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February 27, 2023

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

I am writing on behalf of my husband and I, in support of HF1434 - to eliminate the parental fee tied to TEFRA option for children with disabilities.

Here's our story:

We currently live in Faribault, my home town. Our son Jack, now 18yo, has numerous disabling conditions...he was born with Temple Syndrome (aka Uniparental Disomy 14 - maternal), which brings with it many features such as cognitive delays, autism, short stature, low muscle tone, small hands/feet/ears, to name a few. Jack is also congenitally Deaf, which is the least of our concerns as my husband and I both come from Deaf families.

Jack also had a serious bout with major depression and anxiety in 2019. It was around that time that we finally bit the bullet and enrolled in the TEFRA option, so that we could access services that Jack so desperately needed. (Truthfully, Jack really needed an in-patient/residential mental health program with direct communication access in ASL, but Rice County, being the gatekeeper, denied our request; but that's a story for another time.) We knew about the TEFRA program, but had avoided it for years due to the outrageous parental fee. Once we joined, we paid approximately \$1200/month due to our previous year's adjusted gross income. Both my husband and I being government employees, we certainly didn't have extra income to afford the fee. In fact, I ended up leaving my full-time job, so I could stay home and support our son through this debilitating mental health crisis. We are thankful that with the Consumer Directed Community Supports program, funded by MA/TEFRA, I was able to become a paid parent caregiver for Jack. However, that caregiver income was a fraction of what I made in my full-time position as a sign language interpreter at the Minnesota State Academy for the Deaf. So while we were down my full-time income, the caregiver income primarily went toward covering the parental fee without much left for our normal household expenses. No family should be put in this kind of position, just for having a child with disabilities.

Early on, when I first learned of the TEFRA option, I was told that the parental fee was instituted in the early/mid 1990s, when we were in a state budget deficit. To add further insult to injury, I learned that the parental fees don't even get funded back toward the DHS programs that we are paying to have access to....it goes to the state's General Fund. What?!? It is truly mind-boggling that we, parents of children with disabilities who are already struggling to support our families, are being taxed to save the state budget! This is outrageous....especially, now that 30 years later we have a budget surplus. There is no reason for this disability tax, especially on the backs of families with children who have special needs. Our struggle to access appropriate programs and services for our children is real; to add a parental fee for these services is entirely unfair.

Please, please...stop the madness and vote in support of eliminating the TEFRA parental fee.

Thank you so much for the opportunity to share our story.

Sincerely,
Amy & Jeff Amundsen



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