

**Testimony
Interim Human Services Committee
Advocacy Group
ND Task Force on Autism Spectrum Disorders
Representative Alon Wieland, Chairman
October 4, 2012**

Chairman Wieland & Members of the Human Services Interim Committee:

I am Vicki Peterson, am speaking on behalf of stakeholder group who in support of the recommendations of the ND Task Force on Autism Spectrum Disorders. I would like to direct you to a letter and chart you have received from this stakeholder group. I am here to comment and answer questions for this group.

Priority 1.

- Looking at the chart provided, I would direct your attention to the change in prioritization beginning with State Autism Coordination and Autism Spectrum Disorder Registry. As stakeholders, we feel this would be best served together; a registry for persons with autism and coordination to develop, operate and maintain a registry. This will be the tool to be able to collect accurate data on persons in the state with autism. Families, providers, and advocates would always want services to be the number one priority. In this particular instance, the infrastructure does not have adequate human resources to support the needs of persons with Autism Spectrum Disorders.

Priority 2.

- Expand and refocus the Autism Medicaid Waiver by beginning eligibility at 18 mos. (*AAP Developmental Screening Tools D-PIP 11/2007*) The stakeholder group believes this should be

considered to be life-long to include adult persons with autism spectrum disorders. There needs to be a process of re-determination at specific ages. Capping the waiver according to a slot system could provide a much needed comprehensive system of receiving services. A proposal of fewer slots in the first year of the biennium would allow for infrastructure to be put in place and allowing more openings for the second year.

Priority 3.

- **Provide comprehensive training.** Training is a vital component to having staff available and knowledgeable about autism spectrum disorders. The trainings need to be coordinated among agencies serving persons with autism. At the present time SAND (Supporting Autism in ND; NDCPD) is providing training to key stakeholders in the state through 2014, so the dollar amount reflects the estimated cost for the second year. This training needs to include cross-training among professionals, parents and self-advocates in achieving success.

Priority 4.

- **Access to Behavioral Analysts.** In ND today, a high priority for families is the need for behavior intervention, for which you heard early testimony on. The experts in this field are located in eastern ND and in one area in central ND. This is not fulfilling the need of families and certainly not in most of central and western ND, where the population is growing. Additionally, would provide needed intervention in the rural areas of the state. This proposal would allow for the financial support of two certified behavioral analysts in each of the 8 regions of ND and would fill the gaps currently existing in the state.

Priority 5.

- **Diagnostics and Service Planning Teams.** Best Practice for diagnosing autism spectrum disorders is a multidisciplinary team of professionals.(*AAP Developmental Surveillance and Screening of Infants and young Children; Pediatrics 2001*) Navigating the systems that families of children with autism and self- advocates with autism will encounter is a daunting effort that needs to begin at the point of concern. The need for more comprehensive teams in ND to do screening is needed due to our growing population and the geographical nature of our state.

Priority 6.

- **As per this advocacy group, the number 1 priority under the ND Task Force on Autism Spectrum Disorders has now been placed number 6.**

The undersigned in this advocacy group supports these recommendations and is asking for your support in consideration of the top priorities listed.

AUTISM SPECTRUM DISORDER TASK FORCE RECOMMENDATIONS
AS SUPPORTED BY ND ADVOCACY ORGANIZATIONS & PROVIDERS

Priority	Prioritized Recommendations	Estimated Biennial Costs
1	State Autism Coordination and ASD Registry <ul style="list-style-type: none"> Staffing and related support = \$494,135 <ul style="list-style-type: none"> HSPA V salary, benefits and operating = \$242,122.48 Admin. Assistant I salary, benefits, and operating = \$132,768.88 Website development & maintenance; travel for outreach, planning, coalition-building; family support; etc. = \$119,243.64 ASD Registry <ul style="list-style-type: none"> Development and maintenance = \$200,646 	694,781
2	Expand and Refocus the ASD Medicaid Waiver <ul style="list-style-type: none"> Eligibility would begin at age 18 months and be life-long, as needed Re-determinations could be done at specified ages (e.g., 8 and 12 years old) to ensure continued need and eligibility Budget based on average spent on individuals under the traditional DD waiver of \$27,239/person 75 'slots' for the first year of the biennium = \$2,042,925 200 'slots' for the second year of the biennium = \$5,447,800 	7,490,725
3	Comprehensive Training <ul style="list-style-type: none"> Training provided until 8/2014 through SAND grant (NDCPD) Funds for the second year of the biennium for training for direct support staff, parents, professionals, physicians, daycare providers; some funds allocated to family support agencies for statewide coordination services for a total of \$79,016 	79,016
4	Access to Behavioral Analysts <ul style="list-style-type: none"> Financial support for sixteen people (two in each region) to complete an online board-certified behavioral analyst to include required supervision up to the point of taking the certification 	198,872

5	Dedicated Diagnostic, Evaluation, & Service Planning Teams <ul style="list-style-type: none"> Funding for evaluation, diagnostic, and service planning teams comprised of a physician, occupational therapist, physical therapist, certified behavioral analyst, and family support professional Evaluations and screenings currently range from \$1,725 to \$5,045 per child Estimated biennial cost for 16 individuals in each region (for a total of 128 screenings) would range from \$220,800 to \$546,760; the average between these two costs = \$383,780 	383,780
6	Private Insurance Coverage for ASD Care and Treatment <ul style="list-style-type: none"> SB 2268 (2011) was accompanied with a fiscal note of \$5.8 million for State government for the 2011-2013 biennium 	5,800,000

October 1, 2012

SUBJ: Autism Spectrum Disorder (ASD) Task Force recommendations

Dear Chairman Wieland & Members of the Human Services Interim Committee:

The ASD Task Force, as constituted by NDCC § 50-60-32 (2009), has met numerous times to discuss, plan and share information about ASD services in North Dakota. The Task Force has completed research and conducted surveys, including input from families and providers, to aid in its deliberations. Through the leadership of JoAnne Hoesel, the Task Force has thoughtfully put together recommendations as requested by the Human Services Interim Committee.

While the Task Force recommendations may seem overwhelming in terms of scope and cost, we believe they are all valid. At the same time, we understand that the Legislature may not believe it is in a position to fund all remedies.

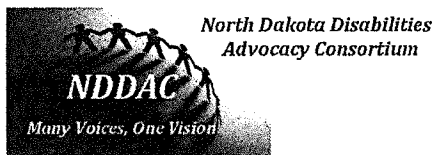
We know that you have heard from many individuals and families who have told their stories about the challenges and difficulties they face in attempting to manage life while dealing with the added stress of Autism. We also know that you want to help.

Attached please find the chart of Task Force recommendations as prioritized and supported by the undersigned. While other suggestions have been presented to you, we speak as one voice in asking you to seriously consider funding the top priorities we've listed. As stakeholders representing advocacy organizations, families, and service providers, we believe this is the most effective, efficient, and consumer/family-friendly way to approach resolution and service delivery.

A representative from our stakeholder group, Vicki Peterson, will be present to provide testimony at your October 4th meeting and will be happy to answer questions. Thank you for your consideration.

Sincerely,

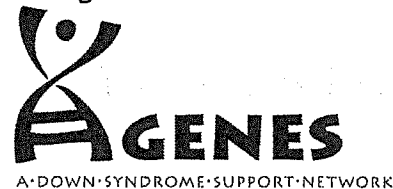
North Dakota Disabilities Advocacy Consortium



The Arc of ND



Designer Genes of ND



Family Voices of North Dakota



Pathfinder Parent Center



North Dakota Association of Community Providers



Protection & Advocacy Project



NDAD



Federation of Families for Children's Mental Health



North Dakota Center for Persons with Disabilities



Development Homes, Inc.

