

MFTD Waiver Families Respond to Medicaid Budget Cut Negotiations

The MFTD Waiver Families want to thank the Department of Health and Family Services (HFS) and Governor Pat Quinn for arguing for renewal of the Medically Fragile/Technology Dependent (MFTD) home and community based services waiver.

We want to make it clear, however, that we remain frustrated by the lack of information we have been provided throughout this process. Moreover, we would remind state officials that the Center for Medicare and Medicaid Services (CMS) strongly recommends including public input from stakeholders such as families in any home and community based services (HCBS) waiver renewal process, and pending rule changes, if approved, will make this mandatory. These guidelines are in place to ensure that any changes in the program are understood by and acceptable to those most directly affected by those changes.

As the state has not invited us to participate in the renewal process, we have taken the initiative of presenting our opinions and ideas through this document. We believe strongly that the state can, and must, address its fiscal crisis without putting our children and families at risk. We address suggested cuts to the MFTD Waiver, as well as other components of Governor Quinn's Medicaid proposal, in the sections that follow.

Summary of Positions

1. We oppose income caps.
2. We oppose any cost sharing that exceeds federal guidelines (greater than 5% of family income) or exceeds the premiums paid by families of the same income levels in AllKids.
3. We question the purpose of cost sharing since it will not raise significant revenue.
4. We support with reservations income-based cost sharing that is focused toward wealthy families, if and only if adjustments for out-of-pocket medical expenses and private insurance are made, and cost sharing is applied equally to all children's waiver programs, as well as to children residing in institutions.
5. We oppose cost sharing based on services provided.
6. We oppose tightening medical eligibility requirements for this program.
7. We urge an equitable overhaul of medical eligibility requirements so that all children receiving home nursing care would be held to the same eligibility standard, regardless of Medicaid program.
8. We support the choice of receiving some homemaker hours in lieu of nursing care hours.
9. We oppose the use of unskilled providers such as Certified Nursing Assistants or Personal Care Attendants who cannot legally care for children in this program.
10. We strongly support private insurance mandates that would make all plans, including self-insured plans, cover the equivalent of the Medicaid EPSDT package for children.
11. We oppose a cap on the number of allowable prescriptions for children.
12. We support a cap on incontinence products, if prior approval can be obtained for conditions that require a greater amount of incontinence products.
13. We urge the state to consider novel cost saving strategies that do not affect eligibility or dramatically reduce services.

Income Caps

Information obtained from the ARC of Illinois indicates that HFS and legislators may be considering an income cap on waiver services. **The families strongly oppose any income caps on this program, as they are counter to the philosophy underlying these waivers, which were specifically designed to waive parental income in favor of the child's needs.** Eligibility should continue to be determined solely by the child's condition, income, and assets.

Should Illinois go forward with such a plan, our research suggests that Illinois would be the *only state in the country* to institute such caps for pediatric TEFRA or HCBS waiver programs. TEFRA programs are by definition barred from using parental income in determining eligibility, and we have been unable to find any HCBS waiver program targeted to children who are medically complex with any sort of income cap.

The reason these programs were created in the first place is that the cost of caring for medically fragile and technology dependent children at home exceeds the ability of most families—even those whose incomes may appear substantial—to pay. Moreover, it is well understood that private insurance will not step in to fill the gap.

We are sensitive, however, to the potential misuse of this program by extremely wealthy families. We would argue, however, that instituting a graduated income-based cost-sharing plan would better address such extreme cases. This approach would separate eligibility, which needs to remain child-focused, from measures that later address the financial situation of the child's family.

If an income cap were to be proposed, any cap must be substantially greater than \$188,210, which is the average cost per child on the waiver, as families would otherwise have to pay this amount out of pocket. Because this amount is an average and nursing care alone for some children may cost as much as \$235,872, we would strongly recommend a minimum income cap of 1500% of the federal poverty line.

Cost Sharing

We also note that the Governor's proposal includes a plan for cost sharing in the MFTD waiver, as limited by federal guidelines, which restricts family contributions to no more than 5% of family income. While we understand the initial appeal of such a plan, we would point out that most states have found that any revenue raised by cost sharing is minimal to none, because cost sharing payments are not matched by federal dollars and charges related to administration and collection of payments cancel out revenues. For example, cost sharing in an Idaho program four times the size of the MFTD Waiver only brought in about \$114,000.

As such, very few states employ cost sharing. We have only been able to identify 7 states that use cost sharing in children's HCBS and TEFRA programs, and the majority of these are TEFRA programs. Only two states use cost sharing in HCBS programs that target populations similar to the children in Illinois' MFTD Waiver. Note that states are not allowed to refuse services to children if families do not pay their premiums, and in at least one state, the US Justice Department has made it clear to families that payments are optional.

The knowledge gained from other states and an extensive body of research on cost sharing in general clearly indicates that any cost sharing that exceeds the “nominal” level is likely to increase costs. If families are forced to forego medical care or prescriptions in order to pay their monthly cost sharing amount, hospitalizations could increase dramatically, more than canceling out any revenues generated.

Even HFS has admitted that cost sharing following federal guidelines will not raise revenue in the end. As such, we do not see how cost sharing following federal guidelines is a viable strategy for reducing the financial burden of this program to the state. It seems to serve no purpose other than to financially punish families who are already overburdened by their child’s care.

In the event that the state nonetheless remains committed to cost sharing, we present the following suggestions and concerns:

- 1) **The families oppose in the strongest terms any cost sharing that is above the 5% income threshold allowed by federal law.**
- 2) **We also strongly oppose any cost sharing that is determined by the volume or type of services instead of by family income.** One proposal that was initially created by HFS was to split the cost of home-based nursing care evenly between the state and families. Such a split would result in an average payment of \$51,000 per family, an amount vastly beyond the means of most families on this program. In addition, such a proposal would penalize families with sicker children—who would have to pay as much as \$100,000—which effectively discriminates based on disability.
- 3) **Any cost sharing plan based on family income must be adjusted for out-of-pocket medical expenses, including private insurance premiums.** We feel it is vital for HFS to recognize that most families in this program pay substantially more than the average family in uncovered medical expenses, and these expenses must be taken into consideration when calculating a family’s income. Based on our calculations, the average family pays about \$12,000 per year out of pocket for medical expenses not covered by insurance and Medicaid. The average cost of private insurance in 2011 for family coverage was \$15,073. In other words, families in this program routinely spend about \$27,000 per year on health insurance and uncovered expenses. Families save the state millions of dollars by maintaining their private insurance and must have an incentive to continue to hold private insurance.
- 4) **The state cannot discriminate against children with disabilities by charging their families higher monthly payments than families of similar incomes are charged under AllKids, as this would be a violation of the Affordable Care Act.** Therefore, monthly premiums must be the same or lower than the premiums currently charged for AllKids levels 1-8.
- 5) **Models exist that can achieve cost sharing without burdening families in ways that would ultimately undermine cost savings.** We have reviewed cost sharing proposals in the handful of states that have implemented cost sharing in TEFRA and HCBS programs for children with medical technology. Payments in most states, including Maine, Nevada, and Arkansas, are nominal, graduated by income, and lower for families who hold private insurance. Arkansas’ payments range from 1-2.75% AGI, while Maine’s are from 0.3-1.4% AGI.

- 6) **If cost sharing must be implemented, we strongly suggest a model similar to Nevada's.** Nevada applies cost sharing to all of its programs. Families receive a \$300 credit on their monthly payment if they keep their child at home. The family's monthly health insurance premium is subtracted from this monthly payment. As such, most families with private insurance up to 400% FPL pay nothing, while families above this level—especially without private insurance—pay fair cost sharing amounts that sharply increase with income.
- 7) **Cost sharing must be equitably applied regardless of setting or program, including children who reside in institutions.** In order to comply with *Olmstead*, cost sharing must be applied to all children regardless of the type of disability they have. It is unfair and illegal to target children who receive home nursing simply because their disabilities require a higher level of services. Therefore, identical cost sharing must be implemented in the Children's Support Waiver and the Children's Residential Waiver. If not, children from the MFTD Waiver could simply apply for the Children's Support Waiver—where they would be viewed as requiring the highest level of need—and obtain similar services without cost sharing.

Medical Eligibility

The families urge the state to approach the question of eligibility with great care, keeping in mind the following:

- 1) **We strongly oppose the implementation of any assessment tool that further limits medical eligibility for the MFTD Waiver.** Illinois already has some of the tightest eligibility requirements for its program. In most states, children with feeding tubes or oxygen are routinely eligible for waiver programs. In Illinois, children must have a much higher level of medical technology and fragility than virtually any other state in the country, with even some children with tracheostomies excluded from the program.
- 2) **Instead, we urge the state to more critically review and reform current practice regarding eligibility determination for services across ALL Medicaid programs for children.** For instance, other programs, including the Nursing and Personal Care Services (NPCS) program and nursing care for foster children, routinely provide extensive services to children with much lower levels of need than the MFTD Waiver. The families urge the state to undertake a system-wide overhaul that fairly provides nursing care to all children who meet eligibility requirements for nursing care.
- 3) **Furthermore, the families strongly oppose the continuing use of any assessment tool that does not allow for subjective analysis.** Many families find that the current Level of Care Tool unfairly limits the impact medical fragility and developmental needs can have on a child's score. For example, a child who has seven medications will score the same as a child who has twenty medications—this is self-evidently not a fair measure of medical fragility. Moreover, some medical issues, such as unstable vital signs, are severely undervalued as markers of fragility, or not included at all, while others lead to a “high” score. In addition, a child's developmental needs are not taken into account, so that a child with a trach who is fully independent would receive the same score as a child with a trach who needs total assistance with all activities of daily living. Finally, some medical conditions, technologies, and procedures are not even included in this assessment, and there is no way to adjust the tool to account for the needs of a child with a rare condition or unusual care requirements.
- 4) **Families also oppose the assessment tool's bias toward hospitalizations and ER visits as predictors of the child's need for nursing care. The entire point of the MFTD Waiver is**

to keep children at home and to avoid hospitalizations. To that end, these children receive palliative care, hospice care, care coordination services, and other forms of care that, though hospital-level, is provided at home, even through major illnesses. Thus, lack of hospitalizations and ER visits demonstrate the *success* of the current program and level of service families are receiving. Limiting the services that are effectually preventing hospitalization is extremely shortsighted. Children should not be penalized (and actually put at risk of hospitalization) because their families have provided exceptional care for them at home.

Homemaker Services

The families support allowing the *option* to exchange a small portion of their nursing hours for homemaker services. This provision would allow families to personally direct and design a portion of their family's services while simultaneously reducing costs to the state. Note that homemaker services could only be provided when a parent or other caregiver is available to provide skilled care for the child.

Unskilled Providers

We strongly oppose the substitution of unskilled providers, such as Certified Nursing Assistants (CNAs) or Personal Care Attendants (PCAs), for Registered and Licensed Practical Nurses. CNAs and PCAs cannot legally care for children in the MFTD Waiver under the provisions of Illinois' Nurse Practice Act. Even if the Nurse Practice Act were altered, in the vast majority of cases, the children in this program are too medically complex to be cared for by an unskilled provider.

We do believe it is possible for some children in other programs, including children in the NPCFS program and the Department of Children and Family Services (DCFS), to receive care from CNAs or PCAs, depending on the needs of the child.

Private Insurance

We strongly support the proposal to require private insurers to pay for all services required by children with special needs. Though such a private insurance mandate could not fully replace the MFTD Waiver, which would still be needed as a safety net for these families, it would dramatically reduce expenses to the state for this program, perhaps by as much as 50%.

Private insurance has neglected to pay its fair share for decades by intentionally excluding as "custodial" or "convenience" care the expensive medically necessary services required by children who are medically complex, such as nursing, therapies, and other services and supplies.

Such insurance reform thus must be explicit in what insurers are required to provide. We encourage the state to require insurers operating in Illinois to provide benefit packages for children that meet Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) guidelines. We encourage the state to make this mandate apply to self-insured insurance plans as well.

Prescription Caps

The Governor's proposal contains a measure to limit pediatric prescriptions to five per month. **We fully oppose this proposal as medically dangerous, fundamentally impracticable, and of**

doubtful fiscal value. Most children in the MFTD Waiver (and others who are medically complex but not in the waiver) take a minimum of seven prescriptions, and many use as many as 20 or more prescriptions. For families to obtain prior approval for all of these medications represents an undue burden on physicians and families, and could easily lead to longer and additional hospitalizations. For example, if a child visits the emergency room and needs an additional prescription urgently, that child may need to be admitted to the hospital if the family cannot afford to pay out-of-pocket for the prescription.

Many prescriptions used by these children are complicated, unusual, or nonstandard. Reviewing all of them, even on an annual basis, would be extremely time-consuming and costly. Moreover, it is an open question about who would be qualified to do this review.

At the same time, we understand the state's desire to avoid the misuse and overuse of pharmaceuticals, both to preserve good health outcomes and to manage costs. Families therefore recommend that existing nurse case managers and nursing agency supervisors for children in the MFTD Waiver be required to review prescriptions monthly. Any anomalies could be reported and reviewed.

Incontinence Products

The families support a cap on incontinence products as long as prior approval for higher amounts is available to children with certain gastrointestinal conditions, such as short gut.

Any limitation that does not provide an exception for children requiring treatment for severe gastrointestinal conditions is a violation of EPSDT.

Additional Cost Saving Strategies

The families have many ideas for thoughtful cost savings that do not impact eligibility or services. We would be happy to discuss these strategies at greater length with HFS. These include:

- Monthly/yearly caps on waiver-only services
- Flexibility in usage of hours
- Substitution of homemaker services for some hours
- Payment stratification by medical complexity
- Use of electronic medical records
- Oversight of DME companies
- Targeted emergency care and telemedicine to prevent hospitalizations
- Improved care coordination

We believe these strategies have the potential to reduce the cost of the program substantially without any loss of eligibility or services, and with a much less draconian financial impact on families.