

ND STATE PLAN ON AUTISM

WORK GROUP - MEETING NOTES

Thursday, May 7, 2009

Present: Brent Askvig, Deb Balsdon, Cathy Haarstad, Christy Carroll, Jim Carter, Bob Hoffert, JoAnne Hoesel, Holly Major, Carlotta McCleary, Tammy Gallup-Millner, Barbara Murry, Carol Olson, Vicki Peterson, Bob Rutten, Mark Sloan, Sandy Smith, Tricia Kiefer, Lynn Dodge, Sharon Solum, Kerry, Chassen, Connie Irely, recording secretary. Marcia Gums participated via phone conference.

Purpose: To review a comprehensive set of data currently available that describe ND populations of children with ASD and provide insight the needs of families and providers when attempting to meet the needs of this population.

Legislative Update:

- SB2174 was signed into law in April. This legislation authorizes the NDDHS to form a Governor's Autism Spectrum Task Force. JoAnne Hoesel described Task Force positions to be filled by Governor. The NDDHS is inviting the current work group to offer recommendations for each position (10) to the Governor's office for his consideration. JoAnne will email a list of criterion out to members of the work group.
- The State Task Force will develop a state Autism Spectrum Disorder plan to be presented to the Governor and Legislature Council before July 1, 2010. Thereafter, the State Task Force will continue to periodically review, update and amend the State Plan and issue an annual report to the Governor and the Legislature Council.
- HB 1012 gave the NDDHS authorization to create an Autism Spectrum Waiver. The waiver is intended for children under age 5 years of age and children must have an ASD diagnosis. This is a home and community based waiver. It still needs to be written and submitted to CMS. It is expected to be implemented by July 1, 2010 but is contingent on MMIS implementation. There is no budgeted money for staff positions to develop or manage this waiver.

Data Sharing:

Department of Public Instruction: Focus on School-aged Children and Youth

- **DPI** – An overview of the data shared by Bob Rutten, director of the ND Department of Special Education may be found on their website <http://www.dpi.state.nd.us/speced> Click on State Guidelines block scroll down to Autism Spectrum Disorders in Public Schools
- A new employee at DPI – Lynn Dodge, recently returned to North Dakota from Washington, D.C. working as a teacher with students with ASD and just finishing her doctoral degree. Bob would like Lynn be considered as his designee for the position on the State Task Force as this is her expertise. She has co-authored a document for the National Education Association on "The Puzzle of Autism".

- Much of the funding for serving children in public schools comes from the U.S. Department of Education. A requirement of federal funding is that there be performance measurements. Another federal law, the Government Performance Results Act (GPRA) also requires federal agencies to measure effectiveness over time. This is required from states to indicate if federally funded services are in fact doing what they are intended to do.
- Data on race held some surprises for the team and more assessment is needed to determine its meaning and significance for ND.

Special Ed Directors: Focus on Current Professional Development Activities Initiated through Special Education Unites

Jesse Krieger and John Porter conducted a survey of special education directors. They were not able to be present to share the data in person but Cathy Haarstad shared it out for the group (see attached).

Early Intervention: Focus on Children ages Birth – 2

Ten % of people served by the NDDHS-DD services have ASD diagnosis (446) and are receiving services through program management (see attached). The data reflects the age of the people who are receiving DD services now not their age of diagnosis. There are an increasing number of children coming into the system. Early Intervention feels they could possibly do better with the Autism Waiver if there is a multidisciplinary team assessment.

State Team Act Early Summit – Members of the State Team on Autism travelled to Utah March 5th & 6th to attend the Act Early Regional Summit which is sponsored by the Association for Universities Centers on Disabilities and the Department of Health and Human Services Maternal Child Health Bureau and the CDC to help states pull together teams to look at the “Act Early Learn the Signs” information regarding screening, diagnosis and identification of autism at a very young age.

ND was invited to assemble a team and put together a state plan (Logic model template) with resources, activities, output for responding to the newest resources and recommendations. This plan should not be confused with State Plan on Autism that this group or that the Governor’s Task Force will be doing. The group recommends three activities as their top priority:

- 1) Design a comprehensive and annual system to disseminate Act Early – Learn the Signs materials. Provide them to families, physicians, other community providers who may come in contact with families and children who may have ASD.
 - 2) Coordinate and identify training resources for providers and families.
 - 3) Apply for Technical Assistance from the National Professional Development Center on ASD. This process helps states to coordinate, emphasize and try technical assistance models within the state to support providers – Birth through 21 who are serving youth and children with autism and their families. (DHS, DPI, NDCPD). More information is available at www.AUCD.org Click on initiatives.
- AUCD, CDC and MCH will give states opportunities to apply for mini grants (\$2,000 - \$5,000) later this year. If the Governor’s Task Force team wants to look at early intervention or information dissemination regarding Act Early – Learn the Signs to pediatricians, primary care physicians, and family physicians they could access this money to help this move forward. We do not know all details on this yet as they have not been announced yet.

National Professional Development Center on ASD – State Application

The team discussed a pending opportunity to apply for technical assistance from the NPDC. The deadline to apply is June 1, 2009 for this year. Applications will also be available to apply in 2010. The invitation to participate is predicated on three programs in the state. Application process requires State Part C Coordinator, State Part B Coordinator, and UCEDD sign off. This would help ND get access to:

- 1) Training materials – onsite and online
- 2) Training for model site teams – Birth – 21
- 3) Ongoing technical assistance as our state develops a process or procedure on to be experts about serving children and youth who have ASD.

Comprehensive Services: Focus on support for families, children youth and adults:

DD and MH Services – Deb Balsdon shared data on the DD population. JoAnne shared non-DD information (7/07-6/08). The data is attached. This is only public data not private or aggregate.

ND Families – Vicki Peterson reported results from survey sent out to ND families. Survey (see attached). Many parents are unfamiliar with the technical language used to describe ASD. There is a need out there for parent education on ASD and a need to ask families about what is working as well as what is problematic. For example, some families are unaware of the difference between an education diagnosis vs. medical diagnosis. Follow-up surveys are needed.

Research – Attached to these minutes is an article “Evidence-Based Practices and Students with Autism Spectrum Disorders” by Richard L. Simpson for your consideration.

Meeting Adjourned: The team ran out of time at 2 PM and some people did not get an opportunity to present data.

Next Meeting: Agenda

1. Present data from JoAnne Hoesel and Tammy Gallup Milnor
2. Form recommendations for services, service coordination, data collection, equity and workforce development.

Meeting Date: Thursday, June 11, 2009 8:30 am – 10:30 am in person in Bismarck or via IVN in Minot, Grand Forks and Fargo.

IVN is set up as follows:

Bismarck – State DD Office – Prairie Hills Plaza, Prairie Room Ste 1A

Fargo – Southeast Human Service Center – Cass East Room

Grand Forks – Northeast Human Service Center – Room 5E

Minot – Minot State University, Memorial Hall – Room 207

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