NORTH DAKOTA BRAIN INJURY NETWORK

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North Dakota Brain Injury Council & Stakeholder Meeting
Wednesday, June 15th 2016
10 a.m. – 4 p.m., Central Time
Pioneer Room, North Dakota State Capitol
600 E Boulevard Ave, Bismarck, ND 58505

Meeting Summary

43 total attendees:
Alexander Herz, Ann Carns, Arlene Havig, Becky Hintz, Bill Carns, Blaine Kincaid, Brandi Charnholm, Brent Askvig, Brittany Hunt, Carmen Hickle, Corean Swart, Darcie Hanson, David Folden, David Law, Ed Biniek, Elaine Grasl, Gail Mooney, Heather Steffl, Heidi Gustafson, Jake Reuter, Jeannie Pedersen, Jennifer Vigen, John Wanecke, Joyce Wolter, Karen Law, Kaylen Morast, Kim Mathwich, Kristi Whitaker, Kristine Medeiros, Lynne Ostrem, Mandy Slag, Melanie Phillips, Melissa Seitz, Nicole Livedalen, Penny Woodward, Randee Sailer, Rebecca Quinn, Robin Rosendahl, Sandra Eisenbarth, Shannon Binstock, Sharon Swanson, Stacie Dailey, and Trina Gress

Welcome, Introductions and Purpose of the Meeting

The intent of the meeting was to select inaugural Brain Injury Advisory Council members, receive a presentation of the draft results from the Brain Injury Needs Assessment and have discussion on the nest steps in the development of brain injury services.

Introduction of New Advisory Council

Formation of Advisory Council-
Purpose is to build a council that will be more official, have a larger presence in the public arena, and hold a stronger base with more power from which to propose legislation from. Intent is to be introduced during the 2017 legislative session to become an official Governor's Council. Vision, Mission and by laws were adopted by the previous Advisory Committee during the fall of 2015.

Application process was adopted by an application sub-committee for final vote of council members to be voted on by the stakeholder group. Received 21 applications for the 9-13 members allowed in the bylaws. By-laws does include non-voting members from state agencies.

Discussion on nominee categories
Concern was raised regarding conflict of interests in those in the service provider's category. Some stated this council should be for the people impacted daily and not providers, and feels the majority of votes should come from family and caregivers but not agencies. It was pointed out that there is value having many perspectives at the table, and inclusion helps with transparency. Additionally, there will be some cross over as many wear several different hats.

north dakota department of human services

Presentation of the Providers Coalition
Formed fall of 2015 as a voice for providers. Advisory Council bylaws are set up for one representative from the Provider Coalition be a member of the Council to represent the Coalition.

Call for Nominations:
Lynn Ostrem was nominated to be a family member. Lynn accepts the nomination
Elaine Grasl was nominated as a family member, but she declines at this time
Native voice need to fill council requirements discussed at this time. Lee Redhorse was nominated. Provider nominations called for and none were noted.

Individuals voted and handed ballots to NDBIN representatives. Meeting broke for lunch.

Draft Results from the Needs Assessment by North Dakota Center for Persons with Disabilities
Presented by Dr. Brent Askvig and Kim Mathwich

Explanation of report still being in draft form and there are no recommendations in report yet. This presentation of the assessment report is to have people look over the format and layout. Asks people to look over document and consider how the information is presented and organized. Would like to know aspects such as: if the graphs and tables are better than wordage, are there flaws in set up, and presentation, and what can be done to streamline document.

Discussion

- Include a mix of graphs / charts for visualizations
- Representative Mooney states that graphs and tables are more Legislator friendly. She explains the more clearly and quickly information can be disseminated the better and increases the chances of success.
- Individual added that work related injury to list of cause- such as: fall, machine, etc. Workman's comp, method of payment
- Need to refine the information regarding the Medicaid waiver and Aging Services Division.
- Final Report Due June 30th - please email him with suggestions if thought of after today. brent.askvig@minotstateu.edu

Key Findings

1. Needs to be more public education and targeted education
2. Families are a huge resource to those during recovery process
3. Documented frustrations with eligibility for services and treatment options
4. People need transitional services, case management and housing
5. Difficulty getting accurate counts of brain injury survivors in North Dakota
6. Need for Support system for survivors, families, caregivers
7. Lack of continuum of resources and services in North Dakota and difference in available services depending on where you live
8. Conditions associated with BI (mental health, substance use, etc.) impact daily functioning and services, sometimes people are kept out of services due to a crossover of symptoms and dual diagnosis. For example- An individual may be needing services for BI but is kept from substance abuse treatment.

9. Problems with care coordination with existing services- "For people with brain injury in ND; services are few, disparate and disjointed."

Announcement of elected Advisory Council Members

Individuals with brain injury
- John Wanecke
- Joyce Wolter
- Sara Gerdon
- Shannon Binstock

Family Members
- Karen Law
- Kristine Medeiros
- Pat Eide

Legislators
- Tim Mathern
- Gail Mooney

Providers/Interested Community members
- Brittany Hunt
- Nan Kennelly

Provider Coalition Voting Member
- Trina Gress

Native Representative
- Lee Red Horse

Discussion on the development of Strategic Planning/Policy Platform

- Gail Mooney presented on information on working with the legislature and adopting a "Lean and Mean" platform. Need to speak with one voice and be strategic about what we are asking for. Needs assessment is first step to guide process. Representative Mooney feels it is a good first step to get progress moving forward with a united voice. We have a great need in ND and we have lost footing due to budget cuts. Need to have a concerted effort from the entire group to take before the legislators. Brain injury on its own is a separate group that legislators do not know what to do with. Consolidate with Behavioral Health System and push for brain injury to become a priority in BHS- Getting the council approved by Governor to give the council a vote in the larger BHS. Brain injury need to be included in services in Behavioral Health so that we can get individuals the ability to access services. Brain injury has no home nationally ND needs to determine where we want it.

What can in the short term?

- Data Hub- This group can support Senator Judy Lee's efforts toward the development of one health data hub by being in the room, testifying in both the house and senate, presence needed for success. Data needs to streamline- one data = one human- Combining. Privacy a problem with registries.
- Consider where does BI fit? –BHD or Aging? DHS is going to begin conversations between Behavioral Health Division and Aging Services to bridge the gaps of accessing services for the individuals.

- Increase public knowledge and awareness- Money Follows the Person program funded $325, 000 of a media campaign. The Behavioral health Division is evaluating proposals for the one year project to start July 1, 2016.
- What do to with definition- Broaden it or keep it the same? Will need the data numbers first. Legislators will not want to open up a broader definition without knowing the numbers
- Support services – continuum of resources and services- weeding through the services and finding the providers- laying out the continuum and fitting in the services – John feels they are top priority, but if we ask for the "elephants" we are back to the beginning if denied we have nothing.
- Representative Mooney points out if BI becomes part of Behavioral Health and bill is constructed a number of the assessment's key findings, may potentially be combined or folded in along with it.
    - Public and targeted education
    - Role/support
    - Access to treatment and continued treatment
    - Case Management
    - Housing
    - Support Services
    - Service Access