

Testimony SB2012
Senate Appropriations
Human Resources

Senator Dever and Members of the Senate Appropriations Committee

My name is Vicki L Peterson, I am a Family Consultant for Family Voices of ND, the Family-to-Family Health Information Network in ND. I am also a parent of a young adult with autism and intellectual disability. I am here today to provide testimony on SB2012.

I have been a Family Consultant for Family Voices of ND for 19 years. I have been a parent to a child with autism and intellectual disability for 21 years. I am testifying on behalf of Family Voices of ND but feel it is pertinent to this testimony that you understand my lived experience as a parent as well. Donene Feist, the director of Family Voices of ND, has offered much testimony and the data we have for the non-profit agency, I am here today to speak to the day-to-day encounters we have with families across the state of ND.

- A mother of a young teenager calls very distressed. She relays to me she received our contact number through a counselor in private practice. Initial conversation is, **“My daughter is in trouble and I have no idea where to start to help her. I have tried with the school whom tells me that they cannot help outside of school environment, sorry. I have heard of some services but have no idea who to call or what to ask for. Please can you help. My daughter’s counselor we see for therapy said you were the one to call.”** My first priority is to listen to the caller. Active listening is a skill I need to help families. I let her know I will help and that I am also a parent of a child with a disability. After listening and hearing the information, learning that her daughter is suicidal but she does not know where to access help as she does not have health insurance and has limited income to pay for services and has been using the left-over money, she has to access a counselor and has no more. I carefully explain to her the programs available to her and their family to access insurance and to start the process of receiving the care and

attention through programs to help her daughter be in a better situation and to work on getting her healthy. Again, she replies, **"I think we make to much money for Medicaid."** I let her know there are several ways to enter a Medicaid funded program and we would check them all and if none work, we would work on other programs that may help with those costs. I could see the relief, even in just in her voice. As the days and weeks that go by, together we find solutions. We did. Her daughter is now receiving services that are helping her understand herself, services for her daughter's education, services at the home and my help continues with the follow-up and care that not only her daughter needs but that the family needs.

- I receive a call from my director that a referral has come to her through a physician in Minot. I reach out to the nurse with a release of information and gather all the details of the case. Turns out that a baby was shaken and the mother is seeking support. I immediately try to contact the parent as to make sure she knows there is help here including emotional support. A situation such as this needs the most care and privacy in the moment. This situation would not only involve much medical help and care coordination but also legal issues, mental health and delicate support. I have for over 5 years helped coordinate the services this family's needs including, health and well-being, coordination of multitudes of physicians and specialists, Early Intervention Program, programs throughout the Brain Injury and Developmental Disabilities system, Education, held her hand, wiped her tears, stood by her while her child was life-flighted out-of-state in the middle of the night, connected her to every resource I know possible in ND. Through all of this, building her confidence as a parent of a child with special needs, and knowledge of advocacy on her part. I will also mention, she has another child with PTSD and challenges as well. Key here is family, piece together every known service ND offers, and be there for her family.

I have spoke about two real-life situations that Family Voices of ND staff work with every day. Many more happen every day. We encompass all health areas physical and mental health to help families navigate systems. We support families in education environments, we navigate the private

and public insurance systems, we make it our priority to search programs and agencies that support families with children and youth with special health care needs, chronic health conditions and disabilities. We are active with policy makers both locally, statewide and nationally. We support families so their voice may be heard. We work with providers so families have a place to go and know they are talking with someone with lived experience. We train families, self-advocates and professionals. For myself, personally, the most important part of my job is to be there when families need you the most.

I want you to know after 19 years as a consultant and many more as a parent, many of our calls come in times of crisis. If I can help support that family by my knowledge, empathy and caring way, I have achieved the number one goal of what we are about. I have stayed with this job as it has given me confidence as a parent from many years ago when I as a parent needed the help of Family Voices of ND. As a staff member of Family Voices of ND, as hard as it can get, it is the most rewarding opportunity I have ever had. I am part of a wonderful team at Family Voices of ND and a very large village of parents who have children with special needs. We as staff members, are all persons who have children with a disability or special health care need. We support and learn from each other as well every day.

I encourage all of you to go to the ND Family Voices of ND website www.fvnd.org that offers a look into 2 families that Family Voices of ND supports and their story and how our support has helped their families.

I want to take this opportunity as well to encourage you not to terminate the ND Autism Voucher Program. I had the privilege of being part of the original stakeholder group that advocated for the ND Autism Medicaid Waiver and the ND Autism Voucher Program. I can tell you that if the Autism Voucher Program is terminated, families and their children will have a gap in services that is needed and cannot be provided by the Autism Waiver as their child will not meet the level of care needed for the Autism Waiver. Autism is a spectrum disorder, there are many children with autism diagnosis receiving little if any services. The level of care may

not be met for the ND Autism Waiver, the education system is not required to offer educational services as not meeting their strict criteria for special education, that is followed as their challenges may be more mental and behavioral health then academics. The newly created 1915i state plan amendment has to meet eligibility of Medicaid which many families do not due to income and lack of mental health providers in our state and therapy providers especially in speech have long waitlists, which is a large barrier to services. Many families that can access the autism voucher may lose valuable access to help their child with an autism spectrum disorder. Respite is a service that can be offered in this program, key to keeping families together; sensory type equipment could be approved that will help the day to day living of a child with autism; safety equipment for the child as many children with autism are "runners" with elopement issues. These items are not covered by traditional insurance.

I am requesting that you restore or make sure that the dollars in the general budget for SB 2012 for Family Support stay. I am also requesting to not terminate the ND Autism Voucher Program for the reasons above and or until a Cross Disability Waiver would be in existence that could possibly or intended to cover those under this program.

Thank you for your time and consideration.

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