

Testimony on SB 2012
2023 Legislative Session
January 23, 2023

Sen Dever Senate Appropriations Human Resources Division Chairperson

Senator Dever 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 2012.

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.

As an agency, we continue to experience an increase in the number of calls and requests for assistance from families and providers. We have received general fund dollars since 2015 through Children and Family Services.

We are requesting that the dollars described below be fully funded and distributed through the general funds process in SB2012. Both of these were maintained in the 2019 and 2021 legislative session under 2012/1012 for a total of \$175,000 in general funds via contract with DHHS.

The need for family support is not going away. The first section has been provided since 2015. Language is as follows.


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

In 2017 SECTION 5. APPROPRIATION - DEPARTMENT OF HUMAN SERVICES - FAMILY-TO-FAMILY SUPPORT SERVICES. There is appropriated out of any moneys in the general fund in the state H. B. NO. 1040 - PAGE 2 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.

Again, both of these were maintained in the 2019 and 2021 under 2012/1012 session for a total of \$175,000 in general funds via contract with DHHS.

I want to talk to you a bit more about children with medical complexities and disabilities:


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.

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.

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 %
Received care in a well-functioning system	%	13.4	86.6	100.0
	C.I.	9.7 - 18.2	81.8 - 90.3	
	Sample Count	51	267	
	Pop. Est.	4,183	27,127	
Did not receive care in a well-functioning system	%	20.7	79.3	100.0
	C.I.	17.9 - 23.8	76.2 - 82.1	
	Sample Count	283	972	
	Pop. Est.	30,229	116,018	

C.I. = 95% Confidence Interval.

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

As you can see in the above diagram, our children have many complex needs.

The diagram identifies, how many of the 34,000 children receive services in a well-functioning system of care. 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 often assisting with care coordination for their children.

About FVND:

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 designated by HRSA. 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.

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.

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. Through funds appropriated above we were able to increase and maintain staff time. An inflationary increase of 15% would be appreciated.

We often encounter families who are in crisis and experiencing difficulty accessing services because of denials and ineligibilities. 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 7800 across the state.

FVND currently as we did last session have concerns regarding the 1915i, and how many children will be screened eligible. We are also very concerned about the Department eliminating the autism voucher and moving those funds to the autism waiver. Some of the children and youth that were served through the voucher will

not be transferred to the waiver which will again cause a gap for those with an autism diagnosis. This would be a travesty for some families. There continues to be a wait list for the autism waiver, in my opinion, this would not be eliminated by moving voucher funds to the waiver and again, what happens to those children and youth who are already being served. More so we would like to see an increase in age for the autism waiver. We believe there is room for both.

We are grateful to the Senators of this committee in being one of the sponsors of SB 2256, which approved a study to be done on children and youth with a developmental disability, identifying the gaps in services and how they are being served. Many children do not qualify for the DD waiver, unless they have an ID diagnosis which leaves many children behind. Diagnosis such as Down syndrome, Spina Bifida, cerebral palsy, muscular dystrophy and autism etc. to name a few. While we have done well in trying to gap fill with the medically fragile waiver, hospice waiver and autism waiver, we have not gotten to the meat and potatoes to look at the system as a whole and how to best serve all children and youth with a developmental delay. This has been a vital need for a long time as many families continue to not receive any services. The work done with Alvarez and Marsels provides a wonderful road map in implementation and improvement of our current system.

I would also like to point out the resource section of the Alvarez and Marsal study. It referenced 2 agencies for family navigation and supports. These were Texas Parent to Parent and Missouri Family to Family, both of these entities are sister agencies across the country who provide family support in the same model that FVND does. They too are Family to Family Health Information and Education centers designated by HRSA. https://ndlegis.gov/files/committees/67-2021/23_5168_02000presentation1230.pdf

What we know through prevalence data for ND from the Data Resource Center 2020-2021 is there are approx. 34,412 children and youth who have a special health care need in ND. One in five families in North Dakota has a child with special health care needs.

That data also indicates that:

40% of this population utilize public insurance (this may include income eligible Medicaid and waived Medicaid)

14.6% use only private insurance

44.9% of this population use both private and public
 12.2% of this population were currently at the time of the survey uninsured.
 The number of uninsured for this population has dropped 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.

In previous years 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. ***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?

Most recently, through focus groups to identify family’s needs, 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 recent survey of DD Program
 Managers 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 below our last data that was pulled. Our data collection system has
 changed beginning 1/1/21. This was due to an unfortunate cyber-attack. However
 the upside was that we are now using the same data system now that our sister
 agencies across the country are using.

Table 1. Total Encounters and reasons for calls

Total Encounters of all calls 12/1- 12/31, 2022	2022		
<i>Families unduplicated</i>	2810		
<i>Families duplicated</i>	11595		

Of the total instances of service for families, we provided		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)	4016	Partnering/decision making with providers	7366
Basic contact information and referrals	320	Accessing a medical home	2167
Group training opportunities	1610	Financing for needed health services	3864
Meetings/Conferences and Public Events (includes outreach events and presentations)	4952	Early and continuous screening	2560
		Navigating systems/accessing community services easily	7077
		Adolescent transition issues	1184

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,

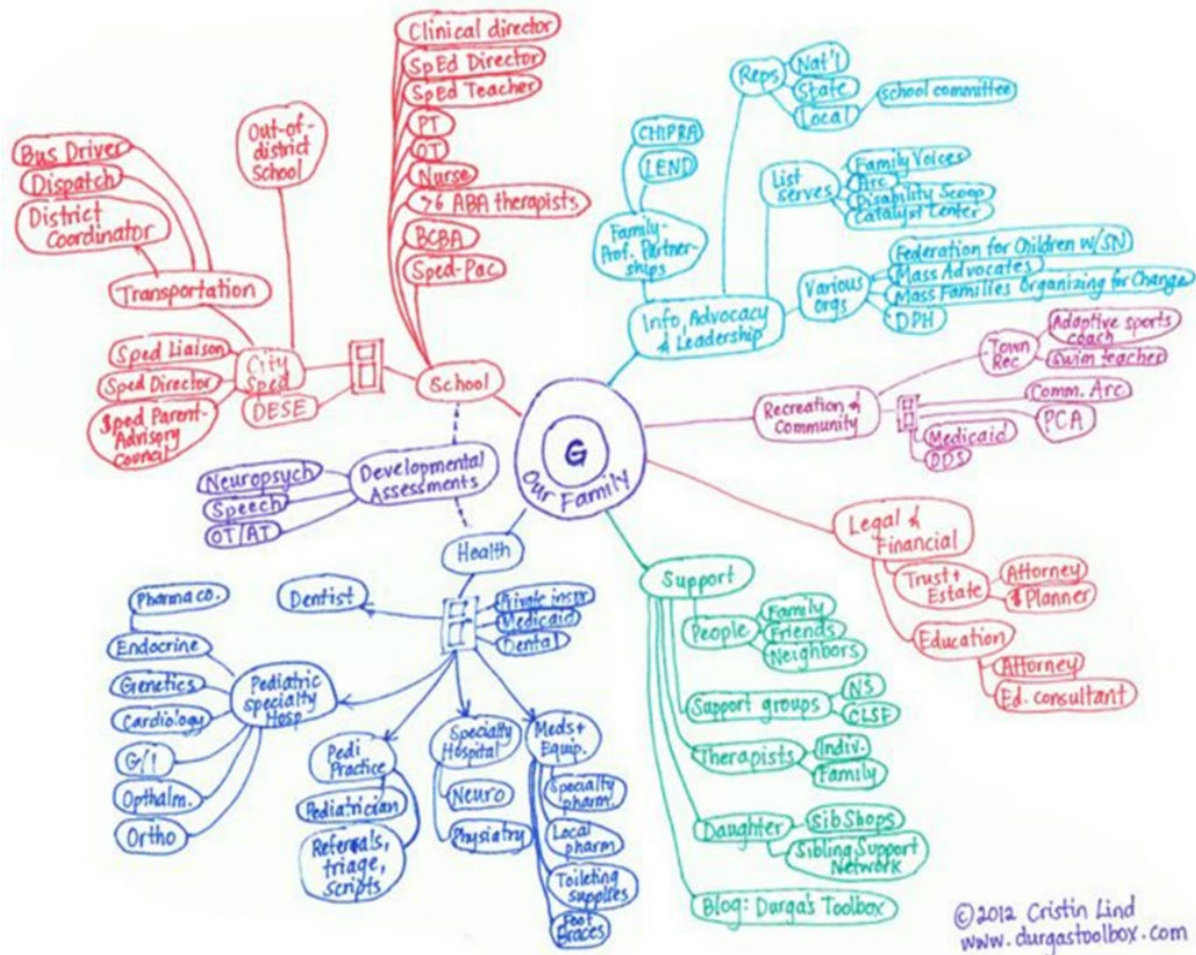
follow up with them to assure their family needs are being met, and provide ongoing emotional and informational support.

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	2022
<i>Professionals unduplicated</i>	1304
<i>Professionals duplicated</i>	13975
Of the total number of providers served/trained, instances of service related to the following issues:	
Partnering/decision making with providers	9018
Accessing a medical home	2334
Financing for needed health services	4212
Early and continuous screening	1882
Navigating systems/accessing community services easily	8052
Adolescent transition issues	2271

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.



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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.

Senator Dever 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."

Again, we are requesting that the dollars described remain in and disseminated in the general budget for SB 2012. The need for family support is not going away. Do the most vulnerable families in the state not deserve assistance?

North Dakota in 2015 when we began receiving general fund dollars is a bit ahead of the curve as we began that process and hope that we will continue to do so.

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.**

Enclosed in the following pages are testimony of some of the families we serve

We thank you for your consideration.

Donene Feist
FVND Director
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To the Members of the Senate Appropriations,

My name is Toby Lunstad and I live in Mandan with my family, including our 8 year old daughter Addilynn. Addilynn has a very rare genetic disorder with life-long neurodevelopmental symptoms that include difficult to treat epilepsy, lower threshold to experience hemiplegic migraines, developmental delays, and an overall medical fragility that has proven to be very challenging for us and her medical team to manage.

Some of her medical challenges are listed below:

2018: Addilynn was fighting for her life in PICU in Minnesota after seizures nearly took her from us.

2020: Addilynn experienced a hemiplegic migraine that drastically changed her ability to eat and drink...which resulted in her needing a feeding tube placed.

2021: Addilynn was unable to sleep without experiencing life-threatening seizures and she ultimately needed to have surgery to help better manage her epilepsy.

2022: Addilynn experienced post operative complications after a routine hip surgery that resulted in another life-threatening event resulting in a PICU and 6 week hospital stay.

In 2017, 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. As I reflect on the numerous health events Addilynn has experienced, I am grateful that I had the opportunity to attend Parent Leadership Institute and reach out to Family Voices for guidance support over the years. My ability to confidently advocate for Addilynn as she experiences medical events due to her diagnosis began because of Family Voices of North Dakota. I know that I would not have the ability to advocate for her care with grace and strength if I did not have the support of Family Voices behind me...coaching me and supporting me along the way.

The programs and support Family Voices provides to families like mine are invaluable and dramatically impact lives for the better. I urge you to continue the allocation of funds Family Voices of North Dakota programs. Families 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 Lunstad

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Al Gobierno de Dakota del Norte

Mi nombre es Yomiara Crespo y mi hijo es Michael. Somos del territorio estadounidense Porto Rico y ahora vivimos en Watford City. Mi hijo Michael tiene muchos problemas con su cerebro y salud mental. Ha tratado de lastimarse a sí mismo muchas veces y fue colocado en diferentes lugares por tratar de lastimarse a sí mismo o a otros. Las escuelas de Watford City han ayudado mucho.

North West me dijo que debería llamar a Heather Wheeler con Family Voices of North Dakota cuando comencé a tener problemas nuevamente con los registros y a entender qué hacer a continuación para mi hijo. Heather me envió un mensaje de texto en español y otro defensor también. Ellos trabajaron duro, pero yo trabajé más con la Sra. Ella me ayudó a arreglar la forma en que trataron a mi hijo y la forma en que me tratan a mí porque no hablo bien inglés. Heather habló con Dakota Boys and Girls Ranch sobre no tener un intérprete para mí y obtuvo los papeles que necesitaba.

Durante muchos meses, la Sra. Heather me ha ayudado a entender lo que debería hacer para ayudar más a Michael. Ella está en las reuniones, me ayuda a asegurarse de que tenga a alguien que hable español, así que entiendo todo. Siento que me tratan mejor ahora. Antes de la Sra. Heather no sabía que se podía hacer más. Antes de la Sra. Heather no sabía que podía obtener documentos en español y que siempre puedo tener a alguien que me ayude a entender. No soy tonto, pero necesito ayuda para entender el inglés que está escrito.

Muchas veces, he enviado a la Sra. Heather documentos que están en inglés y no entienden lo que la persona quiere y la Sra. Heather me ha ayudado a obtener la información que necesitan. El condado de McKenzie me envía documentos sobre Michaels Medicaid y otros documentos en inglés y la Sra. Heather me ayuda a entender lo que quieren. La Sra. Heather habló con ellos por mí y ahora recibo algunos documentos en español. Siempre tienen un intérprete en el teléfono cuando hablamos ahora también.

Quería que supieras que gracias a la Sra. Heather y su trabajo con Family Voices siento que los profesionales quieren ayudarme más con Michael. Me ven. La escuela en Watford siempre ayudó, pero ahora todos están haciendo aún más. Recibo ayuda con las facturas de Michaels en North West y recibo consejos para Michael. No sé si estaría aquí sin su ayuda. Michael lo está haciendo muy bien y eso es lo que importa.

Gracias por leer esto para mí.

Yomaira Crespo y Michael

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ENGLISH TRANSLATION

January 9, 2023

To North Dakota Government

My name is Yomiara Crespo and my son is Michael. We are from US Territory Porta Rico and now live in Watford City. My son Michael has many problems with his brain and mental health. He has tried to hurt himself many times and was placed in different places for trying to hurt himself or others. The Watford City schools have helped a lot.

North West (Human Service Center) told me I should call Heather Wheeler with Family Voices of North Dakota when I started having problems again with records and understanding what to do next for my son. Ms. Heather texted me in Spanish and another advocate too. They worked hard but I worked with Ms. Heather more. She helped me fix the way my son was treated and the way I am treated because I don't speak good English. Ms. Heather talked to Dakota Boys and Girls Ranch about not having an interpreter for me and got my papers I needed.

For many many months Ms. Heather has helped me understand what I should be doing to help Michael more. She is at meetings, she helps make sure that I have someone who speaks Spanish, so I understand everything. I feel like I am treated better now. Before Ms. Heather I didn't know that more could be done. Before Ms. Heather I didn't know that I could get paperwork in Spanish and that I can always have someone to help me understand. I am not dumb, but I need help understanding English that is written down.

Many times, I have sent Ms. Heather papers that are in English and don't understand what the person wants and Ms. Heather has helped me get the information they need. McKenzie County send me papers about Michaels Medicaid and other paperwork in English and Ms. Heather helps me understand what they want. Ms. Heather talked to them for me and now I get some papers in Spanish. They always have an interpreter on the phone when we speak now too.

I wanted you to know that because of Ms. Heather and her work with family Voices I feel like professionals want to help me more with Michael. They see me. The School in Watford always helped but now everyone is doing even more. I get help with Michaels bills at North West and I get advice for Michael. I don't know if he would be here without their help. Michael is doing great and that is what matters.

Thank you for reading this for me.

Yomaira Crespo and Michael

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

I have a son Kaden who is now 20. He has a rare disease called Leukodystrophy. This disease requires him to be totally dependent on others to care for his needs. Being a parent of an adult with special healthcare needs can be very overwhelming. For this reason it is absolutely vital that programs like Family Voices of North Dakota keep their funding.

I have many stories I could tell about the impact Family Voices has had on our family. I will share the one that really introduced us to the agency and all it offers. In 2010 my son Kaden fell during a bad seizure. This caused a brain hemorrhage. He needed to have emergency brain surgery followed by months of recovery in the hospital. I was the most afraid and overwhelmed I had ever been during that time. In that moment I called Family Voices and their response was immediate and helped my family immensely.

I could not totally express in words what this meant to us. We were so grateful. They went above and beyond in helping to point me in the right direction to get the services we needed for our son.

The wonderful people who work at Family Voices are unique in their ability to jump in and really be there for families during their challenges in raising their children with special healthcare needs.

They have helped me through navigating medical situations, understanding the services available for Kaden, supporting me emotionally as a parent, and training me to be a better advocate for my son.

I have worked with many non-profit agencies, and Family Voices is the most caring and efficient that I have experienced. Thank you FVND for all you have done. I know I could call tomorrow, and get my questions answered. That is a rare quality.

Thank you,

Amanda Burner
Minot North Dakota
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To Members of the Senate Appropriations Committee,

SB 2012

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 15 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 15 now (in 3 days) and we are in a groove they are still there for us. I do believe that we will be counting on them more due to this is the last year my son can be on the Autism Waiver. He was the first one of the waiver but will not be the last. There are more and more parents with kids Autism and other disabilities that will need the support that we have received from Family Voices. 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 were also with us when we adopted 2 more children this year.

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. I just don't know how to stress that enough, And just imagine what they have done for my family alone and then multiply maybe by 50 or 1000 and that will truly tell you how much they need this funding.

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

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