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Human Services Finance & Policy Committee 100 Dr Martin Luther King Jr Blvd St. Paul, MN55155

To Member of the Human Services Finance & Policy Committee:

Good morning, my name is Greg Wisher from Roseville, MN. I am writing to you today to ask for your support of SF 1201 Elimination of Parental Fees for parents of disabled children under the TEFRA option. I will be sharing our personal struggles related to these fees as well as some of my professional experiences in helping families navigate this program for their own children.

My daughter Madison is 8yrs and was born with Spina Bifida Myelomeningocele. She is a happy fun-loving little girl who loves to try just about anything and loves to make other people happy. Before she was born, we were given the news of her diagnosis and it was heartbreaking. The prognosis the Dr's gave us was bleak and hard to comprehend. They informed us of the procedures she would have to endure in her first 24hrs of life and the hospitalizations and extended NICU stay that was ahead of us. We knew that all of this wasn't going to be cheap and could potentially bankrupt a family. Fortunately for us we had decent private health care through our employer. However, that was still not enough as they would deny the needed medical treatments and physical therapies that she so desperately needed to thrive.

We were told while we were in the hospital after her birth of this program for people who make too much money to be on MA. That's when we were introduced to TEFRA. We were told about the parental fee at the time and we had made the decision to pursue this. The program has been amazing in every way except for the parental fee. We have been able to get our daughter the needed physical therapy to help her to be able to walk which we were initially told was not a possibility. It has allowed us access to a wheelchair for when walking is just too much during long days at amusement parks. It has also allowed us access to other therapies that our private employer-based health care does not which has only added to Madison's quality of life.

Now come the parental fees. The fees are billed as a monthly fee to allow families an easy payment option to keep current on their fees. However, from the time the initial application for TEFRA and the determination is made can be on average 90 days but in our case it was close to 6 months since it was many years ago. So, we already started out the programs 6 months behind in our fee payments. We had been sent to revenue recapture due to the outstanding

debt to the state. We had already been stressed about the multitude of Dr appointments and therapies in her first 6 months now add in thousands of dollars in debt all to help our child succeed.

The stress of the fees is overwhelming at times and is a constant in the back of our minds. We as parents want what is best for our child and to ensure she can live the best life possible. When it comes to our professional lives if we are even considering a career move or a promotion, we always have to first take into account what this would do to our parental fees. I always have to check the parental fee calculator on-line to see what any movement in our income would do to the fees and determine if a promotion is even worth it or not with the additional taxes and fees to DHS. I have also asked elected officials for verification of where these fees go since I could not find them in the DHS budget, and I was told that they are directed to the General Fund and not DHS. If that is the case these fees are essentially a tax on parents with children with disabilities.

This brings me to my professional life. With the stress of getting our daughter set up on public programs I decided that I will do whatever I can to help other families navigate the system. I left my job in the Corrections Field and moved to program eligibility with a local county. I have since been promoted and now assist families in navigating the programs and put-on trainings on the TEFRA program. I work with families weekly who are struggling with the thought of adding a parental fee of hundreds to upwards of \$2,500 per month so their children can receive the services they need.

Families are already struggling, and the added expenses is taxing on their wellbeing. When families find out about what their parental fee is they are shocked with how much it costs. I always talk them through the reconciliation period but its still a hard pill to swallow that they are on the hook for so much. I also help families who get bills for \$50,000 for services from the Parental Fee unit because paperwork was lost or missed and they are billed for all services rendered to their child. If they can't afford to pay they get sent to revenue recapture and income tax refunds are with held, bank accounts garnished, wages garnished and more. There really is no way for a family to get their fees lowered.

The fees are based on the prior years earnings so if a family cashes out a retirement account the year before their child was born to purchase a new house their fee includes that income. Even though that income is not on-going and not reflective of what they can afford in that current year. In reading the policy related to fees they are so well written that there is essentially no way a family can take any extra income without being assessed a fee. Families have talked about getting second or third jobs to pay down their fee but I have to advise against that because that will only increase their fees for the following year. Ultimately it is the families decision but they are in such stress that they just want the fees to go away.

MN is only one of 5 states that assesses a fee to their parents using the TEFRA option. Its about time we join the rest of the union and put an end to these fees once and for all and become a leader in disability rights and advancement and help these families help their children.

Thank you for your time and I encourage you to please vote yes on this bill.

Thank you,

Gregory Wisher