MFTD Waiver Families
www.SaveMFTDWaiver.com
mftdwaiver@gmail.com

Cost Cutting Strategies for Children with Complex Medical Needs

As parents and guardians of children with complex medical needs who participate in the Medically Fragile Technology Dependent (MFTD) Waiver, we know our kids are expensive. They are expensive to us, and expensive to the state.

But we have also seen first hand how many inefficiencies exist within the system. We see waste in this program on a daily basis. As insiders, we know where money can be saved. We also have many innovative ideas, some borrowed from successful programs in other states, on ways we can improve this program while also saving money.

We would be delighted to work together to help redesign and strengthen the MFTD Waiver, so that children continue to receive exceptional care within their homes, while also saving Illinois money.

We have included the following potential strategies for savings in this document:

proposal	**potential savings per year**
Third Party Liability Proposal	$7,870,468
Essential Health Benefit Coverage for Pediatric Private Duty Nursing	$4,082,480
Improved Care Coordination and Reduced Hospitalizations through a Home Visiting Model of Care	$5,963,356
Replace Respite Care Hours with Flexible Hours of Service	$3,103,200
Use of Homemaker Services	$8,840,355
Rapid Transition from the Waiver	$1,530,930
Stratify Payment by Acuity	$7,001,560
Implement Electronic Medical Records	$250,000
Reduce DME Inefficiencies	$2,492,763

TOTAL POTENTIAL SAVINGS OF ALL STRATEGIES: **$41,135,112**

MFTD Waiver Third Party Liability Proposal

Overview

The experience of other states has demonstrated that maximizing third party liability by identifying alternate sources of funding and payment can dramatically reduce costs to Medicaid, especially for high-cost users. For example, a program in Massachusetts provides premium support to individuals to purchase employer-based insurance policies, and saved $194 million in 2010 alone.[1] Another program in the same state targets high-cost users and ensures that private insurance companies are appropriately reimbursing for claims by advocating with insurers on their behalf, saving an additional $50 million annually.[2]

Illinois already has in place a program that assists high-cost users of healthcare to pay their monthly insurance premium, called the Health Insurance Premium Payment (HIPP) program. This program reimburses families for health insurance premiums or directly pays COBRA payments for comprehensive private insurance plans. As long as the cost of the monthly premium is less than the child's monthly costs, the state will save money by maximizing enrollment through private insurance premium payments.

By applying these third party liability techniques to high-cost users, such as children in the MFTD waiver and NPCS PDN programs, Illinois has the potential to save enormous sums of money. While these children require costly private duty nursing, they also tend to be high-cost consumers of more standard forms of health care. They have frequent costly hospital stays, often for weeks or months, that more often than not require a stay in the intensive care unit. They also have numerous primary care and specialist physician visits, frequent surgeries, large numbers of medications, and expensive medical equipment that requires ongoing supplies. 49% of their total state Medicaid plan expenses are for standard health care services, with the remaining 51% of expenses for private duty nursing and other home health services.

In 2010, Illinois spent $77,093,127 on health care services for children in the MFTD Waiver and NPCS PDN programs that could potentially be covered by most standard private insurance plans.[3] This amounts to $81,408 per child per year, and primarily includes costs for inpatient hospital stays, surgery, medications, physician visits, medical equipment and supplies.

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[1] http://chcf.umassmed.edu/services/third-party-liability/premium-assistance

[2] http://chcf.umassmed.edu/services/third-party-liability/enhanced-coordination-benefits

[3] Data determined by taking the total cost of 2010 Medicaid state plan services for the MFTD Waiver and NPCS PDN programs and subtracting the costs for nursing care, home health services, and long term care facility costs. This statement also assumes that children in the NPCS PDN program are rolled into the MFTD waiver and/or remain eligible for Medicaid even if they hold private insurance. All data is from HFS, and available at http://www2.illinois.gov/hfs/PublicInvolvement/ccmn/Documents/090811_ccmn_ncps.pdf

Approximately 90% of these standard health care services would be covered by most private insurance plans, meaning Illinois has the potential to save 90% of costs for each child enrolled in a comprehensive insurance plan. If just 100 additional children were enrolled in private insurance, Illinois would save nearly $6.9 million annually.

Using Existing Resources to Maximize Enrollment in Private Insurance Plans

An informal survey of MFTD families identified numerous families who have access to private insurance but who have not enrolled their child. There are numerous reasons why children are not enrolled, including:

- Parent can only afford the premiums for him/herself, and cannot afford the higher cost of family coverage
- Parent cannot afford the premiums for employer-based coverage at all
- Parent lost a job and cannot afford COBRA payments
- Child lost insurance due to lifetime maximums before implementation of the Affordable Care Act and has not been added back to the insurance plan
- Child between 18-26 years of age is now eligible to be covered by a parent's insurance plan after implementation of the Affordable Care Act but has not been reenrolled
- Custodial parent is/was unaware that child has access to private insurance through a non-custodial parent
- Parent is/was unaware the child has access to private insurance through a pension plan, trust, settlement, or other unusual mechanism for insurance coverage
- Many children in the NPCS PDN program are ineligible for Medicaid if they hold comprehensive private insurance, and some families choose to forego private insurance in order to gain access to Medicaid services

By using the already existing HIPP program to increase private insurance enrollment among high-cost children, Illinois can ensure that all eligible MFTD Waiver and NPCS PDN families are enrolled in private insurance plans with virtually no additional administrative costs to the state.

The following steps are suggested for full implementation:

Guarantee eligibility for the HIPP program. A current burden to enrolling all children in private insurance plans is the tedious process of qualifying for the HIPP program, which requires a letter of medical necessity, copies of 6 months of insurance statements, and copies of benefit plans. Since all children in the MFTD Waiver are high-cost users, guaranteed eligibility for the HIPP program to all children in the MFTD waiver would greatly simplify the enrollment process and ensure more children have access to private insurance plans. The only verification required would be an evaluation of the private insurance plan to determine if it is comprehensive.

Determine private insurance availability upon initial enrollment in the MFTD Waiver and offer HIPP coverage. Upon initial enrollment in the MFTD waiver, DSCC care coordinators could ask questions about potential access to private insurance as part of the normal enrollment process. If private insurance is available but the child is not currently enrolled, the DSCC care coordinator could determine the allowable enrollment dates and assist the family in enrolling the child. All families who have access to private insurance plans could be offered the option of enrolling in the HIPP program.

Use pre-existing care coordination phone calls and care coordinators to periodically update status and assist with private insurance enrollment. DSCC care coordinators currently are required to check in with families at least once per month. During each phone call or visit, care coordinators could ask about access to private insurance, including whether a parent/guardian has gained, lost, or changed employment. If private insurance is available, the DSCC coordinator could assist in enrolling the child or could note the dates of the enrollment period and assist the family during that time. DSCC coordinators could also make families aware of the HIPP program and offer the option of enrolling. Once per year, before the final quarter of the year when most insurance policies have open enrollment, the DSCC coordinator could verify the presence or absence of a potential private insurance plan and assist families in enrolling in both the insurance plan and HIPP program.

Potential Net Savings: $6,895,120 for 100 children enrolled in private insurance

> **Total Medicaid savings before costs**, assuming 100 children can be enrolled in private insurance and private insurance covers 90% of costs: $7,326,720
> **Potential costs**: $4316 average cost for insurance premiums per child or $431,600 total for 100 children[4]

Coordination of Benefits

Some nursing agencies and family members have had success in obtaining coverage through private insurance for services that may not be part of the standard insurance coverage plan, or services that have been denied. Coverage has been obtained for private duty nursing, durable and specialized medical equipment, and medical supplies.

Many families are unaware that these options are available or they may be unable to appeal denied claims without assistance. In other cases, families do not appeal denied claims since they know Medicaid will cover the cost, and the appeals process is so tedious.

Appointing a dedicated insurance benefit coordinator for MFTD families could potentially save the state tremendous amounts of money by holding insurers accountable

[4] Average 2012 employee cost for health insurance obtained from the Kaiser Family Foundation, http://ehbs.kff.org/pdf/2012/8346.pdf

for coverage they should be providing and determining if they will extend additional coverage for services that typically are not covered.

Illinois already does appeal some claims that should have been covered and were denied. However, a dedicated coordinator who specializes in obtaining coverage for private duty nursing and medical equipment/supplies is likely to have more success in obtaining coverage.

While the savings for this type of program are unknown, Massachusetts saves $50 million per year using a similar approach. If only 10 children received private insurance coverage for just their nursing care, the state would save $1,020,620 annually. The only administrative cost for this type of program would be the employment of a specialized benefits coordinator, at approximately $45,272 per year.

Future Possibilities

Once the Affordable Care Act is fully implemented in 2014, Illinois will have the ability to purchase individual private insurance policies for children in the MFTD waiver, NPCS PDN program, and children in DCFS who receive PDN. It is possible that the state could cover all children in these three programs through individual private insurance policies, using Medicaid only as a wrap-around service. In addition, purchasing individual policies for other high-cost Medicaid users, including children with cancer or bleeding disorders, could save even more funds. Although the costs of these insurance plans is unknown at this time, ensuring all high-cost children have private insurance coverage could potentially save the state more than 50% of the current price tag for children's health care in these programs.

Essential Health Benefit Coverage for Pediatric Private Duty Nursing

As the Affordable Care Act is implemented over the next year, Illinois has the opportunity to define what essential health benefits private insurance plans must cover. While the federal government has created broad categories of coverage, it is allowing states to determine the specific types of coverage within each category.

The federal government has already set a precedent in providing more benefits to children by creating category 10, which extends additional benefits, such as vision and dental care, to children only. Modeling the Early Periodic Screening, Treatment and Diagnosis (EPSDT) provision of Medicaid, this category is intended to help prevent childhood medical problems from becoming lifelong medical conditions and expenses.

Illinois Medicaid currently pays for expensive nursing care for a number of children who are simultaneously enrolled in private insurance plans. It also pays for therapy services, durable medical equipment, and other services that are often not covered by private insurance. If Illinois could shift the burden of these costs—in full or in part—back to private insurers, Illinois could save a tremendous amount of money each year.

There is already a precedent in Illinois for requiring private insurers to cover the costs of children with special needs, specifically children with autism. Current code mandates that private insurers pay the first $36,000 (adjusted for inflation) in services provided to treat or diagnose autism. A similar approach could be expanded to include additional services for children with special needs, including private duty nursing.

Possible approaches include the following:

- Adding private duty nursing for children (without service limits or restrictions) as an essential health benefit for children
- Adding private duty nursing as an essential health benefit for children, but capping the yearly cost to insurers, such as a $36,000 cap per year to parallel the autism insurance law, or a higher cap of $100,000 to match the average cost of nursing care per year
- Adding private duty nursing as an essential health benefit for children, but restricting it to a lifetime cost of a certain amount, such as $1,000,000 lifetime

Possible savings, if an additional 40 children receive coverage through insurance, could be as high as **$4,082,480 per year**.

Improved Care Coordination and Reduced Hospitalizations through a Home Visiting Model of Care

Children's Hospital of Boston operates a home visiting and care coordination program, the CAPE program, for children on ventilators or receiving complex home-based respiratory care. Most children in this program rely on Massachusetts' version of the MFTD Waiver, called the Kaileigh Mulligan Home Care Program, or similar programs in neighboring states. Those who participate in CAPE receive a home visit from a physician, respiratory therapist, and/or a nurse as often as needed, typically monthly for less stable children, and every few months for stable ones.[5] Additional care coordination is provided by telephone, and ICU admissions that do occur are streamlined.

Children's Hospital of Boston estimates that their program saves $1 million a year by eliminating 100 hospital stays or ER visits, a cost reduction of about $10,000 per child per year.[6] They anticipate that even more dramatically lower costs could occur with the addition of a telemedicine component to their program. They have received a grant to replace many home visits with less expensive telemedicine consultations, and will soon have data on the cost savings resulting from such a measure.

Many children in the Chicago area have begun participating in a pediatric palliative care program developed by JourneyCare (formerly Hope's Friends). This program matches children with a palliative care nurse who visits the child at home regularly, typically once a month, to ensure the child is healthy, discuss any problems, and create plans to improve the child's health. When a child becomes sick or needs an immediate intervention, a nurse comes to the child, calls the child's physician, or treats the child at home to avoid costly ER visits and hospital stays. Nurses are on call 24 hours per day, and can come to the home to perform anything from simple tasks (blood draw or ear examination), to complex IV infusions and other care.

Families who have participated in this program rave about its ability to keep children out of the hospital, dramatically reducing the cost of healthcare, limiting missed parent work hours, and reducing the rate of hospital-acquired infections. For these families, care coordination is streamlined, children can receive routine care at home instead of risking infection by going to a clinic or ER, and hospitalizations are reduced dramatically.

While JourneyCare is palliative in nature, the principle could easily be expanded outward to all children in the MFTD Waiver, especially those concentrated in urban centers, including Chicago and Peoria.

It is critical to note that currently JourneyCare receives no reimbursement for nursing visits for MFTD Waiver children because HFS will not allow nursing visits to be billed for these children. Because of this factor, JourneyCare must restrict which children they see and what areas they serve. Instead of refusing to provide this type of care, HFS

[5] See http://childrenshospital.org/newsroom/Site1339/mainpageS1339P785.html
[6] http://www.childrenshospital.org/views/february12/home_ventilation.html

should be expanding and funding programs like JourneyCare, that provide increased health benefits for children and reduced costs for Medicaid.

Putting in place or partnering to create a home visiting program for MFTD kids, ideally with a telemedicine component, has the potential to reduce hospitalization costs as much as 20%. This type of program, if implemented correctly could save as much as **$5,963,356 per year.**

Additional Cost Cutting Strategies

1. Most children in the MFTD Waiver currently receive 336 hours (2 weeks) of respite care nursing per year. Many families are unable to use these hours due to difficulty finding caregivers to provide them. We propose that the Respite nursing component is eliminated, and instead replaced with a Flexible Hours Account that would allow families to bank all unused hours to be "spent" on an as-needed basis.

Current estimated cost of respite if all hours are used: $5,712,000[7]

Potential Savings: $3,103,200[8]

2. Some families would prefer to provide more care to their children themselves, but are unable to do so because of other obligations, including care of siblings, care of the home, laundry, errands, and other duties. If families chose to do so, homemaker services could replace a small portion of nursing care hours, allowing parents to care for their children while a homemaker assists them with tasks in the home. Parents could elect to have 0-25% of their child's nursing care 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[9]

Potential Savings if all families chose this option: $8,840,355
Potential savings if half the families chose this option: $4,420,177

3. Sometimes children remain in the MFTD Waiver for long periods of time after their health has improved and they no longer require nursing. Removing children from the program promptly, and gradually weaning down their hours is essential to make sure children are not receiving unneeded services. We propose a rapid transition of children who are no longer eligible for waiver services, within three months of losing eligibility. During this time, nursing hours would gradually be reduced 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[10]

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[7] 336 hours per child multiplied by 500 children at an average rate of $34/hour.
[8] Assumes 60% of hours are used, which is the standard percentage of total nursing hours used currently.
[9] 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.

4. Children in the MFTD Waiver vary from moderately complex to extraordinarily complex. Currently, all nurses are paid the same rates, regardless of the acuity of the child. Paying appropriate rates by stratifying payments based on the needs of the child could dramatically reduce costs in the program. Children could be grouped into 4 categories based on need. The child would be reimbursed at one rate, regardless of what type of nurse (RN or LPN) was staffing the case. This would encourage the use of LPNs for simpler cases. Children would also receive a particular range of hours based on their group.

Group 1: Stable children with lower levels of technology
Group 2: Children with tracheostomies and moderate levels of medical fragility
Group 3: All children with central lines or on ventilators
Group 4: Select group of children with extreme needs

Potential savings: $7,001,560[11]

5. Children with complex medical needs generate a lot of paper. Reducing the use of paper, exchanging information electronically, and reducing mailing costs could save significant amounts of money each year.

Potential savings: $250,000

6. Some Durable Medical Equipment suppliers are known for their poor business practices, and in some cases, their extreme markup of supplies and equipment. Wrong orders are routinely shipped to children. These items cannot be returned, and are often still billed to the state, even if they are discarded. Oversight of durable medical equipment companies, with strict guidelines on rental payments, such as rental to purchase price, could dramatically reduce costs. We also suggest a pilot program for reuse of Medicaid-purchased items, including wheelchairs, standers, lifts, and beds. The goal would be to reduce DME and supply costs by 30%.

Potential savings: $2,492,763

[10] 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.

[11] 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.