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For Immediate Release

Cuts to Medicaid Waiver Threaten Children with Permanent Hospitalization

Cost Sharing, Income Limits and Reduced Eligibility Could Lead to
Increased Hospitalizations at a Higher Cost

Governor Pat Quinn has recommended a \$15 million cut to a critical Medicaid program for 500 of Illinois' most medically fragile children. This joint state/federal program, the Medically Fragile and Technology Dependent (MFTD) Waiver, currently provides home nursing care to children across Illinois with tracheostomies, ventilators, central lines, and other forms of medical technology.

The \$15 million in cuts could include charging families a monthly fee to participate, limiting eligibility by parental income, cutting services, and reducing costs by forcing less medically-involved children out of the program.

According to the ARC of Illinois, the state hopes to gain \$5.1 million by charging families to participate, with premiums of \$10,000 or more per family.

Kira M. is one child in the MFTD Waiver, a typical second-grade honor roll student who uses a tracheostomy and a ventilator due to a potentially fatal breathing regulation disorder. But because she receives home nursing care paid for by this program, Kira can live at home with her family and attend school much like any child her age.

That could all change if Kira's family loses eligibility for the MFTD Waiver or cannot afford the monthly premiums. Without the nurses who monitor her ventilator, suction her airway and maintain her tracheostomy, she could suffer a sudden respiratory arrest.

Children like Kira could end up living permanently in Illinois pediatric hospitals at an average monthly cost of \$55,000. In contrast, the state is now paying on average \$15,684 per month for home nursing care under the Waiver, three times less. Illinois is obligated to pay for eligible children's care in institutional settings, including hospitals, but paying for these children to receive home-based care is optional under federal law.

Losing her home nursing care would gravely disrupt Kira's life. It would take her from the love of her family and the routines of a supportive home life. She would no longer be able to attend school, forcing her to leave her teacher, classmates, and friends. She would be relegated to a bed in a hospital for the rest of her life.

If only 23 of the 500 children currently in the program end up permanently hospitalized, the state would see all \$15 million in anticipated savings disappear.

Terra Atkinson, parent of another child on the Waiver, expressed the profound effects of losing this program: “Losing the MFTD Waiver would tear our close knit family apart, forcing us to place our daughter in a hospital setting in order to receive the care that she would need. At home, with her three sisters who all adore her, she thrives.”

The proposal to cut the budget of the Waiver comes directly out of Quinn's call to trim Medicaid spending to resolve the state budget crisis. Ironically, cutting the budget of the MFTD Waiver could well saddle Illinois taxpayers with steeply higher Medicaid bills, raising spending instead of cutting it.

Virtually every state has program like the MFTD Waiver that allows working and middle class families with children who have catastrophic medical conditions and expenses to qualify for Medicaid. The child's medical condition, income and assets determine eligibility for these programs. In contrast to Illinois' proposal, only a handful of states charge nominal monthly premiums, and virtually all states base eligibility off of the child's income, ignoring parental income.

While many children in Illinois' MFTD Waiver have private insurance, these policies sharply restrict or even deny home nursing care outright. Without the Waiver, even families substantially above the poverty level would be unable to absorb the extreme costs of keeping their children at home.

Children like Kira could be forced out of their homes and become permanent residents in hospitals.

Losing the MFTD Waiver would be devastating for these families. As Atkinson stated, "To lose the Waiver would be to lose our daughter."

About MFTD Waiver Families

MFTD Waiver Families is a group of about 50 concerned families of children on the Waiver or in other Illinois programs. We advocate for renewal 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>.

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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>.