

Chairman Nelson and Members of the Committee,

My name is Lynne Ostrem. I wear numerous hats with concerns of HB 1012.

- I have an adult son, David, with a Traumatic Brain Injury.
- I have been David's Guardian and Conservator and responsible for completing the applications for services with DHS since 2012.
- I worked with Senator Mathern, Royce Schultze (DCLI), Representative Anderson and Stacie Dailey (DHS) to set up By Laws and legislation for the ND Brain Injury Council.
- I worked with Representative Anderson to pass legislation to study the use of Hyperbaric Oxygen Therapy for individuals with Traumatic Brain Injury.
- I started a QSP Agency to provide services to Brain Injured individuals.
- I worked with others to form the "North Dakota Brain Injury Advocates" a Non-profit organization.

A common statement in the Brain Injury World is "No 2 brain injuries are alike". There are a number of medical studies, journals and papers where you can find evidence that brain injured individuals can make gains with rehabilitation years after their injury. The gains may not be as dramatic as the initial year but functional gains are noted.

Brain Injury Association of America – March 21, 2017 "Brain Injury Rehabilitation Outcomes"

*The National Association of Insurance Commissioners defines rehabilitation as:
"Health care services that help a person keep, get back, or improve skills and functioning for daily living that have been lost or impaired because a person was sick, hurt or disabled. These services include physical and occupational therapy, speech-language pathology and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings."*

Although earlier access to post-acute rehabilitation is associated with greater gains and overall cost reduction, later rehabilitation also results in significant functional treatment gains and reduced costs, even many years after injury or for those patients who have an overlay of psychiatric or behavioral issues.

BrainLine; Institute of Medicine. 2011 and Reviewed July 26, 2018

Cognitive rehabilitation therapy may be like the proverbial elephant — it feels different to different people depending on their circumstances and perspective. But, as patients and families will attest, CRT is as fundamental a need in TBI recovery as physical rehabilitation — and for some, even more essential to their quality of life.

David's disability necessitates the use of many services. Most of those services are in different silos within DHS. We have used North Central Human Services, Medicaid, Behavioral Health, Aging Services, Vocational Rehabilitation, and Economic Assistance.

Each one of these services involves a different application and verification of all expenses. Since 2012, I have filled two - 18 gallon totes with files of DHS related paperwork with applications, appeals and legal action that needed to be taken for David to receive the services that are valid and available according to the DHS manuals and the North Dakota Administrative Code.

I have been listening online to DHS personnel testimony this session concerning HB 1012. I have heard several times that some departments have funds still remaining. When I hear that comment, from a consumer/advocate standpoint, my question is, "Why are there remaining funds?"

I can tell you from my son's experiences and trying to access services, it has not been an easy adventure.

When we tried to access services with North Central Human Services we were told there was no one that specialized with brain injury. When we tried accessing services with Vocational Rehabilitation, I found the "job" for David, but there were no consistent options for job coaches that would work with a brain injured individual so between the employer and David we turned it into a volunteer position and I made sure someone was with him and supervised him.

I have requested various services for David and told either he was not eligible for services, or there were no services in ND so "DHS" will not list it on the Care Plan.

David and I met last week with his case manager and requested cognitive therapy or behavioral therapy added to his Care Plan. It was not added. The case manager said she would check on it and let us know. DHS only wants services that you are actually using put on the Care Plan. Every time you add or take something off the Care Plan, there is a Case Management Charge of \$131.42 in David's case.

There are a number of cases like this that I could point out but I don't think we have the time. From past experiences, it is not very easy to access the services you as a Committee are allocating money for. The current system is not very "user friendly" and I would venture to say that most people give up. I on the other hand, am part Polish – (no offense meant).

I understand that there may be some that label me and others that advocate for loved one as “problem people”. Please understand, we are human and we are struggling to get services for our loved ones in a system that is very difficult to navigate. Many times the first response we receive from DHS personnel is “No”. We are forced to take the next step to continue to find a way to receive services. I feel it is only through this process of giving our personal testimony that we can change the system to hopefully make it more user-friendly.

There are limited residential options for the brain injured population in North Dakota. The 2 specialized skilled nursing homes are always full along with a wait list. The Nursing homes are not interested in admitting a young “mobile” brain injured client because the rate of reimbursement does not allow for the specialized care required.

Brain Injured individuals can access Transitional Living Services through the HCBS waiver. This service has to be provided by a licensed QSP agency.

In 2016 I believe there were only 3 QSP Agency that offered this service. All 3 of them had limited staff and were not willing to take on an additional client. This put me in a position where I felt like there was no other option but to start a QSP agency to provide transitional living services for my son. I have found barriers for QSP agencies to provide quality care with the rate of reimbursement is almost parallel to the barriers for consumers looking for services. QSP agencies are required to have employees complete a Document of Competency and training. These expenses are bore by the Agency without reimbursement. It is recommended that new employees “shadow” a seasoned employee that understands the client to ensure the best possible care. Those costs are not reimbursable. My average costs to “train” an individual are approximately \$3,000.00. That amount is not reimbursable. I have questioned Nancy Meier about the possibility of QSP Agencies being reimbursed for administrative costs or training but was told that it was not possible, DHS is only allowed to reimburse for “face-to-face” units.

Another financial hindrance is the unit rate of pay for Transitional is reimbursable only when there is “face-to-face” engagement with the client. If I have overnight staff at his house, my billable units stop when he goes in his bedroom at night. I continue to pay staff at an overnight rate that I cannot get reimbursed for.

For overnight staff to be reimbursable I would have to add Supervision on to the Care Plan and the agency rate of pay drops to \$9.96/hour with the condition the staff is required to stay awake. I will admit, I didn't try to add that to the Care Plan.

From my understanding, the December 2021 DOJ agreement with DHS has a timeline where individuals are suppose to be transferring out of the institutional setting and into community. There are already limited QSP Agencies in the state. I have talked with many of them and it is a reoccurring problem – lack of employees to meet the workload. From my perspective, the current program that is set up for licensing QSP agencies is going to make it very difficult to meet the increasing needs of individuals looking for Home and Community Based Services because of the DOJ settlement.

I'm not sure what the process would be to get help to cover some of the QSP Agencies' administrative costs, training costs or increase the rate of pay. I have reached out to North Dakota Association of Community Providers for assistance. The Director, Bruce Murry, has been very helpful and has reassured me that I am not the only one with this dilemma.

This past year, I have found 2 great organizations that I have relied on for resources. Family Voices have hosted several informational Zoom meetings that have been very beneficial for me and my son. There are resources and supports on their website that can be used for a wide variety of consumers.

The other is Protection and Advocacy. Teresa Larsen has done an outstanding job keeping those of us informed as to the legislative happenings and any updates. I have needed to use the Advocacy services in the past and it is helpful to know they are there.

I respectfully submit that you reconsider and replace the funds that were cut from their budget. The support and guidance they offer to all families dealing within this system is something we need to rely on to help us.

Thank you for your time and your consideration in these matters. If you have any questions I would be happy to try and answer them.

A handwritten signature in cursive script that reads "Lynne Ostrem".

Lynne Ostrem
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