

**Testimony**  
**Human Services Committee**  
**Governor's Task Force on Autism Spectrum Disorders**  
**Representative Alon Wieland, Chairman**  
**October 4, 2012**

Chairman Wieland and members of the Human Services Committee, I am Carolyn Fogarty, a member of the Task Force representing parents, and a member of the Task Force's executive committee. I am here today to provide comments on behalf of the ASD Task Force regarding the legislative bill drafts being discussed today.

First, I want to stress that the concepts contained in the parental proposal are highly supported by the Task Force. Many of the elements are similar to the task force recommendations presented to you earlier.

It is the **methods** chosen and the **timing** to implement the concepts where Task Force concerns lie. Before I list those, the task force feels it important for you to understand the depth of review and time taken over the last 2 ½ years that went into the recommendations.

**Year One**

Met eight (8) times

- Reviewed other state's legislation,
- Reviewed other state's ASD information, plans, and funding mechanisms
- Formed five workgroups
  - evidence-based services
  - training and education
  - infrastructure
  - funding structures
- Developed, disseminated, and summarized a statewide ASD Needs Assessment Survey

- Identified available services and service gaps
- Wrote an 'Initial State Plan'

### **Year Two**

- Worked on action steps contained in the 'Initial State Plan'
- Received presentations from three large insurance products/coverage approaches
  - BCBS, Sanford, Medicaid
- Received regular updates on ASD Waiver

### **Year three – current year**

- Met with Psychological Association regarding Behavior Analyst Legislation SB 2155
- Reviewed ASD waiver
- Recommendations forwarded to DHS on suggested changes to ASD waiver
- Participated in calls with the SAND grant
- Continued to refine the State Autism Plan and focused on the 'Quality Providers' and 'Appropriate and Effective ASD practices' sections of the plan
- Received updates from Anne Carlsen Center
- Received updates from NDCPD- Minot State University
- Formed an Executive Committee
- Updated the strategic plan and presented to legislature
- Prioritized recommendations and included funding amounts as per the request of the Human Services Interim Committee – May 2012

### **Registry**

The Task Force has spent hours reviewing and discussing other states' autism programs. Although we believe the registry is important, there is little reason to track individuals with an autism spectrum disorder when there is limited infrastructure available to serve them. Although the state does not currently have a registry, there is no reason to believe that North Dakota is different from other states in that autism is impacting our citizens. In fact, the testimony over the course of this study supports the need. It is a national trend. The registry is part of needed infrastructure, but its purpose

has not yet been clearly defined. The registry without training and coordination is not the most important thing to do at this time.

### **Training**

Education and training is important. Again the concept of training is agreed upon. The task force recommendation 'comprehensive Training Fund' reaches teachers, doctors, day care providers, public health, communities, therapists, and parents. In order to build the infrastructure there is a need to expand knowledge to a wide variety of people.

### **Voucher**

The task force supports funding for services but asks, 'What good is a voucher system if you cannot use the voucher?' It seems that building and enhancing a system must occur before vouchers are distributed. The task force wants whatever actions taken to be successful and sustainable.

Task Force top recommendations include the coordinator, training fund, enhanced behavioral analyst services, diagnostic and services planning teams. We completely understand the reasons for the proposal submitted to you at the last meeting. The need and want is there – the resources and means are not in place. The duties cannot be delegated to an existing person and should not be looked treated as an 'add-on' if the goal is successful management of this important area of need. The issue needs

attention and expertise. The process you choose is important and for the good of the state needs to be sustainable and successful.

I want to quote a statement from New Hampshire's autism state plan.

'This "infrastructure" encompasses the complex support system that stands behind the delivery of front-line services. It includes: 1) personnel preparation, 2) technical assistance, 3) applied research and program evaluation, 4) communication, 5) demonstration programs, 6) data systems, 7) comprehensive planning, and 8) coordination of support.<sup>8</sup>

Gallagher has likened these elements to the societal structures behind a medical practitioner. While the patient may be unaware of it, the treating physician relies upon numerous other systems, including medical education, pharmaceutical research, and laboratory protocols, to ensure the provision of quality health care. What the patient sees as a "good doctor" is in reality a good medical system.'

We want 'good' teachers, 'good doctors', 'good therapists' but behind these good people needs to be an entire system supporting their work. That supportive system is represented in the prioritized recommendations and begins with someone who leads this effort; is focused on the entire issue; and is charged with assuring the work is successful and sustainable.

Thank you for your time.