

Testimony
House Bill 1012
Grand Forks Growth and Support Center by Julie Erickson
Senate Appropriations – Hon. Ray Holmberg, Chairman
March 11, 2021

My experience with the developmental disability field over the past 15 years has been unique, challenging at times, and very passion filled. For you to best understand my perspective, I will share the trifold areas of different roles in my life that have shaped this view. First, I am the executive director for a Day Support program in Grand Forks called Grand Forks Growth and Support Center. Secondly, I had the privilege of teaching at the University of North Dakota in the rehabilitation and human services Undergraduate program. Lastly, and what I believe to be my most important role, I have the honor of being the mother to an amazing 14-year-old boy named Ryan.

Ryan is my third child and I knew he was a little bit different from my other children almost immediately after he was born. He did not meet his milestones at the same rate as my other two children and would often learn a skill and then lose that skill such a smiling or sitting up. We started Ryan in the infant development program to start tracking his progress and laying the foundation for services to help him thrive. At seven months old, Ryan began having severe seizures that ranged from 2 to 10 minutes long. There were periods of time where all Ryan did was seizure or sleep. He tried and failed seven different seizure medications before we were sent to Saint Paul Children's Hospital for further help. Ryan underwent a left functional hemispherectomy at the age of 11 months old. As his parents, we were very aware that the removal of the left hemisphere of Ryan's brain would have many impacts on his functioning and skills throughout his whole life. We also knew the other option is that he would probably die from his seizures if we did not choose this surgery. Ryan had two major brain surgeries within a week of each other to remove the tissue that was causing the seizure activity. The surgery was successful but left him with many major deficits. His right peripheral vision field is cut and will never be repaired, he can use his right arm but his hand is not functional to do skills with. He walks and gallops with a limp and an uneven gait pattern. And lastly, since they removed his speech center, Ryan has many challenges with communicating. Intellectually, he functions at about a three or four-year-old level. He can understand anything and everything that people say to him and is able to talk in small phrases that are sometimes hard to understand. He is the most loving, sensitive, caring, and exceptional boy I have ever met. He values the small things in life like his family teachers and those around him and just really likes to be with people. He is in eighth grade at Schroeder Middle School in Grand Forks and is surrounded by a wonderful staff and also has a wonderful medical team. Ryan has received

services through North Dakota Medicaid since he was nine months old. He has been through five brain surgeries, three orthopedic surgeries, months and months of hospital stays filled with uncomfortable tests and procedures. He has been through more hours of therapy than I can count. He is a fighter! He is my why! I tell you about my son Ryan not for your pity or for you to admire me for surviving the tough times that I have been through, but to show you the credibility of my testimony not only as a developmental disabilities provider but as the mother of a child with very severe disabilities.

The skills I gained navigating through the years of raising a special needs child actually was the greatest experience I could have had to become the director of Grand Forks Growth and Support which was formally known as Agassiz Enterprises. Agassiz enterprises was a developmental disability provider that started in the late 1970s. When I took over as their director in 2017, I most definitely had my hands full and many challenges against me. In a nutshell, I took a place that was basically functioning as a bland institution type center. A place that needed tremendous updates to be accessible, ethical, and most of all a place that I would even feel comfortable bringing my son for care someday. This set the bar very high for all employees that worked at our center. After seven weeks as the executive director, we rebranded and changed our business name to begin a new start. I couldn't be more proud of the team that I have and how far we have come in 3 1/2 years. This experience gave me the perspective to know that the disability field still needs so much work and it needs to come from multiple entities who come together to work for the greater good of this community.

I will speak now to what I have seen in the last 3 1/2 years of being a provider of developmental disabilities services. As a standalone day support program our agency relies solely on the funds of Medicaid. We do not get paid for the services if the individuals that we support do not attend day program. During the Covid pandemic, We have faced major financial challenges from the decrease in attendance of those who attend our day program due to obstacles that were outside of our control. We were fortunate to apply and receive the PPP loan funding in April which eventually turned into a grant. This funding however was not enough. Myself and a few other smaller providers gathered and asked for more financial assistance from the state. We were able to Apply and received four separate retainer payments which have helped us maintain our staff and stay open. We have 36 people who attend our day program close to 40 hours a week and there were days in November when we only had nine of these people present for services due to many Covid related reasons. Somehow, we survived 2020 and have started to return back to more of a normal attendance rate in the new year. Although we survived this challenging time, we do not have much left in our reserve fund going

forward and any cuts to developmental disability providers would severely impact us. I fully believe that people should have options for their services in their life. Without smaller providers these options would be taken away. I think it is important to look at a smaller providers as the small town businesses. We have heart, integrity and passion for our work and those we support at our agencies. We are the directors and staff who go above and beyond to make sure that people are receiving the best services that they can. Throughout the Covid pandemic, we had multiple testing events at our agency to decrease Covid risk on our staff and those supported. You could find me, dressed in full PPE climbing in and out of the vehicles to assist, calm, and hold the hands of the individuals we support while they were getting their Covid test. This is just one example of the small provider flavor I was speaking of. North Dakota needs providers with these qualities and if we face more financial strain there may be many of these providers who can no longer keep their doors open.

I would like to talk briefly about why it is so important that the House remedied the proposed \$11 million cuts in the area of developmental disabilities would have on the agencies that provide services and those that receive services in the state of North Dakota. As a whole, developmental disability providers struggle to find a workforce that will bring high-quality care to the people that we support. Direct support professional's are the biggest group of staff that we struggle to hire and maintain. Although it is a rewarding job at times, it is also a very physical and stressful job. Cuts in our budget would present us with many more challenges when hiring, training and maintaining these employees. With low paid or not enough direct support professional staff, agencies are unable to provide high-quality care! High quality care is the most important thing. I can tell you right now, I struggle as Ryan's mother to think about it would be like to put him in a residential facility. My husband and I hope to keep him at home with us as long as we can, and we also hope and pray that the quality of services continues to grow and increase in the years to come.

People with intellectual and developmental disabilities need the highest care possible. They have already experienced so much hardship and struggle in their life and often times don't even know that they have actually faced those hard times and struggle. This is shown by the love, smiles and happiness that many of the people who receive DD services display every day of their lives. Plain and simple, they deserve the very best from the developmental disabilities industry.

Thank you again for the opportunity to stand before you and give my testimony. I welcome any questions that you may have.