KATIE BECKETT OPTION

A LITTLE GIRL AND HER PRESIDENT

Katie Beckett was a happy five-month-old living with her family in Iowa when she contracted a devastating brain infection. She suffered paralysis that left her hospitalized on a ventilator. Katie’s middle-class family had a million dollars of insurance, but that was soon exhausted. Medicaid picked up her coverage and paid for her hospitalization for nearly three years, but when she improved enough to live with her family, Medicaid cut her off. The family needed the help of professional nurses to meet her needs at home, but even though home nursing care was much cheaper than hospitalization, Medicaid would not cover it. Medicaid would only pay for Katie’s care if she remained in a hospital or nursing home – at much greater cost to taxpayers.

Katie’s family faced a cruel dilemma. They could let Medicaid cover her institutionalization for the rest of her life at enormous taxpayer expense. Or she could live at home with a loving family, but without the nursing care her fragile medical condition required. Medicaid simply would not pay for her care unless it was in an institution, even though home care was what the family desperately wanted, and it would be less costly to taxpayers. In 1981, President Ronald Reagan heard about Katie’s dilemma and personally intervened.

President Reagan created the Katie Beckett Waiver, which allowed Katie, and children like her, to receive their care at home, while retaining their Medicaid coverage, regardless of their parents’ income. Katie grew into an accomplished motivational speaker and was a champion for people with disabilities until her death 31 years after President Reagan changed the course of her life and the lives of other children like her. In addition to President Reagan’s Katie Beckett Waiver, Congress has created other options for states to serve children like her. Thirty-six years later, every state - except TN - has a Katie Beckett waiver or an equivalent option.

Now, by what sense do we have a regulation in government that says we'll pay $6,000 a month 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?

President Ronald Reagan
TENNESSEE IS THE ONLY STATE THAT STILL DENIES MEDICAID TO CHILDREN LIKE KATIE.
WE CAN DO BETTER!

WHAT'S THE PROBLEM?

- Children who have severe physical and mental health care needs and whose parents make too much money for Medicaid (TennCare) face the risk of not being able to access necessary health care and long-term supports and services.

- If middle-income families have private insurance, but not TennCare, out-of-pocket expenses and gaps in services can spell financial ruin, leaving the families unable to meet their children's needs.

- Some families are even forced to give up custody of their child or put them in an institution because they can’t afford their care.

WHAT CAN BE DONE TO HELP TENNESSEE FAMILIES AND THE STATE?

Thanks to President Reagan, states have several options to cover children like Katie.

Covering children like Katie would reflect Tennesseans’ strong family values. It would use state dollars more efficiently. Other states have shown that the overall cost to the state is low because most children who get Medicaid through these programs also have private insurance. Some states pay a fraction of the children’s health care costs, with private insurance, families and other sources covering the rest. And children who grow up with their families and receive the health care they need are more self-reliant as adults and less dependent on government services.

If your family could benefit from an option to cover children like Katie Beckett, Tennessee lawmakers need to hear your story! To get help with sharing your story, please contact Family Voices of Tennessee at 615-383-9442 or familyvoices@tndisability.org.