



Testimony on HB 1441  
2021 Legislative Session  
February 3, 2021

Representative Lefor 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 1441

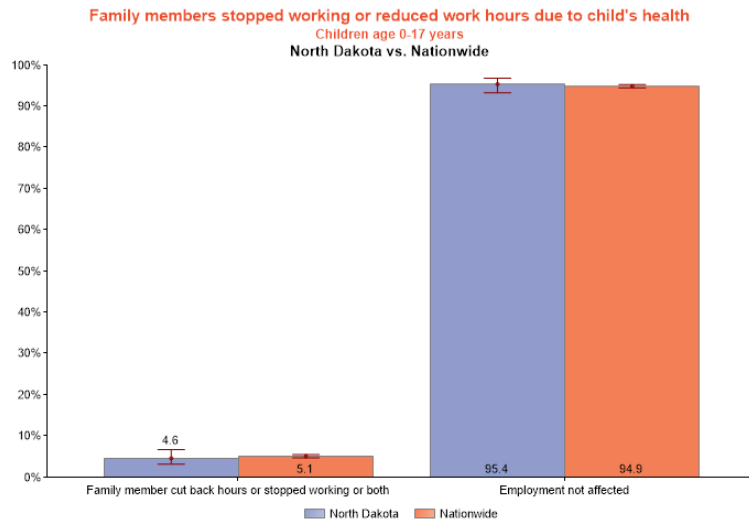
Family Voices of North Dakota is statewide family to family health information and education center who serves families of children with special health care needs in ND. Each state in the country and our territories has one family organization that has been designated as a family to family health information and education center by HRSA federally. We are that entity for ND.

We provide emotional and informational support to many families across North Dakota who have a child who has a chronic health condition and/or disability. 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. Our staff, who all are parents to children with special health care needs, 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; by providing emotional support to assist with their unique and individual needs.

National prevalence data estimates from the National Data Resource Center indicates there is an estimated 30,224 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.**

That being said for many of our families who have a child with a chronic health illness or disability, while they may have the time off, certainly does not address what happens if they do not have the amount of sick leave or vacation time to be paid.

We know and hear from many families across the state the financial impact of having a child with a chronic illness and disability. Additionally, data from the National Data Resource Center, we can identify that 4.6% of families who have a child with a disability as compared to 5.1% nationally are having to stop working or reduce hours to care for their child.



Some of these families may be a family who has a newborn that run into complications and have to be at the NICU or the PICU, for an extended amount of time. We have had families who have had to stay with their family in the cities for nearly 2 years, staying with their child while the other parent returns to work.

We have families in ND who due to the child's condition ended up in the hospital setting up to 20 times within the year, who are to medically compromised to return to a child care setting following those hospitalizations. The scenarios are many.

We assist families across the state who really are some of the most vulnerable. By and large North Dakota families are hardworking individuals who take pride in their employment and are dedicated to the employer. We as a state have always taken pride in this fact.

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. We cry in our bedrooms at night. In the dead of night, many families lie awake, overcome by fear of the unknown.

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.

More and more crowd funding has happened because of the time families are left not working and caring for a loved one. I recently read a report that of the 5 billion dollars raised by apps like Go Fund Me, 30-35% of those funds are for individuals who are paying medical bills and time away from work.

We also can identify that more and more families are caring for their own child with a disability but also caring for an aging parent. An increasing population are grandparents are raising their grandchildren who may have a disability. Family dynamics are changing.

With a fund where both families and employers pay into, to have paid leave while they are able to care for family members would be very helpful. Many caregivers are returning to their place of employment who have not taken the time to care for themselves due to having to return to their employment in order to keep milk on the table. Many return to work to avoid the loss of health insurance that cover the cost of their children's care. HB 1441 would help with that. 84% of employees across the country support a comprehensive paid family and medical leave.

We also have families who have given up seeking employment because of the care that they have to provide for their family. Many employers do not cover sick leave and annual leave benefits. This bill would provide an option for employers and employees. 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.

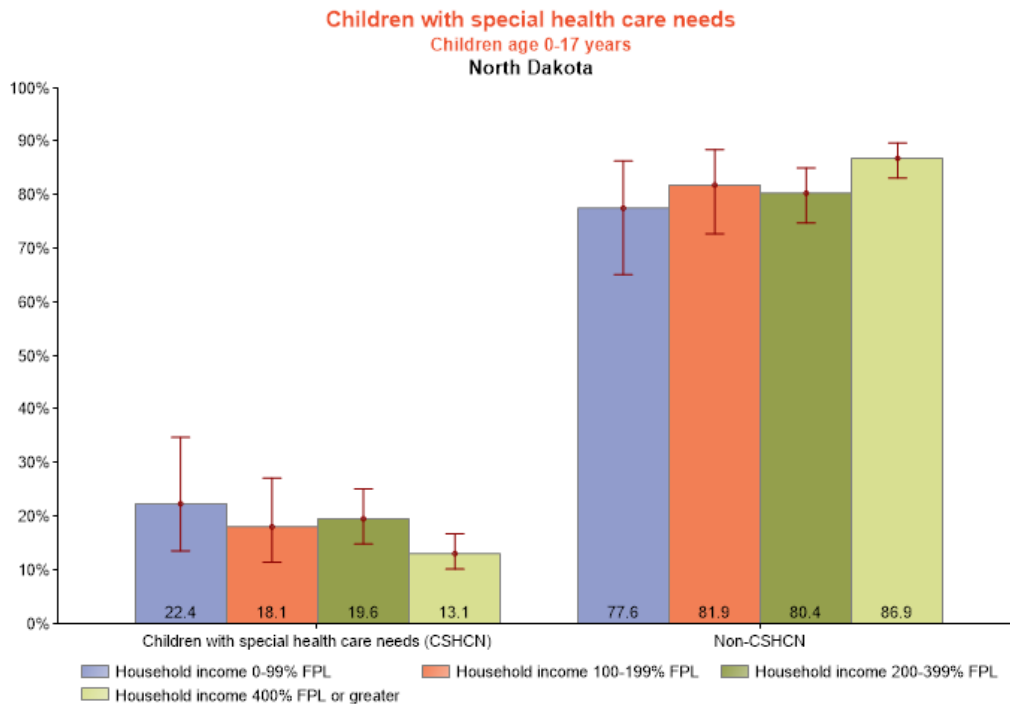
We know the financial hardships that families face. We have heard some devastating stories from families. Health costs are continuing to rise. Exacerbating the scenario even further is if they have to take leave with no pay. This bill would certainly assist the families that we serve who find themselves in this situation. It would keep families employed and not have to do crowd funding to stay afloat. To me, each and every day when I see this happening it is heart breaking. Families work hard. Lets' protect them.

In closing, let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child’s most basic human rights. 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. Let’s help them.

I have included some data below

Please support 1441

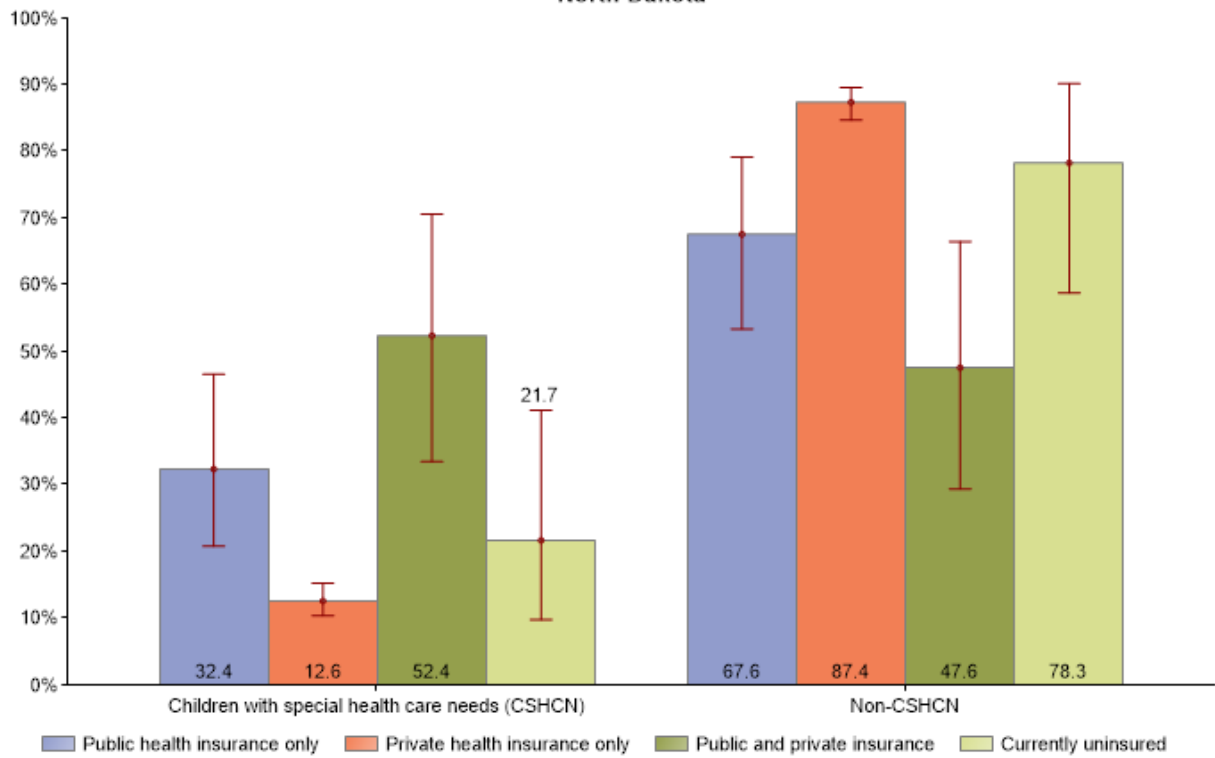
Thanks for your time,  
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Data Source: National Survey of Children’s Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.hrsa.gov/data/national-surveys>

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).

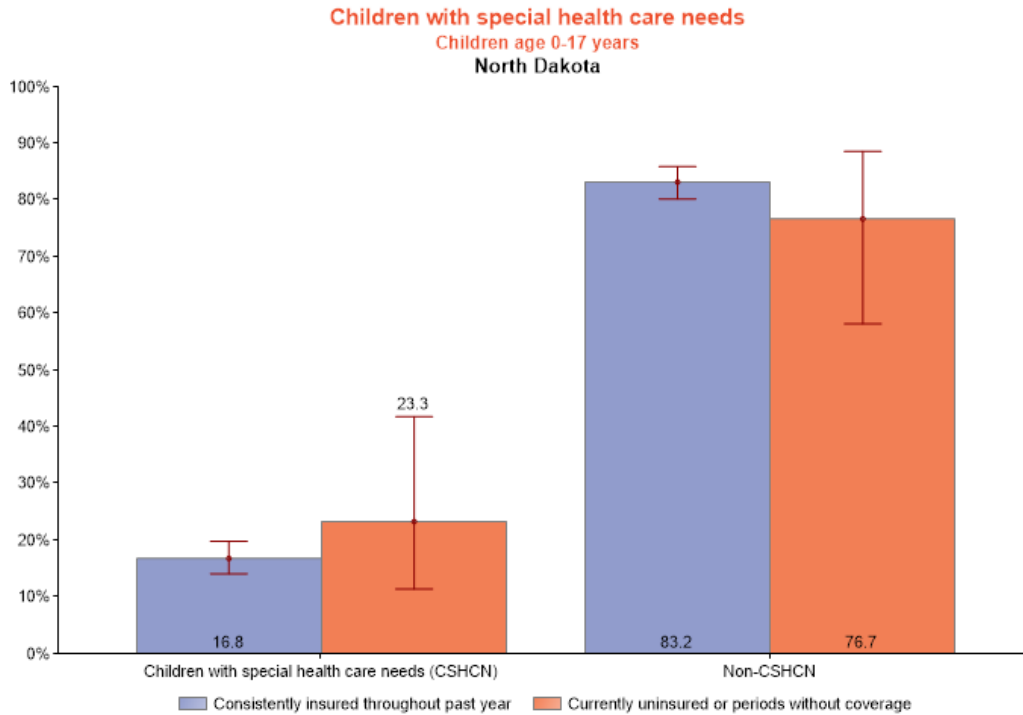
**Children with special health care needs**  
 Children age 0-17 years  
 North Dakota



**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).

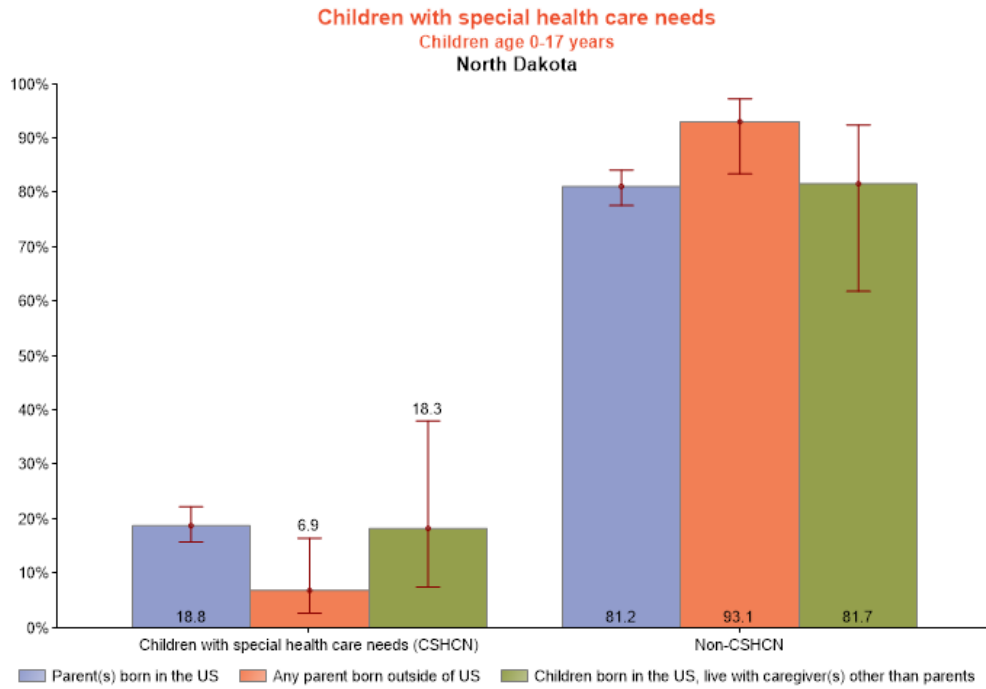
Number of children with special health care needs continuously covered. I find this diagram a bit alarming.



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).

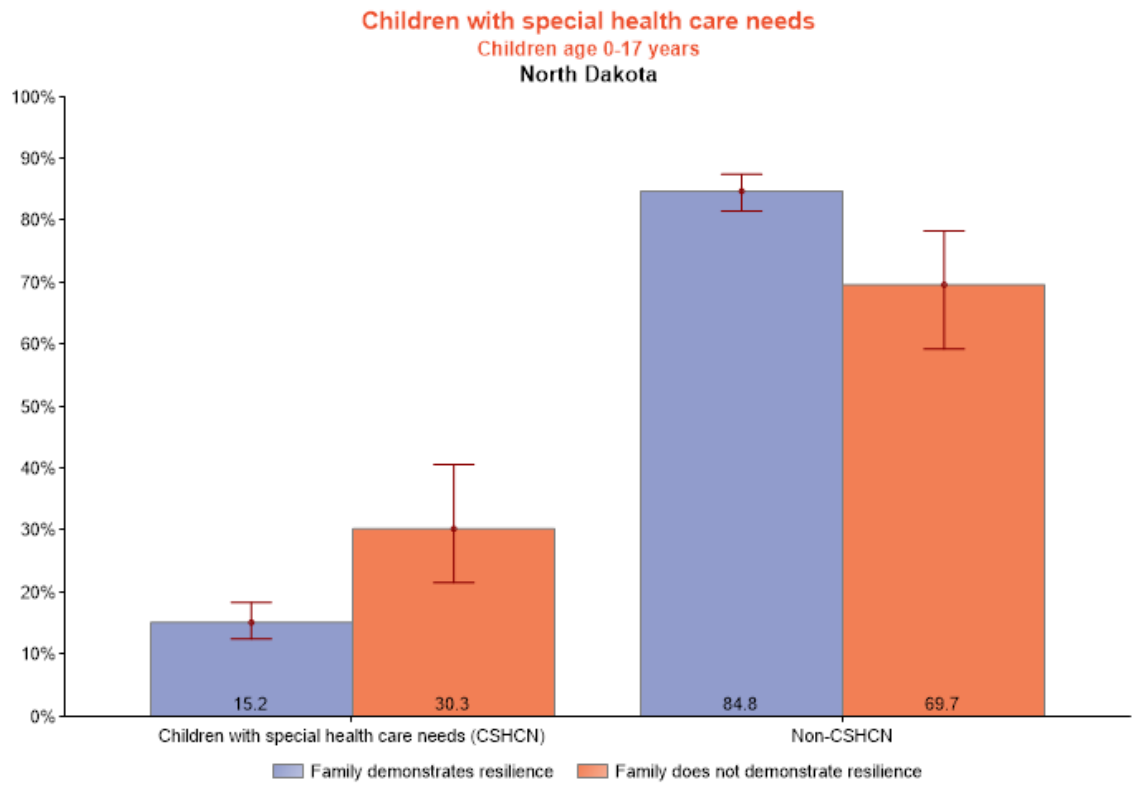
**ND demographics. Of concern here is the increasing number of children being raised by someone other than their parent is alarming. That may mean a grandparent, sibling, foster care, who may or may not have the means if the child does not have access to services.**



**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).

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>

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