

Save the Waiver Fact Sheet

What is the MFTD Waiver? The Medically Fragile and Technology Dependent Waiver (MFTD Waiver) is a home and community based services waiver. It is a Medicaid program that the federal government has granted to the state of Illinois to prevent costly institutionalization and permanent hospitalization of children with catastrophic medical conditions and expenses. It is called a "waiver" because it waives standard Medicaid rules by evaluating only the child's income when calculating eligibility. Otherwise, children are eligible for Medicaid only while living in an institution/hospital, but not once they return home unless their family qualifies financially for Medicaid. Virtually every state has some form of this program.

Who uses this program? Most children on this Waiver are ventilator-dependent, have tracheostomies, or have central IV lines, and require extensive care and services. Most Waiver expenses are used to provide home nursing care for these children, which is typically not covered by private insurance. Without this Waiver, 95% of these children would require permanent hospitalization to receive their care. The capacity of the Waiver is 700 children, and at any time there are approximately 500 children in the program.

How does the MFTD Waiver save money? If these children cannot be cared for at home, 95% would require permanent institutionalization in a hospital. The average cost for hospitalization in a pediatric hospital is \$55,000 per month, while the average cost for children on the Waiver cared for at home is \$15,684 per month. In other words, it is three times cheaper to care for these children at home than in hospitals and institutions. Only 23 children would need to be permanently hospitalized to erase the \$15 million Governor Quinn hopes to cut from the program's budget.

Why is this program necessary? Private insurance does not cover home nursing in most cases, and children from working and middle class families are only eligible for Medicaid if they live in an institution or hospital. This program allows these children to receive nursing care at home, dramatically lowering their expenses to the state. Families in this program would otherwise have to pay out-of-pocket for nursing care and other services currently covered by the Waiver, which average \$188,210 per year. Obviously, most families in Illinois are unable to pay such a high amount out-of-pocket each year.

What would happen if the MFTD Waiver is eliminated or restructured? The only options for families whose children lose the MFTD Waiver are:

- **Permanently hospitalize their child**, so the child then becomes Medicaid-eligible, which would cost the state at least three times as much per child.
- **Quit their jobs or reduce work hours** to financially qualify for Medicaid.
- **Give up custody of their child to DCFS**, meaning the entire cost of the child's care--medical and otherwise--would need to be shouldered by the state.

What is Illinois' legal obligation to these children? Waivers are optional programs, so the state is not required to offer them. However, multiple laws and legal decisions, including the Americans with Disabilities Act and the *Olmstead* decision, support the right of citizens to be cared for at home and not in institutions. Any policy change that increases institutionalization, such as eliminating this Waiver, is subject to legal redress.

What is Illinois' proposal for this program?

Initially, the Department of Healthcare and Family Services (HFS) recommended eliminating the waiver and creating a state program that would provide home nursing care for children who don't qualify financially for Medicaid. Thanks to our advocacy efforts, Governor Quinn has suggested renewing the program, but with a \$15 million budget cut. Our most recent information comes from a proposed amendment to SB 2840, which states the waiver would be limited to families who earn less than 500% federal poverty line (\$95,450/family of three) and would impose exorbitant copays and premiums on every hour of nursing care received. If this amendment goes through, hundreds of children would be cut out of the program and would end up hospitalized at three times the cost of home care. Many other families would be unable to afford the exorbitant copays and premiums and would lose eligibility and services as well.

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