

# **MFTD Waiver Background Information Packet**

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**Please refer to our website, <http://www.SaveMFTDWaiver.com>, for more detailed information, as well as photos, videos, and blog posts.**

**A list of our sources is available at <http://savemftdwaiver.com/sources.html>**

## **Current Status of the MFTD Waiver**

As of 5/24/2012, both Governor Pat Quinn and the Illinois legislature have indicated they will renew the MFTD Waiver, but with a massive \$15 million budget cut that includes limiting financial and medical eligibility and imposing premiums and copays.

Today House amendment 4 to SB 2840 was filed, which continues to state that the MFTD Waiver will be limited to families with incomes less than 500% federal poverty line. Unfortunately, because of the high cost of home nursing care, it is mathematically impossible for families under 1300% federal poverty line to pay out-of-pocket for their child's nursing care. The average cost per child is \$188,210, and a family with an income of \$95,450 (500% FPL for a family of three) would have to pay nearly 200% of their income to keep their child at home.

This eligibility change will result in as many as a hundred children losing their home nursing care. These children will need to be hospitalized permanently, at three times the cost of home care.

Additional changes in this proposed amendment include exorbitant copays and premiums for every hour of nursing care received. Another provision would strike down a current state law that guarantees home and community based services through Medicaid for children under age 21. Eliminating this provision could potentially force all the children in the MFTD Waiver, children with autism and developmental disabilities in the Children's Support and Residential Waivers, and all individuals with disabilities between 18 and 21 receiving state-funded services back into institutions and hospitals.

# **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 and creating a state program that would provide home nursing care for children who don't qualify financially for Medicaid. Thanks to our advocacy efforts, Governor Quinn has suggested renewing the program, but with a \$15 million budget cut.

Our most recent information comes from an to SB 2840, which states the waiver would be limited to families who earn less than 500% federal poverty line (\$95,450/family of three) and would impose exorbitant copays and premiums on every hour of nursing care received. If this amendment goes through, hundreds of children would be cut out of the program and would end up hospitalized at three times the cost of home care. Many other families would be unable to afford the exorbitant copays and premiums and would lose eligibility and services as well.

## 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 (proposed amendment to SB 2840) includes a provision that would create 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.

## **History of Illinois MFTD Waiver**

In Illinois, the Division of Specialized Care for Children (DSCC) began its home care program in 1979, when the first Illinois child on a ventilator was discharged into the home setting. By 1983, eleven children on ventilators received care through a three year grant from the Division of Maternal and Child Health. This increased to 73 children by 1986, served through a Title XIX waiver administered by DSCC on behalf of the Department of Public Aid and the University of Illinois. In 1994, Illinois continued its program through a 1915(c) waiver serving children who are both medically fragile and technology dependent.

The Medically Fragile and Technology Dependent Waiver (MFTD Waiver) is a home and community based services waiver, also called a 1915(c) waiver. It is a Medicaid program that the federal government had 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. Otherwise, children are eligible for Medicaid while living in an institution/hospital, but not once they return home unless their family qualifies financially for Medicaid.

Most children on this waiver are ventilator-dependent, have tracheostomies, or have central IV lines, and require extensive care and services. Without this waiver, 95% of these children would require permanent hospitalization to receive their care. The remaining 5% could be cared for in a skilled nursing facility. Children who have private insurance only receive supplemental Medicaid coverage to cover expenses their private insurance does not pay for, while uninsured children can receive full coverage.

Children throughout the state are eligible for the waiver as long as they are under 21, meet medical eligibility, require ongoing home nursing, can safely be cared for at home, and the cost of care is less than it would be in a hospital or skilled nursing facility. 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. In other words, it is three times cheaper to care for these children at home than in hospitals and institutions.

Currently, the capacity of the waiver is 700 children, with 666 of these spots designated for children who require a hospital level of care. As of May 1, 2011, there were 498 active children on the waiver. The average cost per child in fiscal year 2010 was \$188,210 per year.

## Selected Waiver Myths

more available at <http://www.SaveMFTDWaiver.com/myths.html>

**Myth: The state can save money by requiring high levels of cost sharing**

**Truth: Cost sharing, by HFS' own admission, raises minimal revenue. Studies have shown that cost-sharing also leads to worsened health care outcomes.**

The state itself acknowledges this would not raise money in a 1/24/12 Children with Complex Medical Needs Workgroup. Idaho only raised \$114,000 from cost sharing, and their program has four times the number of children in it. Wisconsin raised about \$300,000 in 2007 from ALL of its programs combined.

Counterintuitively, cost sharing can actually cost the state more money.

Here's the math. Let's say that 200 families are subject to cost-sharing, and their average income is \$80,000. The state potentially could raise \$800,000 if each family paid 5% of their income, which, incidentally, is far more than the "nominal" percentage of three states that use cost-sharing (Maine, Arkansas, and Nevada) charge. But cost sharing dollars are not matched by the federal government, meaning that if Illinois had instead paid half that amount, \$400,000, they would have received \$400,000 back from the federal government (assuming a 50% federal match).

Thus, by taxing these families, the state LOSES \$400,000 in federal dollars, meaning they only end up making half the expected amount from cost sharing. Add in the cost of collecting payments, and pursuing families who do not pay through collections, and most of the revenue simply disappears.

Moreover, if just a few children are hospitalized because they sacrifice necessary medical care to avoid cost-sharing, the expected benefits of cost-sharing would disappear entirely.

Any cost sharing that must be adopted for political purposes should be applied equally to families of children living at home and children who are institutionalized for fairness. In addition, the state cannot single out one population, such as children who receive home nursing, and be in compliance with the *Olmstead* decision.

**Myth: Families earning 500% of the federal poverty line (\$95,450 for a family of three) or more are wealthy enough to afford home nursing care themselves**

**Truth: The cost of caring for these kids is more than most families can afford.**

The math is simple: the average cost of a child on the waiver is \$188,210. A family who earns \$95,450 a year cannot afford to pay \$188,210 a year out-of-pocket for nursing care. Even a family who earns twice this amount could not afford nursing care.

A family would have to earn \$300,000 or more to be able to afford home nursing out-of-pocket for most of these kids.

The state has proposed cost sharing within this program, and hopes to raise \$5.1 million from it. If only families over 300% paid in, the average family would have to pay \$51,000 a year. They are asking a family who earns \$70,000 to contribute 73% of their income for nursing care! Obviously, virtually all families would be unable to afford these amounts.

**Myth: Families can just get private insurance to cover these expenses**

**Truth: Private insurance does not cover nursing care in most instances.**

Very few insurance companies cover nursing care at all.

When nursing care is covered, it is typically limited by a maximum dollar amount or number of hours, which rarely covers more than a few days of nursing per year. For example, a plan may only cover 320 hours of nursing--roughly the equivalent of three weeks of care for many of these children. Or a plan may only cover \$1000 of nursing care per month, which may only add up to one to two days a month.

Illinois does not mandate private insurers operating within the state to cover home nursing. The state could save a tremendous amount of money by passing this simple requirement. The state actually sued Blue Cross Blue Shield on behalf of the MFTD Waiver for failure to cover home nursing--and won \$25 million in a settlement--but still does not legally require Blue Cross Blue Shield or any other insurer to cover home nursing.

All children on the waiver who have private insurance ALWAYS have the private insurance as the primary payor. Medicaid is ONLY billed if private insurance denies a claim, only pays a portion, or does not cover a service.

**Myth: "Wealthy" families are getting completely free health care through this program**

**Truth: Their children are considered medically needy, and in most cases are severely underinsured by private insurance, due to lax insurance regulations.**

Illinois has the highest rate of underinsurance for children with special needs in the country, with 38% of children considered underinsured.

In addition, these families have extensive out-of-pocket costs that neither insurance nor Medicaid covers, often totaling as much as \$10,000 to \$30,000 a year, including:

- Insurance premiums
- Uncovered disposable supplies, such as gauze, betadine, surgilube, etc.
- Physician-prescribed OTC medicines and supplements
- Specialized equipment for visual and hearing impairments
- Medical equipment, such as medical strollers, adapted car seats, or positioning chairs
- Wheelchair van purchase
- Noncovered home modifications
- Assistive devices, such as communication devices, switches, computers, and software
- Specialty therapy visits, such as respiratory physical therapy or communication therapy
- Special education costs
- Special needs trusts and other legal fees
- Travel and lodging for frequent medical visits
- Increased utility costs for medical equipment, typically \$100/month

**Myth: The waiver is a "cadillac plan"**

**Truth: Most of these families are struggling on a daily basis to meet the uncovered needs of their children, due to unfilled nursing shifts, difficulties navigating the system, and financial, educational, medical and legal problems.**

Only 60% of allotted nursing hours are actually provided. While some of these hours are not used due to hospitalization, the vast majority remain unfilled because nurses cannot be found to staff the cases. Nurses who work in home care earn about \$10/hour less than nurses in hospitals or outpatient facilities.

It is routine for families to have periods of 48 consecutive hours with no nursing, meaning a parent must stay awake for two days straight to care for the child. This happens frequently on weekends and holidays.



Some of these children are so medically complex that they cannot leave home, meaning a parent cannot even run an errand, go to the pharmacy, attend a school event for a sibling, or even get a cup of coffee when a nurse is not available to watch the child. Many parents have not had a night out or vacation in years.

Nurse turnover is frequent and replacement is not guaranteed. Many nurses call in sick at the last minute and typically no replacement is available.

Families must spend hours per day navigating the system, dealing with equipment providers, durable medical equipment companies, home health agencies, nursing agencies, therapists, schools, pharmacies, and insurance companies, while also coordinating their child's care.

Studies show that most of these families are struggling financially, emotionally, and physically on a daily basis just to get by. Caregivers have higher rates of physical injuries directly related to caregiving, financial troubles, and mental health disorders, including depression and PTSD.

**Myth: Letting the waiver expire will save the state money**

**Truth: If the waiver is eliminated, many children will have no alternative but to live permanently in hospitals, and it costs three times as much to care for these children in hospitals! They can be cared for at home for \$15,684 a month, but it costs \$55,000 to care for them in a pediatric hospital. If only 30 (6%) children are placed in hospitals, the entire \$19 million anticipated budgetary savings will be erased.**

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

**Permanently hospitalize their child, so the child then becomes Medicaid-eligible.** The state itself has said 95% of children on the waiver are too medically involved to go to a skilled nursing facility and must live in a hospital. Children become eligible for Medicaid under federal law if they are institutionalized in a hospital.

**Quit their jobs or reduce work hours to financially qualify for Medicaid.** If nursing care is taken away, parents will have to stop working to take care of their children, which will then qualify the entire family for Medicaid, but now without private insurance paying a large portion of the child's bills. In addition, there will be less tax dollars generated if parents quit their jobs. Eliminating the waiver creates a disincentive to work and maintain private insurance coverage.

**Give up custody of their child to DCFS.** 1 in 6 kids who receive home nursing in Illinois are already in DCFS. Children who receive home nursing are 34 times more likely to be in DCFS than the general population of children in Illinois. Eliminating the waiver will make this problem even worse. Because most of these children are so medically fragile, most would end up hospitalized or in institutions. Those that can be placed in foster homes typically receive substantially more nursing hours and other services than they would with their biological parents. The entire cost of the child's care--medical and otherwise--would need to be shouldered by the state.

A large percentage of kids on the waiver qualify for Medicaid financially, and their home nursing costs will not decrease with the elimination of the waiver.

Illinois will lose much of the \$30 million in federal matching dollars it receives specifically for this program if it is eliminated.

Most of these children still require a nurse 40 hours per week to attend school, which is federally mandated by *Cedar Rapids Community School District v. Garret F.* If this nursing is not covered or billable through Medicaid any longer, the cost will fall completely on local school districts, who cannot receive federal matching Medicaid dollars for nursing. Just one child easily will cost a local school district \$50,000 per year.

# Cost Cutting Strategies Suggested by Families

## 1. Eliminate the Respite nursing component and instead replace it with a Flexible Hours Account that would allow families to use any unused hours as needed.

Current estimated cost of respite if all hours are used: \$5,712,000  
(336 hours per child multiplied by 500 children at an average rate of \$34/hour)

**Potential Savings: \$3,103,200**

(assumes 60% of hours are used, which is the standard percentage of total nursing hours used currently)

## 2. Allow families to elect to have 0-25% of their child's hours replaced by homemaker services. A trained caregiver (parent or guardian) would need to be in the home to care for the child's medical needs while homemaker services are provided.

Current estimated cost of 25% of nursing care hours: \$15,819,582  
Estimated cost if all families chose this option: \$6,979,227  
Estimated cost if half the families chose this option: \$11,399,405  
(Total cost of nursing care \$15,819,582 divided by average cost of \$34/hour and then multiplied by the average cost of homemaker services at \$15/hour.)

**Potential Savings if all families chose this option: \$8,840,355**

**Potential savings if 50% of families chose this option: \$4,420,177**

## 3. Rapid transition of children who are no longer eligible for waiver services off of the waiver, within three months of losing eligibility. Gradually reduce nursing hours by 25% the first month, 50% the second month, and 75% the third month.

**Potential savings by reducing hours: \$510,310**

**Potential savings by ensuring children are removed from the waiver promptly: \$1,020,620**

(Assumes 40 children leaving the waiver at an average nursing care cost of \$102,062 per year, reduced by 50% over three months. Assumes these 40 children would otherwise remain in the program for six months after losing eligibility.)

## 4. Reduce hospitalizations by 20% through a series of strategies:

- Use of telemedicine (cost=\$200,000 for four telemedicine nurses, with an additional one-time expense of \$500,000 for equipment)
- Targeted increases in nursing when needed (cost=\$360,000 for 20 emergency hours at 36/hour for 500 children)
- Purchase of private employer-based health insurance plans for families who cannot afford them (cost=\$240,000 for 20 families at \$1000/month)
- Improved care coordination (cost=\$250,000)

Potential savings: \$5,963,356

Potential increased cost: \$1,550,000

**Net savings: \$4,413,356**

**5. Stratify payment based on need of the child. Children would be grouped into 4 categories based on need, and paid the same rate, regardless of what type of nurse was staffing the case. This would encourage the use of LPNs for simpler cases. Children would also receive a particular number of hours based on their group.**

- Group 1: Stable children with lower levels of technology \$32/hour, 28-56 hrs/week
- Group 2: Children with tracheostomies and moderate levels of need \$34/hour, 56-84 hrs/week
- Group 3: All children with central lines or on ventilators \$36/hour, maximum of 70-112 hrs/week
- Group 4: Select group of children with extreme needs, \$38/hour, maximum of 84-140 hrs/week

**Potential savings: \$7,001,560**

Assumes 50 children in Group 1, 200 children in Group 2, 200 children in Group 3, and 50 children in Group 4, and assuming only 60% of shifts continue to be filled. Compares them to a group of 500 children at \$102,062 each.

**6. Use of electronic medical records, increasing care coordination, and reducing costs for mailing and paperwork.**

**Potential savings: \$250,000**

**7. Oversight of durable medical equipment companies, with strict guidelines on rental payments, such as rental to purchase price. Also pilot a program for reuse of Medicaid-purchased items, including wheelchairs, standers, lifts, etc. Goal would be to reduce DME and supply costs by 30%.**

**Potential savings: \$2,492,763**

**TOTAL POTENTIAL SAVINGS: \$27,632,164**

# Family Stories

## LY's Story

LY is a four-year-old brilliant and amazing little girl with a sense of humor and a lust for knowledge! She is diagnosed with a rare muscle disorder called CFTD and is ventilator dependent, tube fed, and requires assistance for all activities of daily living. She is nonverbal but highly intelligent and has been able to read since she was 2.5 years old.

She has a future that is unknown, yet VERY hopeful! We cannot predict the future for any child; however, if LY does not receive her frequent therapies or her 24/7 care and treatments, she will never reach her full potential.

LY is such a beloved and important part of her family of four. Her parents cannot imagine not having her home with them. Without the waiver she could not live at home because her private insurance won't pay for her nursing. Her family is so thankful for her home nursing care through the waiver.

## KM's Story

KM is a second-grader who gets good grades, is on the honor roll, loves animals and loves to go to the zoo. She has a tracheostomy and uses a ventilator to breathe due to an extremely rare syndrome called Rapid-onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation, more commonly known as ROHHAD. This syndrome causes major medical issues in many parts of her system. She has balance complications, temperature regulation problems, and some vision difficulties. But the most dangerous part is that her body may "forget" to breath. KM's brain does not recognize a lack of oxygen or build up of carbon dioxide until it's too late and she's stopped breathing.

KM's nursing care keeps her healthy and out of the hospital. For example, her nurses are able to recognize infections very quickly, and can intervene by altering her ventilator settings and give her medications. She has avoided numerous hospitalizations due to the diligent care she receives from her nurses.

Without the MFTD Waiver, KM would have to live in a hospital, and could not attend school or enjoy her trips to the zoo. She is just a regular kid who happens to have some extra medical equipment. She needs to live in the community with her family who loves her and helps her to thrive.

## Stephanie's Story

Stephanie lived a happy life attached to a ventilator and in a wheelchair. She died at the age of 19 on May 1, 2010.

Stephanie was mainstreamed in school, was on the A honor roll for 4 years in high school, attended events such as dances, sports, and prom, and graduated in 2009. She even won boccia tournaments in Illinois on the state level and then moved on to Nationals. Her dream was to go to college and write children's books. She was well on her way to becoming a productive, independent adult at the time of her death.

Her family was lucky in that they held private insurance for almost 16 years and it paid for private duty nursing 24 hours a day. Unfortunately, Stephanie hit the lifetime maximum of her private insurance plan, and once capped out of insurance, she entered the MFTD Waiver.

Without the Waiver, one or both of her parents probably would have had to quit their jobs. If both parents had quit their jobs, the entire family would have ended up on public assistance, and that would cost the state even more money.

### **Craig's Story**

Craig is a very sweet, curious and loving 9-year-old boy who was born with a type of Muscular Dystrophy. He has a tracheostomy and uses a vent for most of the day. He has a G-tube and uses a cough assist machine and nebulized medications to help keep his lungs clear of infection.

Prior to being on the MFTD Waiver program, Craig was hospitalized 3-4 times per year. In the eight years since coming home on the MFTD Waiver in 2004, he has only spent 4 days in the hospital.

Craig's parents both work and have private insurance, but insurance only pays for 100 hours of nursing per year, which is simply not enough, as Craig needs 24 hours/day nursing level care. His parents do provide 60+ hours a week of his care but they need nurses to care for Craig when they work and sleep. Even with insurance and the MFTD Waiver, they pay for most of his medications and many other supplies he needs on a daily basis out-of-pocket.

Without the MFTD Waiver, one or both of Craig's parents would be forced to quit their jobs and his family would most likely have to depend on state assistance and disability benefits to supplement their income. Alternately, Craig would need to be hospitalized, and would need to be at an ICU level of care, which is very expensive. If hospitalized, all of his expenses would be paid for by Medicaid, which would ultimately cost the state much more money.

### **C's Story**

C is an 8-year-old diagnosed with cerebral palsy, Down syndrome, stroke, hypoxic brain injury, seizures, heart defect, pulmonary hypertension, primary immune disorder, severe lung damage, and reflux/silent aspiration. He has participated in the MFTD Waiver since 2005. He currently uses a pulse oximeter, suction machine, is on oxygen, has a G tube for nutrition and is continuously fed via feeding pump. He requires nursing-level care at all times. Since his medical needs change--sometimes from hour to hour--his family depends on nurses who can assess the situation and act quickly.

C's family is very thankful for the Waiver program. While C's family has a PPO private insurance plan, his family's out-of-pocket expenses per year without the Waiver are more than \$200,000. Before participating in the Waiver program, C's parents had no choice but to divorce and live separately so that C would qualify for a medical card as secondary insurance to pick up the extra expenses not covered by primary insurance. While on the Waiver, C's family has been able to keep him at home and relatively well. Without the Waiver, C's father would either have to leave the home again, or C would need to live in an intensive care unit, running the risk of acquiring hospital-borne infections. Because C is so medically complex, it would cost about six times more money to keep him in the hospital than it does to provide him with nursing care at home.

### **BJ's Story**

BJ is a charming 15-year-old who used the MFTD Waiver for many years. He was born 3 months prematurely with Spina Bifida and an Arnold Chiari Malformation, which compressed his brain stem. After 8 months in the hospital, he went home on a ventilator 24 hours a day, G-tube dependent for nutrition and on numerous medications. He required 24 hour hands-on care because of "blue spells" and apnea episodes when he would stop breathing. He also developed a seizure disorder at 16 months old that required he be monitored constantly.

His family used private insurance for nursing as long as possible and then started using the MFTD waiver when insurance would not cover his nursing. He slowly began to wean off the ventilator during the day but needed it at night for many years. Eventually, he slowly weaned off the ventilator at night as well. This was a very slow and complicated process that his family could not have done without the diligent and compassionate care he received from his home care nurses.

This past summer, he had his trach stoma closed and no longer needs the MFTD waiver for nursing care. He is still medically involved, but is doing great and could have never gotten to where he is without the nursing care he received from the MFTD waiver.

### **KP's Story**

KP is an 8-year-old diagnosed with cerebral palsy and an unnamed progressive disorder. She has participated in the MFTD Waiver since 2006. She currently uses a ventilator, has a central IV line in her chest for nutrition, is on oxygen, has a GJ tube, and has a foley. She requires intensive care level nursing at all times, gets more than 50 doses of medication a day, and requires 6 hours of respiratory treatments each day.

KP's family is incredibly thankful for the Waiver program. She has only had one hospitalization in two and a half years, thanks to the Waiver. While KP's family has a PPO private insurance plan, her family's out-of-pocket expenses per year without the Waiver are more than \$237,000. Without the Waiver, she would need to live in an intensive care unit.

### **RD's Story**

RD is a beautiful, loving, bright little 4-year old girl who was born with a rare life-threatening gastrointestinal illness. This illness is so rare that it does not yet have a name. It results in severe bleeding from the esophagus, stomach and intestines, persistent vomiting and intestinal failure, just to name a few symptoms.

RD has had over 30 hospitalizations to date. She has been on the MFTD Waiver since May of 2011. Since being on the waiver, RD has had only 1 major hospitalization. RD and her family are so grateful for the waiver program as it has allowed them to have some semblance of "normalcy."

Without the waiver program, RD would spend much more time in the hospital where she would be exposed to serious infections. Any sort of infection, even the common cold, causes serious complications for RD, which often become life-threatening.

### **D's Story**

D is a 17-month-old with an undiagnosed neuromuscular disorder. He has paralyzed vocal cords, he is not able to swallow and has other neuromuscular issues. He has a trach, G-tube and uses oxygen when he is sick. He has participated in the MFTD Waiver since 2010 when he came home from the hospital after spending the first 3.5 months of his life in the hospital. We are very thankful for the Waiver program, as it allowed us to bring our son home.

D has only been hospitalized once since he came home from the hospital, and we attribute that to the level of care that we are able to provide for him at home, thanks to the Waiver. The Waiver is a much more cost effective way to provide care for D. The cost for the first 3.5 months of his life in the hospital was over \$650,000. Because of the waiver, his family is able to keep their jobs and primary PPO insurance. Without the Waiver, D would have to live in a hospital.

## Family Quotes

If we are to lose the waiver program because of shortsighted and economically unsound political mismanagement, many families will be unable to care for their profoundly complex children. These children are better in their parents' care and will be more likely to reach their full potential and possibly find independence. Can you imagine having your child taken away from YOU?? These children have no voice!  
*MY, parent of a child on the waiver*

Losing the waiver would mean that my children would not be together. That our family would essentially be torn apart. My marriage, my own health and my children's health would all suffer dearly. It would be catastrophic.  
*LD, parent of a child on the waiver*

If we didn't have the Waiver program, my husband and I would have moved heaven and earth to make sure that our daughter was able to stay home, go to school and do what she was supposed to do...to be a kid. I don't know how we would have survived. I just know that my daughter would not live in a hospital or an institution. She belonged at home, as all our children do.  
*KB, parent of a child who previously was on the waiver*

Losing the MFTD waiver wouldn't make KA any less medically fragile, or technologically dependent. It would only serve to tear our close knit family apart, forcing us to place her in a hospital setting in order to receive the care that she would need. At home, with her 3 sisters who all adore her, or in her special preschool where her friends all love her, she thrives. To lose the waiver would be to lose our daughter-- we've fought WAY too hard for the 3 years of her life to keep her here with us to give up now!  
*TA, parent of a child on the waiver*

Losing the waiver would financially devastate our family and risk the health of our son. Just having open spots in our schedule when we don't have nursing causes financial, emotional, and health issues for us. Only, we know that usually we will have the opportunity for rest when the next nurse comes in, even if we have to wait 24 hours. Without the waiver, we would not have that EVER and I can't even imagine never having that rest.  
*HT, parent of a child on the waiver*

Losing the waiver would mean my child would not only lose his freedom, but he would also lose his education without a nurse to take care of him at school. We would lose everything we have gained over the last 12 years.  
*KB, parent of a child on the waiver*

Losing the waiver would mean that my daughter would spend much more time in the hospital. It would mean that I would never sleep at night, causing an enormous amount of stress within our family and our marriage. It would also mean that we would go back to spending \$3000 a month on medical supplies, go in even more debt and possibly lose our home. Even though my husband is wonderful, I can't imagine my marriage surviving through it. I also don't know if my daughter would survive.  
*PD, parent of a child on the waiver*

Losing the waiver would mean my child would have to live in the ICU for the rest of her life. She would probably die within months because hospitals simply cannot provide the same level of care as we can at home. I can't imagine what her last months would be like, alone in a hospital, away from her family who loves and adores her. It would tear us all apart.  
*SA, parent of a child on the waiver*