

Public Testimony
Study on System of Care for Individuals with Brain Injury
Interim Human Services Committee June 19, 2014
Submitted by Rebecca Quinn, Program Director
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Chairman Damschen and other members of the Committee. I am Rebecca Quinn and serve as the program director for brain injury programs at the Center for Rural Health, University of North Dakota. My testimony today is on behalf of the individuals and families impacted by brain injury.

You have heard me testify numerous times regarding the needs of individuals with brain injury in North Dakota and proposed plans for solutions. In fact you just heard what the department thinks it will cost to implement my comprehensive system of care. I want to continue to be a part of the development of services and think that we do need to look at this as the development of new programming. In the 5 short months ND BIN has been taking referrals we have had over fifty. All of these have some unmet need that is preventing them from living to their fullest in community. Clients being referred to ND BIN are looking for supportive employment, day programming, supportive housing options, and more options for community integration and socialization. This is not even getting into the request for specialized care like cognitive rehabilitation therapy and neuro-behavioral rehabilitation. Yesterday I found out that North Dakota did not receive a Federal HRSA TBI Grant. A major requirement of this grant was to show that the grant would assist more individuals in accessing extended rehabilitation and community based treatment.

Currently, we treat brain injury as a medical disability in North Dakota. This was true back in the 80s and 90s when our services were developed, but brain injury is changing and we need to have services that are designed to meet the changing needs. In order to properly serve individuals with brain injury we need to create a system that has enough variety to meet individuals' needs based on their choice and function not on our trying to fit them into what we have designed.

I am honestly not aware of what the next steps are, but I welcome the opportunity to work toward developing our service plan. I always want to make sure that brain injury is considered when developing programming specifically for the population or determining how the population can fit within other developing programs.

A few points that I will make that I think will need to be addressed:

1. The wide variety of needs after brain injury means services need to be choices along a spectrum with a menu of options.
 - o Brain injury often overlaps with other services and we need to ensure that these programs are accessible for individuals with brain injury.
2. We need to start somewhere even if it is as pilot programs.

- On paper currently it looks like we are meeting the needs, but we are not. There needs to be a mechanism for looking at quality control to determine if our current and newly developed programs are meeting the needs. Without this type of examination we are unable to continue to ensure our programs are effective and efficient.
- In 2009 the following was added to our century code:
 - 50-24.1-33. Traumatic brain injury - Home and community-based services - Outreach activities - Quality control.
 1. As part of the personal care services program for eligible medical assistance recipients and as part of the department's services for eligible disabled and elderly individuals, the department shall provide home and community-based services to individuals who have moderate or severe impairments as a result of a traumatic brain injury. The department shall give priority under this section to individuals whose impairments are less severe or similar to those of individuals who are eligible for Medicaid waivers.
 2. The department shall conduct outreach and public awareness activities regarding the availability of home and community-based services to individuals who have moderate or severe impairments as a result of a traumatic brain injury.
 3. The department shall conduct quality control activities and make training available to case managers and other persons providing services to individuals under this section.
- 3. Assessment and funding needs to be structure to not penalize individuals for improving.
- 4. Unfairly rate physical needs as more important than behavioral/cognitive.
- 5. Services need to be designed and encouraged to work together. With the menu approach individuals may be accessing multiple services from multiple providers—in order for this to work services must allow for collaboration.
- 6. Currently many of our programs are set up with small glitches to our administrative policies that make programing difficult to access, complex and inefficient. Yesterday I was on a webinar regarding brain injury waivers in other states. During this call many states shared ways they are overhauling their whole long-term care system to make it more efficient, streamlined and better able to meet the needs of individuals. I am not expert in this, but I am seeing other states do it so I know it is possible.

I have numerous examples of these but include the following to show the complexity and inflexibility.

The following example is from the ND DHS Home and Community Based Policy Manual:

Adult Day Care 525-05-30-10 section it is defined as a community based service that “provides a variety of social and related support services in a protective setting during a part of the day”; However, it lists unallowable tasks as: Shopping, Community Integration, Housework, Money Management, Laundry, Social Appropriateness.

- This means that adult day services cannot be used to address social appropriateness, shopping, money management or community integration. The words community and social are in the definition of the service but those cannot be tasks provided by the service? Based on the brain injury clients I see the some of the most needed services are community based group programs that are able to provide social appropriateness training, shopping money management training and community integration. All of these are things that could be done by a program designed to serve the needs of individuals with brain injury, but it is not an option because they are not able to be authorized.
- Even if an individual with brain injury were to need one of the allowed task related above there still is the second hoop that the eligibility is more stringent for day services make most individuals with brain injury not eligible.
 - Adult Day Care 525-05-30-10 Service Eligibility, Criteria:
 - The individual receiving Adult Day Care will meet the following criteria:
 - Must be eligible for the programs of Medicaid Waiver for Home and Community Based Services, SPED, or ExSPED;
 - The client is able to function in an ambulatory care setting.
 - The client is able to participate in group activities.
 - *The client requires assistance in Activities of Daily Living and Instrumental Activities of Daily Living as determined by the Comprehensive Assessment.*
 - When the client is not living alone, the primary caregiver will benefit from the temporary relief of caregiving,