

**Comments to North Dakota Human Services Committee
regarding Study of Autism Spectrum Disorders
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Chairman Wieland, senators and representatives of the committee. I am Brent Askvig, Executive Director of the ND Center for Persons with Disabilities at Minot State University. I am here today to offer comments on the Study of Autism Spectrum Disorders as proposed in Section 2 of Senate Bill 2268.

NDCPD is a university affiliated center authorized by the US Congress under the Developmental Disabilities Act. Our mission is to provide education, training, community service, research and information dissemination regarding issues for persons with developmental disabilities in our state. Autism spectrum disorder is one of these developmental disabilities.

NDCPD has had considerable interest in and experience with state issues in autism spectrum disorders over the past four years. We have worked closely with state and national organizations and funding sources to provide services, research, training, and information regarding ASD. In fact, today we are hosting a three day conference in Minot with national speakers and over 175 attendees from across the state.

Since 2008 NDCPD has garnered several grants and contracts in ASD. These include funds from the US Department of Human Services, Maternal and Child Health Bureau, the Administration on Developmental Disabilities as well as funding from the ND Department of Health, and from the ND Department of Human Services. This funding has allowed NDCPD to gain valuable information on ASD and to provide needed services and training in our community.

For today's comments, I would like to list and briefly discuss several needs assessments that we have conducted that may factor into your discussions about the ASD study. First, in 2008 NDCPD hosted a statewide training and information event on ASD. The 300 people who attended completed a quick survey of services and needs. Early intervention was identified as the most important service needed by children with autism, as the majority of respondents were concerned about early diagnosis. Intensive in-home behavioral support was selected as the most important support for families. This was followed by financial support and trained respite providers. Across all respondents, the top three changes needed in the future were access to assessment clinics, develop models for successful intervention in our small communities, and refine the diagnostic and labeling features of ASD.

Second, NDCPD worked with the ND Autism Task Force on a large needs assessment of programs, services, training needs and family/parent issues for our state. This study was developed by the Task Force, and the information guided the development of the initial state

plan in 2010. Either the Task Force or NDCPD could share those data with you. Access to quality services and providers, community training and early diagnosis were some of the important results.

This past year NDCPD conducted two other needs assessments that may pertain to the Committee's study. We did a needs assessment where 250 participants described the top three training needs for our state. These were (1) behavioral interventions, (2) social skills instruction, and (3) handling child and family stressors at home and in the school. The second study examined the medical profession's views of early screening and identification, diagnosis procedures, resource availability, and knowledge of evidence-based practices. Perhaps most alarming was the finding that less than 11% of surveyed clinics followed the American Academy of Pediatric guidelines for 18 month and 24 month screening of children for autism. Also more than 4 of 5 respondents felt uncomfortable providing a medical diagnosis of autism. Finally, 3 out of 4 respondents felt they were not up-to-date with information on autism.

NDCPD offers the following recommendations for the Committee.

- That the Committee examine the ND ASD Task Force state plan and survey results to avoid duplication of questions and items.
- That the Committee examine all available state reports and studies already conducted regarding survey questions and results.
- That the Committee consider the following items in a future survey or needs assessment:
 - Service disparities in rural and urban areas in North Dakota,
 - Service access issues regarding evidence-based services, quality and quantity of service, and service provider training,
 - Parent education and family support issues for all families of children with ASD,
 - Access to interdisciplinary team assessments for diagnosing ASD,
 - Services provided and/or gaps in services for adults with ASD,
 - Cost coverage issues related to public/private insurance, private pay, and long term cost benefit analyses of services for children and youth with ASD.

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