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 Vicki Peterson, I am a Family Consultant for Family Voices of ND and I am also a parent of a young adult with Autism Spectrum Disorder. I am here today to testify on SB2089 in opposition but in favor of the proposed amendments to the ND Autism Voucher Program and in support of a Legislative Study on the ND Autism Services.

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. Since that time, there has not been a change in "need" for this service but a lack of utilization due to unawareness of the program, confusion on the families' side of how the dollars can be used for the services that may be required, and lack of some type of case management to help the families use what was created and signed into law in ND. You may see that dollars in this program are not being spent which is hiding the real fact that this program should be and is providing a gap in autism services that is not able to be obtained by any other If this program is to be not funded at the proposed program. amendment amount of will be a large gap for families who have their

children qualified for this program and could have major family consequences.

There is a missing part to currently how the Autism Voucher Program is administered, the key here would be the word "family". The diagnosis of autism in a child, has effects on the whole family. Having a child with autism has an impact on the whole family. Various aspects of family lives are affected including housekeeping, finances, emotional and mental health of parents, marital relationships, physical health of family members, limiting the response to the needs of other children within the family, poor sibling relationships, relationships with extended family, friends, and neighbors and in recreation and leisure activities. A study done in 2019 showed that parents of children with an Autism Spectrum Disorder have one of the highest divorce rates in the United States compared to other developmental disabilities, (Floyd F, Greenberg J, Osmond G, et al. The relative risk and timing of divorce in families of with an autism spectrum disorder. Family Psychology 2019;24(4): p:449). In a time when you as a legislative body are discussing juvenile justice reform and de-institutionalization, we need to keep and work better at the programs you have already decided on as being a vital program for children with autism and their families.

In ND, we also have many grandparents raising children with ASD, the needed support the autism voucher provides is critical. A study was conducted that found 7% of children with ASD were hospitalized for psychiatric reasons in a single year (2019; David Mandell, SCD). His study examined the use of respite care for children with ASD and found that a \$1000 spent on respite services resulted in an 8% decrease of hospitalizations from 26, 000 children. Imagine the help of respite services could do for the families who have children and youth with ASD lead more productive lives? It is huge and a highly requested service from this program. If the ND Autism Voucher Program is funded at much lower dollars, families will loose out on the possibilities of this service. Children

could end up in foster care or juvenile justice because these families cannot get the service, they need to benefit their child with autism.

I do support a legislative study for the ND Autism Services. I was a ND Autism Task Force Members for several years and continue to participate as part of the public, the dollars for these programs seem to not be getting utilized though we know the need is there. The waitlists are long for the ND Autism Waiver, why such waitlists when the money is there? The ND Autism Voucher has a lack of utilization, but families are still struggling, and we have not filled that gap the way the program was intended to. As a parent of a young adult with autism, as a family consultant that works with many families across the state of ND with children with autism, we can do better, we can make these programs work for families.

I am requesting that you adopt the amendments proposed. Thank you for your time and consideration. I would be happy to answer questions you may have.

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