



Testimony on HB1012
2025 Legislative Session
January 27, 2025

Rep Nelson, House Appropriations Human Resource
Committee Chairperson

Representative Nelson and members of the Committee,

My name is Donene Feist and I am the Director for Family Voices of North Dakota (FVND), Inc. I want to provide to you today testimony on HB 1012 and the Special Health Services (SHS) Division within the Department of Health and Human Services. In my testimony will be providing input on the services of the SHS Division in addition to information on Family Voices of ND and the general fund dollars that flow through the SHS Division.

Family Voices of ND provides educational, informational, and peer support to families of children with special health care needs, medically complex or have a disability. For many years, a vital partner for us as an organization is the Department of Health and Human Services, specifically SHS. Family Voices of North Dakota is statewide family to family health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center. We are that entity for ND.

National prevalence data estimates from the National Survey obtained through the Data Resource Center indicate there is an estimated 39,467 children and youth with special health care needs (CYSHCN) in ND. One in five families in North Dakota (ND) has a child with special health care needs.

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 %
%	21.8	78.2	100.0
C.I.	19.2 - 24.7	75.3 - 80.8	
Sample Count	346	1,179	
Pop. Est.	39,467	141,451	

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

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		Children with special health care needs (CSHCN)	Non-CSHCN	Total %
North Dakota	%	21.8	78.2	100.0
	C.I.	19.2 - 24.7	75.3 - 80.8	
	Sample Count	346	1,179	
	Pop. Est.	39,467	141,451	
Nationwide	%	20.8	79.2	100.0
	C.I.	20.4 - 21.3	78.7 - 79.6	
	Sample Count	26,489	82,776	
	Pop. Est.	15,144,222	57,591,048	

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

As you can see from the comparison charts we have a higher number of children with special health care needs, chronic conditions and disabilities than nationwide. <https://www.childhealthdata.org/>

The Special Health Services Division has provided services to many of the families we serve for many years. They have been a partner with Family Voices of North Dakota since its beginning in 2001. A continued investment in this program is encouraged and supported. The programs offered within the Department should not go unnoticed. It is our belief these services play a crucial role for families of

CYSHCN in the state. Services to families often serve a role in gap filling of necessary services not otherwise obtained.

Some of these services are:

Financial Coverage Program--helps families pay for medical services for eligible children. They can help pay for health visits and tests needed to diagnose many chronic health conditions. It may also provide the specialty care that is treated for an eligible condition, based on medical and financial eligibility. When there is suspicion of a diagnosis, it is a great comfort to know there is a resource that can assist with the diagnosis and treatment.

- **Diagnostic Services** – Provides coverage for services that promote early diagnosis of SHS eligible medical conditions to all children who meet medical and financial eligibility criteria.
- **Treatment Services** – Provides coverage for services to children with chronic health conditions who meet medical and financial eligibility criteria.

Multidisciplinary Clinics--our staff provides outreach to families at many of the multidisciplinary clinics. We repeatedly hear from families how wonderful it is to have these clinics throughout the state. These clinics allow families to see a number of providers regarding the child's condition along with expertise in a manner that is easily accessible. Seeing providers at one time, avoiding multiple appointments decreases stress for the family. Examples of these clinics: Asthma, Down Syndrome, Cleft Palate, Spina Bifida, Cerebral Palsy, Muscular Dystrophy, and Cystic Fibrosis. Families remain positive regarding these clinics and are grateful that they are available across ND.

Russell Silver Syndrome and Metabolic Food Program--the Metabolic Food Program provides medical food and low-protein modified food products to individuals with Phenylketonuria (PKU) and Maple Syrup Urine Disease (MSUD). Russell Silver provides growth hormone treatment for children with Russell Silver Syndrome.

In addition to the services above provided, they also partner with many efforts across the state such as: Autism initiatives, Newborn Hearing Screens, Newborn Screens, and Medical Home initiatives. The Division provides to other agencies and community members a wealth of knowledge in implementation of care for children and youth with special health care needs and disabilities.

Newborn Screening and Follow-up--program is to identify conditions at an early age when treatment and intervention can prevent health problems, support early

development, and save lives. Newborn screening is a very important test that every baby can benefit from. The testing involves a heel prick on a newborn between 24 and 48 hours after birth that can identify certain metabolic or genetic disorders that can cause serious illness, disability or death to the baby if not identified early. Newborn screening is a screening test and if there is an abnormal result, the newborn always requires further testing to confirm whether he or she has a disorder. There is a treatment available for all of the disorders that are screened, although some treatments may be lifelong.

Newborn screening consists of three simple tests:

Blood Spot – Newborns are screened for nearly 50 genetic and metabolic conditions.

Hearing Screening – Newborns are screened for hearing loss.

Pulse Oximetry Screening – Measures the amount of oxygen in a newborn’s blood and can identify serious heart problems. This is also known as Critical Congenital Heart Disease (CCHD) screening.

Family Voices of ND plays a role as advisory members of the New Born Screen and Early Hearing Detection and Intervention. In both of these programs we assist with care coordination for these new families as they are receiving a new diagnosis and connection to services and follow up.

Care Coordination-Care coordination provided through SHS helps families access services and resources in their community, and when needed, across multiple service delivery settings. Although the primary focus of the care coordination is on the health care of the child, this service also attempts to meet the needs of the family.

There are many children who have very complex medical needs. The needs for families are many. While FVND also provides care coordination assistance, it cannot be understated, that care coordination for children with special health care needs is a vital component to continued access of services. The needs are very much increasing each and every year.

Family Advisory-SHS has a family advisory committee. This committee advises and provides valuable input as family members on the ongoing services that is provided by the SHS Division. These families also provide valuable input to any changes that may take place and how would this affect families. There are not enough words that can be expressed for the valuable input of this committee. It also

cannot be understated the enormous respect that the Division provides as equal collaborative partners at the table to families for their input. In my opinion a model for other state agencies. The SHS Division truly embrace family-centered care and the components of it.

In addition to the programs that are provided through SHS, it also is charged by the federal government to monitor and provide education and services on the following six core outcomes of children with special health care needs. The SHS Division has the expertise and knowledge, as well as partners, in all these areas. We encourage the legislative body moving forward on legislation for children with special health care needs to understand the following core outcomes and the technical assistance that can be provided by SHS.

Six Core Outcomes for children with special health care needs:

1-Children with Special Health Care Needs (CSHCN) whose families are partners in shared decision-making for child's optimal health. In all of SHS' work, the value placed on family is immeasurable.

2-CSHCN who receive coordinated, ongoing, comprehensive care within a medical home. SHS has provided expertise and continues to participate in development of medical home and the importance of comprehensive care.

3-CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need. SHS understand the critical importance of both private and public funding to assure care for this population.

4-CSHCN who are screened early and continuously for special health care needs. SHS embraces the importance of identifying and treating children early and continuously.

5-CSHCN who can easily access community-based services. Many of the issues that both SHS and FVND hear from families are access to services. In ND, in a geographically vast state, access is not always easy. ND also does not always have the specialty providers available needed by this population of children.

6-Youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence. This is crucial for our youth who are transiting into adulthood.

While policies are fluid and ever changing we have moved beyond the Six Core Outcomes of children with special health care needs to a Blueprint for Change by the Federal Maternal and Child Health Bureau. The Blueprint for Change presents a vision for how to improve the system of services for CYSHCN through improved equity, access, quality of life and family well-being and financing. For more information on the Blueprint for Change a link to the National Center is here:

<https://www.aap.org/en/patient-care/national-center-for-a-system-of-services-for-children-and-youth-with-special-health-care-needs/>

SHS supports school nursing initiatives and promotes the connection between health and academic achievement by ensuring nursing care is safely and effectively delivered to schools, particularly in rural communities.

The SHS Division is a model program that provides a great deal of services with a limited budget. FVND over the years has participated in the Block Grant and Needs Assessment process, which the Division takes very seriously. I hope you would consider an increase in the investment made to this program. It makes a huge impact for families of children with special health care needs and the children themselves. It is a model for agencies to replicate. Your ongoing support for this program is vital to families and children.

For the new members of the committee a little about Family Voices of North Dakota. We are one of three statewide parent organizations in the state. Last biennium we received \$175,000 in general funds that flowed through the SHS Division.

In addition to the support and 1:1 assistance we provide to families, we also provide various trainings and workshops, which help families understand how systems work so that they can also be good stewards of state dollars and the programs of which their children are enrolled. This is done under the Family to Family Health Information Centers. There is one Family to Family in every state across the country. We are a chapter of Family Voices National who oversees all of the Health Information and Education Centers.

Our staff, who all are parents to children with special health care needs, medical complexities and disabilities provides assistance to families by helping them access and navigate services; explaining what the services mean, how systems work, and where the funding comes from. We provide emotional support to assist with their unique and individual needs. In many ways, we also have an Ombudsman type resource as when things go awry or something goes wrong our staff are often who is contacted to help them sort through and navigate this very complex system of care. We have staff in Fargo, Grand Forks, Bismarck, Dickinson, Williston and myself in Edgeley. Staff in Bismarck cover the Minot area, and I cover the Jamestown and Devils Lake area.

All of our services under the auspices of the statewide health information and education center are performed through a parent-to-parent or peer to peer mechanisms through our staff. Additionally, we operate a parent-to-parent matching program called North Dakota Parent-to-Parent which provides connection of one parent to another as a mentor for emotional support. Sanctioned by Parent to Parent USA. Additionally, in partnership with Designer Genes since 2012, we provide support through a project called Project Carson. Project Carson provides emotional and informational support to families who may receive a *prenatal diagnosis or an at birth diagnosis*.

Families desperately need a place to go to get the help that they need. We often encounter families who are in crisis and experiencing difficulty accessing services because of denials and ineligibilities.

Again according to the 2022-2023 National Survey of Children's Health, there is approximately 39,467 children and youth who have a special health care need. FVND follows the Maternal and Child Health definition of children with special health care needs, which is those children and youth who have a chronic condition of at least one year, a physical disability or mental health/behavior health diagnosis. Additionally, there are many children and youth who may have a physical disability and a chronic health illness but also may have a co-occurring mental health diagnosis. Because of many families have a co-occurring condition, it often leaves families having to understand and navigate many systems and complicated silos. We receive our referrals through agencies, physician offices, out of state hospitals where a child/youth may be receiving services.

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

		CSHCN who receive care in a well-functioning system	CSHCN who do not receive care in a well-functioning system	Total %
CSHCN qualifying on mental health criteria	%	17.4	82.6	100.0
	C.I.	10.5 - 27.5	72.5 - 89.5	
	Sample Count	23	144	
	Pop. Est.	3,642	17,285	
CSHCN NOT qualifying on mental health criteria	%	21.2	78.8	100.0
	C.I.	14.5 - 30.0	70.0 - 85.5	
	Sample Count	34	145	
	Pop. Est.	3,938	14,603	

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That data also indicates that:

29.1% of this population utilize public insurance (this may include income eligible Medicaid and waived Medicaid)

17.5% use only private insurance

50.2% of this population use both private and public

27.2% of this population were currently at the time of the survey uninsured.

The number of uninsured for this population has doubled since my last testimony. One of the reasons may be that from the start of the pandemic as it was deemed a public health emergency, they may have been covered through public insurance.

People cannot access what they do not know exists. In essence, we do assist families, one of our most vulnerable population in accessing services they will need in raising their child with a chronic illness and disability. A common theme we here from families is they were not told where to go to access services. If we were not available to provide that assistance, who then would provide this service to families?

Total Encounters of all calls from 6/1/22-5/31/24	6/1/22-5/31/24		
<i>Families unduplicated</i>	2302	First time callers or new families to us	
<i>Families duplicated</i>	20704		
Of the total number of families served/trained, instances of service related to the following issues:			
Individualized assistance (Includes one-on-one instruction, consultation, emotional support, care coordination and mentoring)	9896	Partnering/decision making with providers	15042
Basic contact information and referrals	340	Accessing a medical home	4587
Group training opportunities	1772	Financing for needed health services	6133
Meetings/Conferences and Public Events (includes outreach events and presentations)	7926	Early and continuous screening	3625
		Navigating systems/accessing community services easily	14528
		Adolescent transition issues	2000

As stated earlier, many times, our encounters with families are heightened because the family is in crisis. We have noted that the issues being presented by families today are being increasingly complex.

Our staff work with a large number of families who experience gaps in service, have difficulty understanding the complexities of our Medicaid systems and Medicaid waivers, and their private insurance who have children with very complex medical issues.

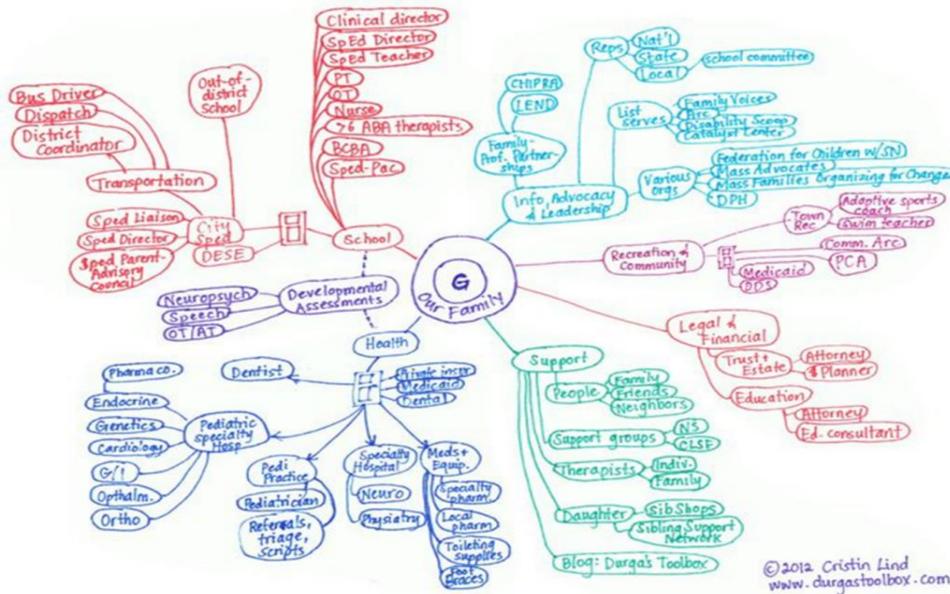
Many providers contact us to make a referral or to assist them in locating resources for families they are working with. Families often do not know where to begin. We will partner with them in making those connections to community resources, possible eligibility criteria and programs, assist them with the application process, follow up with them to assure their family needs are being met, and provide ongoing emotional and informational support.

This table is an example of the categories of calls, trainings and meetings with providers.

Table 2. Provider calls

Our organization provided health care information/education to providers to assist them in better providing services for CSHCN	6/1/22-5/31/24
<i>Professionals unduplicated</i>	1532
<i>Professionals duplicated</i>	22479
Of the total number of providers served/trained, instances of service related to the following issues:	
Partnering/decision making with providers	14947
Accessing a medical home	4084
Financing for needed health services	7316
Early and continuous screening	4116
Navigating systems/accessing community services easily	12416
Adolescent transition issues	4780

In the diagram below you will see children with a chronic condition or disability utilize many services. Most services that families encounter are in silos.



We know and can identify as best practice that families thrive when supported by others with lived experience. We also know that families build capacity, strength and confidence through support and coaching from another parent. Active engagement with families through responsive listening from others who have walked in the same shoes assists families in a manner that allows them to receive services necessary to meet their family and child's needs.

Families across North Dakota have repeatedly shared the difficulty in locating and accessing services when they call our offices. Raising a child or youth with special health care needs, accessing quality services and paying for them while still meeting the needs of the entire family and maintain employment is stressful. Following the pandemic emergency as the system changes within the Department as a whole this has been especially true. It has been most difficult for families to navigate this very complex system.

Representative Nelson and members of the committee, I have stood before you all for many years. The needs for families to live, thrive and survive in their community has also increased. We often hope for the best, but don't know what the future holds in a world and system that wasn't built for our children. There is no handbook or parenting book about raising a child with special health care needs and disabilities.

Most of our children don't fit a mold. All are uniquely their own, and many have multiple diseases or disorders so rare that often doctors have never seen. Early on families realize with a heavy heart, the world we live in isn't built for our children. Each and every day families are fighting someone about some aspect of their care. It could be a doctor, nurse, therapist, educator, or an insurance company. Every day families launch battles for what we know our children need to thrive, and sometimes our fight ends in defeat.

Every day many families are fighting a battle against a disability, disease or chronic illness that we will never beat. Most of families know the very real implications of what can happen to our children at any given time.

Our role is not only to provide support, assistance in navigating and connecting to services to families, but through or various trainings and workshops, help families understand how systems work so that they can also be good stewards of state dollars and the programs of which their children are enrolled. A valued provider has stated "It is important to ensure that there are adequate supports for families, as these strengthen the family unit as a whole. This results in a decreased demand for providers as you are creating lasting change within the family unit."

We are requesting continued support of general fund dollars through SHS. The need for family support is not going away. Do the most vulnerable families in the state not deserve assistance? Our staff does incredible work in helping families with emotional and informational support. I couldn't be prouder of them.

A few things following other testimony by Departments: We are pleased that there is funding to move forward with the Cross Disability Waiver. We feel this is a vital step in closing the gaps in many areas for our families across the state. We are pleased also with the Family Caregiver Pilot that has transpired over the interim and that we hope will become active regularly within the waiver.

We are very concerned with the decrease of dollars in the autism waiver, as were told there are still at least 68 that remain on a wait list to access the waiver and can receive as many as 15-20 new applications per month. From the number of calls that we receive regarding new families diagnosed with autism, we believe this to be true. We realize that the cause is from utilization, however we feel if respite would move

to in home supports utilization would be increased. In our other 1915c waivers, respite assists in home support according to their person centered plan. It also provides respite when a caregiver needs a break, a night out per se. Families need both. For many families with autism, they need respite for in home support which is not currently an option.

While the system as a whole particular for SNAP, TANF and Medicaid, am sure a new call center automated system is great but we hear from families and have experienced ourselves that when things go awry it is very difficult to get the answers that our families need. During the renewals at the end of the pandemic and the reauthorizations one could be on hold over an hour and still not get the assistance they needed. Just last week, one staff was on hold over 45 minutes. Some of the folks on the call center did not have the expertise needed to get the help that was needed. We have requested a specific line or toll free number for the incidents that are difficult to help navigate an error, or identify how to help a family. Specifically to speak to someone in house with that expertise. Sometimes when families are in a crisis for time sensitive information or an approval to go out of state a call center is not helpful.

We hope in the future the state will really work hard to eliminate the gaps in services for children and youth across the board. While we have made huge strides for the adult systems including the mental health system, for children and youth we feel more could be done in this area.

Families are not looking for handouts, but they often need a rope to hang on to, to keep from drowning in an every changing system. Family support and assistance in service navigation is vital to help them live, thrive and survive in an every changing world. Again, we are most appreciative of our partnership with SHS Division and their work, and DHHS who work toward filling the gaps for children.

Thank you for your consideration
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