

Support for SF 807/HF 1182 Lowering TEFRA Parental Fees in Minnesota: A Case Study

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Abstract:

Medical Assistance (MA)-TEFRA is the Minnesota run option that provides children with disabilities, who would not otherwise qualify for Medicaid due to their parents' income, the state's Medicaid coverage and services. Proponents believe this program directly affects the health and well-being of children living with disabilities in Minnesota and their families. MA-TEFRA requires that parents of eligible children pay using a sliding scale according to their income. However, there has been growing concern over parental fees, which some describe as causing additional burden on their family. Additional concerns include: the concept of in-equity due to limitations of accessing care for children needing more health services and resources; the complications and effects that outside private insurance coverage in combination with TEFRA; and related Medicaid eligibility issues. Therefore, there was need to address these concerns about the parental fees for MA-TEFRA. Through the ongoing work by families and non-profit organizations to lower TEFRA parental fees, SF 807/ HF 1182 was passed in the 2017 Minnesota Legislative Session. This bill lowered parental fees by 13% for Minnesota families. In this case study, an analysis of the many different factors that played a role in the success of healthcare legislation, as well as a description of the role that organizations, grassroots coalitions, legislative relationships, and personal stories play in increasing families' access to necessary services to allow children with disabilities to be raised in the community as opposed to institutions.

Medical Assistance for Children with Disabilities in Minnesota

Medical Assistance (MA) is Minnesota's Medicaid program to assist lower income families in paying for necessary health services that are difficult for them to afford. Regardless of family income, children with disabilities can also receive MA for some health services via different options in the state of Minnesota. Until 1988, MA could only be accessed through meeting the low-income qualifications for MA coverage set by the state. These qualifications, based on the income of household, cover certain populations with income up to a certain percent of the federal poverty line and vary depending on age and whether someone is pregnant (Norrie, 2016). However, these qualifications for MA do not allow support for families with children with disabilities whose income does not fall below these levels. Due to the financial difficulties of paying for resources for a child with disabilities and Medicaid's role in providing families access to health services, the MA-TEFRA option was passed.

The Purpose of Supplemental Healthcare Access for Children with Disabilities

The Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 is a federal law that gives families with children with disabilities access to Medicaid (called "Medical Assistance" in Minnesota) even if they do not meet the lower income qualifications to otherwise receive Medicaid. An additional goal of TEFRA is to expand Medicaid coverage by providing families that need often many expensive health services to care for a child with disabilities or to improve the wellbeing and independence of their child a way to raise and care for their children in the community at home. This is done by giving them access to Medicaid coverage through a sliding scale TEFRA parental fee. The child and family must meet a list of eligibility requirements to qualify for the MA-TEFRA option. Conditions of eligibility in Minnesota include:

1. The child must be under 19 years of age;
2. The child must live with at least one biological or adoptive parent;
3. The child's disability has to be reviewed by the State

Medical Review Team Team as a certified disability (if the child was not already considered as having a disability under the federal Supplemental Security Income (SSI) disability program guidelines);

4. The level of care the child with disability needs has to be the equivalent of care that would be provided by a hospital, nursing home, or other institutional facility if the child was not being cared for at home;
5. The child's income is under the Federal Poverty Guideline for a household of one person (with exceptions of spending down income)

(State Medical Review-Team Minnesota Department of Human Services, 2010).

After a child and family meet the eligibility requirements for receiving financial assistance for health services with the MA-TEFRA option, families who apply and get MA coverage for services still have to pay a fee or a "financial obligation" for this, otherwise nonexistent, path to access Medicaid health coverage (Chan, Jahnke, Thorson, Vanderburg, 1999). The monthly MA-TEFRA fee is determined based on the Adjusted Gross Income of the family, size of the family, if the family has another type of private insurance, the extent of health coverage from another source if the family has one, and other factors (State Medical Review-Team Minnesota Department of Human Services, 2017). One study found that health status, other private insurance coverage, household income, and the total number of years using the TEFRA option were significant factors that predicted a family's monthly parental fees through the TEFRA option (Chan & Vanderburg 1999). However, when personal financial situations of families caring for children with disabilities in Minnesota are studied more closely, it is clear that TEFRA fees can also create a great financial burden that adds to the often continual stressors that already come with caring for a child with disabilities.

History of TEFRA in Minnesota and the Importance of Community-Based Health Services

The Minnesota Legislature authorized the TEFRA option in 1988 after societal expectations for the care of children with disabilities began to change in the early 1980's (Chan et al., 1999). With an increase in community-based care programs, an increased understanding of the benefits of de-institutionalization of those with disabilities, life changing advances in medical technology, and developments of home medical devices all led to opportunities for children with disabilities or chronic illnesses to be raised at home. Some of the benefits for keeping children with disabilities at home include: allowing families to see their child, providing opportunities for social interac-

tions with siblings and friends, increasing independence, and keeping children and families involved in community activities. In addition, there are fiscal benefits of keeping children with their families. A study that analyzed Medicaid found that although initial spending on community recourses are higher, well developed community supports save significantly more money than a community with fewer supports and, thus, a greater institutionalized population of people with disabilities (Kaye, LaPlante, & Harrington, 2009). Health outcomes, including death, remain similar about individuals who stay at home versus those who live in institutions. In a study that compared mortality rates of those who left institutions as compared to those who stayed between the late 1990's and early 2000's, there was no difference found in mortality rate and health risk for those who left institutions and instead received care through community services and at home as compared to those who stayed (Lerman, Apqar, & Jordan, 2003). The MA-TEFRA option was one of Minnesota's responses to give financial aid to care for children with disabilities based in the community as a result of de-institutionalization.

Clearly a barrier for a family caring for a child with disabilities at home is being able to pay for ongoing medical treatment and health services, continual use of prescription drugs, medical treatments, home modifications to fit the needs of the child, therapies, mental health services, in-home care, hospital stays, and much more. It is for this reason that studying the effects of the MA-TEFRA option and its costs and coverage is beneficial in analyzing the difficulties that families caring for children with disabilities face.

Studies of TEFRA at the State and National Levels

In 1995, seven years after MA-TEFRA's inception, the Minnesota Children with Special Health Needs (MCSHN) section of the Minnesota Department of Health along with the Minnesota Department of Human Services conducted an in-depth study of the children using the TEFRA option (Chan et al., 1999). They found that children using the TEFRA option have a wide range of disabilities and that 80% of children on TEFRA have more than one diagnosis with an average of three (Chan et al., 1999). There were also clear trends in the types of daily needs, health services needed, and the need for long-term care. Sixty-seven percent of children needed prescription drugs; over 25% of kids had been hospitalized in the year before the study. Eighty-two percent of children needed frequent to constant supervision and 20% of children were totally dependent in all daily activities (Chan et al., 1999).

Another area of focus for this study was the financial costs to families using the MA-TEFRA option. In the 1995 study, MA-TEFRA covered only 23% of total costs of medical related needs for children in the study (Chan et al., 1999). The remainder was covered through out of pocket costs, private health plans, and schools. Even with families that spend a large portion of their income on medical expenses, there were many costs/burdens to the family that affected more than just the costs of services. Surveyed parents responded to having stressors put on other children in the family, stressors on marital relationships, difficulties in maintaining employment, exhaustion and stress due to giving prolonged care, and social isolation (Chan et al., 1999). These combined burdens on families showed that the needs of children with disabilities and costs are often great and long-term.

Nationwide, a study of families accessing the TEFRA option compiled information on the difference in amounts of kids using the TEFRA option to receive coverage for health services on a larger level per state where TEFRA is offered. This study found that 25,000 children living with disabilities qualified to receive Medicaid coverage through the TEFRA option in 2001 and that the distribution of children varied depending on the state. Minnesota, Arkansas, Georgia, South Carolina, and Wisconsin contained 70% of all children using the TEFRA option (Semansky and Koyanagi, 2004). This does not suggest that there has been an even distribution of children using the TEFRA option even in the 20 states where the TEFRA option was available and that Minnesota has been a state that has allowed a greater number of children to receive MA coverage through the TEFRA option.

This national study found that of the 20 states that have the TEFRA option available, Minnesota was one of 10 where children were able to qualify on the basis of mental health disability. Sixteen percent of children using the TEFRA option in Minnesota qualified on the basis of a mental health disability and the total percent of the children in the state using the TEFRA option was 2.8% (Semansky and Koyanagi, 2004). The study also found that 90% of all children using the TEFRA option nationwide had a physical disability or mental retardation, while only 8% qualified because a mental health disability (Semansky and Koyanagi, 2004).

A study on children living in Minnesota with autism also looked at the demographics of children with autism using the TEFRA option. The researchers looked at the intensity of mental health services used per month to find out which groups of children of different genders, races, and ages were utilizing mental health services the

most. In addition, how children were getting coverage for their health services was also examined. Of the three different user intensity levels of mental health resources the highest intensity users of mental health services of children with autism (over 160 hours/month) had the highest percent (66.7%) of children using the MA-TEFRA option as compared to the middle intensity users (53.4%) and the low intensity users (14.9%) (Gulaid, Hall-Lande, Hewitt, Kleist, Moore, Nord, Opsal, & Timmons, 2012).

Findings from these studies showed that even with Medicaid coverage through the TEFRA option, families with children with disabilities are paying for health services through many other ways including out-of-pocket costs and private insurance premiums. The Minnesota study also concluded that parents caring for children with disabilities using the TEFRA option often struggle to pay TEFRA fees and still have high medical costs without them. The national study showed that of the states where TEFRA is available there is a lack of coverage for children with mental health issues; it also found that Minnesota is one of the few states allowing children to qualify for TEFRA on the basis of a mental disability. Considering that many sources analyzed in this review show the difficulties that families have in paying TEFRA fees, accessing and paying for health resources for their children, and dealing with different stressors with raising a child with disabilities, these suggest there are issues with the federal TEFRA option that may be problematic for families raising children with disabilities who need supportive resources.

Problematic Issues with TEFRA

Since 1988, when the TEFRA option became authorized in Minnesota, there have been ongoing issues that could create difficulties for families even though the law itself was intended to help.

1. TEFRA as a Financial Burden

The extent to which TEFRA expenditures have already been studied combined with extensive observations of Minnesota families caring for children with disabilities today, shows that the parental TEFRA fees do create financial burdens for families already dealing with the stress and other expenses involved in caring for a child with disabilities. The Arc Minnesota is a statewide non-profit organization that works to promote and protect the rights of those with different types of disabilities through connecting families with resources, creating a community that works to keep those with disabilities in the community, and by advocating for public policies that benefit those with disabilities. The Arc works to help families for which

TEFRA fees cause financial burdens and this leads them to support and promote legislation to lower them (Arc Minnesota, 2017). The organization has observed that some middleclass families' fees are several hundred dollars a month and these families spend down savings or retirement accounts in order to meet fees (The Arc Minnesota-Parental Fact Sheet, 2017).

According to the Kids Waiver Project by Complex Child Magazine, parental fees for the TEFRA program can be up to 11.25% of family's incomes (Complex Child Magazine, 2017). This financial issue could cause families to choose not to apply for MA-TEFRA services that would greatly benefit their child or face choices that put the financial stability of the whole family at risk. Alicia Munson, Senior Policy Director at Arc Minnesota, describes this problematic issue. Munson describes how the TEFRA option allows some children with very high levels of need, who would otherwise be hospitalized, to receive the services that allow them to live at home and improve their quality of life. She goes on to talk about how high TEFRA parental fees make this problematic because there are families who choose not to apply for TEFRA because they simply cannot afford the high fees. She also mentions that depending on how high family's parental fees are, it may not be worth it for families to seek the services through MA-TEFRA (A. M.). This means that TEFRA parental fees could totally exclude children from accessing many services that could be vital in improving their lives.

Finally, Munson raises the point that nowhere in the federal TEFRA option legislation does it say that parents need to pay a fee for accessing Medicaid through the TEFRA occupation. Minnesota parental fees are set by the state legislature (State Medical Review-Team Minnesota Department of Human Services, 2010). Considering families with children with disabilities are not granted access to Medicaid services through any other option other than TEFRA and these fees are based on a sliding scale involving family income, this probably means that the TEFRA option to Medicaid will not become an available resource without a fee for access. This might be a reason why there seems to be very little information about the legality of parental fees through the TEFRA option.

2. Equity Issues with TEFRA

The strict eligibility requirements to qualify for TEFRA also raise some strong equity issues related to the differences in needs of a child with disabilities as compared to needs of a child of similar age that does not have disabilities. When promoting legislation to lower TEFRA parental fees, Arc Minnesota raised the point that families

with children with disabilities simply have to continually pay more for health services and care as compared to those without (The Arc Minnesota-Parental Fact Sheet, 2017). This can become problematic when there are many benefits for the state of Minnesota, communities, families, and children themselves to raising children with disabilities at home. Munson talks about how the needs on some children with disabilities can be extensive and can include children needing help in and out of bed, up and down stairs, and up to assistance with almost all forms of daily living (A. M.).

To add to the discussion on needs of those with disabilities, a national study of families using the TEFRA option in 20 states (number of states where the TEFRA option is available) in 2001 found that children with mental disabilities are much less likely to be able to qualify for the TEFRA option as compared to children with physical and developmental disabilities. More specifically, it found that children with mental disabilities in half of the states that had the TEFRA option available were not able to qualify despite federal rules and regulations that make it illegal to discriminate based on type of disability (Semansky and Koyanagi, 2004). In 2001, this could have been influenced by the extent to which mental health was viewed as being just as important as physical health. This study found that depending on the state medical institutions may not clearly include psychiatric hospitals or other mental health facilities. The study found that some states formally included psychiatric hospitals as a medical institution, some states interpret psychiatric hospitals as medical institutions in less explicit ways, and one state only considered medical institutions to be institutions dealing with physical disabilities (Semansky and Koyanagi, 2004). The extent to which states consider mental health issues and disabilities an important issue for which to receive health services and therapies would have an effect on if children were able to qualify for the TEFRA option.

3. Outside Insurance Complications in Combination with TEFRA

Another issue that complicates the TEFRA option is how its coverage and cost in parental fees is affected by the combination of coverage with other forms of insurance. One study of families using the TEFRA option in Minnesota found that families using the TEFRA option in combination with managed care plans such as Health Maintenance Organizations (HMOs) had higher parental fees than families that were using the TEFRA option in combination with more conventional indemnity plans also called fee-for-service plans. This study also found that

most of Minnesota's managed care plans also provide the same if not better coverage for core medical items as indemnity plans but less for supporting services such as medical equipment, in-home care, and therapies (Chan & Vanderburg, 1999). This issue creates variability in costs for insurance and for TEFRA fees while making different levels of necessary services available to a child with disabilities. These inconsistencies of the costs and coverage for insurance plans and how a specific type of insurance plan affects their TEFRA parental fees can greatly complicate family's decisions in choosing health insurance plans that will help determine what services children with disabilities receive.

This issue may cause families to choose between plans that are cheaper and plans that cover needed services when they also affect their TEFRA parental fees in addition to the cost of other insurance plans. The varying coverage and costs by health insurance plans in combination with the parental fees for the TEFRA option could also affect the likelihood that families seek certain services due to costs and coverage. Children using the TEFRA option in combination with an HMO had a lower probability of filing claims for psychiatric or mental health services, nursing home care, and outpatient visits with TEFRA as compared to indemnity insurance plans but the same number of claims for medications and miscellaneous items (Chan & Vanderburg, 1999).

If a child who qualifies for the TEFRA option also is covered by a private insurance or an HMO those plans are billed first and then the remainder of the bill requested from MA-TEFRA. The Minnesota study found that most inpatient care services were paid for by children's insurance rather than through the TEFRA option. The study also found that more claims were made to TEFRA for medications rather than claims for home care, physician visits, nursing home care, and mental health resources (Chan & Vanderburg, 1999). This issue makes TEFRA parental fees problematic and an added financial burden because these fees can be affected by the type of insurance (often also a financial burden) and there are still many services that do not end up being covered or aided through the TEFRA option but rather the child's private insurance with cheaper HMOs.

Another study examined different types of insurance usage and MA-TEFRA option usage for children receiving mental health services for autism in Minnesota. This study found that the children using the most mental health services per month had the highest percent of the group using the TEFRA option (66.7%) and fee-for-service insurance plans (94.6%) in 2010. This was compared to the children with autism using less mental health services.

This group of children with autism had a lower percent of the group using the TEFRA option (14.9%) and was the group with the highest percent using managed care plans (13.6%) or both managed care plans and fee for service plans (21.4%) (Gulaid et al., 2012). These data suggest that children with autism were able to utilize more mental health services using the TEFRA option than children who had managed care plans. This study stated that it is harder for children with autism to qualify for managed care plans and that many managed care plans also do not cover intensive interventions for autism (Gulaid et al., 2012). These data do not necessarily mean that children with autism have more difficulties utilizing mental health services with managed care plans and intense mental health interventions may not be the best option for a child with autism.

A 2010 National Survey of Children with Special Health Care Needs shows that 37% of families whose household income is under 400% of the federal poverty level and 32% of families over the FPL who are insured describe that their insurance for their child does not adequately meet the child's needs (Comeau, 2015). Yet, paying for different types of expensive insurance coverage does not mean that the needs of the child will be met through available health services.

4. Problems in the Medicaid System and Limitations to Qualifying through TEFRA

In a journal article, Muscumeci argues Medicaid eligibility requirements through the TEFRA option create a system in which it is very difficult for children with disabilities to get the best care, services, and preventative health resources that could allow them to need less expensive services later because they would be higher functioning children (Musumeci, 2011). Access to mental health resources, therapies, and preventative health resources may allow a child with disabilities to be higher functioning, more independent, and have a healthier life.

A child must meet the need of a level of care equivalent to the care that would be provided by a hospital, nursing home, or other institutional facility if the child was not being cared for at home (State Medical Review-Team Minnesota Department of Human Services, 2010). Muscumeci argues that this issue is one example of how our Medicaid system is framed to only give aid to children with disabilities when they reach a certain level of need. This, ironically, is possibly due to the fact that they have not been utilizing preventative healthcare services and therapies and that the system functions on the idea that those who receive aid have to be the sickest (Musumeci, 2011). This criteria to access care does not

encourage the use of preventative healthcare services that could avoid a need for later, more intense, expensive treatments or health services. This also is not an efficient or effective way of keeping anyone healthy let alone children with disabilities who need more health services that can be expensive. More efficient healthcare systems can help people choose to utilize beneficial health resources and ensure that aid is used to provide for necessary resources for the children that need it most.

While it is necessary to classify who is eligible for aid through the TEFRA option, however, creating strict definitions of who qualifies as a child with disabilities is problematic because it does not acknowledge the extent to which modern medical practices allows specialists to diagnose conditions that can range in severity and greatly affect children's lives. The definition of who qualifies as child with disabilities from the federal Supplemental Security Income Program's is used to determine if a child qualifies for Medicaid through the TEFRA option. Under the law, children are considered to be "disabled" if:

1. He or she has a medically determinable physical or mental impairment (or a combination);
2. The impairment(s) results in marked and severe functional limitations; or
3. The impairment(s) has lasted for at least one year or to result in death

(Social Security Administration, 2017).

In comparison, an example of an alternative to using exclusive language can be seen in The Children and Youth with special Health Needs Program Annual Report by the Minnesota Department of Health. This program approaches defining children with disabilities in a much more inclusive way. It states, "Children and youth with special health needs are those who have, or who are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition. They also require health and related services of a type or amount beyond that generally required" (Dalbec, 2015). This definition is intentionally broad and recognizes that children with disabilities, regardless of specific conditions, require strong community-based resources and services (Dalbec, 2015). Inclusive language is important because not only does it incorporate a wider spectrum and variety of conditions of children with disabilities, but it also recognizes that all children with disabilities benefit from a wide variety of health resources aimed at improving their daily functioning, independence, and well-being.

Personal Accounts of Need

MA-TEFRA parental fees are a financial burden

if there is no other way a family could access Medicaid or services through other private insurance. Perhaps some of the clearest examples of issues with the MA-TEFRA option that cause difficulties for Minnesota families caring for children with disabilities can be understood from personal accounts of families.

A personal experience of a family that has accessed Medical Assistance in Minnesota through the TEFRA option in the past can be heard from Debbi Harris and her husband. They needed services through MA-TEFRA for their son. Debbi's son needed the MA services provided through the TEFRA option because he needed a nursing level of care and supervision 24 hours a day and their family's insurance only covered limited in-home care and had a dollar cap on coverage that would only last a few months for her son. Debbi continued to say that not only were parental fees through MA-TEFRA extremely expensive for her family, but there appeared to be changing factors used to determine the yearly fee. She explained how every time her family had a change in income they had to report it. Her husband served in the armed forces and every time he was given a stipend to live somewhere abroad they would have to report it, and this would potentially change their parental fees.

Debbi expressed some fear regarding the amount, and the penalties if the fees were not paid on time. She had heard of families paying upwards of \$1200 per month in parental fees, and if fees are not paid on time families can even get a lien put against their house until their debts are paid off. As an example of her fear, she described the scenario of what could happen if a family falls behind on paying their parental fees. Even though parental fees technically stop when a child reaches 18 years old, she described that this is not always the case due to the fact that families can easily get behind on paying for their parental fees and, therefore, these families can be paying them off for years after their child stops receiving benefits. This may be evidence that the cost of parental fees can be so high that if parents get behind on paying and will continue to pay even after their child is off the option. Debbi also said that what is really problematic to her is that MA-TEFRA parental fees go into a general fees fund for the state, so it feels to her as if the state is charging extra taxes on an already vulnerable population that may need MA services to live. However, in the end, Debbi said that she was grateful for the MA-TEFRA because her family had no other option, however, the parental fees are very troubling.

Kelly Kausel is another parent who advocates for lower parental fees. Kelly is raising an 8-year-old son with autism and was denied prescribed services and therapies

therapies by their family's insurance provider after applying when their son was diagnosed as a baby. After having to apply for MA-TEFRA her family was faced with parental fees that they could not afford. Kelly had to cash out her 401K, spend a family inheritance, and borrow money from her parents in order to pay for health services for her son. She talks about how her family still owes money in parental fees and they are living pay-check-to-pay-check. Kelly currently has to choose not to work, which will then prevent MA-TEFRA parental fees from increasing even higher; in addition, it has been suggested that her husband quit his job that is supporting the family, which they have refused to do. Another issue with the MA-TEFRA option that Kelly has noticed is that many other families raising a child with autism, choose not to pay the MA-TEFRA parental fees due to high costs and other issues connected with the MA-TEFRA option.

Kelly believes that our society creates a cycle where those with mental disabilities are unable to receive the services that they need as children due to lack of access and high costs options like MA-TEFRA. These barriers cause those with disabilities to grow up to be lower functioning adults that can have more difficulties with daily functioning, holding a job, keeping a home, and are even more likely to commit suicide because they feel that they have no other option. All of these issues are due to the fact that people did not receive the health resources that they needed when they were children. She believes that expensive options for care such as the MA-TEFRA option can also have societal economic costs because people are less able to be employed adults, are more likely to become homeless, and will need more expensive treatments.

Like Debbi, Kelly considers these fees to be a "disability tax" that families often have no other choice than to pay to access health services for their child with disabilities. Kelly advocates on behalf of other families she knows who have faced home foreclosures, bankruptcy, divorce, and medical problems related to stress. She hopes to help families find access to the necessary resources for their children with disabilities so that they can grow up to be higher functioning adults and have a better quality of life. It is for these reasons that many parents are rallying, advocating and testifying at legislative hearings while raising their children in the hopes that legislation to reduce or eliminate parental fees through MA-TEFRA will be passed.

The 2017 SF 807/ HF 1182 Bill

Following Minnesota's 2017 Legislative Session, Governor Mark Dayton signed the state's Health and

Human Services Spending and Policy Bill on May 31st, 2017. This occurred after the Minnesota House and Senate passed the bill on May 26th, 2017. A part of this HHS bill included the SF 807/ HF 1182 that effectively lowered parental fees under the TEFRA option for Minnesota families by 13% starting July 1st, 2017 (The Arc Minnesota-HHS Bill, 2017). The SF 807/ HF 1182 greatly impacted Minnesota families using the TEFRA option to obtain MA services for a child with disabilities.

The grassroots group of advocates from the Coalition to Lower Parental Fees with the Arc Minnesota were the primary groups who proposed and pushed this bill to be passed by the Minnesota State Legislature (A. Munson, personal communication, October 20th, 2017). When originally proposed, the SF 807/ HF 1182 bill requested a 50% reduction in MA-TEFRA parental fees (Peterson, 2017). Munson explains that the difference between what is proposed and what is passed is not necessarily due to the fact that the proposed percent was intentionally set high with the assumption that what could potentially pass due to funding would be lower, but rather that the Arc Minnesota really tries to structure legislation proposals based off of families' needs in Minnesota (A. M.). Even 13% reduction in MA-TEFRA parental fees provides some relief to families raising children with disabilities.

Factors that Led to the Success of the Bill Getting Passed

To determine what factors led to the successful passage of SF 807/HF 1182, the role of individuals and local advocacy organizations should be examined.

1. The Role of a United Community and Personal Stories

Voicing personal stories of families using MA-TEFRA has profound effect. Munson believes that families sharing personal stories had the greatest influence on lowering parental fees through the legislation passed in 2017 (A.M.). Both Kausel and Harris agree that there is strength in sharing stories and getting more parents involved in testifying at the capital would be beneficial (K.K, D.H). Senator Clausen explained how talking with families, as a lawmaker, assisted him in improving his understanding of the issues (G.C.).

The Coalition to Lower TEFRA Fees is a grassroots group of parents and advocates that helps propose legislation to lower TEFRA fees in Minnesota. The Coalition is an example of the presence of grassroots organizations in this movement, and the importance of their role in the success of the legislation. The individuals and community groups that helped organize events and meetings at the capital to testify for legislative sessions and connect

with legislators allows for individuals to share their stories and present MA-TEFRA parental fees as an issue that is affecting a large population of Minnesotans who needed support and a reduction of parental fees.

2. Organizational Support and Resources

Many organizations supported and advocated for SF 807/HF 1182 or the Coalition to Lower MA-TEFRA fees initiative in Minnesota. Some of the organizations that supported the coalition or advocated for SF 807/HF 1182 include: The Arc Minnesota, The Autism Society of Minnesota, Minnesota Organization on Fetal Alcohol Syndrome, NAMI Minnesota, and Autism Minnesota. These organizations argue that MA-TEFRA parental fees can act as barriers to insurance coverage (Autism Society of Minnesota, 2016). State-wide organizations help provide resources for families with disabilities, help raise awareness for the needs of these families and children, and help organize communities to provide them with a means of fighting for resources and support at a policy level. Organizational support helps communities unite and individuals have more of an organized presence that help get the attention of lawmakers.

3. Legislative Connections

Munson explains that part of Arc Minnesota's role in the legislative process is writing and presenting legislators with the bill (A.M.). This proposal of legislation from community individuals and organizations allows coauthors of the bill in the Minnesota House and Senate to eventually start the process of getting the bill passed. This reflects a necessity of having legislative connections to start conversations around issues related to TEFRA and propose legislation to lower fees. Legislative connections are also needed to coordinate meetings between families, organization leaders, and legislators.

4. Funding for Health and Human Services

There currently are difficulties at a policy level to address and change many of the issues related to the MA-TEFRA option. Senator Greg Clausen (57th District, DFL) is a co-author of the 2017 bill that lowered MA-TEFRA parent fees. Prior to proposing the legislation, Senator Clausen identified barriers to the reduction of parental fees, which included: healthcare funding at a national level, the increasing costs of healthcare services, the specific \$463 million cut to Health and Human Services in FY 2016, and the lack of staff related to special education, nursing staff, and PCAs (G.C.). The cuts to Medicaid funding and cuts to the Health and Human Services De-

partment in Minnesota both specifically affect how much funding schools get with children using TEFRA and other similar services. However, statewide concerns were not the only barriers to this legislation. Additional federal issues affected policymakers' ability to address TEFRA related issues suggests that there are greater issues including how our nation's healthcare system functions, nationwide Medicaid cuts, and the extent to which national policy makers have the power to cut funding for resources that directly affect people's wellbeing and health. But despite these barriers, Senator Clausen continued to support the legislation because of his belief in the investment of early treatment for children with disabilities (G.C.).

Supporters of the bill consider the 13% reduction in MA-TEFRA fees for families in Minnesota to be a collective achievement. However, the effort is ongoing because the reduction can be reversed simply by the amount of money in the budget. Both Kausel and Clausen agree that it is unrealistic to consider this type of legislation a long-term solution to the issue of high MA-TEFRA parental fees because the funding will not always be available. Going forward, this this calls for feasible and sustainable solutions for families, states, and nationwide.

Conclusions

We have identified several problematic issues with the MA-TEFRA option in Minnesota, which can present a financial burden on families. There are also equity-related issues, specific to the TEFRA option in combination with other private insurance plans, and the issue of availability of services regardless of obtaining coverage. In this analysis we observe that the TEFRA option may induce the opposite effect of what is intended. For example, high parental fees can cause a family to choose not to apply for services for a child that may need them. The many factors that designate eligibility for the TEFRA option also make this option difficult and confusing for families to access. From hearing personal stories from parents, it is also clear that there are issues with the TEFRA option that are not even mentioned in any literature, studies, or governmental pages of regarding the option. It also seems that the greater issue is the nation's Medicaid system, and that as a society there may be little support for providing the necessary therapies and services needed for disabilities, which may then lead to people not being able to function as well as they could as adults, hold jobs, keep their homes, and affect the families' mental health. There are clearly very large problems and systemic healthcare issues that are affecting people's lives to the extent that these issues will have serious repercussions in people's lives and consequences in

our communities in the future.

There are also many factors that influenced legislation getting passed in Minnesota in 2017 (SF 807/HF 1182) that reduced parental fees. These influences are sometimes limited to the extent that the state cannot pass legislation to lower fees continually without an increasing in funding for Health and Human Services or a surplus in the budget. It is also clear that creating a means for families to share personal stories is vital in connecting with policy makers and had the power to affect health resource availability, cost, and coverage of services through MA-TEFRA by passing legislation to lower MA-TEFRA parental fees in 2017.

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