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### **The little girl and the Great Communicator, years later**

by [Luther Granquist](#) // November 10th, 2011

Thirty years ago, on Nov. 10, 1981, President Ronald Reagan told a story about an Iowa girl story at a press conference. “We just recently received word of a little girl who has spent most of her life in a hospital. The doctors are of the opinion that if she could be sent home and receive her care at home, it would be better for her; this spending most of her life there and away from the home atmosphere is detrimental to her. Now, it would cost \$1,000 a month for her particular ailment to send her home. Her parents have no way that they can afford that, and the regulations are such that Medicaid now cannot pay for that if she goes home. The alternative is Medicaid continues to pay \$6,000 a month to keep her in a hospital, when the doctors say she would receive better treatment and be better off at home. But her parents can’t afford to have her taken off Medicaid.”

“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 of that amount to keep them at home?” Reagan, who was the 40th President of the United States, was known as the “great communicator.” He often used personal anecdotes to make his point. The statement drew widespread media coverage and ignited nationwide debate over home care.

Earlier that year Reagan had proposed that states should be able to seek Medicaid home and community-based waivers so that persons with disabilities in institutions could receive medical assistance services in a community setting. Bob Gettings, the Washington guru for state mental retardation directors, wrote at the time that the Reagan administration viewed this waiver proposal “as a mechanism to help states curb future increases in Medicaid costs,” and not as a means to provide more humane and effective services. Congress included the waiver provision in the Omnibus Budget Reconciliation Act of 1981 approved that summer. Katie Beckett, the three-year old child from Cedar Rapids whom Reagan spoke of, could not benefit from a waiver program.

Those hadn’t been implemented yet. As a child with a disability, she was eligible for Social Security Insurance (SSI) and Medicaid but Medicaid only while in a hospital. At home, her middle-class parents’ income would disqualify her for Medicaid. Two days after Reagan’s press conference, his Secretary of Health and Human Services authorized an exception for Katie’s parents’ income, making Katie eligible for Medicaid. She could then go home and did so, shortly before Christmas. Press reports indicated that the Reagans sent her a rag doll.

Reports differ whether the Reagan administration authorized exceptions for other children in Katie's circumstances. But his administration did propose and the Congress did adopt the policy that in determining Medicaid eligibility for children who met SSI disability standards and needed an institutional level of care parental assets would not be considered and parental income would not be deemed available. The premise for this so-called TEFRA eligibility option was that the state would spend less for medical assistance for these children outside of an institution.

Whether Reagan wanted to do right or just sought another way to cut Medicaid expenditures, the waiver and the TEFRA eligibility option created three decades ago have greatly enriched the lives of children and adults with disabilities and provided essential support for their families.

As for Katie Beckett, she continues to live in Cedar Rapids, where she and her mother Julie are advocates for disabled children. Although she typically shuns the limelight, she has spoken at national gatherings of children's advocates.

"Just because you reach a certain age does not mean that you are miraculously cured of all the things you have endured," she told one group in Washington, D.C. in 2010. At that time, she was advocating for an expansion of home and community-based care so that people with disabilities have more options to live outside of nursing homes and institutions. She still lives with her family and relies upon nurses who give her in-home treatments. She uses a ventilator to breathe, up to 15 hours a day. She has taken classes in counseling but pursues a goal of writing children's books and has taken writing classes to reach that goal.

Katie Beckett told National Public Radio last year that her goal is to have as normal of a life as possible. "Living at home," she told her audience in Washington, "is where we learn to be a part of the larger picture of life."

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