

TESTIMONY – PROTECTION AND ADVOCACY PROJECT

Human Services Committee

Honorable Alon Wieland, Chair

May 30, 2012

Autism Spectrum Disorder Task Force

Chair Wieland, and members of the Human Services Committee, I am Christine Hogan, a lawyer with the North Dakota Protection and Advocacy Project (P&A). The Protection & Advocacy Project is an independent state agency that acts to protect persons with disabilities from abuse, neglect, and exploitation. We advocate for the disability-related rights of persons with disabilities. Our executive director, Teresa Larsen, is an active participant in the Autism Task Force. She has a prior commitment that conflicts with this hearing time and she asked me to represent her regarding P&A's position in support of the Task Force recommendations.

P&A strongly supports all the recommendations of the Task Force. We believe that, if implemented, these recommendations will address many of the problems identified by the parents and families of children with ASD. My testimony today is focused in particular on the Task Force's recommendations regarding improvements to the ASD Waiver.

As you know, in late 2010, the Centers for Medicare and Medicaid approved a waiver so that North Dakota could provide services for children aged birth up to their fifth birthday who have autism spectrum disorders (ASD). The waiver program was created to address existing problems and to give families access to an evaluation team to validate their child's diagnosis and serve as a resource to connect families with local service providers.

In order to determine whether the waiver is effectively addressing the identified problems, Family Voices of North Dakota conducted a survey of parents of children in this state who participated in the autism waiver program in 2011. In interviews conducted in person or over the telephone, the parents were asked the same series of questions designed to elicit information about how the program is working and to identify problems and potential solutions. The Protection and Advocacy Project collaborated with Family Voices in preparing a report of the survey results.

P&A then worked with Family Voices and members of the DHS DD Division to analyze the results of this parent survey and to make recommendations for provisions to be included in a new Waiver that will be proposed when the existing one expires. Our committee of representatives of these three organizations—two state agencies and a statewide parent advocacy group—conducted a series of meetings over the winter and spring for the purpose of bringing our perspective based on our experience with the

current waiver to this legislative body as you consider the best way to approach autism services and funding in this state in the future.

Our committee came to consensus on the key provisions of what we like to call our Dream Waiver. It is sung to the Reo Speedwagon tune Dream Weaver:

Waiver coverage from age 3 through life

- if needed, prioritize ages to be covered based on funding as well as family and public input
- consider redetermination at specific age benchmarks

Waiver should better target services needed by individuals with ASD and their families

- current waiver has too much focus on equipment and AT
- should include:
 - evidenced-based practices for direct therapy for ASD
 - intervention coordination up to age 7 or after 2 years in school and case management for ages 7 and up
 - in-home supports (including respite care)
 - equipment and supplies
 - environmental modifications
 - home monitoring (through AT support)
 - residential supports and services
 - “extended” vocational services
 - behavioral consults
- if needed, prioritize services to be covered based on funding as well as family and public input
- Capacity (# of slots) needs to be increased to address more individuals/families with unmet needs
- Increases resources for timely determination of Waiver eligibility (and, potentially, redetermination) by EDT Teams
- Training for case managers on ASD and the ASD Waiver

In conclusion, P&A strongly recommends adoption of the recommendations of the Autism Task Force, including the proposed improvements to the ASD waiver.