Testimony on SB 2276
2023 Legislative Session
March 8, 2023
Representative Weiss House Human Services Chairperson

Representative Weiss and Members of the Committee

My name is Donene Feist, I am the Director for Family Voices of North Dakota. I come before you today regarding SB 2276, for an Act to create and enact a new section to chapter 50-24.1 of the North Dakota Century Code, relating to legally responsible individuals providing Medicaid waiver services.

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 by HRSA federally. We are that entity for ND.

According to the 2020-2021 National Survey of Children's Health, there is approximately 34,412 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.

The National Data Resource Center for Child and Adolescent Health https://www.childhealthdata.org/ provides clear data on the complexities of children and youth with special health care needs. It also

compliments with statistical data, information that has been provided to you all from the Alvarez and Marsal study.

The needs for our families are great. We are pleased with the outcome of that study and hope the legislative body, policymakers and families will continue to work to assure we are closing the gaps for families.

Table 1: Number of children and youth with special health care needs in North Dakota

National Outcome Measure 17.1: Percent of children, ages 0 through 17, with special health care needs (CSHCN)

	Children with special health care needs (CSHCN)	Children without special health care needs (Non-CSHCN)	Total %
%	**19.4**	**80.6**	**100.0**
C.I.	16.9 - 22.1	77.9 - 83.1	
Sample Count	334	1,240	
Pop. Est.	34,412	143,176	

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

As the diagram indicates the number of children in North Dakota who have one or two life long illness.

Table 2:

Does this child have current or lifelong health conditions from a list of 24 health conditions?

	Does not have any current or lifelong health conditions	Has 1 current or lifelong health condition	Has 2 or more current or lifelong health conditions	Total %
%	**63.4**	**19.1**	**17.4**	**100.0**
C.I.	60.2 - 66.5	16.7 - 21.8	15.0 - 20.1	
Sample Count	997	300	277	
Pop. Est.	112,634	33,983	30,971	

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

Many advocates and providers have shared over the years the gaps in services in North Dakota. The Alvarez and Marsal study did a tremendous job of aggregating those needs in their study. This illustration identifies how many of these children receive care in a well-functioning system as compared to national data.

My point in sharing this information is more and more states are already supporting a program such as this or are considering this due to the many barriers identified.

Across the country, policymakers are tackling this very issue. Children with medical complexity require a substantial amount of medical care and activities-of-daily-living support to live at home. However, due to a shrinking pool of available home health care workers and narrow state eligibility requirements for services, most of their care is increasingly delivered by families without pay. In response, the option to pay family caregivers for their children's medical labor is gaining national traction.

The National Academy for State Health Policy (NASHP) developed a brief that was published 1/15/21 ***State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid***

https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/

National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

	Receive care in a well-functioning system	Do not receive care in a well-functioning system	Total %
%	**12.2**	**87.8**	**100.0**
C.I.	8.7 - 16.7	83.3 - 91.3	
Sample Count	51	283	
Pop. Est.	4,183	30,229	

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

The next illustration is the number of families who have had to leave a job, take a leave of absence or cut down hours because of their child's health condition.

Indicator 6.18: During the past 12 months, have you or other family members left a job, taken a leave of absence, or cut down on the hours you work because of this child's health or health conditions?

		Family member cut back hours or stopped working or both	Employment not affected2	Total %
North Dakota	%	**6.1**	**93.9**	**100.0**
	C.I.	4.6 - 8.0	92.0 - 95.4	
	Sample Count	90	1,475	
	Pop. Est.	10,724	166,267	
Nationwide	%	**6.5**	**93.5**	**100.0**
	C.I.	6.1 - 6.9	93.1 - 93.9	
	Sample Count	5,820	87,012	
	Pop. Est.	4,642,802	67,130,912	

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

What we know and have heard repeatedly from families for many years are heartbreaking stories of not only families who have left a job but additionally families who have been dismissed due to their child's condition, perhaps needing more time off if their child is sick, for appointments, therapy visits, hospitalizations and care.

Day care is an additional barrier for our families. Centers are full, and despite our best efforts often times providers will also say they are not adequately prepared for many of our children. This is especially true for our families who have high medical needs and care.

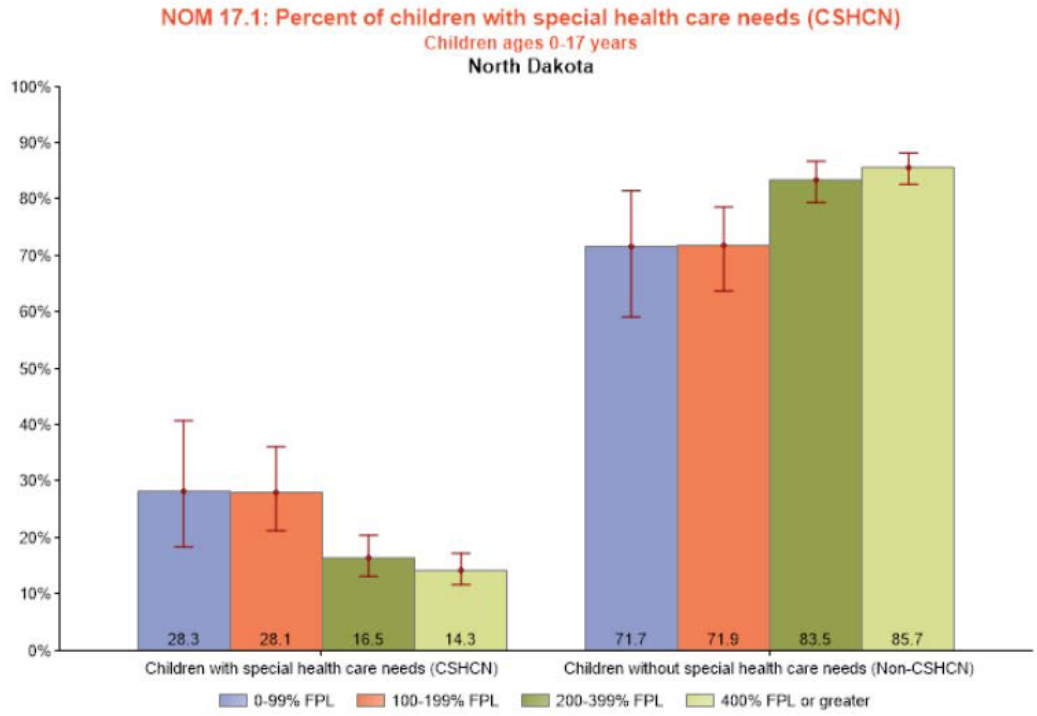
Indicator 6.17: During the past 12 months, did you or anyone in the family have to quit a job, not take a job, or greatly change your job because of problems with child care for this child, age 0-5 years?

		Yes	No	Total %
Children with special health care needs (CSHCN)	%	12.1	87.9	100.0
	C.I.	5.8 - 23.7	76.3 - 94.2	
	Sample Count	11	58	
	Pop. Est.	901	6,515	
Non-CSHCN	%	7.4	92.6	100.0
	C.I.	4.9 - 11.2	88.8 - 95.1	
	Sample Count	32	496	
	Pop. Est.	3,862	48,096	

C.I. = 95% Confidence Interval.

As you already know workforce issues impact our families tremendously. Many are struggling to hire and maintain staff. Staff availability has shrunk many times over adding additional barriers to the families we serve with complex medical needs. This diagram identifies the number of families who have left a job, taken a leave or cut hours because of their child's health condition. 6.1% of ND families fit into this category.

I also felt it is important to illustrate the federal poverty level for our families. As you can see from the diagram, families are struggling. These additional barriers for families only adds to the many complexities that families with high medical complexities face.



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. 2020-2021 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].

Passage of The Family as Paid Service Providers bill would create a pathway for legally responsible individuals to be paid to provide services to meet the extraordinary care needs of their loved one.

We believe, looking at new approaches to identify and amend gaps in services are necessary. A policy such as this will keep our North Dakota family units intact, close a workforce gap that feels at times that is getting larger than smaller. A policy such as this would also provide a consistent quality of care for our children and youth. Families are in crisis, we hear the dire needs of families who contact us for help. In neighboring states who have this option it has been lifesaving for many. Colorado and Minnesota are an example of this.

Families are not looking for handouts, but they do often need a rope to hang on to, to keep from drowning in an every changing system.

Thank you for your consideration

Donene Feist

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