

ND STATE PLAN ON AUTISM ADVISORY COUNCIL

MEETING NOTES

Thursday, January 8, 2009

Webinar

Present: Cathy Haarstad, Christy Carroll, Brent Askvig, Wendy Thomas, Chad DeCoteau, Marcia Gums, Cheryl Collins, Mark Sloan, Bob Hoffert, Wendy LaMontagne, Cindy Sheldon, Bruce Murry, Deb Balsdon, John Porter, JoAnne Hoesel, Holly Major, Janice Kern, Donene Feist, Sandy Smith, Dan Ulmer, Bob Rutten and Lynn Dodge, Tammy Gallup-Millner along with Tricia Kiefer, and Brenda Munson, recording secretary.

Welcome: The meeting was originally scheduled to meet in Bismarck, however, due to predicted deteriorating weather conditions; it was decided to hold the meeting via webinar. Attendees for the teleconference were introduced.

Survey Results:

- The survey was conducted to take a look at what services and resources are available in our state for autism.
- Last meeting we came up with four areas that we wanted to center a plan around to include Services, Service Coordination, Equity and Workforce. Cathy added a 5th one which was Data.
- As we review the survey results Cathy asked that we organize our thinking in these areas around some pivotal questions, “what do we know,” and “ what don’t we know.”
- Cathy reviewed the data results for the ND State Plan on Autism December 2008 Online Survey that was completed by Cathy and Chad DeCoteau. The survey was mailed to 156 people/agencies with 105 persons completing some part of the survey and 68% of the respondents completing the entire survey.
- Statistical data as discussed at the November meeting:

NATIONAL

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|------|-------------|-------------|
| CDC* | <u>2000</u> | <u>2004</u> |
| | 4.4 | 6.6 |

*Per 1000 school-aged children

| | | |
|---------|-------------|-------------|
| NDDPI * | <u>1999</u> | <u>2007</u> |
| | 102 | 444 |

* Of 13,600 children/youth ages 3-21

| | | |
|---------|-------------|-------------|
| NDBCBS* | <u>2004</u> | <u>2007</u> |
| | 256 | 382 |

* Of 56,468 children insured by BCBS, 2008 updated data not available yet.

NDDHS: JoAnne Hoesel indicated that she looked at the Regional Human Service Center service data for fiscal year 2008 and results revealed (indicating that this is not a complete picture) 183 individuals with a primary diagnosis of PPD were served at the Human Service Centers; this includes all ages, 3 to adult; this data will be included in the PowerPoint.

- Cathy invited individuals to share data or information that is significant to the survey
- Survey results included service areas within North Dakota; primary role of services provider; populations served; services offered at No Cost, services costing <\$100; and services costing \$101-\$500.
- Cheryl Collins questioned relevance to breaking down the data into age and categories.
 - ✚ JoAnne, Bob Rutten and Dan Ulmer stated that they could break it down by age.
 - ✚ Joanne would want to know from the group what diagnostic category to pull the data from.
 - ✚ Deb stated that they could pull the data from birth to three and then the older group, putting in the diagnoses for comparison.
 - ✚ Bob explained that one of the disability categories permitted and used in North Dakota is Non Categorical Delay which extends up through age 9 and the purpose of this is to allow parents and educators time to really obtain more information about what is occurring with the child, and that a number of children showing up in that Non Categorical Delay group could, in fact, be children who are on the autism spectrum.
 - ✚ Bob H. asked what the final goal for splitting up the ages, to take the data set and split it up into different ages as opposed to using the number of 444 school aged youth with a primary diagnosis of autism?
 - ✚ Cheryl's thought would be that within the different age categories you do find some unique needs that should be addressed and this would be one way to identify those needs.
 - ✚ Brent verbalized that activities related to services and service coordination will often be dependent on numbers of individuals within each of those areas, and remembering again that a lot of children birth to age 3 don't have a diagnosis of autism, so those kinds of things are helpful in breaking the numbers down. Usually primary diagnosis is used when collecting data, there is a place for a secondary categorical label on the IEP, does that exist for students in the ASSIST program, in the general DHS data set, and in BCBS? It was agreed that additional diagnoses could be included in the collection.
 - ✚ It was suggested that when collecting data, to use additional diagnosis in the numbers. We collect data differently between the systems, but we will make a reasonable effort to present the best data sets available.

- The study reveals that there is an array of options out there, but what we don't know is what are the best options or what of the recommended options are available in our state.
- Looked at service costs to consumer and families and the breakdown. Part of what we don't know is how much it is costing to supply any of the services that we asked about in the survey, if there was an average cost and if the families can afford the cost; this survey was agency related.
- Respondents volunteered information on the survey and time and money were consistent factors in the response.
- Cathy will go back and clarify costs for residential treatment dollars.
- Surveyed if agency offered training and then showed the recipient of training by category; a number of respondents were from an education perspective.
- Ethnic group identification was not completed, but there was a diverse group involved in the study.
- A breakdown of Urban to Rural is available, but cannot be categorized by individual respondents; rather, data was gathered by general regional areas.
- Summarization of the survey includes solutions, resources and system change.
- The PowerPoint with the survey data and today's handouts on Perception of Barriers to Meeting the Needs of ND People with ASD and Suggestions for Meeting the needs of ND People with ASD will be attached to the email sent to Advisory Council committee members.

TimeLine

- See if we can start developing goals and objectives, what is the consensus of the participants?
- Bob R. suggested some possible other information that his office might be able to supply to the group prior to the next meeting which could include age, race ethnicity, primary language use in the home, and also by more specific to regions in parts of the state.
- At next meeting review a more comprehensive data sets developed by individuals and try to do some planning from there, giving people time to look over the survey results and analyze the data. Cathy and Chad will also try to do some more number crunching by geographic area.
- Vicki raised a point to look at developing a category for "what we don't know" and include a possible goal or action step to work on over the next year or two that would include input from parents, their perception and feelings, data collection and analysis; this could be decided by the group.

Legislative Review:

- Senator Joan Heckaman introduced the Autism bill, Senate Bill 2174, will be on the web. Senator Gary Lee and Rep. Dennis Johnson co-signed on the bill. Agencies have been notified and the purpose of the bill discussed with them, no hearing date established at this sitting yet.
- Coordinate advisory council committee members thought and comments regarding the legislation.

Plan Outline:

- Continue with the established categories which include Services, Service Coordination, Equity, Work force, and include Data.
- Development of work force development across systems, or another strategy would be to work with the workforce groups to see if it includes ASD. Bruce Murry is willing follow through on this task.
- Make certain that all North Dakotans have equitable services at whatever age they are and the differences between rural and urban, housing, employment, social options, including education.
- Bruce is willing to involve FamNet as an appropriate vehicle to advocate for awareness of needs with the work force, to provide some kind of link.

Next Steps:

1. Take the five categories and look at the survey results, jot down 2 or 3 main ideas that you would like to see developed into a plan related to the category areas.
2. At the next meeting come together and see if we can draft an outline, establishing some broad goals and some specific objectives.

Next Meeting: Monday, February 23, 2009 10 a.m.-3 p.m. at the Heritage Center.