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Dear Chair Peter Fischer and Members of the House Human Services Policy Committee,

I am writing to you as the parent of a child who has significant disabilities, as a participant in the MN TEFRA program, and as a Constituent of House District 7B. My son, Parker, was born with a long list of disabilities and conditions that require around the clock care and supervision. He is now 11 years old and every day of his life has been spent managing his feeding tube, changing diapers, handling mountains of paperwork necessary to receive services, monitoring for seizures, and trying to ensure that his quality of life and that of my other two children are the best that they can be.

In Minnesota, parents who find themselves caring for a child with disabilities and do not qualify for Medicaid based on parental income, can access Medicaid for their disabled children by paying a parental fee, or a "disability tax" as we call it. Minnesota is one of only a handful of states in the country who charge a parental fee in order for disabled children to access Medicaid, and in turn access waiver services. Medicaid enrollment is a necessary first step in the process of accessing services. These parental fees charge families up to 11.25% of their adjusted gross income in order for their children to receive the very important services that help them access the care they need and help bridge the gap between what their primary insurance covers and what would be the family responsibility. These parental fees are dutifully collected and then dumped into the Minnesota state general fund. Over \$10 million annually is collected from Minnesota's working families who are struggling to care for their disabled children, and then those funds do not go towards the programs these families are paying into; the funds are going into our surplus general fund.

When our son was born, we were a dual income family. Due to his level of needs and the fact that there is not adequate staffing in the United States for Direct Support Workers and Home Health Nurses, we had to make the difficult decision to become a single income family in order to meet the needs of our son. I resigned from my long-term employment; ironically, I had worked in the health insurance industry. We struggled to figure out things on our own for our sons first few years of life until we were finally informed of the state's waiver program and we began the process of having him certified as disabled by the State Medical Review Team (SMRT). Once he was certified by the SMRT process, we then applied for Medicaid for him, on his behalf. He was approved based on his profound needs and then we received a form in the mail that asked us for income information and had a long series of equations which calculates how much parents will have to pay on an annual basis for their child to receive the Medicaid and waiver services. This amount has changed year to year for us as our income has fluctuated. A real worry for us has been when my husband has received a profit-sharing bonus at work; would this bonus throw us into a financial nightmare the following year because it increased our income to the next fee bracket. I have contemplated taking on a part-time job in order to help financially with the parental fees, however, any increase in income increases the parental fee, so this would only create a bigger hardship on our family. Our two other children have had to forego activities and experiences because the parental fees use up too much of our income. We have had to work extra hard to not have our two daughters feel resentment towards their brother for being born with disabilities and

therefore, in the state of Minnesota, adding to our family's financial strain in order for him to receive the services he needs.

I am asking for support in both the MN Senate and the MN House of Representatives for SF 1201/ HF 1434, to eliminate the parental fees (TEFRA) in the state of Minnesota. It is long past due for Minnesota, who takes pride in being a progressive state where all are supposed to be seen as equal, to stop penalizing families who, through no fault of their own, have the huge responsibility of caring for our most vulnerable citizens; disabled children. Raising children is already a huge financial commitment but I can attest to the fact that raising disabled children is exponentially more expensive, without even factoring in TEFRA parental fees. With the huge budget surplus in this state, NOW is the time to eliminate this discriminatory disability tax and help level the playing field for ALL Minnesota families.

I appreciate your time and efforts on this matter and would greatly appreciate your support for these bills. Our disabled community cannot wait another year; now is the time to get this done.

Sincerely,

Heather Kainz