

**SB 2089/ ND Autism Spectrum Disorder Voucher
House Human Services Committee**

Wednesday March 3, 2021

**Chairman Representative Weisz and Vice Chairwoman Representative Rohr and
Members of the House Human Service Committee**

My name is Donene Feist and I am the Director of Family Voices of ND. I am here today to testify on SB2089 in favor of the proposed amendments to the ND Autism Voucher Program and in support of a Legislative Study on the ND Autism Services.

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. Our parent-to-parent matching program called North Dakota Parent-to-Parent provides connection of one parent to another as a mentor for emotional support.

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 parents 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.

Lastly, the bulk of our work is assisting families in navigating the services that they receive or connect them to those community resources in raising their child with a disability.

FVND is an affiliate chapter 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 receive many calls from across the state who have a child or youth with an autism diagnosis. We feel it is imperative that these families have the adequate supports needed. The autism voucher was created as the waiver did not encompass all the needs that those with an autism diagnosis needed. However, underutilized which we believe to be for a couple of reasons: Lack of awareness, confusion for families on how they can utilize the funds, and mostly lack of coordination with families. We feel it is imperative to assure that there is coordination of care in the voucher program. Families are often confused by the silos and maze of what is available and often do not know the questions that need to be asked. Having someone who can assist them with this process is vital. Not only to FULLY understand the services that they qualify for but also to be good stewards of state dollars. Family Voices of ND has assisted many of these families that qualify for the voucher and waiver since it was passed in the 2013-2014 session.

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. 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. Making the coordination with families vital.

I continue to have concerns about not funding the voucher. If the voucher is not funded it will again leave a gap for those who have previously qualified and was a lifeline. Autism is not going to go away. Families need the tools and resources as they move into adulthood. If anything there also needs to be additional resources as children transition into adulthood and assistance to these new adults. We don't want to create another gap. If services and supports are not available, potentially

where are they to go. ND is investing many dollars to de-institutionalize. Cost of care to have children at home within their families is much less expensive than serving them in a residential setting. Disability affects the entire family. Adequate supports however are vital including parent support to assist families. Family/Professional collaboration are a must. Hence if there were some form of care coordination the voucher program would be much better utilized.

Family dynamics in ND has been changing for some time. We have single parent homes, foster homes, grandparents raising grandchildren. There is no one size cookie cutter approach. The Autism Voucher provided much assistance for all of these scenarios. With coordination and assistance to families it will be better utilized.

I am also in support of the legislative study on ND Autism Services. I am actually in support of a study regarding all services of children with chronic health conditions and disabilities. It is needed.

Never doubt that families are struggling as they are. 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.

Please adopt the amendments proposed.

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