

Dear Health and Human Services Conference Committee members,

I'm writing to ask for your support by including the elimination of MA TEFRA Parental fees in the final HHS budget. This bill will affect many families with children with disabilities, including ours. When our son Victor was 3, we were in the process of receiving diagnostics, care, and treatment for his rare genetic condition that includes global developmental delays due to a rare genetic disorder and epilepsy. At that time we were told by our employer-provided insurance plan that we had capped all therapies needed by a typical individual and we should be getting our son Medicaid services to cover his additional needs as a child with disabilities. We went through the long, confusing, and cumbersome process to access MA, not knowing that disability services in the state of MN also come with fees on top of the premiums we already pay through our employers. We were told our fee would be approximately \$800 a month and we realized we could no longer afford both child care for our three pre-school children and the fees to get our son the needed medical care and therapy above and beyond our standard insurance plan.

As a teacher, I was lucky enough to have a strong union that supported our family and allowed me to take a leave of absence and return once my children were in kindergarten. This lowered our income enough for their early years to be able to have MA for our son without a fee, but it meant my leaving a career I love and taking a step back in my field for three years. It put real financial constraints on our family for all our other basic needs during that time. It also meant we no longer had my quality employer-provided coverage for our other 2 children and myself, as my husband worked for a small business that didn't have a cost-effective family plan. So aside from all the personal hits that we took for these fees, the impact that our family had on our state budget multiplied because we couldn't afford for me to keep working and provide necessary medical and therapeutic interventions for my son. Our lowered income reduced the amount we as a family were paying in income tax, 3 of our 5 family members ended up on income dependent MA in addition to our son on disability MA. Our other 2 boys were not disabled, but they were still medically costly as 28-week preemies. They had weak lungs and immune systems and other developmental issues that meant their early years were still full of medical interventions as a result of their early arrival. We cost the state a significantly greater amount as a family in order to support one member of the family with disabilities. If the MA-TEFRA fees were eliminated or reduced to a reasonable amount, only one of my children would have been receiving state dollars for health care, and since I would still have had my quality employer-provided insurance, he would have cost less too. Having returned to work and paying in MA TEFRA for the last 6 years as my children are now 5th Graders, we are able to make the payments, but they are what prevents us from putting sufficient money into savings, retirement for ourselves and college funds for our children. We have what would be comfortable salaries, but this additional monthly bill is practically all of our discretionary income.

The exorbitant MA-TEFRA fees push families to make impossible choices. These choices leave us even more dependent on the state or worse, leave our children without services as families decide they can't afford it and their children go without early intervention and therapy. The impact of early intervention is well-documented, and it is clear that if we continue to make these services inaccessible and cost-prohibitive to young families, we are going to have adults with greater needs.

I am asking that you as conference committee members eliminate MA TEFRA parental fees as part of the final HHS budget bill. Feel free to contact me with further questions.

Ariane Kokes