

# Impact of New MFTD Waiver on Families Fact Sheet

Please note: HFS has provided us with incomplete and in some cases inaccurate information, so this is our best understanding of what may happen as a result of waiver restructuring.

1. **36-50 families will be cut from the new waiver due to income caps.** The new waiver will now be limited to families below 500% federal poverty line. This means approximately 36-50 current families will be removed from the program, and any future families in this bracket will be ineligible. A family of three at 500% FPL would have to pay more than 200% of their income to keep their child at home, causing these children to be forced into hospitals and institutions.
2. **All families above 150% federal poverty line will be forced to pay exorbitant copays that charge children with disabilities a greater amount than children without disabilities.** A family of 3 who earns as little as \$28,635 will be required to pay a copay on each hour of nursing care, up to the federal maximum, which is 5% of their income. A family in this program who earns \$30,000 a year will have to pay \$1432 a year. In contrast, families of non-disabled children who receive Medicaid and have the same income only have to pay a maximum of \$100-\$280 a year. These copays will force many children—especially those in lower income brackets—into institutions because families cannot afford the copayments.
3. **Some children in the current program could lose all services because they have a hospital level of care, and the new waiver serves children with a nursing facility level of care.** The new waiver will now be designated as serving children with a nursing facility level of care. Currently, 99% of children in the program have a hospital level of care. If these children continue to be designated as having a hospital level of care, they will be ineligible for the new waiver. This could mean as many as 610 of the 619 children who participated in the program in 2010 would become ineligible to participate, though some lower income families could retain Medicaid and nursing care without the waiver. Alternately, the state could redesignate these children as having a nursing facility level of care, which is in many cases inappropriate, and directly contradicts the state's own physicians, who have previously designated these children as having a hospital level of care.
4. **The nursing facility level of care designation will reduce nursing hours by 1/2 to 2/3 for all children currently in the program.** 99% of children currently have a hospital level of care and the total cost of their services is compared to a hospital, or \$55,000/month. Under the new program, their total cost must be compared to a nursing facility, which will be at most \$9,429/month. Many of these children will only be able to receive \$9,429/month in nursing care and other services, which will severely limit their nursing care hours.
5. **The sicker or more complicated the child is, the fewer hours of care they will receive.** The state will be using a budget-based approach, assigning a specific budget to each child based on a level of care tool. Children with lower levels of technology, such as oxygen only, will be able to stretch their benefits by using unskilled providers (who receive less than half the pay) to provide much of their care. Children with central lines or ventilators who can only be served by nurses will see their hours limited severely because they can only use more costly nurses. In IL, only nurses are permitted to give medications. In addition, copays will only be assessed on nursing care hours, once again penalizing families of the most complicated children.