

April 26, 2023

Dear Co-Chair Paul Torkelson, Co-Chair Zack Stephenson & Committee Members,

My name is Julie McDonell and I live in Bloomington with my husband and two children. I am writing on behalf of my 7 year-old daughter, Macy, as well as other families of medically complex people with disabilities. Macy has a rare neurodevelopmental disorder. She has profound physical and intellectual disabilities and is nonspeaking. Macy is also medically complex, has multiple medical diagnoses, and at times her condition can change within seconds. Macy's needs are significant and she qualifies for MA-TEFRA. She receives home care nursing and has multiple medical and therapy appointments every month. Macy will always require 24 hour care.

I am deeply concerned about some of the provisions included in HF2434. It includes significant cuts to disability services and will have a lasting impact on the most vulnerable in our state. First, I strongly support preserving the A-4 amendment language in HF2434. The A-4 amendment is essential to protect the federally mandated right of individuals with disabilities to self-direct their services under the ADA and Olmstead decision. Concerns about RN and LPN licensure are misplaced; the A-4 amendment is about preserving choice, autonomy, and community integration, not about staffing regulations and licensure. Removing the A-4 amendment or adding language would nullify the intent and violate disability rights and push individuals into unnecessary congregate care institutionalization in a Community Residential Service formal setting. Please keep the A-4 intact to support the most significantly disabled Minnesotans.

Second, I am deeply concerned about the reintroduction of TEFRA fees to access Medical Assistance. Our children qualify for medical assistance as a secondary insurance because they have no income. In 2023, Minnesota was one of only five states to charge this fee and tax on parents. When the legislature voted to remove these fees, there was bipartisan support. This fee was not small. We had to make many sacrifices in order to pay our parental fee, which was roughly \$600.00 every month. For two elementary teachers with two young children, this was a huge struggle. Macy also uses a wheelchair, which required us to purchase a wheelchair modified van. This also comes with a high monthly payment. When I referenced the poverty chart, my husband and I would be very close to needing to pay the fee. A small raise or an increase in pay for additional education may put us over the limit. Again, we are teachers; we are not wealthy. Macy's needs required us to buy a different house in order to modify it to meet her needs. We would not be able to afford this fee at this point.

We cannot go backwards as a state in reintroducing these fees - a tax - on parents of children with disabilities. While it starts at a higher income level, there is evidence in prior legislation that these fees applied to many more families as the years went on. This may also have the unintended consequence of holding people back from pursuing other employment opportunities and promotions that result in them crossing the threshold to pay the fee.

Please reconsider these issues and make the right decisions for people with disabilities and their families.

Thank you for your consideration,

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