



MFTD Waiver Families

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Media Packet

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Illinois Medicaid Matters Statement

Our children are on the Medically Fragile and Technology Dependent or MFTD waiver, which is a Medicaid program that allows about 500 children to live at home instead of in institutions. They receive nursing care at home at 1/3 the cost of hospital care.

Thirty years ago children like ours lived in hospitals. Then a little girl named Katie Beckett changed things. She, like many of our children, required a ventilator. She lived in a hospital for three years because Medicaid would not pay for her care at home, even though it was cheaper. Because of Katie, Medicaid waivers were created, and there are now over one million children and adults living at home instead of in institutions.

Katie lived a full life, graduating college, getting a job. Sadly, she passed away on May 18 at age 34. Kathleen Sebelius, Secretary of Health and Human Services, called her, “an inadvertent pioneer in the civil rights movement for people with disabilities.”

How did Illinois respond to the passing of this civil rights pioneer? The day before her memorial, legislators gutted the MFTD Waiver. A new low for a state that already ranks 48th because it institutionalizes so many people.¹

You may have heard this only impacts “wealthy” families, but legislative cuts and HFS administrative actions threaten to institutionalize children of all income levels.² This will hit the sickest, most fragile children the hardest. Nursing care hours may be eliminated or cut in half. See our website <http://www.SaveMFTDWaiver.com> for the details.

And what was the point of these cuts? Supposedly to save \$15 million.³ But this doesn't account for increases in costs from institutionalization. Recently Director Hamos conceded that the number is inaccurate.⁴ Will we have to hospitalize our children because legislators were given sloppy guesstimates?

We need your help. We don't have lobbyists. Children can't vote. There aren't many of us. The state won't even share its plans with us. We're easy targets.

Just as Katie Beckett opened the door to home care for so many, we stand with you to advance the rights of people with disabilities of all ages and needs.

Help us Save the Waiver! Let's keep our kids at home where they belong. Thank you.

¹ http://www.ucp.org/the-case-for-inclusion/2011/state_scorecards.html

² <http://savemftdwaiver.com/issues.html>

³ <http://www2.illinois.gov/gov/Documents/Medicaid/Medicaid%20Spending%20Reductions.pdf#42>

⁴ <http://savemftdwaiver.com/downloads.html> video at 1:22:30.

MFTD Waiver Fact Sheet

What is the MFTD Waiver?

The Medically Fragile and Technology Dependent Waiver (MFTD Waiver) is one of Illinois' home and community based services waivers. It is a Medicaid program that the federal government has granted to the state of Illinois to prevent costly institutionalization and permanent hospitalization of children with catastrophic medical conditions and expenses. It is called a "waiver" because it waives standard Medicaid rules by evaluating only the child's income when calculating eligibility. Without a waiver, children are eligible for Medicaid only while living in an institution/hospital, but not once they return home unless their family qualifies financially for Medicaid. Virtually every state has some form of this program.

Who uses this program?

Most children on this waiver are ventilator-dependent, have tracheostomies, or have central IV lines, and require extensive care and services. Most waiver expenses are used to provide home nursing care for these children, which is typically not covered by private insurance. Without this waiver, 95% of these children would require permanent hospitalization to receive their care. The capacity of the waiver is 700 children, and at any time there are approximately 500 children in the program.

How does the MFTD Waiver save money?

If these children cannot be cared for at home, 95% would require permanent institutionalization in a hospital. The average cost for hospitalization in a pediatric hospital is \$55,000 per month, while the average cost for children on the waiver cared for at home is \$15,684 per month. It costs THREE TIMES AS MUCH to hospitalize or institutionalize these children as it does to care for them at home! Only 23 children would need to be permanently hospitalized to erase the \$15 million Governor Quinn hopes to cut from the program's budget.

The cost per child on the waiver has remained virtually flat over the past ten years when adjusted for inflation. In fact, the cost per person has decreased 7% compared to 2000. Because there can never be more than 700 children in the program, costs will never increase dramatically. This program contains costs dramatically for this population and has been fiscally responsible year after year.

Why is this program necessary?

Private insurance does not cover home nursing in most cases, and children from working and middle class families are only eligible for Medicaid if they live in an institution or hospital. This program allows these children to receive nursing care at home, dramatically lowering their expenses to the state. Families in this program would otherwise have to pay out-of-pocket for nursing care and other services currently covered by the waiver, which average \$188,210 per year. Obviously, most families in Illinois are unable to pay such a high amount out-of-pocket each year.

Without the Waiver, children are eligible for Medicaid only if they live in an institution or a hospital. They lose their eligibility if they want to live at home unless their family qualifies financially for Medicaid. Currently, a family of 4 must earn less than \$34,575 to qualify for Medicaid (without buying in). Families may buy-in to Medicaid for their children if their income is under \$69,150 and they don't have private insurance.

It is impossible for a family who earns between \$69,150 and \$200,000 a year to pay the \$188,210 per year for nursing care and other services, which is the average cost per child on the MFTD Waiver.

What would happen if the MFTD Waiver is eliminated or restructured?

The only options for families whose children lose the MFTD Waiver are:

- Permanently hospitalize their child, so the child then becomes Medicaid-eligible. This option would cost the state at least three times as much per child (\$55,000/month in the hospital and \$15,684/month at home). The entire burden of the child's care--90% of which may have been paid by private insurance previously--falls on Medicaid.

- Quit their jobs or reduce work hours to financially qualify for Medicaid. This would likely mean the entire family would lose their private insurance, and the entire family would become fully dependent on Medicaid, and potentially other state benefits as well.
- Give up custody of their child to DCFS. Because most of these children are so medically fragile, most would end up hospitalized or in institutions. The entire cost of the child's care would need to be shouldered by the state.

If these children are permanently hospitalized, they will take up a large number of ICU beds, especially in the Chicago area. These beds would be unavailable to children who are acutely ill, leading to a critical shortage of ICU beds.

Even if the Waiver is eliminated, many of these children will still need one-to-one nursing to attend school, and schools are mandated to provide this service. In this instance, local school districts would be responsible for paying the entire cost of nursing per child--about \$50,000 per child.

These children WILL end up on Medicaid, one way or another. It is better to continue the current program, which has the lowest price tag.

What is Illinois' legal obligation to these children?

Waivers are optional programs, so the state is not required to offer them. However, multiple laws and legal decisions, including the Americans with Disabilities Act, the Supreme Court decision *Olmstead vs. L.C.* (1999), and the Affordable Care Act, support the right of citizens to be cared for at home and not in institutions. Any policy change that increases institutionalization, such as eliminating this waiver, is subject to legal redress.

What is Illinois' proposal for this program?

Initially, the Department of Healthcare and Family Services (HFS) recommended eliminating the waiver. Thanks to our advocacy efforts, the state is in the process of renewing the MFTD Waiver, but with significant cuts that effectively gut the program.

In May, the Illinois legislature passed SB 2840, the "SMART" Act, which states the waiver will be limited to families who earn less than 500% federal poverty line (\$95,450/family of three) and imposes exorbitant copays on every hour of nursing care received. About 50 families will be cut out of the program and will likely end up hospitalized at three times the cost of home care. Many other families will be unable to afford the exorbitant copays and may have to institutionalize their children as a result.

On June 5 the state submitted its plan for the waiver to the federal government. This plan limits eligibility to children with a nursing facility level of care, even though 99% of children currently in the waiver are too fragile to live in a nursing facility and have a hospital level of care. Under this plan, the state could eliminate all children with a hospital level of care from the program. If these children remain eligible, they will likely see a 50% reduction in nursing care hours.

Timeline

February 10, 2012

Julie Hamos, Director of Healthcare and Family Services (HFS), announces that HFS will not recommend renewing the MFTD Waiver at a public stakeholder meeting.

May 24, 2012

The Illinois Legislature passes the SMART Act, which preserves the MFTD Waiver, but places an income cap and high copays on the program. This Act also removes a guarantee to provide home and community based services to all Illinois children with disabilities who require an institutional level of care.

June 5, 2012

HFS submits its application to the Centers for Medicare and Medicaid Services, the federal agency that oversees Medicaid. This application includes many changes to the program, such as eliminating “Hospital” level of care, adding Personal Assistance Services, and eliminating Respite.

June 14, 2012

Governor Pat Quinn signs the SMART Act into law.

July 9, 2012

Class action lawsuit filed on behalf of all current children in the MFTD Waiver.

July 11, 2012

Stakeholder meeting with Director Julie Hamos of the Department of Healthcare and Family Services leaves more questions than answers.

July 16, 2012

State agrees to a request by the federal government to delay changes to the waiver for 3 months. The current program will likely stand until November 29, 2012.

Primary Issues with the Proposed New Program

Elimination of the Hospital level of care

Currently, 99% of children in the program would require care in a hospital without the MFTD Waiver. The state plans on eliminating Hospital level of care from the new program, which has the potential to make 99% of children ineligible for the MFTD Waiver. If children do remain eligible, this change would likely reduce the quantity of nursing hours children receive by up to 50%. For more information, see <http://savemftdwaiver.com/LOC.html>

Exorbitant and misdirected copays

Copays would be imposed on every hour of nursing care for families earning as little as \$28,000 until they have paid 5% of their income in copays. Institutional care, however, would be free of copays. These copays will devastate low-income families, and many will be unable to pay, forcing institutionalization.

Use of unskilled/unqualified providers

The state has estimated 75% of children in the program will be cared for by unlicensed and unqualified personal assistants instead of nurses. Care from unlicensed staff will be free of copays, creating an incentive for unsafe and inappropriate care. Currently, it is illegal in Illinois for personal assistants to provide the required ventilator, tracheostomy, central IV line, and feeding tube care these children require.

Income caps

The state has restricted the program to families earning less than 500% federal poverty line, even though a family of three at this income (\$95,450) would have to pay 246% of their after-tax income to cover the average cost of care (\$188,210). These families will either have to quit their jobs or hospitalize their children.

Level of Care Fact Sheet

Children with disabilities have such high care needs that they are at risk of being institutionalized, and the state is required to pay for their costs in institutions according to Social Security Administration rules. Depending on their level of need, children could end up in an Intermediate Care Facility, Nursing Facility, or Hospital if they cannot be cared for at home. When states offer home and community based services as an alternative to institutionalization, whichever type of facility a child would require if he/she could not receive care at home becomes the “alternate placement” and the designated “level of care.”

Level of Care	Where Defined in Federal Code	Type of Care	Cost per Month in Institution	Max Home Nursing Hours to be Cost Neutral
Intermediate Care Facility	42 CFR §440.150	Non-medical care for individuals with cognitive, mental and/or development disabilities	\$7880	7.6 hours per day
Nursing Facility	42 CFR §440.155	Care for individuals who require daily medical care but do not need intensive monitoring or constant care	\$9406	9.1 hours per day
Hospital	42 CFR §440.10	Care for individuals requiring constant, intensive monitoring and ongoing medical care, such as children with trach, vent, central IV line, or medical instability	\$40,000-\$56,000	24 hours per day

In Illinois, the Medically Fragile Technology Dependent (MFTD) Waiver currently serves children who were designated as having a Hospital level of care OR a Nursing Facility level of care, though 99% of participants in 2010 had a Hospital level of care. Most children have tracheostomies, ventilators, or central IV lines. All Hospital level of care children need constant monitoring of their life support equipment at all times.

The level of care is critical because it essentially sets a cap on the amount of services that can be delivered, either in the aggregate for the whole program or at the individual level. All waiver programs must be cost-neutral, which means it has to cost a state less to keep the children in the program at home than it would cost to keep the children in whatever type of institution--Intermediate Care Facility (\$7880/month), Nursing Facility (\$9406/month), or Hospital (\$40,000-\$56,000/month)--the children would require.

The federal government mandates that all waiver programs must be cost-neutral on an aggregate basis, which means that the average cost per child in the program must be less than the average cost of institutionalization.

States are given the **OPTION** of whether they also want to impose an individual cost limit on individual children. In Appendix B-2 of every waiver application, states may choose to have no individual cost limit or an individual cost limit that is based off of institutional care costs. **Illinois has always chosen to include an individual cost limit in the past, and did so in the “draft” application for the proposed MFTD Waiver that was submitted to the federal government on June 5, 2012.**

Illinois completes an individual cost neutrality assessment for all children in the waiver on a regular basis to ensure they are still eligible. Here is an example of one Hospital level of care child’s individual cost neutrality statement:

V. Cost Comparison Analysis

Institutional	\$ 55,967.13
Home Care	\$ 24,925.96
Potential Difference	\$ 31,041.17

Take a look at the line labeled “Institutional Care,” which in this case lists the cost of a Hospital, \$55,967.13. Under the state's proposal to only use a Nursing Facility level of care, that number would be capped at \$9406 (and perhaps up to \$14,785 to account for other incidental costs) instead of the current figure of \$40,000-\$56,000, which is the cost of care in the hospital of discharge in most cases.

Currently, this child could receive up to \$55,967.13 in home nursing care, which is far more than 24 hours a day (though the state never grants this much care, even when needed), and still be eligible for the program. But if the Institutional facility cost is restricted to \$9406, this child could only have a maximum of 9 hours daily of nursing care in order to stay under the \$9406 cost limit. If the doctor says the child needs more hours to remain home safely, the state can “refuse entrance” to the waiver, effectively forcing institutionalization on the child.

The state has repeatedly said that the level of care comparison is only being calculated in the aggregate, and not on an individual basis, even though their own federally submitted application contradicts this statement. For the sake of argument, we will hypothesize that the state drops the individual cost neutrality requirement and only looks at the hours in the aggregate. If so, they can give one child 12 hours a day instead of 9 hours. But that means that another child would have to get 6 hours instead of 9 to keep the average at 9 hours a day.

If the level of care is calculated individually, 99% of kids in the program are no longer eligible for the waiver due to the change to a Nursing Facility level of care. Their monthly costs exceed the \$9406 monthly facility cost of a Nursing Facility, as shown in the example above. If it is calculated in aggregate, families would be limited to an average of 9 hours of nursing per day. This is not enough hours for children who require constant monitoring. Most of these children need 24/7 nursing care, but the state already restricts most to 12-16 hours per day, and pays the nurses so little it is hard to even find nurses willing to cover those hours. To reduce hours even further will result in institutionalization or force families to use the “option” of unlicensed personal care attendants who are not qualified to provide a Hospital level of care.

For the full document on this subject, visit <http://savemftdwaiver.com/LOC.html>.

Income Caps Fact Sheet

How much would YOU need to earn in order to pay \$188,210 out-of-pocket for nursing care?

- The SMART Act includes a provision that creates an income cap for the Medically Fragile Technology Dependent (MFTD) Waiver. This income cap would be 500% of the federal poverty line (FPL), or \$95,450 for a family of three.
- The average cost per child in this program is \$188,210. That means that without this program, the average family would have to pay \$188,210 out-of-pocket in order to keep their child at home. Private insurance does not cover or severely restricts private duty nursing care.
- Families would have to pay 200% of their annual income to keep their children at home. It is mathematically impossible for a family of three who earns \$95,450 (500% FPL) to pay \$188,210 out-of-pocket. Even a family who earns double that amount—1000% FPL—could not pay that amount out-of-pocket.
- Children who no longer have access to the MFTD Waiver will need to be hospitalized permanently at three times the cost of home care. This greater amount would still be billed to Medicaid because the federal government mandates Medicaid eligibility for children in institutions. The MFTD Waiver was created for exactly this reason more than 30 years ago—to reduce costs by keeping kids out of hospitals and institutions.
- If only 23 children end up hospitalized permanently, they would erase the entire \$15 million in anticipated savings the state hopes to gain by altering this program.
- This income cap would effectively force children into institutions and hospitals, which is counter to the Americans with Disabilities Act as interpreted by the *Olmstead* Supreme Court Case. Illinois would open itself up to costly litigation on this matter.
- Illinois does not impose income caps on families who choose to place their children in institutions or hospitals, even if they are millionaires, nor on children with developmental disabilities or autism. Only children who require nursing care and whose families make the effort to keep them at home—saving the state money—are being singled out in this way.
- Not one other state has ever imposed an income cap on children with medical technology. This change is unprecedented and returns Illinois to an era when children with disabilities were forced out of their communities and taken from their families.

History of Waivers (Federal)

In 1981, then-president Ronald Reagan highlighted the case of a young girl named Katie Beckett. Katie was on a ventilator and remained in the hospital because Medicaid would pay for her care while in the hospital but she became ineligible for Medicaid if she went home. As Reagan stated,

Now, it would cost \$1,000 a month for her particular ailment to send her home. Her parents have no way that they can afford that, and the regulations are such that Medicaid now cannot pay for that if she goes home. The alternative is Medicaid continues to pay \$6,000 a month to keep her in a hospital, when the doctors say she would receive better treatment and be better off at home. But her parents can't afford to have her taken off Medicaid.

Recognizing that changing regulations would save the government money, Congress passed a provision in the 1982 TEFRA legislation that gave states the option of qualifying additional children for Medicaid if they met standard SSI criteria for disability.

Around the same time, Congress passed Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981 (PL 97-35), which permitted Home and Community Based Services (HCBS) waivers, also called 1915(c) waivers for the first time. This legislation allowed certain Medicaid rules to be waived, permitting states to offer Medicaid coverage targeted to individuals in certain parts of the state, of specific economic levels, or in specific types of groups, such as children who are medically fragile.

The primary goal of both of these pieces of legislation was to remove people with disabilities from institutional care by providing less costly home care services in a community setting.

Since this time, additional legislation has further supported the right of individuals with disabilities to remain in community settings. The Americans with Disabilities Act, passed in 1990, specifies that individuals must receive services, “in the most integrated setting appropriate.” The Supreme Court decision in *Olmstead vs. L.C.* (1999) clarified that people with disabilities should be placed in community settings when appropriate, if this can be accomplished with available resources. It also mandates that states provide community services to any individuals on waiting lists in a reasonably expeditious manner. Finally, as of October 1, 2011, a provision of the Affordable Care Act put into effect the Community First Choice Option, which provides increased support and funding for moving individuals out of institutions and into the community. This legislation is designed to fund the mandate of community care created by the Americans with Disabilities Act and clarified by the *Olmstead* decision.

Originally, TEFRA waivers, which are often called Katie Beckett waivers, were intended for children with extreme medical complexity and catastrophic medical costs, while HCBS waivers focused on individuals with cognitive impairment or developmental disabilities. Over time, approximately half of the states continued to use TEFRA or TEFRA-like waivers for children with medical complexity, while the other half developed new HCBS waivers targeting this population. TEFRA waivers, when implemented by the states, are required to serve all children who meet medical eligibility criteria, and only extend regular Medicaid services to this population. HCBS waivers, on the other hand, are not entitlements and can restrict the number of children served, but they may also provide additional services not covered by Medicaid, such as home modification and respite. Currently, almost all states have some type of program for this population, with about 40% of states offering Medicaid through TEFRA, about 60% offering HCBS waivers, and a few offering TEFRA-like or other unique programs.