

## Testimony

### Interim TBI Study – Human Services Division

Representative Chuck Damschen, Chairman

October 29<sup>th</sup>, 2013

Chairman Damschen, members of the Interim Committee of the Human Services Committee Divisions; my Name is Rhonda Boehm and I want to thank you for allowing me to testify today. My son Eric sustained a Traumatic Brain Injury eleven (11) years ago in a motor vehicle accident.

I am here today to talk to you about how a Traumatic Brain Injury, (the Invisible Injury) has affected and changed Eric's life forever.

Eric was very fortunate and miraculously beat the odds, because he wasn't expected to survive the first night. He was in critical condition and in ICU. He spent the next four months in three progressive hospitals; followed by five years of outpatient and home therapies and is continuing to go to therapy for his Obsessive Compulsive Anxiety. He struggles with organization, memory, social, detailed cognitive skills. He is living independently in his own place, working within the lower wage scale, without benefits. He has recovered many of the essential skills to "live" independently, but he has not recovered completely and he never will: A Brain Injury is forever. Eric is like many individuals living life after a Brain Injury – there will always be a need for some type of assistance – most importantly financial, reminders for meetings and appointments, and employment responsibilities. Yes – he has taken therapy and yes he is on medication but nothing is a "cure" .....the challenges will always be there.

Eric diligently worked to achieve his goal of obtaining a college degree to follow his dreams of becoming a physical therapist. His inability to retain substantial amounts of information at one time has kept him from this dream. In the past seven years he has registered and taken classes at UND three times, only to face disappointment that college was most likely not going to be an achievable goal for him. He couldn't memorize, had trouble sitting by his private tutor because of his OCD, worried constantly about germs. Now he faces his adult life with new challenges that are much more complicated at this time in his life: he is an adult, working a lower wage scale job with no health insurance or retirement benefits, living on his own and wanting to work towards some type of career and to have a life that is meaningful to him.

We worked with Vocational Rehab for several years; Eric would forget appts, forget to submit papers which lead to him receiving a letter he was going to be dismissed from VR assistance because he missed too many appointments. After I contacted VR there was then another meeting was set up, explaining again that Eric cannot remember everything, that he didn't open his mail every day or even for a week sometimes. They "reassigned" Eric with VR, but shortly after, the order of selection was appointed to VR, so he never did get much assistance. I have driven the 200 miles to Grand Forks weekly for the past seven years, to help Eric with paperwork, appointments, and general daily living things. He has recently transferred through his work to Bismarck, which we are anticipating will be beneficial to him to be closer to home and family.

Eric currently does not qualify for SSI, SSDI, Medicare, or Medicaid because he is currently working and is not totally disabled. Yes, he has a disability, but he is "mid-functioning level" and is very capable and wanting to work to sustain a fulfilling and purposeful life. He cannot meet his financial responsibilities with only a net income of \$ 1,097.00 per month, but doesn't qualify for most assistance programs because his "low income" is considered "to high" on the "sliding scale graphs for state and government assistance programs".

While at a previous "review appointment" it was brought to Eric's attention (and mine), that if he would quit work completely, and apply for complete disability; he would qualify for assistance in most every aspect, because of his disability! My thought that day was REALLY??! The "system/assistance programs are going to convey to a young single adult with a Traumatic Brain Injury that this is an option for his life after he recovered, healed, and has come so far? This is a TBI survivor who is capable and wants to work and live a productive life. Eric thought about it for a while.....and said really are you serious? Well.....we had a heart to heart "talk" after that meeting and we have been struggling with this very difficult issue, because honestly; I "knew that" was a possibility for him. I knew he had the "option" to "NOT" continue to work and with complete assistance he could better meet his financial obligations; but how can we as North Dakota, American citizens sincerely feel this is how the system should work for those with disabilities? What would happen to Eric and many others like him if they quit working when their financial burdens become too overwhelming?

My "guess" is they would lie around and watch TV, become lazy, become depressed and even more isolated, probably end up on drugs and alcohol and end up way below poverty level. Unfortunately this happens to many individuals and it wouldn't have to be this way; if there were some mathematical adjustments made regarding assistance for those that are "mid-functioning" Traumatic Brain Injury Survivors that want to live their life to the fullest capacity. Yes work and daily life are a "challenge" for "mid-functioning" TBI Survivors, but they are determined and need a purpose).

I've asked so many times.....Why is it that Traumatic Brain Injury Survivors who are "mid-functioning", (in the middle so to speak); end up being the ones "that fall between the cracks", struggling and having to "fight" for everything, and most often don't know where to turn to, to find what they need to live a fulfilling life. Their only hope is if they have someone (parent, loved one, or case worker) figuring things out, completing applications, pushing every step of the way.

TBI Survivors like Eric who are "mid-functioning", have their determination to return to independence and want to make a life for themselves, want to work, have a family; they should also have assistance available to them ( on a more flexible sliding scale).This will encourage them to work and keep progressing towards a fulfilling life. There is a serious need for more flexible qualifications for assistance to make it affordable for them to work.....YES....I said make it "affordable for them to work".

I am experiencing with my son that the income limit standards that one must meet to qualify for many state and federal assistance programs, due to a disability are not flexible enough. It seems so unfair and unfortunate to continually see this situation, when the state would actually be financially ahead if there were more individuals with disabilities working, and receiving supplemental assistance on a more

flexible sliding scale, rather than going on total disability. Traumatic Brain Injury Survivors that are "mid-function" are simply trying to establish and maintain an acceptable quality of life.

Every entity/assistance program we have worked with has been a frustrating challenge. Eric "almost qualifies" for some assistance but he works too many hours. He cannot financially make ends meet. He makes \$ 11.40 per hour at around 35 hours per week so he isn't considered full time, doesn't receive health insurance benefits'. His wage averages out to about \$1,097.00 net pay per month. His expenses are: \$700.00 per month rent for a very small one bedroom trailer, electricity bill is \$60.00 per month now (winter higher); groceries, gas, car expense, and daily living which average out to a low of \$400.00 per month. And yet he doesn't qualify for assistance and he can't get a college degree or a better paying job because of his Brain injury.....You do the math..... it isn't manageable, so what is our miraculous TBI Survivor going to do now as he has entered adulthood??

We have again "re-applied" for housing, SNAP, Medicaid for him in Burleigh County since his move to Bismarck two months ago. They are "pending" and interviews are set up at this time; although I have been notified through correspondence that he will most likely not qualify because of his income. If he doesn't qualify his medical expenses will not be affordable for him; his prescriptions just went up to \$456.00 per month. He previously qualified for SNAP (food program), receiving \$ 84.00 dollars a month for a while, then that was decreased to \$16.00 per month (as he added a few more hours); and then he didn't qualify at all after a small pay raise; but yet a single mother, not working, with children could qualify for up to \$800.00 per month with SNAP. When Eric and I saw this "sliding scale graph" we both were very frustrated and confused. He then qualified for housing assistance through Grand Forks Housing at \$67.00 per month for one year, and then after the 2nd year review/meeting he no longer qualified. There had apparently been some type of mistake in the housing end of paperwork and there was again some misunderstanding between the case worker and Eric.

This is exactly why I need to say, "Something needs to change"!! I have witnessed through our personal experiences these past years; there is an utmost need to make changes within the "system" of assistance for those with Traumatic Brain Injuries that are at "mid-functioning level". They want to fulfill their lives by working which gives them a reason to get up every morning, making their lives more meaningful and productive. By giving these individuals the opportunity to work and also receive some assistance they will make a life for themselves. This in the long run could affect and reduce the number of homeless, lost, imprisoned, individuals that are in the state of ND, because I truly believe and research indicates, after years of living a long frustrating path of life following a TBI, this is unfortunately where so many TBI Individuals end up, in poverty and/or homeless. We can prevent this in the lives of so many individuals if we only take the time and put in the effort to make the necessary changes to make a difference.

There needs to be a "more flexible sliding scale plan" according to each individual's earnings and general living expenses for the Traumatic Brain Injury Survivors that are "mid-functioning". They are capable of working...."BUT" .... at lower pay rate scale jobs that usually do not include health benefits. They should be encouraged to work; and still receive enough assistance; to keep them above government poverty level which they truly deserve and need. Why?..... Because a Traumatic Brain Injury survivor that cannot

achieve a college degree, or cannot perform the tasks required for a higher wage scale job with benefits did not "chose" this way of life! They wanted to follow their dreams, but this time the "odds" are "against" them. Eric is dealing with these present day issues because he has become an adult living with a Traumatic Brain Injury and has not been able to achieve a college degree or obtain a higher paying job. When he was in high school and trying college things started to change again.

I'm asking you to please review and evaluate the requirements of the sliding scale concepts. We need to move forward to make some changes and adjustments to the assistance/programs that are available for Traumatic Brain Injury Individuals that are "Mid-functioning level". We need to make sure that they can continue to work at a job they can physically and cognitively perform and supplement their income that they have proudly "earned". Brain Injury Survivors have a lot to offer in life if they are truly given a chance; they have been given a miraculous second chance at life; and then when they are up against the financial, and other every day burdens that they aren't "prepared for", their anguish, self-worth, and quality of life slowly decreases. It is up to the government committees/legislature to make these adjustments possible, to allow every Traumatic Brain Injury Survivor that is "mid-functioning" the financial assistance they need to increase their quality of life, so they can live a fulfilling miraculous second chance at life.

"No Brain Injury is too small to ignore, or too severe to lose hope". Thank you very much for your time and the opportunity to speak to you today. I will be happy to answer any questions you may have.