

To Members of the House Ways and Means Committee:

I am writing to oppose parental fees, specifically the proposal in HF2434 to reintroduce these fees and waivers for families with adjusted gross incomes equal to or greater than 675% of the federal poverty limits.

When I'm asked about what it is like raising two disabled children I often think in numbers. The most important numbers in my life are 44 and 45. That's the age my two children will be when I reach the average age of mortality for an American woman. Since I cannot tell how they will develop, if they will need life long support or be able to earn an income, my husband and I must plan and devote our lives to ensuring they are safe and cared for beyond our own lives. Concurrently, we must prepare for our own retirement and long term care. Because we may not have children to care for us in old age.

70% is another number that we think about often. That's an average rate of abuse to a developmentally disabled adult. The only way to increase their safety is to integrate them into their community early and ensure they are not isolated into institutions (rates of abuse are much higher the more isolated a disabled person becomes).

0 is another number we deal with on a regular basis. It's the number left over in our flexible spending account after all the out-of-pocket expenses and co-pays needed for their care. It's the number of people in our lives (family or friends) that are available or qualified to help us care for our children. Many families with disabled children have little to no support. 0 is also the number we hope our mortgage balance is the day we pass so we know they have adequate housing.

In many ways we are lucky, my spouse is able to hold a job that pays well. And this is critical as I am unable to work due to the level of support my children need. But, that's not feasible forever. Children grow, they become teenagers and young adults. Their needs are slowly outgrowing our capabilities. Our income won't continue indefinitely. The waiver program will allow us to hire staff to support our children in the community, offer occasional respite so we can stay healthy and provide tools and resources like specialized camps. Through these experiences our kids gain important skills that increase their independence and thus safety. The services provided through TEFRA are not luxuries; they

are essential supports that allow disabled children to thrive and participate in their communities.

The argument that these fees only impact "higher-income" families is misleading and dangerous. Unless you are a multi-millionaire or billionaire the costs associated with raising a child with disabilities hit hard. Even families with relatively high incomes can struggle to meet these overwhelming expenses, which include medical care, therapies, specialized equipment, home modifications and other necessary supports. Reintroducing parental fees will force families to make impossible choices between their child's care and other basic needs.

Another concern is the precedent this sets. While the current proposal targets a specific income level, history has shown that once these fees are reinstated, it becomes easier to expand them to lower-income families. This would create a devastating ripple effect, impacting the very families who are least able to afford it and further exacerbating existing inequities in access to care. We must not go down this path.

Reinstating these fees is a step backward, undermining the progress we have made and placing an undue burden on vulnerable families.

So, I ask you to forgo reinstating TEFRA fees, and instead continue to support families like ours as we do the hard work of preparing our children for the safe and meaningful life they deserve.

Thank you,

Jessica Anarde