

Testimony on HB 1012

2021 Legislative Session

March 11<sup>th</sup>, 2021

Chairman Senator Holmberg, Vice Chair Senator Krebsbach and Members of the Senate Appropriations Committee:

My name is Vicki Peterson, and I am testifying to restore the 15% dollars cut to Family Voices of ND, which has been eliminated from the Department of Human Services in the budget for the Department of Human Services flow-through dollars per request of the Governor's Budget. I am requesting to restore the original dollars also to ND Federation of Families.

I am a Family Consultant for Family Voices of ND. I have been a Family Consultant for nearly 18 years. I first gained knowledge of Family Voices of ND through my son's Early Intervention Experienced Parent, (also a vital program that is having funding eliminated). My son, Aaron has Autism with an Intellectual Disability and chronic health conditions. At the time, my son was non-verbal but did not have a diagnosis yet, and our insurance was denying speech therapy. I was angry, how could they deny a child who was non-verbal, speech therapy. I spoke with Donene, the director of Family Voices of ND, she guided me to the resources I needed, and I got two bonuses, the first was help with insurance covering speech therapy and I had a connection to another parent who also had a child with an intellectual disability and turned out as well a diagnosis of autism which my son soon received. This started my path to help other families as well and I was immensely proud when I was asked to be a part of this most wonderful family, Family Voices of ND. Over these years I know I have helped many families just as I was helped.

Family Voices of ND is the Family-to-Family Health Information Center in ND. We navigate all systems of care, including those families who have children and youth with special health care needs, chronic health conditions and disabilities. All systems of care mean physical health, mental and behavioral health, navigation of health programs and insurance both private and public. We offer a unique component, lived experience. All staff has a unique connection to other families who have children with special needs as we all have children with special needs, or young adults now with special needs. This is essential for making those connections, not only with families but providers as well.

I would like to briefly describe what a referral to Family Voices of ND and specifically to me may look like.

- Referrals come from providers, schools, lead agencies, could be anywhere that had connections to families that have children and youth with special needs.
- I contact the family within 72 hrs. of receiving the referral and I pride myself that I stick to that rule, as families many times are connected to us when the family may be experiencing some crisis.
- I first need to listen to the issue, or crisis, and need. It is extremely important that the family knows I understand that I too have had some of the same experiences.
- There may be financial issues, they may need resources to find programs that will be of support to their child, they may need and most often do, emotional support, the need to speak with another parent that has some same experiences, maybe they lost health insurance, maybe there are family members with mental health issues and might need referrals to programs, maybe a child's school plan is not working and need support. Many times, they need multiple resources to, multiple programs, the care coordination and navigation of systems, many systems.
- Average calls are around 35 to 45 minutes. I must make sure to follow-up and follow-through for families, as they are counting on the support.
- Typically, there will be referrals to programs and or other resources, often there are many referrals and research as well to make sure we are looking for all resources.
- A call may come from a provider who already has a family on a case load but does not know how to connect them to informal or other formal supports.
- We are not a 1 call and done. I have families I have and continue to help navigate systems of care for over many years, as their child becomes a teenager, and teenager becomes a young adult.
- I am there to listen, I am there to navigate, I am there to support.

I would like to share a recent referral. Single Dad, 13yr old son has Acquired Traumatic Brain Injury, Mental Health Issues, Physical Disabilities attributed to the TBI. Currently in desperate need for services, and most of all respite, so he can go to his job to try and support his son. If he goes back full time, he will have income over the limit for almost all programs for his son; maybe education services when he returns to school, he goes to parttime, he will not be able to afford to pay for all the needs his son has and afford living expenses and most of all the respite services

he so desperately needs. The 1915i State Plan Amendment, meet some criteria as he does have a TBI, but cannot meet the income criteria. The son does not meet the ID criteria for another waiver program, then we have another Home and Community Based Waiver but even though he cannot currently walk unassisted, does not seem to meet Nursing Care Level to qualify for this program. This family needs support to make sure the programs that should have covered services for this child are being looked at properly and then searching everywhere for the needed support, formal and informal supports. Families need this support, as they are not able to find the services they need and when there may be one, the access to this service is so daunting, when all you can do as a parent is worry about what will happen to your child without the needed supports.

In ND, the need for Family Support for children and youth with Special Health Care Needs, is more than ever. Many families due to Covid-19, or terrible accidents as mentioned above, or loss of job, or divorce of parents, or finding out your unborn child will have an exceedingly rare disorder requiring enormous medical attention; Family Voices of ND is there to navigate this confusing system of care.

Family Voices of ND helps train many family members to become strong advocates for their children, a voice. We help families with positive communication with the providers. We help providers communicate with families.

You will hear many times throughout this session, about Person- Centered Planning, keeping children and youth from being institutionalized, more focus on home and community-based services, juvenile justice reform, family-centered care. Family Voices of ND is a part of this, we are all about family-centered care. We focus on the family with children with special needs. Wrap-around services must be in place for the families. If the family is not healthy, the child will not be healthy.

You will be hearing testimony on the ND Autism Voucher Program, where the Department of Human Services is eliminating funding for the program entirely and stating dollar will be added to the ND Autism Waiver to cover the waitlist that exists. In the 2013-2014 ND Legislative Session, HB 1038 passed, and the Governor signed a bill to create an autism voucher program that ND advocates came together to bring forward. This program allows person with autism spectrum diagnosis to access funding for an array of services such as assistive technology, respite service, safety equipment, sensory items and more. Eliminating this program will create a new gap, again, for families who have children and youth with autism without access to any other program. Most of these children will be unable to meet the criteria of Institutionalize Level of Care that is required for the ND Autism Waiver. Once again,

the 1915i will also be out of reach for most. The proposed slots that will be opened by moving the dollars from the Autism Voucher to the waiver will not cover the current waitlist and so even if a child would be able to meet the criteria, would be faced with a waitlist, which has been sometimes 2 years in ND. This program can prevent the very topic you are hearing about in this legislative session which is juvenile justice and keep people out of institutions. The Autism Voucher program needs to be amended to serve the families properly instead of allowing dollars you as legislators allocated for this program be moved to areas of the ND Department of Human Services choosing. There are proposed amendments to SB2089, and I hope you take all of those in consideration. I am a former member of the ND Autism Task Force and for all the years I served as an appointed member the dollars for this program have not been utilized to support the families, just that, the support needs to be for the family, as having a child with autism, effects the whole family. The subject of addressing this was shut down many times. Please consider restoring all funding for this very vital program.

Being a part of Family Voices of ND, has changed my life. It has made me a better communicator and better person. I have opportunities to make a difference in the lives of families with children and youth with disabilities and chronic health, because someone made that difference for me and my family. Family Voices of ND is reaching out to the 1 in 5 children in ND that have those special needs.

I am requesting to restore the full funding of dollars that were cut from the Department of Human Services Budget so that we can continue to do what we need to for those families that need us the most, the most vulnerable.

Thank you for your time and consideration.

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