

## Testimony

## Human Services Interim Committee

## Autism Study

August 30<sup>th</sup>, 2012

Chairman Wieland and members of the Human Services Committee, I am Vicki L Peterson, a single mother of a 10yr.old son with autism. I have given testimony earlier to this committee on my concerns as a parent of a child with autism, as well as a list of priorities I feel are important to have in the state of ND focusing on autism. Today I would like to make some very brief comments on the ND State Autism Task Force Recommendations to this committee and other proposals.

- A recommendation for a State Autism Coordinator has been made. As it is right now in the state of ND, families are very unsure of which agencies could help them with their children and youth with autism. Even within agencies it is very unclear as there has not been funding to have a state coordinator. This presents itself to families and self-advocates as not having a lot of confidence in the programs, if every time they turn to a program no one wants to take ownership of it, or the person that is in charge of the program, has so many other programs it is not being given enough attention. This needs to change if we, citizens of ND, want to help our individuals whom have autism.
- Family Support. ND is a fast growing state now. As we all know the Energy industry has brought many people to our state, families to our state, families whom have children and youth and adults with autism and other special healthcare needs They are in need of services and many in rural ND. How will they get there information? Who will be there emotional support as they became vital members of our community, who will help navigate the array of systems for these families that already exist? Who will help persons with ASD become leaders and work to have quality of life? The answer; Parent Organizations. Parent and Family Organizations are a key component and cannot be overlooked.
- Staff and Personel that are trained in the fields of the core deficits of autism. Communication, Behavioral, Social and Theory of Mind. Behavior Analysts is an area in this state where the persons licensed and trained are very low, in fact in central and western ND almost non-existent, even though this is where the higher growth of population is at this time. In the school systems, where our children and youth spend most of their time, behavioral therapists again are mostly nonexistent. Our population is growing at such a fast rate, especially families with young children, staff anywhere is hard pressed, let alone persons whom are trained to work with persons with autism. As youth transition into adulthood, we need personnel to help persons enter the world of jobs and higher education. Persons whom have autism may have deficits in core areas but with help are very capable of being productive citizens.
- Registry and Tracking System. As you listen to testimony, stories from families, professionals working with persons with autism, I believe all agree, ND does not have a system that is

tracking persons with autism in the state, which makes it hard to produce data in turn to design programs that actually will help the persons it is intended for, persons with autism.

- Another recommendation was to re-look at the Medicaid waiver system for persons with autism. As it stands now, a waiver that is for children birth until their 5<sup>th</sup> birthday may have been a starting point when the program was implemented, but as a parent I believe the critical piece of this waiver was missed. ND has an early intervention program which I believe was key to getting services for my son and he would not have made the progress he did without that service. As a parent I do not believe the Autism Waiver at this time is filling the gaps as it needs to. A good place to start with this would be to look at a different age group to qualify for the program. What age group would that be? It would be hard pressed for a parent to answer that ,or self-advocate, for us we know autism is across the lifespan, but barely a couple years of services at a young age does not seem like the correct starting point.

In conclusion I hope as a committee and policy makers you keep in mind that autism is not something that is going away. Autism is very complex and everyone is different in how autism effects them. Many persons with autism have other chronic health conditions that require specialists and interventions. Persons with autism are vital community members and want the same quality of life that you and I do. I hope that this committee will be able to bring that message to all and as parents , family members, self-advocates and professionals, we all work together to make that happen.

Thank you for your time and attention to autism.

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