

May 20, 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 asking for your support for HF 1434, elimination of parental fees for parents of disabled children. This fee is a barrier to even access medical assistance for some, and a financial burden for many others. My 5 year-old daughter, Macy, has a rare chromosome abnormality affecting roughly 100 genes on her 18th chromosome. She has profound physical and cognitive delays. Macy is also medically complex.

My husband and I are teachers and we have private insurance; however, by the time my daughter was 2 years old, 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 to communicate. She has a wheelchair, which required us to purchase a wheelchair modified van. Macy also requires a nursing level of care in order for us to work or be away from her. 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 just mentioned, 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 in this country that penalizes parents who have a child with a disability by charging us a fee in order for our children to receive medical assistance. This fee is significant for many.

We have had to make many sacrifices in order to pay our parental fee, which is roughly \$600.00 every month. We had to wait until graduate school loans were paid off before we could even apply for medical assistance for Macy because we couldn't afford both. Many other families are charged even more, some paying more than double this per month. There are parents who turn down promotions due to the increase in their fee, as well as those who have liens on their houses or wages being garnished because they cannot afford to pay their fee.

While paying the parental fee is stressful and challenging for many of us, and requires us to make regular sacrifices, 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 in Minnesota are being taxed for having a child with a disability.

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 a parental fee to add to these struggles. The out of pocket cost for my family due to having a child with a disability is at least \$15,000 a year. For two elementary teachers with two children, this is unconscionable. Our family needs to move in order to have more space for Macy's medical and therapy equipment, as well as 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.

It is for these reasons that I urge you to support the bill to remove the parental fee HF1434. With a budget surplus and a relatively small population this tax affects, now is the time to remove the parental fee and join the rest of the country. Minnesota can, and should, do better.

Thank you for your consideration.

Sincerely,
Julie McDonell

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