Save the Waiver
Kids belong at HOME!

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Cost Sharing in the MFTD Waiver

Position Summary

In principle, MFTD Waiver Families opposes the implementation of cost sharing for the MFTD waiver program based on research that strongly demonstrates that such strategies do not raise sufficient revenues to be worthwhile, and often threaten the medical stability of children with complex medical needs.

We understand, however, that legislators have requested detailed information on the available types and implementation strategies of cost sharing. In the face of this, we have engaged in a serious effort to conceive of ways in which the detrimental consequences of such strategies can be blunted as much as possible, with minimal financial losses to the state, and as low a rate of morbidity and mortality as possible for children in the program.

We urge Illinois to commission a full analysis of the financial, legal and medical consequences of cost sharing before adopting any such plan. Precedent demonstrates the value of such an approach. When exploring cost sharing in 2007 for another Illinois waiver, the Children's Support Waiver, Illinois commissioned Navigant Consulting to evaluate the ramifications of such a policy, and based in part on those findings, chose not to impose cost sharing in the Children's Support Waiver.[1] Florida recently explored the idea of adding cost sharing to its children's waiver programs and determined cost sharing would result in net losses after commissioning a detailed analytic report.[2] In light of these facts, we feel it would be irresponsible to implement cost sharing without a detailed analysis of the issue.

We thus offer the following guiding principles and suggestions in a spirit of collaboration in the hopes of protecting the most vulnerable children in our state.

Guiding Principles

Cost sharing typically takes the form of either premiums/fees based on family income, or copayments based on service usage.

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[1] Report available at http://www2.thearcofil.org/secure/reveal/admin/uploads/documents/WaivercommParentalFee082306.doc

[2] Florida's report is available at http://ahca.myflorida.com/medicaid/deputy_secretary/recent_presentations/Premium_Cost-Sharing_Childern_Enrolled_HCBS_Waivers_063012.pdf North Carolina has also put off implementation of cost sharing for 5 years.

We emphatically oppose **Copayments** and will not agree to any plan that includes copayments for the following reasons:

- Copayments on private duty nursing, regardless of their intent, will impose extreme financial and administrative burdens on nursing agencies. This, in turn, is very likely to prompt agencies to refuse to take MFTD Waiver cases, forcing children into hospitals/institutions to receive their medically necessary care. Rather than alleviating the current nursing crisis in the waiver program, this measure is likely only to exacerbate it and put children at risk.
- No children's waiver programs in any of the 50 states currently impose copayments.
- No states charge a copayment for private duty nursing for children in waivers or categorically needy children to our knowledge.
- Because copayments are assigned based on utilization of medically necessary care, families with the most vulnerable children are the most likely to be financially burdened, particularly in the lower FPL ranges. These are also the families most likely to abandon jobs and/or insurance if pressed to the economic brink, putting the state at even higher liability for their children's medical costs.

Family Fees or Premiums represent a fairer cost sharing strategy, mostly because the sharing is administered more perfectly according to means, rather than a child's utilization of services. This approach, however, still runs some of the same risks that research shows has plagued other states:

- Only 7 states to our knowledge currently impose parent fees or premiums on children in waiver programs through various mechanisms, and precedent suggests that CMS may not approve premiums due to Affordable Care Act regulations.
- Cost sharing can, if not carefully administered, incentivize families to drop private insurance policies, leading to higher costs to the state. We estimate the state would have to spend an additional $1,005,200 in health care costs if only 10 children drop private insurance, which far exceeds the likely revenues brought in by cost sharing.
- Cost sharing has been shown to decrease usage of healthcare services, leading to increased morbidity and mortality, as well as costly hospitalization of these children. A single 3-month long hospital stay for one child caused by decreased usage of healthcare services will likely cost more than all the revenues the state would gain from cost sharing payments.

While we understand that HFS prefers copayments to premiums because of the costly administrative burden collection of premiums poses to HFS, HFS's plan to shift this administrative burden onto nursing agencies is alarming. As noted above, nursing agencies are already struggling to provide sufficient nurses to staff the current MFTD

needs, and the added burdens of both administering copayments and coping with financial losses due to unpaid copayments will further strain already stretched resources.

Moreover, such costs have often been the reason that states did not pursue any kind of cost sharing or copayments for these small populations. We believe that it is unwise and shortsighted to further tax the direct care component of the MFTD waiver program in an effort to overcome an inherent basic weakness of the cost sharing approach.

Finally, we believe that in all cases, any cost sharing scheme must meet the following bars:

- It must not incentivize a family to abandon private insurance
- It must not threaten the economic stability of the family, which would in turn threaten the stability of private insurance
- It must not incentivize families to lower utilization of medically necessary care, because this population is so fragile that less care almost inevitably results in greater illness and higher costs
- It must be assessed fairly on a sliding income scale and calculated with attention to out-of-pocket medical expenses and insurance premium costs

What follows is a detailed explanation of how we arrived at these positions, as well as references to our sources and research.

Detailed Analysis

General Information on Cost Sharing

Cost sharing does not raise revenue and may actually cost the state more money to implement than it will receive in revenues.

1. Florida's Agency for Health Care Administration prepared a cost/benefit analysis of imposing cost sharing (including premiums and copayments) on children in waiver programs. Their analysis, "leads to projections indicating that the costs of collection would in most years exceed the revenue collected."[3] The following table summarizes the likely losses in Florida's program over time:

Table 7

Projected Revenue for Premium Collection

Fiscal Year	Projected Number of Individuals Subject to Premium Collection/Cost -Sharing	Projected Total Revenues (*After Allowing for Uncollectible Amounts*)	Projected Revenues Applied to Federal Portion	Estimated Revenue after Uncollectibles and Application of Revenue to the Federal Portion of Service Costs	Projected Costs-Non-Recurring	Projected Costs-Recurring	Net Revenues
2013-14	944	$291,622	$168,353	$123,269	$ 76,875	$184,842	($138,448)
2014-15	755	$481,369	$277,894	$203,475	--	$166,104	$37,371
2015-16	589	$346,536	$200,055	$146,481	--	$150,297	($3,816)
2016-17	463	$289,423	$167,084	$122,339	--	$137,812	($15,473)
2017-18	420	$244,249	$141,005	$103,244	--	$127,437	($24,193)
2018-19	397	$237,143	$136,902	$100,240	--	$123,419	($23,179)
2019-20	377	$228,710	$132,034	$96,676	--	$121,081	($24,406)
2020-21	354	$220,007	$127,010	$92,997	--	$119,010	($26,013)

2. In a Virginia program, the state spent $1.39 to collect every $1 in premiums.[4] This is specifically true for smaller programs, as many administrative costs remain steady no matter how many children are enrolled.
3. All cost sharing reduces federal matching dollars significantly. Half of every dollar of cost sharing must be returned to the federal government (assuming a 50% match), thereby reducing revenues to the state tremendously. Another way to look at this is that copayments are subtracted from the cost charged to Medicaid, meaning that only the remaining portion of a service's cost can be matched by federal matching dollars.
4. In a program four times the size of Illinois' MFTD Waiver, Idaho only raised $114,329 in the first half of 2010.[5] In a program eight times larger than the Illinois MFTD waiver, Wisconsin officials reported collecting $104,058 in 2006

[3] Report available at http://ahca.myflorida.com/medicaid/deputy_secretary/recent_presentations/Premium_Cost-Sharing_Childern_Enrolled_HCBS_Waivers_063012.pdf

[4] Cost Sharing for Children and Families in Medicaid and CHIP, Georgetown University Health Policy Institute Center for Children and Families. Available at http://ccf.georgetown.edu/wp-content/uploads/2012/03/Cost_sharing.pdf

[5] http://www.idahoreporter.com/2010/dhw-slightly-ahead-of-fiscal-projections-on-medicaid-cost-sharing-program/

and $298,047 in 2007, though Wisconsin excludes children with medical technology from cost sharing.[6]

5. Only a small percentage of families actually make payments. In Idaho's waiver program, only 28% of families actually made the payments, and the number has dropped even lower since families were informed that children cannot be denied services even if their families do not pay. The lower the family income, the less likely families are to make payments. In Oklahoma, only 29% of Medicaid beneficiaries actually paid cost sharing payments.[7]

Families of children with complex medical issues already have extremely high out-of-pocket costs.

1. Many costs for children with complex medical needs are not covered by insurance or Medicaid and must be paid out-of-pocket.
2. A study comparing complex and non-complex children with chronic medical needs demonstrated that about half of families paid out more than $1000 a year in uncovered expenses, 57% had financial problems directly related to their child's health care needs, and almost half required additional income to pay for medical expenses.[8] The "complex" population identified in this study includes children with cerebral palsy, autism, and other conditions who are actually significantly less complex than many of the children on the MFTD Waiver.

Table 2. Family-Reported Care Burden of Children With Special Health Care Needs by Complexity[a]

Variable	Less Complex (n=9 897 116)	More Complex[b] (n=324 323)	Adjusted Odds Ratio (95% CI)
Provision of, median (interquartile range), h/wk			
Care coordination	0 (0-2)	2 (1-6)	<.001[c]
Home care	1 (0-4)	11-20 (3->21)	<.001
In the last 12 mo, %			
Family paid >$1000 in out-of-pocket health care costs	19.1	46.3	3.0 (2.3-3.9)
Child's health care caused financial problems	16.8	56.8	3.6 (2.7-4.7)
Family member stopped working because of child's health	12.0	54.1	2.9 (2.2-3.9)
Family member cut work to care for the child	15.4	45.6	2.2 (1.7-2.8)
Needed additional income for medical expense	15.2	48.7	3.0 (2.3-3.9)

3. Illinois has the highest rate of underinsurance for children with special needs in the country, with 37.8% of children holding insurance or Medicaid coverage that fails to cover all of their medical needs. 29.6% of children covered by Medicaid had unmet medical needs and uncovered expenses.[9]
4. Commonly uncovered expenses include the following:
    a. Insurance premiums

[6] http://www.oppaga.state.fl.us/reports/pdf/0815rpt.pdf

[7] Cost Sharing for Children and Families in Medicaid and CHIP, Georgetown University Health Policy Institute Center for Children and Families. Available at http://ccf.georgetown.edu/wp-content/uploads/2012/03/Cost_sharing.pdf p. 4.

[8] Kuo, 1020-6.

[9] MD Kogan et al., State Variation in Underinsurance Among Children With Special Health Care Needs in the United States, *Pediatrics* 2012: 125(4): 673-680.

b. Uncovered disposable supplies, such as gauze, betadine, surgilube, etc.
c. Physician-prescribed OTC medicines and supplements, including vitamins and minerals to treat deficiencies, medications for reflux and constipation, allergy medications, medicated oral care solutions, and specialized skin preparations
d. Specialized equipment for visual and hearing impairments
e. Medical equipment, such as medical strollers, adapted car seats, or positioning chairs
f. Wheelchair van purchase
g. Noncovered home modifications
h. Assistive devices, such as communication devices, switches, computers, and software
i. Specialty therapy visits, such as respiratory physical therapy or communication therapy
j. Special education costs
k. Special needs trusts and other legal fees
l. Travel and lodging for frequent medical visits
m. Increased utility costs for medical equipment, typically $100/month

Cost sharing will cause families to drop private insurance policies, leading to higher costs to the state that will completely erase any revenues gained through cost sharing.

1. Based on preliminary calculations, we have determined that if just 10 children drop their private insurance plans, Medicaid will have to spend an additional $1,005,200 on health care for MFTD children, an amount that far exceeds expected revenues from cost sharing.[10]
2. Requiring an additional 5% of income to be paid in cost sharing may make it impossible for families to continue paying private health insurance premiums. The average employee contribution for health insurance premiums (family coverage) was $4316 in 2012.[11] For a family of 3 earning 200% FPL, this already represents 11.3% of their income. For a family of 3 earning 300% FPL, this already represents 7.5% of their income.
3. Without private insurance, all costs, including expensive hospital inpatient stays, will have to be covered by Medicaid, greatly increasing costs to the state.

[10] Assuming 100 children hold private insurance, we determined which expenses Medicaid pays for children with private insurance (primarily just nursing care) and without private insurance (all costs). We then took the total cost of all Medicaid state plan services and subtracted out the costs of nursing, home health care, and long term care, which typically are not covered by private insurance and are paid for all children in the waiver. The remaining amount, which only includes services typically covered by insurance, was then divided by the total number of children we estimate did not have private insurance in 2010. Data available at http://www2.illinois.gov/hfs/PublicInvolvement/ccmn/Documents/090811_ccmn_ncps.pdf

[11] Data from Kaiser Family Foundation: http://ehbs.kff.org/pdf/2012/8346.pdf

Cost sharing has been shown to decrease usage of healthcare services, leading to increased morbidity and mortality, as well as costly hospitalization of these children.

1. If just one child has a 3-month hospitalization that is a direct result of decreased health care service utilization, it will cost the state an additional $165,000. Based on data from other states, just this one hospital stay for one child may exceed predicted revenues from cost sharing.[12]
2. A Canadian study showed an increase of 78% in institutionalization, hospitalization and death, and an 88% increase in emergency room visits after prescription drug copayments were added, primarily due to people not taking medications.[13]
3. The RAND insurance study demonstrated that low-income children reduced their use of medical services by 44%, and non-low-income children reduced their use of medical services 15% due to cost sharing.[14] Low-income children charged cost sharing were more likely to be anemic and have significant dental problems.
4. In a study of children in Arizona, a 10% drop in Medicaid enrollment would increase costs by $2121 per child or $3,460,398 per year.[15]
5. Numerous studies have shown that about 20% of individuals simply are unable to pay copayments, and forego prescription drugs and other medical care as a result.

Copayments

Copayments on private duty nursing, regardless of their intent, will impose extreme financial and administrative burdens on nursing agencies. This, in turn, is very likely to prompt agencies to refuse to take MFTD Waiver cases, forcing children into hospitals/institutions to receive their medically necessary care. Rather than alleviating the current nursing crisis in the waiver program, this measure is likely only to exacerbate it and put children at risk.

1. According to the American Academy of Pediatrics, low payment to agencies is the largest problem currently in home health care, and leads to providers refusing to take Medicaid cases: "Specifically, Medicaid agencies have been criticized for paying home health agencies at rates that are insufficient to provide beneficiaries with access to home health services....Not surprisingly, many home health agencies simply do not accept Medicaid referrals."[16]
2. Requiring nursing agencies to collect payments places an enormous financial burden on nursing agencies, which are already struggling after receiving a rate cut in 2012. Increased costs would include computer systems for billing and tracking

[12] In a program with about 2000 participants, Idaho raised $114,329 in the first half of 2010. Wisconsin reported collecting $104,058 in 2006 and $298,047 in 2007 in all of its children's waiver programs combined, which total about 4000 children. See http://www.oppaga.state.fl.us/reports/pdf/0815rpt.pdf

[13] Leighton Ku and Victoria Wachino, The Effect of Increased Cost-Sharing in Medicaid, Center on Budget and Policy Priorities, 2005.

[14] Leighton Ku, Charging the Poor More for Health Care: Cost-Sharing in Medicaid, Center on Budget and Policy Priorities, 2003.

[15] ME Rimsza, RJ Butler, and WG Johnson, Impact of Medicaid Disenrollment on Health Care Use and Cost, *Pediatrics* 2007;119(5):e1026-32

[16] Financing of Pediatric Home Health Care. *Pediatrics* 2006;118(2): 834-8.

payments, mailing costs for payment information and collection, and costs related to collection of unpaid fees.

3. Because agencies cannot deny services due to nonpayment, agencies will have to absorb the costs of families who cannot or will not pay required copayments. Reports and studies have shown that only 28-29% of Medicaid recipients typically pay cost sharing amounts.[17] This means that on approximately 70% of cases, nursing agencies will have an effective 5% rate cut, not including the additional overhead costs to manage and administer the billing and collection process.

No children's waiver programs in any of the 50 states currently impose copayments.

1. Traditionally, children in waiver programs are considered to be equivalent to categorically needy individuals, who are exempt from copayments by federal law, with few exceptions, such as non-emergency use of the Emergency Room.
2. Pennsylvania attempted to add copayments to all programs for children, including children with special needs, and has abandoned the plan due to legislator and family outrage.[18]

No states charge a copayment for private duty nursing for children in waivers or categorically needy children to our knowledge, and CMS is unlikely to approve copayments for only one service.

1. Nursing is covered without copayment in all 50 states as part of the Early Periodic Screening, Treatment and Diagnosis (EPSDT) component of Medicaid for children in waivers and categorically needy children.
2. Illinois could add a copayment to their home health care benefit. This, however, would likely only affect children who receive services through the state's CHIP program, which may include some children in the Nursing and Personal Care Services (NPCS) program. It would likely not affect children currently in the MFTD waiver, because CMS would not approve copayments on categorically needy children, and both CMS and Illinois have always treated MFTD waiver children the same as categorically needy children.
3. While about half the states charge some cost sharing in CHIP programs (28/50 states), most apply these selectively to individual services, such as prescription drugs and non-emergency use of the Emergency Room. We have been unable to find data on whether any of these programs charge copayments for private duty nursing; however, in almost all cases, private duty nursing is handled by waivers or other special programs, which exempt children from copayments for nursing care. As of 2003, Arkansas, Florida and Virginia charged copayments for home

[17] http://www.idahoreporter.com/2010/dhw-slightly-ahead-of-fiscal-projections-on-medicaid-cost-sharing-program/and Cost Sharing for Children and Families in Medicaid and CHIP, Georgetown University Health Policy Institute Center for Children and Families. Available at http://ccf.georgetown.edu/wp-content/uploads/2012/03/Cost_sharing.pdf p. 4.

[18] See http://www.post-gazette.com/stories/news/health/pennsylvania-halts-plan-requiring-copay-in-care-of-autistic-children-656347/ for coverage of this issue.

health care visits for children in CHIP programs, but not in waiver or other special needs programs.[19]

4. Florida and California attempted to raise or add copayments in Medicaid (not just in waiver programs) and were denied by CMS within the past year.[20] CMS appears to be overly cautious in granting approval for copayments if they feel the copayments would limit access to services.

Because copayments are assigned based on utililization of medically necessary care, families with the most vulnerable children are the most likely to be financially burdened, particularly in the lower FPL ranges.

1. The more complicated a child is, the more likely the child will require extensive health care services. For example, children with 24-hour ventilator use or other complicated health issues will require significantly more nursing care hours and nursing interventions, meaning the most complex children will be paying the highest total copays.
2. The greater the level of complexity, the more likely the child is to have unmet medical needs and out-of-pocket expenses, including open nursing shifts and unreimbursed medical costs.[21]
3. The families most likely to be profoundly affected by copayments are also the most likely to abandon jobs and/or insurance if pressed to the economic brink, putting the state at even higher liability for their children's medical costs.
4. Families with more than one child in the MFTD waiver will be utterly devastated by copayment costs.

Premiums and Family Fees

Only 7 states to our knowledge currently impose parent fees or premiums on children in waiver programs through various mechanisms, but CMS is unlikely to approve premiums at this time.

1. 6 states impose "parent fees," but all of these programs were created prior to the Deficit Reduction Act and Affordable Care Act, and it is unlikely CMS would be willing to tolerate such payments at this time. Two states impose these payments in 1915(c) waivers, two through TEFRA programs, and two through both 1915(c) waivers and TEFRA programs. One state, Wisconsin, specifically exempts children with medical technology.
2. If a "parent fee" is approved, it would need to be applied to all waiver programs equitably, including children with autism and developmental disabilities who are served by the Children's Support waiver.

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[19] HB Fox, RG Levtov, and MA McManus, Eligibility, Benefits, and Cost-Sharing in Separate SCHIP Programs, Maternal and Child Health Policy Research Center, 2003.

[20] For a copy of California's denial letter, see http://blogs.sacbee.com/capitolalertlatest/T.%20Douglas%202.6.12.pdf. See also http://www.ama-assn.org/amednews/m/2012/02/20/gse0224.htm and http://www.ama-assn.org/amednews/2012/02/13/gvse0216.htm

[21] DZ Kuo et al., A National Profile of Caregiver Challenges Among More Medically Complex Children With Special Health Care Needs, *Arch Pediatr Adolesc Med* 2011;165(11):1020-6.

3. CMS recently "discouraged" Pennsylvania from imposing premiums for children in waivers and other Medicaid programs for special needs.[22]
4. In Florida's analysis, unanswered questions about Maintenance of Effort provisions gave them concerns that CMS might not approve premiums.[23]
5. Only Arkansas has been approved officially to charge premiums using a 1115 demonstration waiver to cover their medically fragile population.

[22] http://www.post-gazette.com/stories/news/health/pennsylvania-halts-plan-requiring-copay-in-care-of-autistic-children-656347/

[23] See p. 3 of the report: http://ahca.myflorida.com/medicaid/deputy_secretary/recent_presentations/Premium_Cost-Sharing_Childern_Enrolled_HCBS_Waivers_063012.pdf