



Brain Injury Advisory Council Meeting Minutes – February 16, 2018

Council Members Present

Lisa Anderson, David Biberdorf, Shannon Binstock Binstock, Jean Herauf, Austyn Kloehn, Sarah Ring, Senator Ralph Kilzer, Shila Thorson, Cheryl Hess-Anderson, Kevin McDonough, Denise Harvey, Tami Conrad, Janna Peitzak, Krista Fremming, Nan Kennelly

Council Members Not in Attendance

Representative Dick Anderson, Mandy Slag

Others Present Jeannie Peterson, Arlene Hauwig, Randee Sailer, Darcie Hanson, Rebecca Quinn, Nickie Livedalen, and Linda Harmon

Call to Order

1:00 PM, Vice Chair, Lisa Anderson

Approve Agenda

Shannon Binstock moved to approved the agenda with no additions, seconded by Jean Herauf, passed.

Review of Minutes

Shannon Binstock requested that the meeting start and end times be noted in the minutes. Present members agreed. Jean Herauf moved to approve the minutes from November 17, 2017. Shannon Binstock seconded the motion. Motion passed.

Election of Secretary

NDBIN will support the secretary position by taking notes at the meetings, the secretary will review and approve the minutes to bring to the following meeting for Board Members approval. The Secretary can be a voting or a non-voting member of the Advisory Board.

Krista Fremming volunteered to be the Secretary.

With no other nominations or volunteers; Krista was voted in as Secretary.

Discussion of Vacant Appointments

There is currently one vacant appointment: the Native American representative. The position is waiting for the Governor's office appointment. One application has been submitted to fill the appointment. It was noted that the Governor's website is outdated, but openings on site (except for the Native American representative) are appointed by state agencies and represented at the current meeting.

Review of Bylaws

The bylaws as previously written have been updated by NDBIN. The update is to reflect the ND Century Code and includes the vision and mission statements of the Advisory Council.

Members reviewed bylaws and suggested the following changes:

Tami Conrad suggested to add contractor/vendor to Section 4H; and to Section 5C. Rebecca Quinn suggested a term limit should be included for the Secretary as already stated for the Chair and Vice-Chair positions to Section 3E.

Jean Herauf stated that there are 2 Letter Es in Section 3 and requested it be updated.

Lisa Anderson asked about the teleconferencing feature in Section 4B; when would that be determined or used? Conclusion was to keep it as an option for bad weather but keep meetings face to face as planned for one year.

Jean Herauf asked about reimbursement for service providers to attend the meeting due to loss of income for time used. As stated by legislation, survivors and family members are the only ones allowed financial compensation. There is no compensation for service providers.

Lisa Anderson questioned 4C regarding the simple majority vote. Does this mean that we do not have to follow the rules? Discussion was held about why this may be needed; an example was that to add an amendment, it is required to be approved in 2 consecutive meetings to be passed. The council may wish to just pass such an amendment with a simple majority vote instead of waiting the entire half a year before a change actually occurred.

Krista Fremming had concerns about the wording in Section 1E. This section states that council members are required to be present at 50% of the meetings. There was discussion regarding the attendance of consecutive meetings. Raised that health issues or other commitments can hinder attendance of meetings and so it should be left for consideration of circumstances. Maybe adding a section stating that if members are not attending meetings, they may be up for removal of being on the council.

Nan Kennelly suggested a change in the language: "not deemed resigned but subject to review. Notification of review will be sent by Secretary of Council." All members will be included in the updated language.

Discussion about what can and cannot be changed by members. It was reported that the portion of the bylaws that are based on the North Dakota Century Code cannot be changed.

Discussion regarding the fact that every two years there will be a new election of the 3 officers. Suggestion that one officer be elected on an off year so that there isn't entirely new leadership every two years. Agreement that this is not a problem since there is the re-election possibility.

Lisa Anderson motioned to approve the by-laws with the updated suggestions for now. Sara Ring seconded. Motion passed.

Review of the North Dakota History and Advocacy:

Tami Conrad shared a handout from the North Dakota Department of Human Services (see attached). Senator Kilzer inquired for more information on numbers of individuals being denied services.

Rebecca Quinn stated that NDBIN keeps numbers on those that NDBIN supports, those that have been referred to other services, or receive support services. The only individual that would be denied would be those who do not meet the definition of having a brain injury. The "Return to Work" program does have a wait list due to the set number of slots that are allowed with the allotted money to the program, but no one is denied the service.

Social and recreational programs do not deny anyone services either as far as anyone in the group knows.

Nan Kennelly stated that it appears to be a daunting task to track individuals in need of services when the services do not exist in our state.

Tami Conrad clarified that the funding listed in her handout includes: expenditures through the end of December 2017.

Senator Kilzer asked if there are any surprises or funding potentially coming from the federal government. There was some discussion about the TBI Grant that has just been released by the federal Administration for Community Living. There are 25 awards possible for \$150,000/year, along with 10 mentorship status awards for up to \$300,000/year. NDBIN could not be included as a mentor state. The other awards specify that a brain injury registry be established. It was reported that in ND, the registry has failed three times legislatively.

Shannon Binstock questioned if a registry could not be populated in a more organized way.

Discussion of the history of the registry: there was a registry up until 1996 when federal funding was taken away for the registry. The registry went to a voluntary report, therefore hospitals, clinics, professionals stopped using the registry. It has been impossible to find the data from that registry. The Department of Health states that there is more to a registry than what one would think; with a price tag of \$300,000 per biennium to run the registry. Then, there is a question of when are people entered into the database? For example, if an individual is air-lifted to an out-of-state hospital, he/she is not entered into the ND registry so we would be missing a lot of numbers that way.

Shila Thorson stated that there is a registry for stroke and it has been very difficult to get hospital staff to see a need to input the data.

Krista Fremming mentioned that the mandatory autism database was created in 2013 and currently there are only about 500 registered in that database. She believes there are many that have missed this list as well. So, even when mandatory the numbers just are not being submitted.

Rebecca Quinn mentioned that the Minnesota Brain Injury Alliance reported that MN does have a brain injury registry but the majority of referrals are from outreach and education versus the brain injury registry.

A line on the document from the Department of Human Services included \$70,739 for travel and dues. Tami Conrad stated that she would find out what this money is allocated for. Rebecca Quinn mentioned that in the past those dollars may have been what was used to pay for a speaker at the Mind Matters Conference, or sending individuals to the National Association of State Head Injury Administrators

conference. The council may be able to guide where this funding would be best utilized for future allotment.

Suggestions to collect Brain Injury numbers:

ND Health Information Network (NDHIN) where hospitals and clinics can share client information.

Senator Kilzer suggested that the Worker's Compensation would have a list of people with brain injuries.

There was a question from the public regarding the accountability of the contractors. Tami Conrad responded that all vendors report the number of individuals that they serve monthly to the Department of Human Services.

Council Goals

A significant finding from the assessment completed in 2016 is that there is a lack of services in North Dakota for persons with brain injury. Lisa Anderson stated that for some individuals there may be a way to piece-meal a solution or some help, but for others there is just nothing available. Jean Herauf asked how do we meet everyone's needs in such a rural state?

Question regarding if case management is a need? Lisa Anderson agreed with this being a need. Case management has many different definitions depending upon the program:

Care Service Coordination: It is really difficult to coordinate care when the services do not exist.

Person-Centered Intensive Case Management: someone who drives individuals to appointments, assists with going through the mail and taking care of business in a timely manner.

Kevin McDonough asked what would case management mean for individuals with TBI? How intensive and what would it need to look like?

Medicaid Home and Community Based services does provide case management, but often they do not understand the cognitive deficits in young survivors. Krista Fremming stated that often times county case load numbers are very high so the intensity of assistance for those with brain injury is not available.

Nan Kennelly suggested that a list of North Dakota services be developed and then build upon that for what a service system could look like and how case management could fit and grow upon that.

Eligibility was brought up regarding how brain injury often times overlaps with a behavioral health diagnosis. There seems to be difficulty in accessing any sort of services with a dual diagnosis. The council would like to review what other states do and if that is something that ND could work towards.

Rebecca Quinn has strategic plans from most other states that she can share with anyone interested in reviewing and coming up with a plan for ND to work on.

Denise Harvey stated that she would like to see immediate change and accomplish something within the first year of the council being developed.

Nan Kennelly would like to know where the best place to start would be. Suggestion was to begin with reviewing the NDBIN Resource Directory; there is a compiled list of services available in ND on the website and a good starting point for a review of what is currently available.

Lisa Anderson brought up Transitional Living and a need for a step down system in ND.

Dakota Pointe is a 20-bed Group Home facility for Brain Injury. Their last opening was over two years ago. There seems to be a need for more group homes in ND. Currently there is not a smaller group home setting that works for individuals with TBI in ND. ND does have the Adult Family Foster Care Home possibility but they are only run by individuals and with brain injury there is such a variety of needs that individually run foster homes do not seem to be a good fit. Other states have moved to corporate/agency run foster care homes so that there is plenty of staff to meet the needs.

Denise Harvey reminded the group that individuals need to have choice. In-home settings are best for people. There is a supervision service under Medicaid Home and Community Based Services but the reimbursement rate is so low that finding a provider is next to impossible. Denise just wanted to remind the Council that lack of choice for individuals leads to an Olmstead violation.

The group took a 15-minute break from 3:20 – 3:35pm.

Discussion of moving forward with formalizing needs and what a good continuum of care would look like for North Dakota:

Janna Peitzak would like to get stroke included in the state definition of brain injury to help with sustainability of the phone support service of the stroke task force. The consensus seems to be to bring this forward at the next legislation session. The cognitive need is so similar in stroke patients.

Nan Kennelly suggested that subcommittees be formed to be able to reach the goals of the Council.

Each subcommittee can put their data together and then bring it to the group.

Sarah Ring stated that there is still a need for education; deficits are still not known or understood by individuals, family members and the general public. There is also a need for awareness and education around the services and different levels that are needed.

Some Subcommittees:

Identify available resources/services and what is needed:

Review of best practices from other states; what could be proposed for our state?

Goal: find the needed services and what a continuum of care would look like.

Jean Herauf moved that the Council form subcommittees; Lisa Anderson seconded; Motion passed.

Shannon moved to have one committee for research within the state and one committee for out-of-state research on services. Motion did not pass as discussion was had regarding more topic-specific research would be easier and then search both in-state and out-of-state for a particular service.

Topics to be explored (committees would look within the state and out-of-state on each topic):

1. Continuum of Care
2. Education and Awareness
3. Transitional Living

Nan Kennelly moved to form these three subcommittees; Sarah Ring seconded; Motion passed.

Call for volunteers of Subcommittee members:

Continuum of Care: Tami Conrad, Lisa Anderson, Cheryl Hess-Anderson, Denise Harvey, Austyn Kloehn
Transitional Living: Shannon Binstock

Education and Awareness: Jean Herauf, Sarah Ring, David Biberdorf

Subcommittee information will be sent out via email so that members not at the meeting can join a group.

Sub-Groups as Support for the Brain Injury Advisory Council

There is a current workgroup that is meeting with Medicaid and other brain injury service providers. There are members from the Council on this workgroup and so it is asked that they bring information from those meetings to the Council.

This council includes more providers than family and survivors and so there is a need to have more of a voice from a family and survivor group to bring that message to the Council. NDBIN could reach out to survivors through support groups that are being offered to be able to hear their voice and report back to the council.

Lisa Anderson moved to form the services workgroup and a family/survivor workgroup; Jean seconded the motion; this will be included in an email through the NDBIN email group to get communication flowing; motion passed.

The services workgroup is already going and NDBIN will bring information from that workgroup to the council meetings.

NDBIN will assist with getting the Family/Survivor group going and conversations started on what they would like to see in the state of ND.

Member Updates

Denise Harvey had handouts regarding the new North Dakota Protection and Advocacy goals and programs.

Cheryl Hess-Anderson stated that there will be public comment hearings on the State Plan for Vocational Rehabilitation on February 27th at all Human Service Centers or Vocational Rehabilitation offices across the state. It will then be posted online for 2 weeks after that date.

Austyn Kloehn mentioned that last year there was no proclamation for Brain Injury Awareness Month. Rebecca Quinn responded that yes, last year there was no mechanism set up for proclamations through the Governor's office but it is in the works for this year.

Next meeting will be held on Friday, May 18th in the Brynhild-Haugland Room at the State Capitol at 1:00pm.

No public comment was shared.

Lisa Anderson moved to adjourn the meeting; Jean Herauf seconded; Motion passed.

Meeting adjourned at 4:26pm