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For Immediate Release

Moments After Medicaid Pioneer Katie Beckett's Death, Legislature Proposes to Gut Illinois' Version of Katie Beckett Waiver

Cuts Would Force Hundreds of Children into Hospitals at Three Times the Cost

Just three days after Medicaid pioneer Katie Beckett died, Representative Sara Feigenholtz filed an amendment to SB 2840 that would effectively gut Illinois' version of the Katie Beckett Waiver. This waiver, called the Medically Fragile Technology Dependent (MFTD) Waiver in Illinois, provides home nursing care for 500 children who use ventilators and other medical technology.

Katie Beckett gained fame 30 years ago when President Reagan took up her cause. Katie had spent three years—almost her entire life—living in a hospital because she needed a tracheostomy to help her breathe. While she lived in the hospital, her care was paid for by Medicaid, as is federally required by Social Security Administration rules. But as soon as she left the hospital, her family's income was counted against her and she no longer qualified to receive Medicaid. Ironically, her care at home cost 1/6 of what it did in the hospital.

President Reagan discussed her case as an example of irrational regulations and cited it as an illustration of his now famous drive to “cut the red tape.” As he stated, “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.”

Katie’s case triggered the creation of what have become known as “Katie Beckett Waivers,” optional programs that states can implement to keep children with enormous medical expenses out of hospitals by providing them with nursing care and other services at home. These programs have proved tremendously successful, saving states millions of dollars each year.

These programs, unfortunately, remain optional for states. In Illinois, where a budget crisis is forcing dramatic cuts to Medicaid, legislators have proposed to gut the MFTD Waiver by introducing an income cap and exorbitant premiums and copayments for the program. The income cap would mean that a family of three earning 500% the federal poverty line would have to pay 246% of their annual income out-of-pocket, which is of course mathematically impossible. These children would be forced to live in pediatric intensive care units, at three times the cost to the state.

While these cuts may save money on paper, the reality is far different. As Reagan realized 30 years ago, cuts like these lead to tremendous increases in costs to taxpayers due to greater hospitalization costs.

As Reagan stated, “Now, by what sense do we have a regulation in government that says we’ll pay...to keep someone in a hospital that we believe would be better off at home, but the family cannot afford one-sixth that amount to keep them at home?”

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>.

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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>.