

February 28, 2023

Dear Members of the Minnesota House Human Services Finance Committee:

I am a resident of St. Paul, MN, in District 66A (Finke) and the mother of an 8-year-old boy with a history of prematurity, born at 29 weeks.

I also am an associate professor in pediatrics at the University of Minnesota, a licensed psychologist specializing in autism and in genetic disorders, and I am currently the co-director of clinical services at the Masonic Institute for the Developing Brain.

I am writing today to support HF1434, which eliminates parental fees for programs like TEFRA.

In my professional role in diagnosing and supporting autistic individuals and their families, I can point to countless families who have been able to access needed services for their child because we had the TEFRA program. I have no doubt that, because these services were provided, many children achieved their goals that allowed them to participate in their communities in the ways important to them.

I also can share countless examples of families who were not able to access coverage through TEFRA due to high parent co-pays. But I want to talk about one family in particular, which is my best friend Jennifer and her son, Henry. Henry was born a few months after my son. Both of our babies ended up having extended stays in the Neonatal Intensive Care Unit, mine for prematurity and hers for an unexpected diagnosis of Williams syndrome. Williams syndrome is a rare genetic disorder that often comes with mild to moderate delays in cognitive development as well as difficulties with attention, anxiety, social skills, and self-regulation. Henry had stark delays in language and motor skills in early childhood. While my son had mild speech delays that were easily remedied through speech-language therapy covered by my private insurance, Henry was not talking or walking independently at age 2 or 3. Despite the known course of Williams syndrome and the obvious delays in development impacting Henry's daily functioning, my friend Jenny's insurance provided coverage for only one speech-language session and one occupational therapy session per month.

"No problem," I said. "You can just apply for TEFRA, and Henry's disability will qualify him."

Jenny went through the extensive and overly complex process of completing the TEFRA application, only to find out that their family income was at a level where the co-pay was equal to their mortgage. Their choice was to pay for TEFRA or to pay for daycare, and as parents working full-time, they chose daycare. Thankfully, Henry talks and walks today at age 8, but his language and motor skills are far behind that of his same-age peers, and he is in a full-time special education setting. He continues to need speech-language and occupational therapies and continues to qualify for one session each per month. We know the power of early intervention, and we will always wonder whether Henry could have made more extensive gains had TEFRA been affordable.

There are so many ways in which our systems fail to support and include people with disabilities. I ask the committee to support HF1434 and remove one barrier for families seeking needed supports and services.

Sincerely,

A handwritten signature in black ink that reads "Amy Esler". The signature is written in a cursive style with a large initial "A" and a distinct "E".

Amy Esler, PhD, LP
Saint Paul resident