

ND STATE PLAN ON AUTISM ADVISORY COUNCIL

MEETING NOTES

Friday, November 14, 2008

Bismarck, ND

Present: Cathy Haarstad, Christy Carroll, Carlotta McCleary, Dr. Patrick Moran, Dan Howell, Bob Rutten, Janice Kern, Sandy Smith, Donene Feist, Senator Joan Heckaman, Tammy Gallup-Millner, Jesse Krieger, Barb Murry, Dan Ullmer, Vicki Peterson, Brenda Munson. Dr. Brent Askvig and Wendy Thomas were available via teleconference.

Welcome: Dr. Askvig presented opening remarks and welcomed those attending the meeting. The ND State Plan on Autism Advisory Council was formed to begin development of a North Dakota state plan on autism by exchange of information, sharing experiences and things being done related to autism that can be used to create a state plan that supports and provides services to stakeholders in assisting people with ASD and their families. Introduction of members attending today's meeting. Cathy Haarstad briefly reviewed the ND State Plan on Autism Talking Points (insert) *Why We are Here*.

Components to State Plans: Cathy went on to discuss *A Review of State Plans on Autism* (insert) indicating a goal of "our" State Plan is to assist in accessing new sources of funding for stakeholders and people with ASD and their families. It was agreed that this committee will talk about Autism as a Spectrum Disorder and that a goal of this committee is to reach a consensus on issues discussed. The advisory committee will look at services for ASD across the life span, comprehensive from birth through adult.

Discussion Points –current challenges:

1. Access to services
 - Funding sources unavailable to bring in behavioral intervention professionals.
 - Individuals with ASD and their families experience daily stressors and isolation.
 - No consistent comprehensive early screening for ASD and if diagnosed then they do not have access to early intervention services.
 - Some individuals with ASD do not have access to services because of eligibility criteria.
 - Transition services.
 - Community services unavailable for adults with ASD.
 - No certification or training for behavioral analysts is offered in ND.
2. Service coordination (availability)-to include training, funding and geography.
 - Pediatrician re-training with screening efforts.
 - ND often lacks effective coordination between service providers.
 - Individuals with ASD and their families often do not know where to go for information and assistance in going through the system.
 - Problems with screening children before age 2.
 - School districts within the state using different assessment tools.
 - Service is not consistent across the life span.

3. Statistics/Data

- In 1999 13,612 children/youth ages 3-21 were receiving special education services of that total 102 were identified as primary disability with autism.
- In 2007 13,606 children/youth ages 3-21 receiving special education services of which 444 through IEP were identified with primary disability.
- Dan Ullmer shared BCBS statistics indicating first diagnosis ages 0-4 @ 12%, 5-9 @29%, 10-14 @ 22%, 15-21 @ 11%. The BCBS numbers show that in 2004, 256 children were diagnosed with autism and 382 children diagnosed in 2007, out of 56,468 children that were insured under BCBS in ND.
- The committee agreed that we need to obtain current statistical data with the data including children/youth through adult with autism.

4. Diagnosis

- Schools are reluctant to give students an educational diagnosis of autism for fear of labeling a child at a time when early intervention is critical
- The basis for the educational diagnoses must be a medical diagnosis but that may not be given even by age nine when the school can no longer use the “non-categorical delay.”

Areas described by committee members to address for state planning project:

- Data
- Screening
 - Functional disabilities affecting adults
- Diagnosis
- Treatment
 - To include medical and educational; which impacts a lot of other pieces to including funding
 - Statewide criteria for treatment, but allowing for family choices
 - Review new treatment options as they become available
 - Best practice individualized treatment with documented improvement
 - Perception and knowledge of treatment options.
- Intervention
- Infrastructure
 - Technical support for parents and therapists (tele-health)
 - Use technology for service delivery
 - Agency specific awareness of services offered statewide.
- Training of personnel
 - Include adult services
 - Training for physician, teachers, parents and childcare.
- Vocational Rehabilitation
- Family Support
 - Parent 2 parent data; moving forward from now.
- Early intervention, school age and adult Services
 - Life span
- Funding

- No funding sources for some of the required services, these then are falling under the mental health system.

Plan:

1. Data
 - NDCPD is committed to doing an online survey with state providers to determine inventory of current services available in the state and training.
 - We will also gather existing data sources on prevalence and service deliver - areas that the NDCPD survey will not cover.
 - Data collection and survey responses will be available by January 15, 2009.
 - Forward information or resources to be included.
2. Additional representation for the task force will be invited to subsequent meetings.
 - Tribal representation
 - Vocational Rehabilitation-suggested Wanda Bye
 - DHS-suggested Robin Hendrickson
 - Adult DD-talk with Carol Olson regarding adult service representation
 - Self advocate
 - Children and family services
 - Mental health service
 - Easter Seals
 - Head Start
3. Discussion of developing a resolution to present to legislature versus establishing a task force, Governors council or Legislative council to develop a state plan on autism within the deadline allowed for the legislative process.
4. Senator Heckaman reported that the OAR (Optional Adjustment Request) initiative is in, asking for \$1.159 million, and working with children/youth ages 3-5.
 - Look at developing in bill format.
 - Autism Advocates will work with Senator Heckaman regarding bill development.
5. It was suggested that we format the ND state plan after the Vermont Autism State Plan looking at four (4) big categories? We need to determine what areas of need we want to include in planning, i.e., services, service coordination, equity, and workforce. This seemed to be generally acceptable to the group present.