

Testimony on HB 1012  
2021 Legislative Session  
January 26, 2021  
Rep Nelson, House Appropriations Chairperson

Representative Nelson 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 to regarding HB 1012.

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 parent 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.

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.

All of our services under the auspices of the statewide health information and education center are performed through parent-to-parent mechanisms through our staff. In addition, we run 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. This program mirrors the “peer support” program that you may be familiar with in the behavioral health system; however funding for peer support outside of the behavioral health system has not been prioritized.

In partnership with Designer Genes in 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.

FVND is affiliated with two national organizations: Parent to Parent USA and the Family Voices National organization, who provide ongoing technical assistance to all states across the country

We continue to experience an increase in the number of calls and requests for assistance from families and providers. On the last few pages of my testimony I have included the data we collect on the calls we receive and the help that is provided.

***We are requesting that the dollars described and removed above be placed back into the budget for HB 1012. The need for family support is not going away.*** Sadly, dollars for family support have been nearly eliminated in the 1012 budget.

Families desperately need a place to go to get the help that they need. Through funds appropriated in the 2015 session and 2017 session, we have been able to increase staff time. Current staff are assisting families across ND. Funds allocated, not only help meet increase in demands for assistance to families and professionals 1:1, but also for ongoing training, and development of educational materials. Our mailing list has steadily increased to nearly 7394 across the state.

In 2015- present we were provided flow through dollars through: **SECTION 20. GRANTS - EXEMPTION - REPORTS TO LEGISLATIVE MANAGEMENT.** The grants line item in subdivision 2 of section 1 of this Act includes \$75,000 from the general fund for a grant to a statewide family-to-family health information and education organization which provides parent-to-parent support for families and is

located in a county with a population of less than 6,000 based on the 2010 decennial census, for the biennium beginning July 1, 2015, and ending June 30, 2017. Funds awarded must be used for family-related information and education services. The organization receiving a grant under this section shall provide a report to the legislative management during the 2015-16 interim on the use of grant funds. The requirements of chapter 54-44.4 do not apply to the selection of a grantee, the grant award, or payments made under this section.

In 2017-present we were provided flow through dollars through: HB 1040 from 2017. FAMILY-TO-FAMILY SUPPORT SERVICES. There is appropriated out of any moneys in the general fund in the state treasury, not otherwise appropriated, the sum of \$100,000, or so much of the sum as may be necessary, to the department of human services for the purpose of providing funds to one or more organizations to provide family-to-family support services, for the biennium beginning July 1, 2017, and ending June 30, 2019. Funds provided under this section must be used for providing support services to families with children who have disabilities or behavioral health needs.

Most recently we have been told that we would be cut \$100,000 and the remainder would need to be put out for a Request for Proposal versus flowing directly through to our organization. We have not received an answer on why this change is occurring. This was flow through dollars through Children and Family Services.

We often encounter families who are in crisis and experiencing difficulty accessing services because of denials and ineligibilities. We end up providing assistance similar to an ombudsman because nothing like this exists for families who are raising children with special health care needs and disabilities in North Dakota.

To be clear, not all of the families that we assist receive Medicaid services. Not all of the families we serve will be served under the 1915i state plan amendment. In previous testimony, Chairman Nelson, you had asked the question of whether some general funds were eliminated due to being able to bill through the 1915i, and the response was yes. We want to be clear that this isn't always the case, as other families may have private insurance and be on one of the waivers. Some may be just on income based Medicaid. There are no two families alike.

IN 2016 ND Kids Count Data indicates that 86% of parents with children eligible to receive services are not aware of available programs. We feel that this is still an issue five years later. *People cannot access what they do not know exists.* In essence, we do the work to help families, one of our most vulnerable population the how to access the provider networks they will need in raising their child with a chronic illness and disability. Who then would provide this service to families?

Most recently, through focus groups to identify family’s needs through the Money Follows the Person initiative, we learned families needed assistance in navigating and understanding the various systems and silos, a streamlined approach, need to connect with others, application assistance and help coordinating services. We also know through a survey that we completed with DD Program Managers which revealed many of them do not know local resources and this is where FVND plays a very valuable part to systems of care.

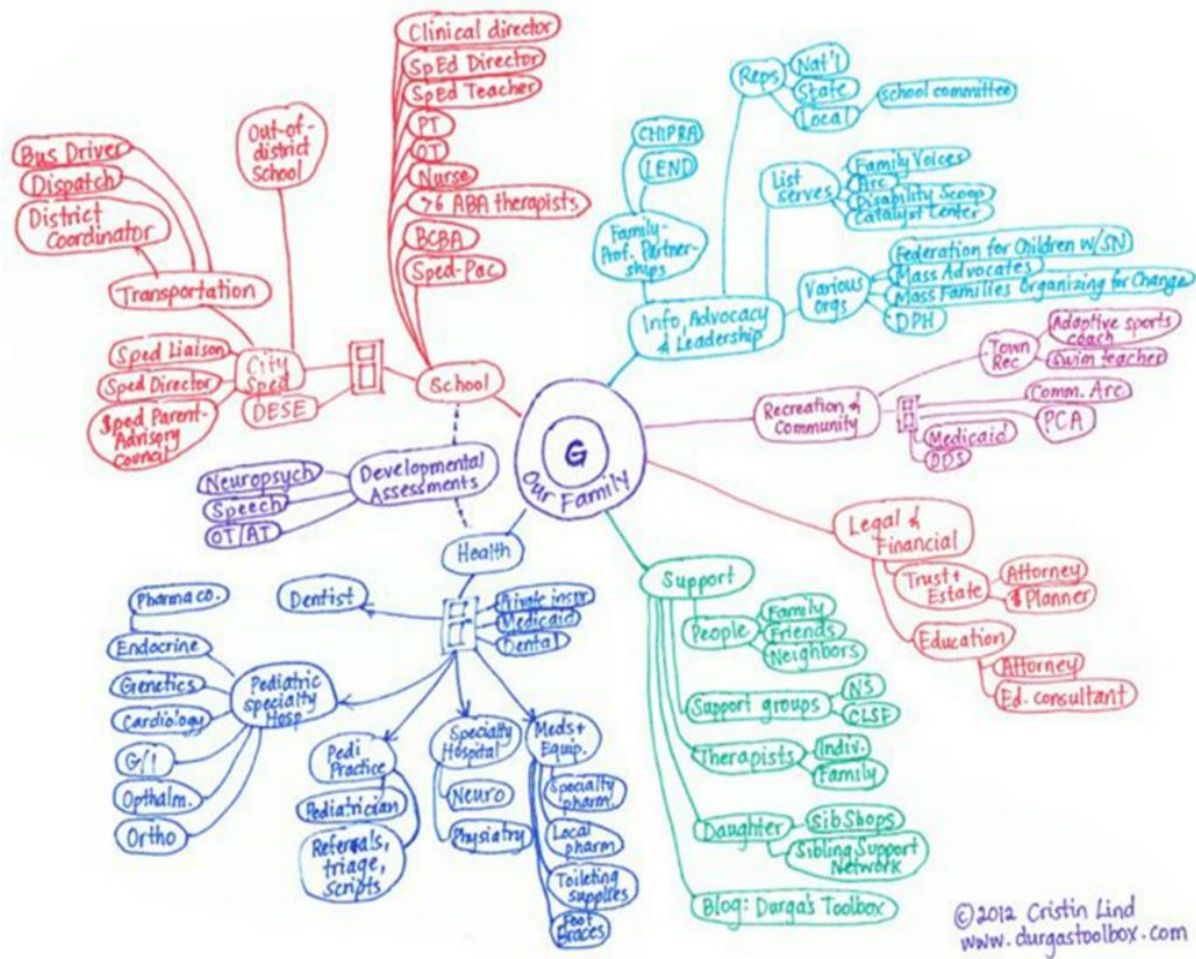
Our data collected below and on the final sheets of this testimony, is information that all staff collect and is aggregated. I share the information to help you understand the magnitude of information that we collect daily.

The included table identifies the ongoing increase in the number of calls that are received by our office. We are on our 20<sup>th</sup> anniversary as a nonprofit. Eighteen years ago, our total contacts were 518 families and 427 providers. As you can see we have had a steady increase in the number of contacts to staff from families and professionals. Our federal fiscal year is July 1 through June 30 of which this data is reflective.

<b>Total Encounters of all calls</b>	<b>2015</b>	<b>2016</b>	<b>2017</b>	<b>2018</b>	<b>2019</b>	<b>2020</b>	<b>June 1, to Dec 31, 2020</b>
<i>Families</i>	<b>2865</b>	<b>3260</b>	<b>3712</b>	<b>4026</b>	<b>4172</b>	<b>4233</b>	<b>2296</b>
<i>Professionals</i>	<b>2339</b>	<b>2499</b>	<b>2893</b>	<b>3076</b>	<b>3158</b>	<b>3273</b>	<b>2173</b>
<i>Totals</i>	<b>5204</b>	<b>6059</b>	<b>6605</b>	<b>7102</b>	<b>7330</b>	<b>7506</b>	<b>4469</b>

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.

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.



National prevalence data estimates from the National Survey obtained through the Data Resource Center indicate there is an estimated 30,118 CYSHCN in ND. One in five families in North Dakota has a child with special health care needs.

IN 2016 ND Kids Count Data indicates that 86% of parents with children eligible to receive services are not aware of available programs. We feel that this is still an issue five years later. *People cannot access what they do not know exists.*

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.

Chairman 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. 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. *All we want is for our children*

*to not have to fight so hard to simply be. Families need support often to get from point a to point b. This is an ever fluid and changing environment.*

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.

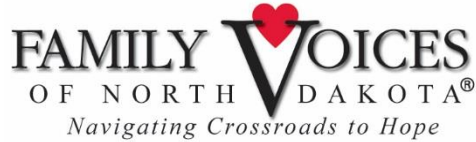
***Again, we are requesting that the dollars described and removed above be placed back into the budget for HB 1012. The need for family support is not going away.*** Sadly, dollars for family support have been nearly eliminated in the 1012 budget. Dollars for the Experienced Parent program which is in the DD Budget has also been eliminated. Do the most vulnerable families in the state not deserve assistance?

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. Family support is vital, to help them live, thrive and survive in an every changing world.**

The data shared on the last few pages are from federal fiscal year July 2019-June 2020 is to illustrate not only the number of calls but the type of information families and providers call us about. Additionally, several families we have assisted have shared information with you.

We thank you for your consideration.

Donene Feist  
FVND Director  
701-493-2634; [fvnd@drtel.net](mailto:fvnd@drtel.net)



## Family Voices of North Dakota

### Family Voices Data Report

From 7/1/2019 Through 6/30/2020

The following data has been tracked and summarized from contacts and activities recorded in FV Solutions. Please print this report and input these totals, matching the questions, along with your other information into the online Data Report Form.

#### SECTION A. UNDUPLICATED COUNTS

##### OVERALL # of Families and Professionals Served

Families	Professionals
1116	560

##### # of Families and Professionals Served by Type of Assistance

Families	Professionals	
1074	534	through 1-1 assistance
272	134	through training (identified individuals)

#### SECTION B. DUPLICATED COUNTS

##### # of Families and Professionals Served by Type of Assistance

Families	Professionals	
4233	3273	through 1-1 assistance
640	247	through training (identified individuals)

#### O1 THRU O6. # of Families and Professionals Served by Outcome

Community-Based Svcs	Families	4186
Community-Based Svcs	Professionals	3362
Financing	Families	717
Financing	Professionals	388
Medical Home	Families	718
Medical Home	Professionals	302
Partnering	Families	1513
Partnering	Professionals	4071
Screening	Families	189
Screening	Professionals	211
Transition	Families	391
Transition	Professionals	263

#### Duplicated Totals of Health Care Financing Issues Reported through 1-1 Assistance

##### Financing Issue: Denial of Coverage Service/Other

Professionals	1 Medicaid
Families	16 Medicaid

##### Financing Issue: Denial of

Professionals	2 Medicaid
Families	33 Medicaid



Families	1 Private Healthcare	Families	1 CHIPRA
Families	1 Other	Families	1 State
Financing Pgm		Families	1 Other
Public Pgm		Professionals	1 Private
Healthcare		Families	3 Private
Healthcare			

### # of Families and Professionals Served by Outcome Sub Category

	# of Families/Profs Assisted 1-1:	# of Families/Profs Trained (Tracked Individually)	# of Families/Profs Trained (Estimated)
<b>Community-Based Services</b>			
Basic Needs (food, clothing, etc)	89		
Bullying/Violence	5		
Child Care	17		
Comm Relationships-Resources	4699	621	946
Cultural Brokering	2	1	
Disability Awareness	19	5	
Disability-Specific Info	849	112	204
Emergency/Disaster Planning	107	26	
Family Support	3507	512	963
Home Care	2		
Home/Vehicle Modification	2		
Hospitals/Clinics	39	3	41
Housing	33		
Immigration/Citizenship		1	
Legal Services	102		
Other	46		
Parenting/Foster Care/Adoption	32		
Pet Therapy/Service Dogs	1		
Recreation	916	10	
Respite	209	23	
Safety/Injury Prevention	15		
Schools	696	65	
Social Determinants of Health	182		43
Special Needs Planning	15	71	
Substance Abuse	1		
Transportation	47		
Unspecified	49		
Utilities	2		
<b>Financing</b>			
CHIPRA	23	69	104
Donations/Grants	3	8	
Health Exchange	22	83	
Medicaid	436	109	207
Other	65	4	37
Other ACA	14		

Other Public	206	26	29
Prescription Assistance	1		
Private	267	4	29
Public Assistance (SSI/TANF)	113	128	
School-based	3		
State-funded	12		
Tri-CARE/Military	1		

### Medical Home

Assistive Technology	27	14	
Care Coordination	330	22	64
Child Development	45	62	
Cultural Competence	24	7	
DME	25		
Healthy Weight	1		
Immunizations/Vaccines	1		
Interpreters/ASL	2		
Life Course		3	
Medical Home (model/concept)	1	25	18
Medications	35		
Mental/Behavioral Health	429	10	
Nutrition	12		
Oral Health	8		
Other	6		
Physical Activity	1		
Primary Care	6		
Record Keeping/Care Notebooks	1	13	
Sexuality	3		
Specialty Care	54	6	
Supplies (diapers, Formula, etc)	5		
Testing	12		
Therapies	83	26	
Unspecified	12		

### Partnering

Advancing Knowledge	435	244	946
Advocacy	749	102	139
Communicating w/ Providers	2780	262	584
Cultural Competence	54	88	315
F2F Collaboration w/ Professional	1651	174	238
Family Collaboration w/ Professional	24	27	
Family-Centered Care	66	95	202
Involvement w/ Title V	494	47	610
Mentoring	98	126	120
Other	10	1	37
Parent Leadership Development	7	87	8
Systems Involvement	1113	227	1063
Unspecified	2		

### Screening

Autism Spectrum Screening	42		
Developmental Screening	64		79
Diagnostic Testing	22		

EI / IEP Screening	49		29
Genetic Testing	71	30	100
Mental Health/Behavioral Screening	17		
Neuropsych Evaluation	4		
Newborn Hearing	121		66
Other	14		
Speech/Language Screening	1		
Unspecified	1		
<b>Transition</b>			
Adult Provider	20	3	
Community Involvement	2		
Driving/Transportation	1		
Guardianship Alternatives	10	80	
Health Skills Training	20	63	15
Higher Education	15		
Independent Living/Housing	5	2	
Navigating Adult Services	142	100	95
Other	14		
Person-Centered Planning	4		
Relationships/Socialization	1	13	
School Transitions	45	18	95
Self-Determination/Self-Advocacy	9		80
Sexuality/Sexual Safety	28	15	
Special Needs Trusts	3	68	
Suicide Prevention	12		
Teen Councils / Leadership	12		
Unspecified	137		
Vocational / Employment	23	16	80

**Total # of Hardcopy Materials Disseminated**

Total Materials Disseminated Through 1-1 Assistance: 1718

Total Materials Disseminated Through Activities: 55262

Total: 56980

**Total # of Trainings:** 144

**Total # of Meetings (not including Trainings):** 518

To the Members of the House Human Resource Committee,

Three years ago, my six year old daughter, Addilynn, was fighting for her life in PICU in Minnesota after seizures nearly took her from us.

Four years ago, I attended the Parent Leadership Institute through Family Voices of North Dakota. I have also reached out to their staff on numerous occasions for guidance and support.

Both of these moments have changed my life and my daughter's. Addilynn has a very rare genetic disorder that causes developmental delays and difficult to treat epilepsy. My ability to advocate for her changed dramatically after attending the Parent Leadership Institute. It has helped Addilynn get the medical treatment, equipment and therapies she needs to thrive. It has helped me insure that she has qualified and competent individuals caring for her when her family cannot. Without the services that Family Voices of North Dakota provides, I would not be able to advocate for her in the manner in which I do now...which would have a great effect on her quality of life.

I urge you to reconsider the budget cuts made to the Family Voices of North Dakota programs. Family of children with special health care needs NEED agencies like Family Voices to help them navigate a confusing and sometimes scary system for their children.

I know that my daughter would not be thriving today without the advocacy skills and support that I have received from Family Voices of North Dakota.

[toby.jean.carlson@gmail.com](mailto:toby.jean.carlson@gmail.com)

To the Members of the House Human Resource Committee,

I would just like to give due praise to Family Voices of North Dakota. This particular program has been so helpful to my family on many levels.

I have a son who is now 18 his name is Kaden and he has a rare disease called leukodystrophy. He is totally dependant on us for all his care. Being a parent of a child with special healthcare needs can be very overwhelming, which is why programs like Family Voices are absolutely vital to families in ND.

I have many stories I could share of the help they have delivered, but I will tell the one that really introduced us to them and what they stand for. In 2010 my son Kaden suffered a brain hemorrhage and needed brain surgery along with months of recovery. It was the most afraid and overwhelmed I ever have been. In that moment I called Family Voices for guidance and support and they were there for my family.

They went above and beyond in support and pointing me in the direction I needed to go. They were amazing in their ability to jump in and really be there. I have used their services for many things from emotional support, help in guidance through the medical system, training me to be a better parent to my son, and help in general questions.

I have worked with many non-profit organizations, and Family Voices has been the most efficient and caring. I can't express enough how much FVND has meant to our family. I know if I call them tomorrow with a question it will be answered. In a world with a lot of runaround that means so much. They are worth every bit of funding and need to stay as a big presence in our state. As a parent I am so grateful for them!!

Amanda Burner

Minot ND

[amanda.burner@outlook.com](mailto:amanda.burner@outlook.com)

To the Members of the House Human Resource Committee,

We are so thankful for Heather Wheeler staff of Family Voices of ND in Williston.

Our family has been blessed with a beautiful little boy who is now 6 years old who faces many challenges due to his disabilities, including Fetal Alcohol Syndrome, Autism Spectrum Level 2, ADHD and anxiety.

As we embrace these challenges along side him we have often felt lost, afraid and very alone. This path will never be easy, but after my first phone call with Heather, I realized that we will never be alone. There will always be someone there to help us navigate through this uncharted path and help us get back up if we fall.

In the world of FAS they say that if you know one child with FAS, you only know one which with FAS. This is because FAS is so different due to the brain damage to each child.

Heather and Family Voices of North Dakota, although she may only know Jaxson; Jaxson is who she knows well. Jaxson needs her and so do we. Thank you so much for putting this support in our lives

The Kostad family

Williston ND

[kostadcrew@hotmail.com](mailto:kostadcrew@hotmail.com)

*To Members of the House Appropriations Committee,  
HB 1012*

*I would just like to speak for a few moments regarding Family Voices of North Dakota. This particular program has been so helpful to my family on many levels. My son was diagnosed at 3 with Autism, he will be 13 yrs old by the time you read/hear this.*

*Being a parent of a child with special needs can be very overwhelming, which is why programs like Family Voices are absolutely vital to families in ND. They have been there for us guiding us thru process's and listening to frantic calls on how to deal with behaviors, schools, and helping guide us into therapies for our son. Even though he is almost 13 now and we are in a groove they are still there for us. They went above and beyond in support and pointing me in the direction I needed to go. They were amazing in their ability to jump in and really be there. I have used their services for many things from emotional support, help in guidance through the medical system, training me to be a better parent to my son, and help in general questions.*

*They aren't just there for the family member with a disability, they are there for the whole family. Specifically, recently my husband ended up in the hospital on a ventilator for 45 days with Covid. They were there thru my tears and my heartache and my joys. They listen and guide without judgement. Without them we would have been lost in the shuffle of the system. We need them so more families do not get lost in the system. They aren't just a vital part of my family; they are my family.*

*Family Voices is the most efficient and caring for the whole family. I could go on and on but there are truly a million reasons why need them. Please restore their funding because without them the state would feel a great loss. As a parent I am so grateful for them!!*

*Toby Cherney  
Jamestown ND  
[chernfamily5@daktel.com](mailto:chernfamily5@daktel.com)*

## Testimony HB 1012

Mr. Chairman and members of the committee:

My name is Stephanie Orr and I am asking you to please protect the general fund dollars that Family Voices receives in HB1012.

My family is one among many, many families within North Dakota that has been helped by Family Voices of North Dakota. I have a 10-year-old son that was diagnosed with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) in 2015. I was referred to Family Voices during one of the darkest years of our lives. I felt absolutely alone and unsure about how to move forward with this rare diagnosis. My son had been kicked out of two separate daycares for violent outbursts that he could not control. Family Voices helped me navigate my childcare options and later pointed me in the direction of Bismarck Early Childhood Education Program (BECEP), which I had never heard of before. Vicki Peterson, from Family Voices, came to our meetings with BECEP staff to help support us. We would have been completely lost without her! She ensured that my son was evaluated for services and, once he qualified, she helped make sure that his needs were covered in an IEP.

Before Family Voices stepped in, I was in way over my head. I had no experience whatsoever with disability and special education services. There are services in place to help families, but when a family is facing a new and scary diagnosis, there is no way for families to find out about those services if someone isn't there to guide them. Family Voices is that someone. Not only were they there to fight for us, but they taught me how to advocate for myself and my child. They have helped me grow in ways I could have never imagined.

Family Voices also supports parents thru their Parent Leadership Institute each year. Every parent that has attended will tell you the same thing – it changed their life. Not only have I learned a ton about advocacy and how our government and healthcare systems work, but I have made life-long friends. I now have a whole network of people in my life that are always there to help, support and encourage me.

I don't know where we would be without Family Voices. I have gained more from them than I could ever put into words. When I look back, it is really scary to think what would have happened had we been on our own. We just did not have the tools or knowledge to navigate what we were going thru. I know other families dealing with the same diagnosis across the nation that have not been so lucky and have had to institutionalize their children because they didn't know there was any other option. Family Voices has played a huge part in getting us where we are today – happy, healthy, together.

I am asking you to please help protect the funding for Family Voices in HB1012 so that more families have a success story like ours!

Thank you for your time and consideration.

Steph Orr, Bismarck [stephanie\\_orr@hotmail.com](mailto:stephanie_orr@hotmail.com)



Testimony on HB 1012  
2021 Legislative Session  
January 26, 2021  
Rep Nelson, House Appropriations Chairperson

Chairman Nelson and members of the Committee

Hello, my name is Beth Larson-Steckler and I am writing in opposition to HB1012 specifically the cut to Family Voices. I am writing as a health advocate, as an individual that worked in mental health and as well as a parent whose children have complex chronic conditions. I submit this letter with the permission of our two children: Ellyse Steckler and Josh Steckler.

My husband had a genetic condition, PRSSI, or hereditary pancreatitis. We were unaware that he carried this gene or the high rate of transmission to our children. His disease advanced and he died of pancreas cancer. Unfortunately, the gene was passed to our two children. This disease is extremely painful. There is no cure, only treatment for symptoms. Our children's health deteriorated to the point where they were constantly in the hospital. We were provided one option. The treatment was a radical treatment called Auto Islet Transplant, pancreatectomy with splenectomy.

Navigating the systems of care when you have a child with any health conditions much less complex chronic health condition is overwhelming and quite honestly brutal. The number of children with chronic health conditions has been rising nationally. Internationally and nationally, it has been recognized that organizations such as Family Voices are vital to families whose children have chronic and or complex health conditions for multiple reasons.

When a child is diagnosed with a chronic or complex condition it is overwhelming, frightening, and often isolating for parents. The medical system as well as other systems that one becomes involved in when a child receives a diagnosis can be very dismissive of families. Professionally, I worked at navigating systems of care for families whose children experienced significant mental health challenges. I saw firsthand the barriers they faced. Those barriers were often erected by those working in the mental health system, as well as systematic barriers. Many in the field had no idea what these families were dealing with. They were provided categorical services that were available, not that met their needs. Their concerns often dismissed. When I met families, they often were overwhelmed, and felt they had no voice and that their concerns did not matter. I always provided information on entities such as Family Voices that could provide support and navigation as well as connection to other parents that had similar life experiences. Family Voices advocated for these families, attended meetings with them. Educated them on their rights and made them aware of supports that those in the system had not made them aware of. With the support of Family Voices, parents found their voice; they felt empowered, they felt supported. They were assisted in navigation of a complex system. They were provided educational opportunities to learn to advocate for their child and other children. This is critical. This is NOT a 'fluff' service. What Family Voices provide is necessary and should be accessible to all families. I believe to this day, that entities are

still not providing this information to family consistently and families often must find out about this through other channels.

When our children started becoming sicker, I thought that because of my previous professional positions and knowledge I would be able to successfully navigate the health care system as well as other systems that my children needed. The sicker they became the harder it became. When my husband passed, I had no support. My children both underwent multiple transplants. The outcomes were poor. My daughter has chronic pain, brittle diabetes, malabsorption issues, gastroparesis, dysautonomia, eating issues as she was starved (per her specialists' recommendation) severe medical trauma, depression, and anxiety among other health issues. My son had chronic pain, battled C-diff for three years, tachycardia, dysautonomia, asthma, medical trauma (PTSD), malabsorption. Neither has a spleen, pancreas and they only have half a stomach. I was overwhelmed. There are only seven places that does this transplant and often those that have complications are on their own to find answers. While prior to their transplant I had support of this medical team, after with their complications, they were unsure what to do. I was on my own. Multiple specialists provided conflicting recommendations, my concerns as well as my children often were dismissed, and their education was suffering. Their mental health issues became worse because of medical trauma which impacted their health and behaviors. I continued to reach out to organizations, supports and services that I was aware of and yet no assistance was provided. Our lives became about literally fighting to survive. I was ashamed that I was failing my children.

The school filed an abuse and neglect on me. Obviously, this is not something I like to discuss as it is embarrassing. I worked in the mental health system. Again, I want to reiterate that I have asked my children's permission to share what I am sharing today. My kids missed school and a lot of it. My daughter had chronic pain as well as my son. They also had GI issues. My son fought C-diff for three years. During this period, I would struggle to get him to school. I did call the police on him several times. They would question why I was sending my son to school when he would have constant accidents. I reached out myself to social services. My daughter started not taking care of her health issues. I should have been cognizant that this was a result of medical trauma but at the time I was unaware. Even though I reached out to social services, abuse and neglect reports were filed. I was doing everything in my power to assist my kids. I had reached out to social services and asked for assistance, I had gone to the top specialists, I had accessed treatment for my daughter. Finally, at this point I reached out to Family Voices. I was lost. I was exhausted and felt I was losing my children I was afraid that they would be taken away or that they would die. Family Voices provided me support at my son's school meetings. They encouraged my voice when it was silenced. Family Voices provided me information about supports and services. They provided me training. I believed that with my education, knowledge of the system that I would be able to navigate the care my children needed. I was not. Family Voices provided me the support that many others did not. This is not uncommon. The more I have become involved in advocacy nationally and internationally I have listened to the stories of many families had multiple resources at their fingertips and they often express how marginalized they were when they advocated for their

children's health. It was organizations such as Family Voices that empowers. As parents, we are the main caregivers of our children. We have expertise in our children and our voices should be heard. We are partners.

My kids are young adults now. We still have numerous health and mental health battles, but things are better. I am Co-Founder of National Childhood Pancreatitis Foundation, state chair of North Dakota National Pancreas Foundation, member of other various national and international advocacy groups focused on treatment of chronic pain, medical trauma and other issues related to health care.

The health care and mental health care systems are becoming more and more complex. As stated, before it can be an enormous undertaking for parents to navigate systems to ensure their child is getting the necessary care. It is overwhelming, it is frightening and isolating. Family Voices is staffed with individuals who understand the experience of parents. They can truly empathize and understand the journey of a new diagnosis, navigating the systems. Family Voices has considerable expertise in the system – not as an untouched medical provider or educational provider- but someone who has experienced and knows the barriers that seem invisible to many that work in the health care system. It has been demonstrated that one of the most effective aspects for parents are organizations such as Family Voices. By eliminating funds, you are essentially eliminating the voices of parents whose children have chronic and complex needs. We need Family Voices. As a parent with a Masters in Sociology of health, a BS in psychology and criminal justices and years working to assist other families to navigate care, when I found myself in a similar position, I struggled with that navigation. Not, that I did not have the skills. The system is brutal and complex, I began to not trust myself, I became overwhelmed and depressed. Family Voices honestly, helped me get my voice back. Quite honestly, we need more funds allocated to Family Voices and more staff. As parents, we provide most of the care to our children. We ARE partners and should be treated as such. Cutting Family Voices is not only inconsistent with national and international steps working to increase organizations like Family Voices, it is silencing the voices of North Dakota caregivers, parents, and patients. Cutting allocations is cutting a lifeline of support from parents, children, and youth. This would be extremely detrimental.

If you would like to speak to me more, please do not hesitate to contact me. My phone number is 701-202-1522. You can also e-mail me at [socnavigations@yahoo.com](mailto:socnavigations@yahoo.com)

Sincerely,

Beth Larson-Steckler