

May 2, 2023

Dear Chair Noor and Committee Members,

My name is Julie McDonell and I live in Bloomington with my husband and two children. I am writing to request that you include SF1201/HF1434, the elimination of parental fees for TEFRA and HCBS within the final omnibus bill. My 5-year-old daughter, Macy, has a rare chromosome abnormality affecting roughly 100 genes on her 18th chromosome. She has significant physical and cognitive delays.

My husband and I are both elementary teachers and we have private insurance, but by the time my daughter was 2 or 3, her needs were greater than what our private insurance would support. Macy requires special seating as she is unable to sit on her own. She has an eye gaze device and receives speech therapy to help her learn how to use it. She has a wheelchair, which required us to purchase a wheelchair modified van. Macy is also medically complex and requires nursing care in order for us to work. None of these things, along with many others I didn't mention, are covered by our primary insurance.

When Macy was around 3 years old, we applied for medical assistance and she went on a waiver. Thankfully, medical assistance pays for all of the things I mentioned above, but unfortunately, it comes with a significant cost to us. Our children qualify for medical assistance as a secondary insurance because they have no income; however, Minnesota is one of only a few states that penalizes parents of disabled children by charging us a parental fee in order for our children to receive medical assistance. This fee is not small. We have had to make many sacrifices in order to pay our parental fee, which is roughly \$600.00 every month. For two elementary teachers with two young children, this is unconscionable. Many other families are charged even more, some paying more than double this per month. There are parents who turn down promotions at work knowing it will cause an increase in their fee. There are others who have their wages garnished or liens on their homes due to the inability to pay. This needs to stop.

While paying the parental fee is stressful and challenging for many of us, knowing where the money is going makes it even worse. This money goes into the state's General Fund. Essentially, then, parents of kids with disabilities are being taxed because we have a disabled child. My daughter is beautiful, strong, determined, and amazing just the way she is; however, we face many challenges and hardships due to her disability and medical complexity. We don't need this parental fee to add to our struggles.

Currently, the monthly payment for our wheelchair modified van combined with our monthly parental TEFRA fee is nearly as much as our mortgage payment. My husband and I are spending roughly \$15,000 out of pocket every year due to having a child with a disability. Our family needs to move in order to have more space for Macy's equipment and for her to be able to get around safely, yet we are unable to do so because of the costs that come with having a child with a disability. The removal of this fee would alleviate so much financial and emotional stress for my family and so many others.

With a budget surplus and a relatively small population this tax affects, we believe this is the year to get this bill introduced and passed. I appreciate your consideration of this bill and your support would mean the world to my family.

Sincerely,

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