

**Testimony****To****HUMAN SERVICES INTERIM COMMITTEE  
NORTH DAKOTA LEGISLATIVE ASSEMBLY****By****Eric Monson, CEO  
Anne Carlsen Center  
Tuesday, October 25, 2011**

**Mr. Chairman and Committee members, for the record, my name is Eric Monson. I am the CEO of the Anne Carlsen Center in Jamestown, ND. You have invited comments from those of us that serve the needs and desires of the special kids, young adults and their parents around the state that seek services relative to the autism spectrum – a work we feel blessed to do for them as part of a team with you. Through the gracious heart of each of you as policy makers, we can provide the supports enabling as independent a life as possible.**

**The Anne Carlsen Center (ACC) has begun and will expand Autism Services in the major communities throughout North Dakota for individuals with Autism Spectrum Disorders (ASD). The services will provide an array of activities and program options for individuals and their families. The services include diagnostics, comprehensive evaluations, program planning and development, intervention services, information/referral and family support services, and education and training for families and professionals.**

**By providing the necessary services, the Anne Carlsen Center helps individuals gain functional skills and abilities, including social integration, all of which are vital to a person's overall well-being. Through intervention services and supports, i.e., coaching, mentoring, and training, the overarching outcomes achieved by individuals are:**

- Reducing challenging behaviors**
- Increasing social competency**
- Increasing competencies in the areas of adaptive living skills and academic skills**
- Increasing vocational competencies for adults**

**A team of professionals including a pediatrician, clinical psychologist, behavioral analyst, occupational therapist (OT), physical therapist (PT), speech and language pathologist (SLP) and special educator provide diagnostics, comprehensive evaluations, and intervention services. ACC will continue to collaborate with North Dakota Department of Human Services Developmental Disabilities Division (ND DHS DDD) personnel, other service providers such as medical personnel, allied health professionals, residential support services, and school personnel who are involved with the child or young adult to insure consistency and continuity of interventions for the individual and their families, and to insure that families and providers are well-informed and knowledgeable regarding all aspects of the individual's program and care.**

**Anne Carlsen Center offers the following core Autism Services:**

- Diagnostics services,**

- **Comprehensive evaluations,**
- **Program planning and development,**
- **Intervention services,**
- **Information, referral and family support services, and**
- **Education and training for families and professionals.**

**We were afforded the opportunity to present our plan to the Autism Spectrum Disorder Task Force on May 12, 2011.**

**For the past decade the Anne Carlsen Center has served an average of 35 children on the spectrum with high behavior needs. Our experience indicates that the provision of a very structured program is essential. Our 24/7 environment with residential and DPI approved and accredited school under one roof gives us the ability to provide a continuous intervention curriculum both during school and non-school time.**

**We track data relative to behavior (e.g. head banging, biting, hitting, kicking and self-injury) on an individual and group basis. One of the outcomes we seek with each individual, and one of our marks of programmatic success, is the reduction in the number of incidents with each child and young adult. Our statistics indicate that we have been able to reduce these types of behaviors within a range of 30-70% with an average reduction of 50% for children we work with.**

**Curriculum and intervention, developed for each individual, is incorporated into their Individual Education Plan (IEP) and Individual Service Plans (ISP).**

**Research indicates the long-term outcomes are much improved with earlier intervention. Short-term outcomes are also improved and we see results sooner. Parents/guardians are obviously pleased with these outcomes.**

**Anne Carlsen began its Community-based autism services in 2008 for adults through the day supports program. Though this program is coordinated through our individual Community Services offices located around the State, we consider the day supports program as a program “without walls”, where individuals are served within their home and the community.**

**We believe that this program “without walls” has enjoyed some early success. We appreciate the funding currently made available for day supports and look to continued strong support from the Department of Human Services.**

**Children are the priority focus in our community-based autism services business plan described earlier. ACC is currently providing community-based services to five (5) children under the Autism Waiver in three (3) regions of the state. In addition, we serve seven (7) children identified on the Autism Spectrum through the in-home support waiver. While some service is better than no service, our opinion is that the number of hours approved and paid for is not consistent with evidenced-based practice.**

**In addition to the 12 children mentioned above, we partner with the Center for Persons with Disabilities at Minot State University in providing state-wide diagnostic and comprehensive evaluation services. This collaborative activity is funded through a Children’s Special Health Services Division of the ND**

**Department of Health grant, a federal grant, ACC and Autism Waiver funds. Since 2008 the collaboration has served:**

- 19 children's evaluations**
- 72 Individuals served through diagnostic clinics**
- 62 follow up evaluations in natural settings**

**During 2012 our plans call for expanding the number of children and young adults served. Additionally, the Anne Carlsen Center plans to subsidize the increase in support hours provided to children/young adults and families to reach the hours of service as recommended by evidenced-based research and practice.**

**While we do not, as yet, have longitudinal research data to speak to outcomes and sustainability, allow me to relate an anecdotal story regarding one youngster we have been privileged to support.**

**Maddy, two years old at the time, following an evaluation, received a preliminary diagnosis of Autism Spectrum Disorder (ASD) in July 2010. Intervention options for Maddy were limited due to the family's rural location (90 miles from an urban center). In September 2010, a certified and licensed clinical psychologist with experience with Spectrum Disorders conducted an 8 hour training session for all the team that would be doing Applied Behavior Analysis (ABA) therapy with Maddy. In September 2010, Maddy's parents began ABA therapy training along with a group of 8 volunteers and one ACC staff. Maddy consistently received approximately 30 hours of ABA each week (every day with the exception of Sunday.) The "team lead" was Maddy's**

**mother who wrote the program and conducted weekly meetings with the team to update the target areas as well as the areas that were considered mastered. The clinical psychologist monitored the overall program, data and the progress Maddy had made and gave input and suggestions to the family. Maddy's mother was invited to attend sponsored by ACC. Dr. Jonathan Tarbox, a noted researcher with the Center for Autism and Related Disorders (CARD), conducted the training in October 2010 introducing the CARD curriculum and upcoming availability of their online Skills Program. At the time CARD was planning a trial of the program for a small group of people across the U.S. The ACC Community Services Coordinator and Maddy's parents inquired about Maddy entering the program and Maddy was accepted into the trial group. On November 15<sup>th</sup>, Maddy started the online CARD Skills Program. During January-February, Maddy's intervention hours were reduced from 30 hours/week to 10 hours a week consisting mostly of peer play and generalization skills. After approximately 7 months of ABA, remarkable gains were made. Maddy was re-assessed in June 2011 and had made advanced to the point that she no longer screened for DD services. In July 2011, Maddy was considered to be in "ASD Remission," roughly one year after her initial ASD diagnosis. Maddy's story is an example of how skilled and timely intervention can pay great dividends- for the child, the parents and those providing the essential funding.**

**Recognizing that we are in the early developmental phase of the community-based portion of our business service delivery plan, we offer the following early stage recommendations:**

- 1. Continue strong funding for the Day and In-Home Supports program at rates that incentivize providers to attain evidenced-base service levels.**
- 2. Approve intensive behavioral support hours within the Autism and In-home support Waivers Program consistent with evidenced-based practice.**
- 3. Develop consistent application of program policy/practice across all regions of North Dakota with regard to Autism Services.**
- 4. Include behavior support services in the Autism Waiver, as allowed in the In-Home Support Waiver.**

**Please be assured that the Anne Carlsen Center will always be prepared to provide to you as policy makers the benefit of our experience and observational support in this vital task. We will be available to you when and if you ask for any comments – and perhaps even when you don't ask.**

**I personally invite each of you to tour our facility the next time you travel through Jamestown or one of our community services offices. You have an open invitation. Chat with the kids whom we serve. Ask questions of our specialized pediatric physicians, nurses, therapists, chaplain and the many other caregivers that complete the care teams for the folks we serve. They will all be flattered that you came and will take all the time you require to become more informed about what we do and how we do it. Call if you can to be sure we can give you the best experience possible, or simply show up unannounced. Either way is fine.**

**Finally, I offer my humble thanks to you for allowing the Anne Carlsen to perform its mission. As you know, without your public policy support,**

**including your funding support, we would not exist to do the work you require us to do - for those children and young adults that need supports.**

**Thank you.**

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**Eric Monson, CEO  
The Anne Carlsen Center**