

**Testimony
Human Services Committee
Department of Human Services
Representative Alon C. Wieland, Chairman
January, 17, 2012**

Chairman Wieland, members of the Human Services Committee, I am Dr. Barbara Stanton. I have worked at Southeast Human Service Center (SEHSC) since 2000 as an Advanced Clinical Specialist. I also have a private practice in which I work exclusively with individuals who have autism spectrum disorders who do not meet core service criteria to access services through SEHSC. I am here today to provide comments from the perspective of a treatment provider with regard to the diagnosis, treatment, care for, and education of individuals on the autism spectrum. My comments will primarily relate to my practice at SEHSC.

I would like to thank Chairman Wieland and the committee for inviting me to give testimony today. I would also like to take this opportunity to thank the Autism Spectrum Disorders Task Force for their dedication and hard work. Autism spectrum disorders issues are a very complicated, and I appreciate the committee's consideration.

In the past 11 years, between my work at SEHSC and my private practice, I have provided services to over 500 individuals on the autism spectrum. Ages have ranged from 3 to 58. They have been residents from across the state. Typically individuals with an autism spectrum disorder comprise between 50–60 percent of my caseload; most are children under the age of 18. Working with adults gives me an opportunity to learn more about what children experience and need. I provide assessments, individual and family therapy, collaboration, and case management services. I also facilitate both a weekly and monthly

parent/caregiver support group, and co-facilitate a weekly group for adults on the autism spectrum.

It is important to note that the populations I work with are those who have Asperger's Syndrome, Pervasive Developmental Disorders Not Otherwise Specified, or are considered to have high functioning autism. These are individuals who are of average to superior intellect. This means that they are not eligible for services within the Department of Human Service's (DHS) Developmental Disability program. Providing services for people with high functioning autism spectrum disorders is not a core service of Human Service Centers. Therefore, all of the clients that I work with at SEHSC present with a very complicated profile of co-existing behavioral or mental health issues. This includes those who are at risk of incarceration or are currently in the justice system, those who are currently in or at risk of out of home placements, and individuals who are experiencing significant difficulties in school, in their place of employment, or in maintaining housing. Most display clinically significant symptoms of anxiety and depression which can, at times, incapacitate them. I have also seen a limited number of individuals who abuse substances.

I have provided educational workshops/presentations on high functioning autism at the DHS Clinical Forum and to many groups including Head Start, law enforcement, Pathfinders, educators, and the general public.

My training in autism spectrum treatment has come largely from professional self-development. I collaborate with other professionals knowledgeable in the field, I attend workshops, and read books and professional literature. I check weekly for new information. I often do this at my own expense and on my own time. I also depend on the individuals and families I work with to provide me with resources.

What I have learned over the last several years working with individuals on the autism spectrum includes the following:

- Autism spectrum disorders are a complex neurodevelopmental disorder in which the individual has impairments in functional skills. The autism community uses the term neurodiversity much like you have heard the term cultural diversity. The term neurodiversity refers to differences in how people think and perceive the world around them, which makes it difficult for them to understand the world around them, which results in emotional and behavioral difficulties.
- Professionals and communities need training to understand neurodiversity in order to provide an environment that promotes an opportunity to succeed.
- These individuals are truly unique and require individual treatment approaches and plans. This is definitely not a “one size fits all” population. Adequate care requires an individualized, systems approach that includes the individual, their family/caregivers, the educational and legal systems, medical providers, occupational and speech and language therapists, vocational supports and community supports such as transportation and housing.
- Traditional “therapy” is not effective. According to the Inter-agency Autism Coordinating Committee of the U.S. Department of Human Services (2010) and the Autism Research Council, the only evidence-based practices for individuals with high functioning autism are social stories and video modeling. Unfortunately, there has been limited research focused on older children, adolescents, and adults. There are promising practices emerging. For example the *Life Map* program in Massachusetts suggests that a community based “in the moment teaching” form of case management/coaching can be highly effective, and research is continuing to look into this. The Transition to Independence

Program, recently implemented by DHS, appears to be effective at SEHSC for some individuals on the autism spectrum. Safe and effective interventions are needed across the lifespan.

- It is necessary to include the parents/caregivers in any intervention. There is no other issue where I have worked with parents who feel such a sense of urgency and desperation. This is a complex issue that is difficult for many parents to navigate. Their hope is to move their children beyond their basement. They often do not know where to turn or who to trust. The most effective treatment occurs in the individual's community and home with providers who understand high functioning autism. Unfortunately for many families, services are simply not available or accessible.
- The experts on autism spectrum disorders are those individuals who have an autism spectrum disorder, and I would encourage this committee to include them in the planning and development of programs and services.
- Comprehensive services need to be available across the lifespan. Autism is a lifetime issue; there is no cure. Individual needs change; they do not go away. There is no doubt that early intervention is critical to ensure future success of individuals with autism. However as developmental changes occur, those needs and supports change with them. For those diagnosed in adulthood, the challenges are greater and the services/supports fewer.
- With regard to the identification of barriers, I would direct you to the recommendations of the autism task force. Not only do I agree with their findings but have experienced most of them first hand. When provided with the proper interventions, these intelligent, compassionate, and talented individuals can reach their full potential. Without the appropriate supports, they will find themselves involved in other community services including the legal system, residential placement, shelters for homeless

people, or receiving other forms of governmental assistance such as medical assistance, social security income, Temporary Assistance for Needy Families, and the Supplemental Nutrition Assistance Program. The human and financial costs to the individual, community, and society are high.

- Finally, and most importantly, I have learned patience, understanding, how to open my mind to a different way of thinking about the world and to honor neurodiversity. There must be opportunities for success for individuals on the autism spectrum. When each of them achieves success we all benefit.

Thank you for the opportunity to present this information, and if you have questions, I will do my best to try and answer them.