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## For Immediate Release

# IL Legislature Passes Bill Forcing Children on Ventilators into Hospitals

## Cuts Could Increase Costs to State by 300%

The Illinois legislature has passed Senate Bill 2840, a sweeping Medicaid bill that includes unprecedented cuts to the state's program for children who rely on ventilators and other forms of medical technology.

The state of Illinois, which already ranks 48<sup>th</sup> in caring for people with disabilities in home and community based settings, will now require families who earn as little as \$30,000 to pay 5% of their incomes to keep their children at home. In addition, families of three earning \$95,450 or more would be cut from the program entirely and forced to pay the full \$188,210 average cost of home care out-of-pocket.

Ironically, care in institutions and permanent hospitalization would remain free, even for the children of millionaires. Many families whose children are cut from the program or who cannot afford to pay the new fees would be forced to place their children in hospitals, which would be covered in full by the state, even though it costs three times more.

The Illinois Legislature passed the bill on Thursday, May 24, 2012, one day before the funeral of Medicaid pioneer Katie Beckett, who died on May 18<sup>th</sup> at the age of 34. Thirty years ago, Beckett spent her first three years living in a hospital because Medicaid would only pay for her care in the hospital, even though it was six times more expensive. President Reagan discussed her case as an example of irrational regulations, stating, “When we see a case of this kind, it reveals that hidebound regulations can be a tremendous expense to the taxpayers and do no good for the patient.”

Beckett’s case triggered the creation of what have become known as “Katie Beckett Waivers,” programs that states can implement to keep children with enormous medical expenses out of hospitals by providing them with nursing care at home. The Medically Fragile Technology Dependent Waiver is Illinois’ version of this program, and it saves Illinois taxpayers about \$236 million per year.

SB 2840, expected to be signed by Governor Pat Quinn shortly, would make Illinois the only state in the country that fails to make home-based care available to all children relying on life-saving medical technologies.

Equip for Equality, Illinois’ federally mandated Protection and Advocacy organization, stated in a letter to Illinois’ Governor Pat Quinn, “the income ceiling proposed in this legislation, which would apply solely to services provided in the home, would violate the Americans with Disabilities Act as interpreted by the Supreme Court in the *Olmstead* decision, because it would force children into institutions.”

The cuts to the MFTD Waiver were developed by Julie Hamos, director of the Illinois Department of Healthcare and Family Services, working with four state legislators: Rep. Sara Feigenholtz (D-Chicago), Sen. Heather Steans (D-Chicago), Rep. Patti Bellock (R-Westmont), and Sen. Dale Righter (R-Mattoon).

### **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 program, local media reports, video content and family stories may be accessed at <http://www.SaveMFTDWaiver.com>.

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For more information, please email [MFTDwaiver@gmail.com](mailto:MFTDwaiver@gmail.com). We have families available for interviews and home visits throughout most regions of the state. For sources of information cited, please see <http://SaveMFTDwaiver.com/sources.html>.