

Testimony
Senate Bill 2089
House Human Services Committee
Representative Robin Weisz, Chairman
March 3, 2021

Chairman Weisz and Members of the House Human Services Committee:

I am Holly Johnson, a Licensed Board Certified Behavior Analyst, and appointed Behavioral Specialist member of the ND Governor's Autism Spectrum Disorder (ASD) Task Force. I live in Minot, and I've been working with children and families in the Autistic community in a variety of capacities over the past 15 years. I am here today on behalf of the Autism Spectrum Disorder Task Force (ASDTF), representing them on proposed amendments to the current engrossed version of SB 2089, specific to the Autism Spectrum Disorders Voucher Program, legislative intent, and legislative management study.

The ASD Voucher Program was created to address the gaps in non-therapy related services and to provide education and support to families who may not qualify for other help. Senator Joan Heckaman has provided proposed amendments through Legislative Council as proposed by the ASDTF. I will provide a summary of those amendments and rationale for their adoption:

- **SECTION 2. New subsection to section 50-06-32: (Facilitator for the task force)** The ASDTF has been dysfunctional and ineffective with being an influential part of providing ASD services across the state, likely due to the Department's conflicts of interest. The ASDTF **wants** to work with the Department to improve the program overall, and we want to make meaningful changes to better support families and their children.

- **SECTION 3. AMENDMENT. (Definitions, Expansion of services, Family Care Navigator, Outreach)**
 - Individuals and the families of such individuals: Inflexible statutory language and funding criteria often operates to the exclusion of families' needs and supports directly relative to their child(ren) diagnosed with ASD. A diagnosis of autism touches and impacts the entire family, including their health and well-being, and their capacity to care for their child(ren). Support for the family as a unit is lacking under the Voucher Program, and including this language would instill the original legislation intent of the program to empower families.
 - Include services, care and social activities to compensate for a deficit created by an ASD diagnosis: language would align with medical necessity for those services directly relating to the diagnostic criteria of autism, ensuring a wrap around approach.
 - In-home supports not to exceed 40 hours a month would expand the Voucher comparably to other programs that these individuals do not qualify for.
 - Increase age from 18 to 25: envelops the core nature of ASD as a developmental delay. Increasing the age would help bridge the gap into adulthood, while allowing Autistic people more time to mature and close their developmental gaps.
 - Including community activities: is important for all community members to be exposed to people with ASD, it allows parents to continue working, and it enhances the economy as they become taxpayers and/or employees. Currently, over 50% of people institutionalized in ND have an autism diagnosis. By focusing on keeping funds in communities by integrating this

population early and often, will defray the cost of services for these individuals through the lifespan.

- Including transportation covered by the eligible activities or services under the voucher: would support more rural families who desire services under the Voucher the ability have travel expenses reimbursed. Currently, families may have to financially decide whether to travel great distances to receive necessary services for their child(ren) with ASD or if their other child(ren) play in sports after school.
- Family care navigator services: need to be funded, because families need support to understand the program and services available, which they do not currently have.
- Ongoing outreach efforts: are needed to find and engage families who could benefit from the ASD Voucher Program. The ASDTF did not have access to budget-specific data on current spending for outreach efforts by the Department, we are willing to suggest a percentage of the allocated funds or a specific dollar amount for this component to be included.
- **SECTION 5. LEGISLATIVE INTENT.** The Voucher Programs needs more oversight directly from the ASDTF, with approval of the DHS proposed rules prior to public comment, as a form of endorsement. The ASDTF's historical involvement with the administrative rules process has not been integrated collaboratively or systematically in a formal process. Our goal would be to identify better use and more spending of the funds. The ASDTF current vantage on improving the details of the Voucher Program includes lowering the total amount annually per family (average expenditure was \$4992.09/family in 2020), which increases the number of families who can access the program, which better utilizes funds. We have also discussed

creating documents to support commonly asked questions from families, and improving the contradictory and unclear application details. We are certain that by having all disciplines represented by ASDTF members, and having a seat at the table, there could be multiple ideas and strategies to improve the program.

It is imperative that previous allocation of general funds in the amount of \$1.325M remain, until the legislative management study is completed, so that we are not losing funding without truly understanding if families don't WANT to use the money or if they don't know HOW to use the money. The Department has approved funds for families to access the ASD Voucher, but families have not spent that authorized amount. Without doubt, there is a gross underutilization of allocated funds. The ASDTF agrees that a legislative management study is warranted to understand this, but as the ASDTF, we should be part of problem solving for the lack of spending. Reducing the budget for the ASD Voucher Program will be hurtful to families.

- **SECTION 6. LEGISLATIVE MANAGEMENT STUDY – ASD WAIVER AND VOUCHER PROGRAMS.** In regard to removing the elimination of the ASDTF: We (ASDTF) understand why we have been ineffective, but removing the entire ASDTF is not the answer. The amendments we have proposed would be a start at the answer. Additionally, if the ASDTF was to be removed, it would set precedence for the removal of other ND task forces (e.g., ND Cares, Task Force for Veterans Affairs, Medical Facility Infrastructure Loan Task Force, the Task Force for Higher Education Governance, etc.).

While eligibility for other autism specific programs may exist for these families (i.e., ASD Waiver or Applied Behavior Analysis/ABA), barriers to accessing those other programs will make it problematic for these children to get supports they need. Waitlists for children to receive ABA can be a solid year, if not longer. This program was created to fill non-therapy related gaps. Reducing funding for the ASD Voucher now will mean these families will have to compete for slots on the ASD Waiver; which, at the February 2021 ASDTF meeting, had 70 children on the waitlist with a proposal to increase the total number of ASD Waiver slots by 54, equaling 150 total (currently has 96 slots). DHS is not repurposing the \$1.3M it stripped from the Autism Voucher into the Autism Waiver, so as a task force, we want to know, where does that money go? Can this be reevaluated after the legislative management study? Put the full appropriated amount back (\$1.325M). Then determine if the program budget needs to be reduced. The wait for services causes a further gap in skills, putting these children even further behind.

In summary, I, and the ND Autism Spectrum Disorder Task Force, strongly oppose the language of SB 2089 regarding the ASD Voucher Program. This legislation is hurtful to families and it is harmful to people already struggling with a major, life-altering diagnosis. The ASD Voucher Program should have the intent to reach as many families as possible, filling any gaps left by other ASD programs and services. I hope you hear (or have heard) testimony from parents of Autistic child(ren) who will be directly impacted should the ASD Voucher Program budget be cut so drastically, because they are the families who will suffer and struggle with supporting their Autistic child in North Dakota. The voucher program's effectiveness does not lie solely in its spent or unspent dollars. An

incomplete program will have incomplete results. Please consider the proposed amendments we have provided you today.

Thank you for your time and consideration of this testimony. If I can be of assistance during this time of deliberation, please contact me at holly.johnson.bcba@outlook.com. This concludes my testimony.

Sincerely,

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These opinions in no way represent the Department of Human Services or the Life Skills and Transition Center, all of which I am actively involved with, adding to my unique perspective contained in this testimony. This testimony has been provided on my personal time.