

SF1201/HF1434 Testimony – Jessica Hauser – February/March 2023

Good afternoon. Thank you to all the lawmakers and caregivers working hard to improve access to disability services and eliminate TEFRA in Minnesota.

My name is Jessica Hauser and I live in Woodbury, MN. I'm mom to Wyatt, he's 10 years' old and was diagnosed with a catastrophic form of epilepsy when he was 7 months old. He has seizures every day and requires 1 on 1 adult care and assistance with everything. He also requires multiple medical supports and interventions, including medications, therapies, and expensive durable medical equipment and home modifications.

To cover the cost of his care, we were encouraged to apply for Medical Assistance as secondary insurance because our family's primary insurance did not adequately cover his medical expenses. We began navigating the application process with the support of The Arc.

We discovered that in order to access Medical Assistance we would have to pay an extraordinary amount of money called a Parental Fee through TEFRA program – (Tax Equity and Fiscal Responsibility Act). This name is stunningly inaccurate – it's a tremendously expensive and punitive tax on families who have children with devastating disabilities. It also creates a layer of red tape and bureaucracy that families have to navigate on top of dealing with the difficult and often heartbreaking experience of having a very sick child. It's downright cruel.

The initial monthly fee for our family was equal to another mortgage payment. This was when my husband and I both worked full-time. I was making a six-figure income. Since the fee is a sliding scale based on income, no matter how we did the math, it always ended up with one of us quitting our job to ensure we had the proper insurance to care

for our son. **MA isn't an optional choice for us to care for our son.** First, my husband stayed home for a year with our son. Then he went back to work and I quit my career so we could afford to pay TEFRA.

No Minnesotan should have to choose between working and contributing to the state economy and going bankrupt to pay for the care their disabled child needs.

When Wyatt started school, I was able to go back to work part-time and I'm careful not to make too much money in fear of a higher Parental Fee. We cannot move forward financially while we are forced to pay this egregious tax. It's absurd.

Minnesota needs to do better for families who have children with disabilities. Stop adding to their grief by taxing them for working hard to care for their families and kids.

Thank you for your time and for supporting SF 1201/HF1434 to help families like mine live better lives.