

May 4, 2010

Long Term Care Committee

As a parent of a child who has suffered a traumatic brain injury, I would like to share our story with you. We had never heard of traumatic brain injury until 11-12-07, at we had no idea how Hannah's injury would change our lives forever. My husband and I had no idea how many different medical specialists we would need to find to help Hannah. We had no idea that once you suffer a brain injury you have to relearn everything from the very basics of life like breathing to things the rest of us take for granted, such as walking and talking. For us, this story is very personal, but for you as policy makers, I need to offer you the policy themes to look for: less services and access issues in ND; issues of available providers; distance; coordination of care; financial impact and self-advocacy.

Hannah was 15-years-old when she in a car accident. Our local sheriff pronounced her dead at the scene of the accident. A passerby stopped to see if he could help and found a weak pulse on Hannah. The Leeds ambulance transported Hannah to the Rugby Hospital ER, where they determined her injuries were too severe for them to care for her. The helicopter was dispatched, but they were out on another call, so Hannah was transferred to another ambulance and driven to Trinity Hospital in Minot. The doctors at Trinity were able to get Hannah on a respirator and stabilize her breathing, but she was in a coma and we were told all they can do is "wait and see if she makes it". Even though we were in a state of shock, my husband and I started searching the internet to find someplace that specialized in traumatic brain injury. We would have taken Hannah anywhere USA, but found a program at the Hennepin County Medical Center in Minneapolis, MN. Hannah was airlifted to HCMC where she remained in a coma for 12 days and in the PICU for a month. Her 6 week in-patient rehabilitation was done at Gillette Children's Hospital in St. Paul, MN, where they also specialize in Traumatic Brain Injury.

Finally, after being away from home for almost 3 months, we were coming home. Our son, Michael had been home alone most of this time working on his senior year of high school and now we were able to be together again as a family. Brining Hannah home was the most wonderful and the most frightening day of our lives. Our TBI support team was 8 hours away – who would we call for help and who would answer all of our questions? We were able to find Hannah's occupational, physical and speech therapists right in Devils Lake, so we made the 60-mile-round trip three times weekly.

Some of the medical professionals that Hannah has received care from over the last 2 ½ years include a physical medicine and rehabilitation doctor, a family practice doctor, physical therapist, occupational therapist, speech therapist, neurologist, neuropsychologist, ophthalmologist, vision therapy doctor, urologist and psychologist just to name a few.

Travel includes the 14 hour round trip drive to Minneapolis/St. Paul every 3-6 months.

4 hour round trip drive to Grand Forks weekly to see the neuropsychologist and vision therapist.

5 hour round trip drive to Bismarck to see the PM&R doctor and urologist.

60 mile round trip drive to therapy sessions in Devils Lake three times per week for 116 weeks and counting.

There have also been trips to Devils Lake to start the Voc Rehab process and then the trip to Fargo for Hannah to meet with the people from IPAT about what technology may be available to help her as she prepares to transition out of high school, the trips to Fargo for Hannah to meet with an occupational therapist certified in driving evaluations as well as the trips to Devils Lake to meet with the Human Service Center people to see if Hannah may be eligible for any services there.

My husband and I were with Hannah the entire 3 months that she was hospitalized in MN hospitals. When Hannah came home, she required 24 hour supervision. Since the accident, I have devoted 100% of my time to finding the best care for her. I had to quit my job to be Hannah's full-time care giver/case manager. I spend much of my time researching the internet for answers to our questions, finding the right doctor for the problem and then getting Hannah to that appointment. Then there is the medical insurance to deal with. Getting prior authorization for services, going back and forth between clinics and insurance companies to get services paid for.

After being elected to the TBI Board last year, I was very interested in working for the Head Injury Association of ND and so, I submitted my name to apply for the position of Executive Director. When it came right down to it, though, I had to withdraw my name. Hannah is 29 months post injury and still requires much of my time and energy. We still have many doctor appointments and therapy appointments to attend. Hannah stresses out very easy and when she comes home from school, she needs me to be here to be her sounding board. If she has more than a few things on her "to do list" she gets overwhelmed and cannot figure out where to start first.

Thank you for looking into the issue of traumatic brain injury. This is a very unique medical problem as it crosses over into many medical specialties. We need to have people who work together for the "whole person" rather than just specialists who you go see for this or that and get a hodgepodge of treatment.

I have been blessed to be able to care for Hannah's needs with 100% of my time and attention. I have to wonder though, what do people do who don't have someone working 24/7 on their case, willing to drop everything in an instant to care for their needs. How do people with short term memory problems get to appointments, remember to take their medications or even know how to deal with their insurance companies? Families who have had TBI impact their lives spend much of their time coordinating care for their loved ones. I don't know the "systems" that are out there to help Hannah, I don't know what is available and I didn't know who to contact to find out. Some agencies have gone out of their way to help us, while others gave us pamphlets and we never heard from them again.

Thank you for listening to our story – we pray that by sharing this with you, you will help make things easier for the next family who has to go through all of the things we have had to endure.

From a caregiver/case manager/mother of a daughter with TBI.

Lisa Anderson    Leeds, ND