

MFTD Waiver Families

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Response to Statements Posted by the Illinois Department of Health and Family Services (HFS) in “Questions and Answers on the Medicaid Program For Medically Fragile and Technology Dependent Children”

The following includes exact screenshots of the information publicly posted on June 21, 2012 at <http://www2.illinois.gov/hfs/agency/Pages/MFTD.aspx>.

1. **Why is this program changing?**

The Medicaid program is on the brink of collapse. Changes were necessary to save the Medicaid program and these changes can be found in the SMART Act ([Public Act 097-0689 pdf](#)). One of the changes in the SMART Act was a modification to the program for medically fragile and technology dependent children, found on Pages 81 and 82. A copy of the SMART Act can be found on the [HFS Budget Web site](#).

The MFTD Waiver’s per capita cost has been flat for ten years—it’s actually 7% lower than it was in 2000 when adjusting for inflation.¹ Over the past decade, the state expanded coverage to many other groups of people, and when their budget got too expensive, they decided to gut a program for children with severe disabilities that has been essentially the same for decades.

If the Medicaid program is on the brink of collapse, why shift kids from less expensive home care to more expensive institutional care? How does the state expect to save \$15 million by forcing kids into hospitals at three times the cost? The State should release details on its assumptions and methodology for determining the \$15 million in estimated savings with these changes. What costs do they project, if any, for kids kicked or priced out of the program and forced into more expensive institutions? What quantity of increased hospitalization costs, if any, are projected because of replacement of home nurses with unqualified personal care attendants resulting in lower quality of care and increased medical errors? What loss of state tax revenues and increased government dependency is projected as families are forced to quit jobs and lower their incomes to keep their children at home? How will they make up for the loss of federal matching

dollars that result from imposing cost sharing? Given the magnitude of the state's fiscal crises, wouldn't a data driven discussion based on transparency and intellectually honest projections be especially important?

2. Why do you call this a new program?

This is not a new program; rather, it is a restructuring of two existing programs.

Currently, the state serves medically fragile and technology dependent children in two different ways: approximately 550 children are served by the Medically Fragile, Technology Dependent Waiver ("MFTD Waiver") and there are approximately 500 other medically fragile and technology dependent children under Medicaid who receive in-home services but do not meet the institutional level of care to qualify for services under the MFTD Waiver. The restructured program will use a consistent assessment and care coordination to assist children and their families. The restructured program will also incorporate a philosophy of consumer/family direction and shared financial responsibility, meaning that families will also have more flexibility in accessing and using services.

How will 1050 children fit into a waiver program that will only have 700 spots? Doesn't that mean at least 350 kids will be kicked out, far more than the 5% claimed by HFS?²

How is it that 500 children who currently don't qualify for the MFTD waiver--that services children at both hospital and nursing home levels of care--will suddenly qualify for a new waiver that is only for children at the nursing home level of care?

If there is a "philosophy of consumer/family direction," why did the state not check the option for participant direction in its 1915(c) waiver application on page 5?³ The federal government gives states an option for consumer direction, but the state is not exercising that option. Not selecting this option suggests a hollow "philosophy of consumer direction/family direction" that really means putting medically necessary private duty nursing so far out of reach (see Question 8 below) that families are forced to make "the choice" to pick providers who are not qualified to care for their children safely.

3. I would like a copy of the proposed State Plan Amendment.

The state has not submitted a draft State Plan Amendment at this time. The state has submitted a waiver document, but this document is a draft and, therefore, not final. Draft documents are exempt from release under the Freedom of Information Act (5 ILCS 140/7). HFS will release these documents when they are finalized with the federal government. Please note that HFS had months of stakeholder input that we took into account when developing these documents (see #12).

Here is the statute referenced exempting classes of information from public disclosure: "Preliminary drafts, notes, recommendations, memoranda and other records in which opinions are expressed, or policies or actions are formulated, except that a specific record or relevant portion of a record shall not be exempt when the record is publicly cited and identified by the head of the public body."⁴

Signed and submitted applications from a state to the federal government do not constitute a "draft" and are not covered by this exemption. Moreover, the state has

publicly cited and identified the documents they claim are exempt from the Freedom of Information Act on their website. Therefore, according to the statute they cite, this exemption from the Freedom of Information Act does not apply.

Why is the state trying to withhold these proposals from families under questionable legal pretenses?

4. I would like to know the individual Medicaid costs for my client or child.

HFS would very much like to give you this. The total cost of Medicaid services is \$187 million for both groups of medically fragile and technology dependent children. Individual cost data is protected by privacy laws. HFS wants to assure that these laws are followed when sharing protected health information. HFS will publicize the process to request this information on our Web site.

HIPAA privacy laws do not prevent individuals from getting access to their own information. On the contrary, individuals have a right to their own information in their own files. Each child in the waiver has a “cost neutrality analysis” in his/her file that is the state’s own comparison of the costs for that child at home versus in an institution. Why is the state making it so challenging for families to obtain this information?

These documents that they are not consistently releasing contain proof that the supposed cost savings they claim to realize as a result of cutting people out of this program are false. These documents will also show that they have written their renewal application so that 99% of current children in the program would be denied entrance into the program.

5. How is the change of level of care to nursing facility in the waiver going to affect my child?

The change to nursing facility level of care in the waiver will not affect your child's eligibility for the program. Under a waiver, states are required to demonstrate cost-neutrality on an aggregate basis, not for each individual child. To establish the cost neutrality of the MFTD waiver, the costs of home and community-based services will be compared to the costs of nursing facility services for a population with similar needs as the MFTD population. Individual eligibility and the available services under the restructured MFTD program will be assessed individually, based on medical need, as described in #6 and #7 below.

This is clearly false. The application proposal submitted to the federal government on June 5, 2012 contains the following, provided as images so there is no doubt about the truth, from pp. 2 and 26.

• Hospital level of care has been removed as a comparable population. The institutional cost comparison will be nursing facility, using a comparable population with similar medical and technology needs as those served in the waiver.

4. Waivers Requested B. Income and Resources for the Medically Needy

• The state will not request a waiver to use institutional income and resource rules for the medically needy (parental income will now be considered in determining financial eligibility)

Appendix B: Participant Access and Eligibility

B-4: Eligibility Groups Served in the Waiver:

•The state has removed all other eligibility groups and will submit a state plan amendment for approval to be effective September 1, 2012 to cover technology dependent children up to 500% of the FPL as identified through a level of care instrument. This new eligibility group will be the only eligibility group under this waiver.

- **Institutional Cost Limit.** Pursuant to 42 CFR 441.301(a)(3), the State refuses entrance to the waiver to any otherwise eligible individual when the State reasonably expects that the cost of the home and community-based services furnished to that individual would exceed 100% of the cost of the level of care specified for the waiver. *Complete Items B-2-b and B-2-c.*

What this means is that any child with a hospital level of care—99% of current participants—would be “refuse(d) entrance into the program.” Those are their words, not ours.

Also, what is that, “population with similar needs as the MFTD waiver population,” as shown on p. 135 of the waiver application?

been established through a methodology to approximate an individual level rate. A total of 116 people were identified who: were residing in nursing homes; were under the age of 60; and had a condition requiring a ventilator or tracheostomy, based on identification of ventilator or tracheostomy services for six consecutive MDS quarterly reports. A daily rate was then calculated which incorporates various add-ons related to service needs specific to people with a ventilator or tracheostomy. It is

The state has proposed using older adults in nursing homes as a new comparison group for children who have been classified as needing a hospital level of care. Children often require much closer monitoring because they have smaller airways and less reserve than adults. Small children may pull out their own tracheostomy or feeding tubes out of curiosity if not watched closely. Unlike adults, children attend school and need nursing to do so. Adults in nursing homes are not a credible comparison, and using this comparison to deliver a lower level of care to these children endangers their lives.

6. What is the Level of Care Tool for the restructured MFTD program?

The level of care tool will be the standardized assessment tool that determines eligibility and medical necessity for services available under the restructured MFTD program. The "level of care" in this context should not be confused with the level of care required by the federal government in waivers.

Why is this assessment being developed in secret without expert medical input? Why not release the assessment for public comment, at least by the stakeholders who care and advocate for these children?

If the assessment is being built on the one used in the Oregon Medically Fragile Children’s Unit Waiver, why is an assessment that is used in Oregon’s hospital level of care waiver going to be applied to a nursing home level of care waiver in Illinois? Does this not suggest that that the nursing home level of care designation is being incorrectly applied to this population, if the state is using a tool based on a hospital level population?

In addition, this level of care tool will be used to numerically award a budget (see Question #7) for care and a package of services. How can an imprecise tool with no individual human input be used to award services, including those mandated by EPSDT? Children with rare conditions, unusual medical technologies, and difficult to quantify

medical fragility will be unable to receive the services they require, simply because no level of care tool can ever be comprehensive and all-inclusive of all conditions and treatments.

7. How are the services changing?

Services provided through the program will continue to be based on medical necessity, which will be determined consistently through the level of care tool described above. In the context of this standardized assessment tool, "level of care" means the amounts and types of services necessary to meet the varied medical needs of individual children.

Private duty nursing, the most widely used service by medically fragile and technology dependent children, including those children who currently use the MFTD Waiver, will continue to be available to all eligible children, when medically necessary, under the Early Periodic Screening, Diagnosis & Treatment (EPSDT) requirements.

In fact, most of the medically necessary services to be provided by the restructured program will be available as a result of the State Plan and EPSDT requirements, not the MFTD Waiver. The only services remaining under the MFTD Waiver in its current draft form are home modifications, specialized medical equipment, nurse training, family training, placement maintenance counseling, and medically supervised day care. The most used of these services are the Environmental Accessibility Adaptations (EAA) and Specialized Medical Equipment and Supplies (SMES). These services will continue as waiver services, with limits. The total cost for purchase of all EAA and SMES purchases, rental, and repairs may not exceed \$25,000 over five years. Respite has been eliminated as a waiver service, as families will have more flexible use of nursing hours based on a monthly service allocation and creation of a flexible account that allows families to bank up to a week's worth of unused hours to be used for respite.

How will "medical necessity" be determined? Using an unvalidated level of care tool based on one from another state that is used for a different population? What about diseases, conditions, technologies, and fragility that are not captured in their tool? How can a determination of medical necessity be made without the input of qualified medical professionals?

According to their fact sheet for this program, children will receive a monthly financial budget based on the number they score on the imperfect and unvalidated level of care tool that can be "spent" as families wish on nursing or unlicensed and unskilled providers.⁵ But all standard in-home services, including private duty nursing and personal care services, are EPSDT-mandated services, which means that if a physician prescribes them to treat or prevent a diagnosed condition, they must be provided. States cannot force families—neither explicitly nor implicitly through methods that restrict access to care, such as budgets or copays—to accept a lower level or amount of services than their physician has prescribed.

8. What are my co-pays going to be?

The proposal is for families with income at or over 150% Federal Poverty Level to pay co-pays. The co-pays will be the maximum allowed by federal law, as required by the SMART Act. The amount of co-pay has not yet been finalized. Cost-sharing is an essential component in the SMART Act. With the Medicaid program on the brink of collapse, the legislature imposed co-pays for most, if not all, Medicaid services, to the extent permitted by law.

Why are copays being imposed on families who keep kids at home, but not on those who place their children in nursing homes? Why are copays being applied to use of private duty nurses but not to personal assistants? Does this not discriminate against the sickest children who can only be cared for by nurses under state law and medical standards of care?

The statement that the state is imposing copays on, “most, if not all, Medicaid services,” is simply not true, because federal law does not allow copays in most circumstances for children. No documents have been released that indicate the state will be assessing copays on children in the state Medicaid plan, nor on any service other than private duty nursing. Copays are not being imposed on other pediatric EPSDT services for children in the state Medicaid plan, such as medications, speech therapy, or physical therapy. If HFS plans on broadly assessing such copays, they are obligated to say so publicly to the state instead of doing so in secret state plan amendments. In addition, the SMART Act says nothing about imposing copays on nursing care alone. HFS has chosen to impose copays only on this service.

No other state in the US has ever put a copayment on each pediatric private duty nursing shift, perhaps because when selectively applied in this fashion, it so obviously incentivizes institutional care or unsafe use of unqualified providers.

If copays are being adopted because Medicaid is on, “the brink of collapse,” why did Director Hamos state in a stakeholder meeting on January 24, 2012 that it would not raise much money? See below for a screen shot of the meeting minutes:

percent cost share would be approximately \$11,250/year. The cost share approach is unlikely to produce significant revenue, but is a philosophical approach showing an effort for participants to contribute toward care and share in the cost when their incomes are above the Medicaid eligibility limits. Director Hamos also indicated that a provider

Not only does the cost share approach not raise much revenue, but the state loses a dollar of federal matching funds for every dollar assessed as a copay, further undermining the state’s questionable pretenses for this action.

Given that the state has ignored repeated request to impose equal cost-sharing on families who choose institutional care options, their claims of “philosophical” fairness lacks credibility. Research studies suggest families who keep such children at home make the highest financial, physical, and emotional sacrifices. We have provided the state with ample evidence that we pay high levels of out-of-pocket costs covered neither by private insurance nor Medicaid, yet the state falsely states that we must pay additional cost sharing to prove we are “showing an effort...to contribute.” This is not only wrong, it is also highly offensive.

9. Why was an income cap of 500% Federal Poverty Level imposed?

Because of the budget crisis, the legislature imposed income caps for this program. HFS estimates that 95% of families will continue to be eligible to receive services that are medically necessary. It is possible that there is legislative interest to raise this income cap, if additional revenues are identified. Due to the fiscal resources available to the state at this time, it is unlikely that this program will revert to a program for all families of all incomes.

See answer to #1 regarding the budget crisis. Also, why will HFS not release in aggregate the costs of institutional care versus home care for the 5% of children being cut out of the program so the public can see the true costs of institutionalizing these 5% of kids? This income cap is arbitrary, and will bankrupt middle class families, who will have to pay 200% or more of their annual income to keep their children at home. No other state has ever put an income cap on a program like this because it doesn't make financial sense given the much higher cost of institutional care. Only 13 children would need to be hospitalized permanently to erase all of the savings Illinois hopes to gain by cutting 5% of families out of the program. Families cannot see the mathematical sense of these caps, and HFS has provided no evidence that this policy will reduce costs to the state.

10. Will the proposed changes have a transition period for families who will not qualify? What is the transition plan?

Transition plans will be developed for children who no longer qualify. HFS will make every effort to work with families to make referrals to other programs and services for which your child may be eligible. If you receive a notification that your child is going to lose eligibility, you will also be informed of your right to request a fair hearing.

Why is the state waiting until the last possible moment to release a transition plan? The state has been studying this issue for months. Families need more time to plan for this extraordinary change, especially if 99% of children will lose their home nursing. Their nurses are looking for other jobs while the state dithers. A "hit and run" transition plan is unacceptable.

If HFS is making, "every effort to work with families," why are they refusing to answer questions over the phone, as shown in the image below from the Q&A document?

Please know that our staff will not be able to respond to verbal questions on the telephone. We ask for your patience and will make every effort to work with you in transitioning your child if your child will be affected by the restructuring.

11. Will the children currently in the waiver be eligible until their next renewal date, or are they going to be reevaluated on September 1, 2012?

Financial eligibility will be reviewed prior to September 1, 2012. However, a child's level of care eligibility will be determined at the time of the child's annual reassessment.

Why has the state still not released the exact method of income determination, and why have they not notified individual clients that this change is coming? Not everyone reads

the HFS website. Does the state really think it is fair to give families just a few days to gather the necessary information when they are about to lose their children?

12. How did the state include families in the decision-making process?

HFS engaged in meetings with families and other stakeholders, including doctors, therapists and other healthcare providers, for many months prior to and during the legislative session to brainstorm about ways to make this program more efficient and responsive to individual children and family needs. Many of the suggestions received by the department were incorporated into the proposed program redesign, including cost sharing, the flexibility to bank unused hours, and the use of paraprofessional staff to deliver care.

Families have never been individually notified about potential changes to the MFTD waiver, nor have they been invited to help in the decision-making process in any meaningful way.

With other proposals, the state has published documents for public comment before submitting to the federal government. In this case, they are refusing to share documents already submitted to the federal government! See #3 above for information on the state's questionable claim of an exemption from the Freedom of Information Act to share relevant information with families in a timely fashion.

As for the stakeholder meetings, families were only invited to the fifth meeting, and only by invitation from select organizations. Most families had no idea these meetings were even occurring. Most to this day have no idea what changes are coming because they have not been individually notified by HFS.

At the meeting in which families attended, families were told explicitly by the director of HFS that nobody would be kicked out of the program.

The following elements of the plan were never discussed or agreed to in stakeholder meetings:

- A specific 500% income cap, which was only made public when the SMART Act was introduced, mere days before it was passed by the legislature.
- Copayments on every private duty nursing shift, also only shared publicly days before legislature passage.
- Changing the program to only include children with a nursing home level of care, which was only shared after the state submitted its waiver application to the federal government.
- Substituting Personal Care Attendants for nurses to perform care they are forbidden by state code to do, which was highly criticized in stakeholder meetings as a danger to the health of these children.
- Substituting a financial budget (based on a level of care tool that may be inappropriate and not comprehensive) for physician prescribed hours of EPSDT-mandated nursing care, which was only shared after the state submitted its application to the federal government.

¹ http://www2.illinois.gov/hfs/PublicInvolvement/ccmn/Documents/ccmn_facesheet_history.pdf

² <http://www2.illinois.gov/hfs/SiteCollectionDocuments/MFTDFactSheet.pdf>

³ <http://savemftdwaiver.com/MFTD2012application.pdf>

⁴ <http://www.ilga.gov/legislation/ilcs/fulltext.asp?DocName=000501400K7>

⁵ <http://www2.illinois.gov/hfs/SiteCollectionDocuments/MFTDFactSheet.pdf>