

**Testimony SB2012**  
**House Appropriations**  
**Human Resources**  
**3/22/2023**

Chairman Representative Nelson and Members of the House Appropriations, Human Resources Division.

My name is Vicki Peterson and I am a Family Consultant for Family Voices of ND. Family Voices of ND is the Family-to-Family Health Information Network in ND, a non-profit that works with families, professionals and self-advocates of children and youth with disabilities, special healthcare needs and chronic health conditions. I am also a parent of a young adult with an autism spectrum disorder and chronic health conditions.

I am testifying today in support of SB2012 with a couple concerns in the area of services for persons with autism spectrum disorders. One of my concerns is the removal of the ND Autism Voucher as a state program in ND. The ND Autism Voucher program was created in HB 1038 in the 2013 Legislative session. The reason the autism voucher program was created is, when the ND autism waiver program was established, SB2174 in 2009, there was a gap in services for person with an autism spectrum disorder. This gap consisted of children not meeting the level of care needed to qualify for the ND autism waiver. The level of care needed for the autism waiver and the developmental disability waiver is, ICF, or intermediate care facility. Not all children and youth with an autism spectrum diagnosis will meet that level of care. It was passed as a program that may fill in a gap of services that may be vital for a child with autism that would give support in an area of need. The criteria to meet eligibility requirements for the autism voucher program are a fpl of 200% (currently a family of 4 would be \$55,500.00 p/yr.) an autism spectrum disorder diagnosis and be a resident of ND. The funds originally generated by this program

were \$12,500.00 p/yr. per child, currently that is now down to \$7500.00 p/yr. per child. The funds were cut during the 2021 session. This funding is state dollars not Medicaid dollars. These dollars cannot be used for therapy but were created to help families on some level of need, such as respite care, assistive technology, parent training, specialized camps, tutoring and possibly other services or items. Over the years there has been a struggle to know what exactly the voucher could pay for which led to less utilization. I have helped many families over the years access and utilize this program knowing that there is not another program that could help them in ND. Many do not even receive school services. NDHHS is wanting to remove the autism voucher program and designate more slots for the autism waiver. This just creates a gap in services once again.

The waitlist for the autism waiver is long ,84 currently and can change daily, but this will not be an option for all those currently being served under the autism voucher program. The children and youth being served will not all meet the level of care of ICF (Intermediate Care Facility). For those, they may be out of support completely. Many who applied for the autism voucher program, could and were denied by both the autism waiver and the developmental disability waiver for that very reason. My concern lies that there will be creating a gap again in services. You have heard that moving the persons on the autism voucher to the waiver will happen, but for some this will not happen.

You have also heard that some services may be added to the ND autism waiver, such as tutoring. So, the question would be is that the appropriate service to move? It is currently in the ND autism voucher as something that one could ask for, how many ask for this? As a former member of the ND Autism Task Force, it has always been brought to my attention that respite care has been the most requested. If the goal is to add services to the autism waiver, I would hope it would look at adding services that the participants can utilize and would utilize. Services currently under

the autism waiver, include Service Management, Respite Care, and Assistive Technology. The term respite in this particular waiver is defined *as a parent needing to rest, run errands, clean, take another child to an activity, socialize or take a break*. What I hear from many families is the need for in-home supports for supervision besides and extra pair of hands that helps when the parent is out of the house. Safety equipment can be a high need for some families as persons with autism may have elopement issues. It would seem fit to make sure things added to a waiver include services or items that would serve the greater need for support. Increasing the slots is vital as the number of persons diagnosed with an autism spectrum disorder in ND is continues to grow. In the past two weeks alone, 5 newly diagnosed children with autism have contacted Family Voices of ND or myself to help navigate services. The national average is at a current rate of 1-44 children (*CDC 2022 autism prevalence*). *This is an increase of 178% since 2000*. Families contacting Family Voices of ND are struggling to get an evaluation to even determine if an autism spectrum disorder exists. We can expect that waitlist for ND autism waiver will just continue to increase. The age limit increase is something every session it gets increased by two years to cover those currently on the autism waiver to not fall off of services. Autism Spectrum Disorder is a lifetime diagnosis, it does not just pertain to a child from birth to age 18. Mentioned yesterday a response from a question, "what happens at age 18?" the answer was "look to have them access other voucher programs". I have never heard of another voucher program that would help those with autism at age 18. Many then again are left without services in ND as they do not meet the level of care or the definition of eligibility at age 18.

SB 2256, led to the study of developmental disability services and the autism spectrum disorder programs. The ***Alvarez and Marsal Study*** recommended to look at creating a cross-disability wavier with updating and changing the definition of developmental

disability. This would allow ND to cover the support needs without a disability category. This new definition would recognize adaptive social deficits that would possibly cover eligibility for those currently not qualifying for the autism waiver or IDD waiver currently. This is supported by the *American Association on Intellectual and Developmental Disabilities*.

I would like to just briefly mention that I am in support of increasing the level of benefit and number of slots for the Childrens Medically Fragile Waiver. Having 15 families on the waitlist for this waiver is far too many. The needs for the families in this targeted population are significant and do not wait for time to stand still until a slot opens. The costs incurred by the families can easily make life decisions on how much food to buy or paying for a life-needed medication. I encourage you to please add the request from ND HHS to this waiver.

Thank you for your time and consideration.

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