**Families call for state intervention, parental fees ‘out of control’**

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High fees are keeping too many Minnesota families out of the Medical Assistance/ Tax Equity and Fiscal Responsibility Act (TEFRA) program. Families in the program make many sacrifices to
pay fees meant to keep children with disabilities healthy and living in the community.

More than 50 parents and children gathered January 28 in Roseville to share their stories and mobilize for the 2017 legislative session. The Arc Minnesota is leading the charge, calling for state lawmakers to support a reduction in the fees. The goal is to have the fees halved this year and eventually eliminated.

“People cannot get access to the programs they need because the fees are out of control,” said Melissa Haley, a St. Paul resident and parent of a child with autism. MA/TEFRA covers needed services including include physical therapy, behavior therapy, personal care attendant services, speech and occupational therapy.

Parent after parent, some in tears, described extremely difficult situations they face. Families that provided care for years on their own see MA/TEFRA as saving their families, and helping their children. More than one person described the program as a “godsend.”

But the income-based fees are too much for families already paying rent, mortgages, car payments and other living expenses. Families make one payment for care for their child with disabilities and another payment to cover insurance needs for the rest of their children.

The fees have increased over the years to help balance the state budget. Some families pay hundreds of dollars and others more than $1,000 per month. Rising fees for the program, coupled with looming Affordable Care Act changes at the federal level, have parents worried. If the Trump administrative makes major changes to the insurance system, programs like MA/TEFRA could become more important than ever.

The TEFRA option is intended to allow MA eligibility for children with disabilities whose parents have too much family income to qualify for MA or other Minnesota health care programs. To qualify for MA/TEFRA services a child must live with at least one parent; be younger than age 19, be certified as disabled, and need a certain level of care that is similar to the level of care provided in a hospital, nursing home or intermediate care facility for people with developmental disabilities. Home care costs need to be less than the cost for care in a skilled medical facility.

But the income-based fees are beyond the financial reach of many families. Some families have gone deeply into debt and drained their financial resources. Often one parent has had to stop working. Others have had to give up services their children needs.

Parents at the forum shared story after story about long waits for service, and high fees once services were obtained through MA/TEFRA. “We went from elation to thinking, what have we done?” said White Bear Lake resident Leslie Sieleni after her family got its first bill for the program.

Families are forced to forgo supports their child with disabilities need. Other children in a family suffer from lack of family income. When families get behind on the fees, they are harassed by bill collectors.

Dakota County resident Kelly Kausel has depleted her 401 K and a family inheritance. “I’ve given it all to the state of Minnesota.”

Bob Atkinson, who lives in Scott County, has a young adult daughter with Down syndrome. The family is out of MA/TEFRA, but used the program for many years. “In the beginning we though the fees were very fair and very affordable,” he said. But a fee hike in 2007 changed that. Fees shot up to almost $950 per month at the end of his daughter’s eligibility.

“We are working families,” said Atkinson. “It feels as if we are being punished for having a disabled child.”

“Our fees right now are more than our car payment,” said Moriah Demers. She said the fee structure encourages families to work less and earn less, or to forego treatments needed by their children.

“We are just trying to see our son succeed in life,” said Sieleni. “Why should our child pay the price for this?” She and other parents said the right services for children with disabilities, starting at the earliest age possible, help children live and work independently as adults. Supports early in life will save the state money for years to come.”