

My name is Kayla Gish. I am a Nurse Practitioner at the University of MN. As a healthcare provider, I humbly confess that until 3 years ago, I had not been privy to the issue I would like to address today. Today, I write to you as a mother of a child with a rare neuro developmental disease that causes chronic complex medical conditions. Given her complex needs, she quickly regressed and declined when we put her into a daycare setting. We knew she needed 1:1 care and pulled her from daycare but finding a nanny was cost prohibitive.

We applied for secondary medical assistance through the TEFRA program when my daughter was certified disabled at 6 months of age. To access MN MA and disability services our family is charged 800.00 a month. This is in addition to paying for our primary insurance. With two kids, we do not have an additional 800.00 a month in our budget after bills. It is necessary for my daughter to keep MA through TEFRA to access the disability services which help us support her and meet her needs. One third of the budget allowed for my daughter's care is spent paying back the TEFRA fees we were charged. I regret to inform you that we are not the most extreme case you will hear from. I know of families paying 12,000 a year in fees. Many families are not able to make their fee work and go without services and support they need and are entitled to.

My husband had to leave his job this year to care for our daughter. The financial burden these fees put on my family are significant. We question how to prepare for the future of our children because we have to determine how to pay for the present. Families of kids who are disabled should not have to pay to access disability services. Families should not have to decide between accessing services and a life of debt.

Thank you for considering supporting this bill.

Kayla Gish