

Contact: MFTD Waiver Families
www.SaveMFTDWaiver.com
MFTDWaiver@gmail.com

Chicagoland Press Contact: 630-803-3189
Downstate Press Contact: 217-274-5131

For Immediate Release

House Bill Would Force Medically Fragile Children into Hospitals

Changes in Medicaid program for children on ventilators would cost families 200% of their income or force State-paid hospitalization at \$660,000 per year

The Illinois House of Representatives is set to vote on Medicaid reform this week, and children who use ventilators may be cut off from the program that currently provides their home nursing, the Medically Fragile Technology Dependent (MFTD) Waiver.

The proposed legislation, an amendment to SB 2840, limits eligibility to families who earn less than 500% of the federal poverty line, or \$95,450 for a family of three. Families above this threshold would be forced to pay more than 200% of their income toward private duty nursing if they want to keep their children at home.

When this change goes into effect on September 1, 2012, hundreds of children may need to be hospitalized permanently after losing their home nursing care. Hospital care costs a minimum of \$660,000 per child per year, three times more than home care through the MFTD Waiver. The state is required by federal law to pay for children in institutions, including hospitals, meaning they would need to shoulder the entire cost of hospital care.

If only 23 children are hospitalized permanently, the state would see all \$15 million in anticipated savings from restructuring this program disappear.

Without this program, families in the MFTD Waiver would need to earn enough to pay an average \$188,210 in out-of-pocket nursing care expenses. Yet, the proposed bill cuts off families who earn as little as \$95,450, making it mathematically impossible for these families to keep their children at home.

Most of the affected children have private insurance, but even superior policies do not cover or severely restrict nursing care. The MFTD Waiver is the only funding option for children who require home nursing care due to medical technology, such as ventilators, tracheostomies, or central intravenous lines.

Other provisions in this bill are equally onerous for these children and their families. One section would strike down a law already on the books that guarantees community-based care for children under 21, in direct opposition to Gov. Pat Quinn's call to move citizens into community care settings, and a likely violation of the Supreme Court *Olmstead* decision.

Another provision would force lower income families remaining in the MFTD Waiver to pay exorbitant monthly premiums and copays on every hour of nursing care they receive, affecting the children with the greatest medical needs disproportionately.

Ironically, this same battle was fought more than 30 years ago, when President Reagan championed the case of Katie Beckett, a child with a tracheostomy living in a hospital. The MFTD Waiver was founded around that time to prevent costly hospitalization and institutionalization of these children.

This proposed House bill would undo a thirty-year history of serving these children at a lower cost in the community.

About MFTD Waiver Families

MFTD Waiver Families is a group of 50 concerned families of children on the Waiver or in other Illinois programs. We advocate for renewal without restructuring of the MFTD Waiver to allow our children to continue living at home. Additional details about the Waiver and family stories may be accessed at <http://www.SaveMFTDWaiver.com>.

###

For more information, please email MFTDWaiver@gmail.com. We have families available for interviews throughout most regions of the state. For sources of information cited, please see <http://SaveMFTDWaiver.com/sources.html>.