



Testimony on HB1004
2023 Legislative Session
January 16, 2023

Rep. John Nelson, Appropriations Committee Chairperson

Rep 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 1004 and the Special Health Services (SHS) Division within the Department of Health.

National prevalence data estimates from the National Survey obtained through the Data Resource Center indicate there is an estimated 34,412 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.

Family Voices of ND provides educational, informational, and peer support to families of children with special health care needs. For many years, a vital partner for us as an organization is the Department of Health and SHS.

The Special Health Services Division has provided services to many of the families we serve for many years. A continued investment in this program is encouraged and supported. As you know SHS is administered through the Federal Block Grant Process. We hope you will consider providing increased funding for this crucial program for the state of North Dakota's children with special health care needs. 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.

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.

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. We support increased funding to expand these services. 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.

In addition to the services that they provide within the Division, 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 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.

In closing, 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.

Thank you for your consideration

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