

Monday, April 21, 2025

To Members of the House Ways and Means Committee:

My name is Kelsey Hynes. I am the mother of a 7-year-old daughter named Libby, who has a rare genetic disorder along with severe cognitive and intellectual disabilities. I am writing to strongly oppose the proposed reinstatement of parental fees for families with children enrolled in Medical Assistance under TEFRA, specifically those with incomes at or above 675% of the federal poverty guidelines.

While this income level may appear high on paper, many families in this bracket are still struggling to stay afloat. Mortgage or rent payments, utility bills, car loans, student loans, medical bills, gas, groceries, and the overall cost of living have all skyrocketed. Reintroducing these fees is not just unfair, it's effectively a tax on families with disabled children, punishing them simply because their parents earn more.

Families already pay state and federal taxes that fund Medical Assistance and disability waivers. Asking them to pay again just because they have a child with a disability is wrong. These fees create a barrier to care, and many families may be forced to drop their children from Medical Assistance or disability waiver programs because they simply can't afford the added cost. That means children with significant needs will go without critical therapies and supports, not because their families don't care, but because they're being priced out of the very system meant to help them.

Reinstating parental fees sends a harmful message: that children with disabilities whose parents earn above a certain threshold are less deserving of support. This is discriminatory and deeply unjust.

I know this firsthand. When parental fees were previously in place, my family was one of those who could not afford to pay them. We had to remove our daughter from Medical Assistance and disability waivers, and as a result, she lost out on two years of therapies and services that our private insurance did not cover. Those were critical years for her development, and I carry that guilt to this day. She suffered because we were forced to choose between basic living expenses and the support she needed to thrive.

This is not a hypothetical scenario for many families, it is a devastating reality. I urge you to consider the real-life consequences of this proposal. Reinstating parental fees under TEFRA would not only place an undue financial burden on families but also harm the very children these programs are supposed to protect and support.

Please reconsider this proposal. Our children deserve better.

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