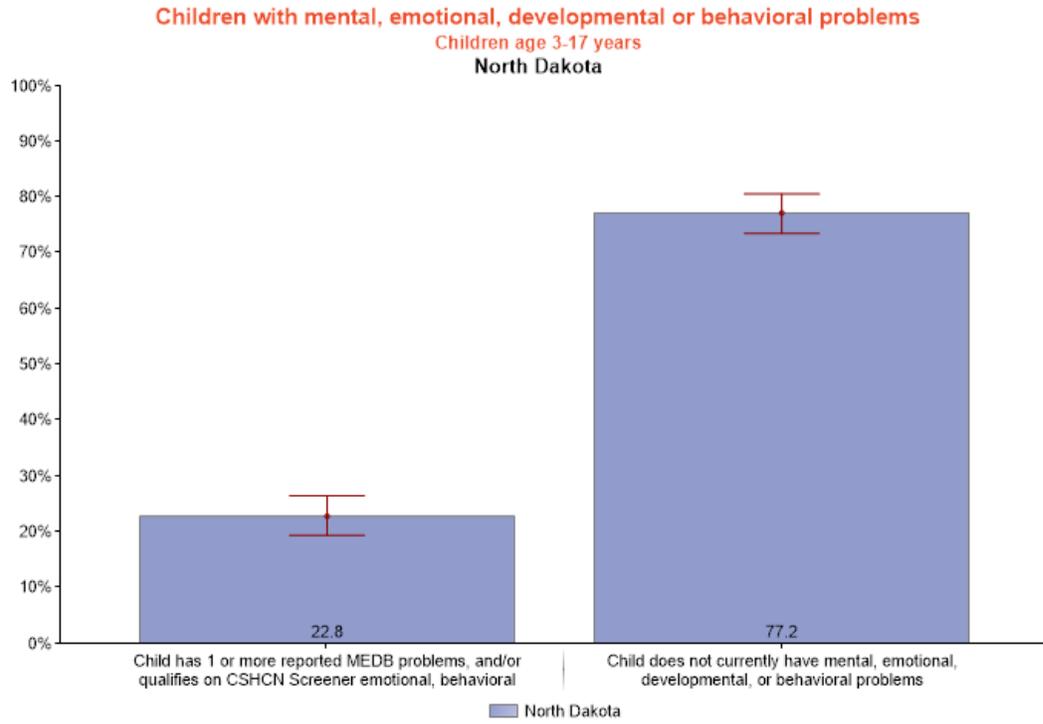
Percent of families who are able to demonstrate resilience. This is also a concerning number and we are seeing this with many of the families we serve. The needs are so vast for families and given the pandemic, that has also increased.



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](http://www.childhealthdata.org)].

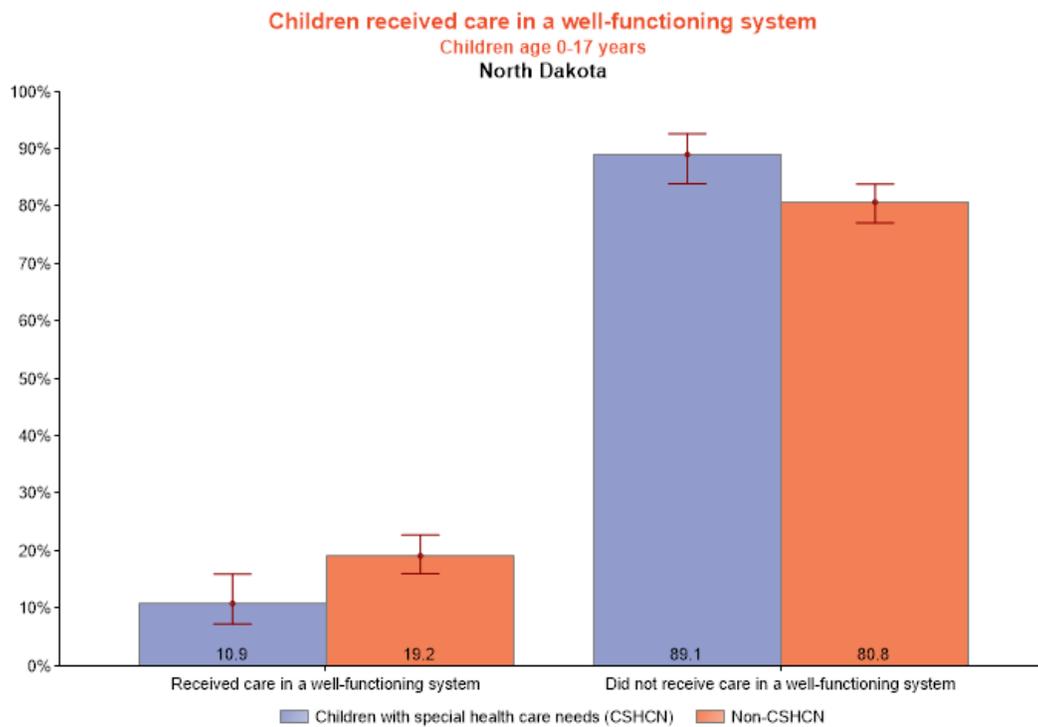
**Percent of children with emotional, developmental or behavior problems.**



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](http://www.childhealthdata.org).

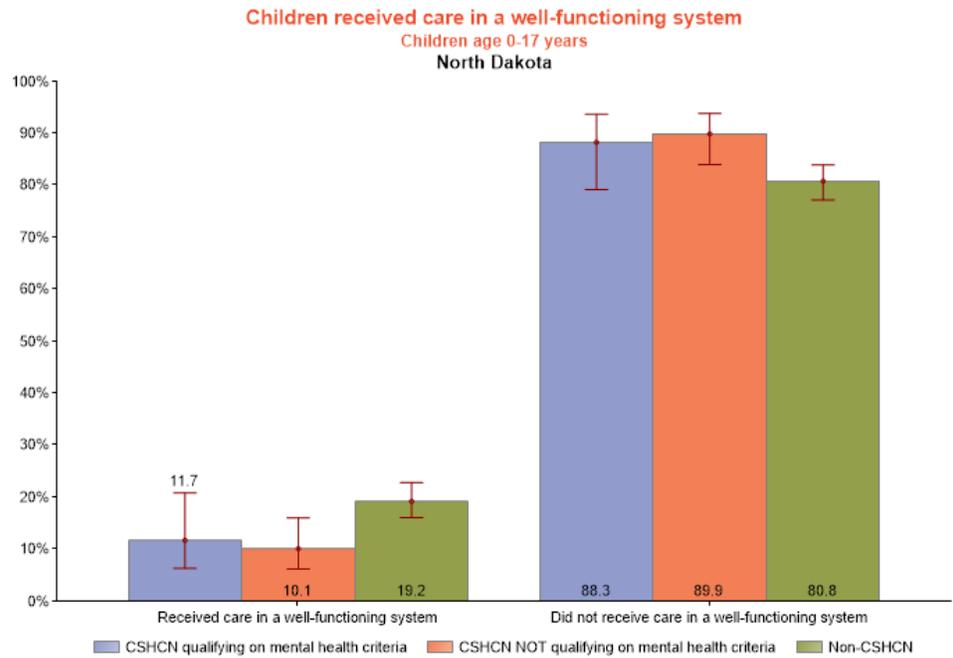
The next 3 slides are the percent of children who receive care in a well-functioning system. To me this is also some troublesome data.



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](http://www.childhealthdata.org).

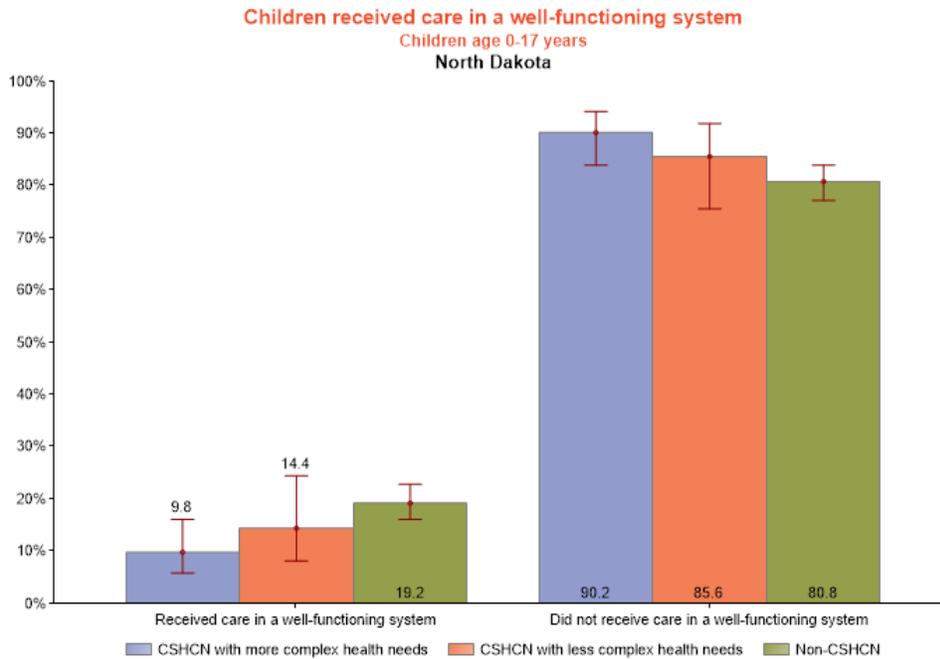
**DATA ALERT:** Children with ongoing emotional, behavioral or developmental problems for which treatment or counseling is needed are identified by the answers to two questions on the validated CSHCN Screener. For more information, email [info@cahmi.org](mailto:info@cahmi.org).



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](http://www.childhealthdata.org).

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**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.