

Katie Beckett: Patient Turned Home-Care Advocate

by JOSEPH SHAPIRO



Credit: John Poole/NPR

November 8, 2010

It started with a 3-year-old girl in a hospital and the president who was angered when he learned that federal rules prevented her from going home.

The president was Ronald Reagan. The girl, Katie Beckett, had contracted viral encephalitis, a brain infection, when she was just five months old. She'd gone into a coma for ten days, and when she came out she suffered a paralysis that left her unable to breathe without the help of a ventilator most of the day.

After more than two years living in St. Luke's Methodist Hospital in Cedar Rapids, Iowa, the family reached the limit of what its private insurance would pay for Katie's care. Medicaid, the state and federal health insurance for the needy, started picking up the cost of that expensive breathing machine and other care.

“

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

But Medicaid would pay only as long as the little girl lived in the pediatric intensive care unit at the hospital.

Beckett's parents, Julie and Mark, said they wanted their daughter at home. The girl's doctors agreed, saying she needed to grow up in a more normal environment than a hospital room.

that amount to keep them at home?

”

- President Ronald Reagan, Nov. 10, 1981

Presidential Intervention



timeline

Milestones In Long-Term Care Policies

At first, federal officials refused to make an exception. But then Reagan was told about the family. A few days later at a [press conference on Nov. 10, 1981](#), Reagan expressed his anger at what he called an example of a cold bureaucracy.

It cost six times as much for the girl to live in the hospital, the president said, and "this spending most of her life there and away from the home atmosphere is detrimental to her."

He added, "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

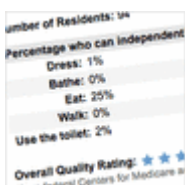
to keep them at home?"

President Reagan changed the Medicaid rules and Katie Beckett left that Iowa hospital and went home in time for Christmas. Shortly after, the government allowed exceptions in other states so that parents like the Becketts, who made too much money to qualify for Medicaid, could be covered for their children with extreme medical costs.

At the time it was thought there were no more than 100 or 200 children in similar situations around the country. But that turned out to be an underestimate. In the three decades since, more than a half million children have received waivers — now often called "the Katie Beckett waiver" — to get their care at home.

When Katie Beckett moved home, the assumption was that government was extending kindness to the family of a child who wasn't expected to live for very long.

"People didn't talk about her in that period of time like she'd survive tomorrow," says Julie Beckett, the Katie's mother.



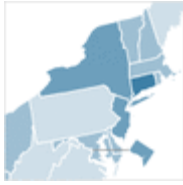
SEARCH: NPR Nursing Home Database

Interactive database: The independence level of residents at nursing homes around the country.

But technology improved and children turned out to be healthier in their own homes. (This was not a surprise: Katie's doctors had also argued that she was better off at home because a hospital is full of sick people and it's easy to pick up an infection while there.)

Advocating For Home Care

Last month, Katie and Julie were in Washington, D.C., for a celebration of the 75th anniversary of a



MAP: Independence Among U.S. Nursing Home Residents

The degree to which nursing home residents can do things for themselves varies from state to state.

provision of the original Social Security Act that set up federal programs to promote maternal and child health.

Katie, now 32, spoke to an audience of children's advocates. She was introduced by Donald Berwick, the head of Medicare and Medicaid, and spoke right after White House senior adviser Valerie

Jarrett.

"Just because you reach a certain age does not mean that you are miraculously cured of all the things you have endured," she told the crowd, arguing 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.

Katie, and particularly her mother Julie, have become advocates for disabled children, crossing the country to argue for the need for states to spend more on programs that allow people to live in their own homes. Sometimes, back home in Iowa, someone will recognize her as the little girl in the hospital who got national news attention 29 years ago.

But Katie says she doesn't enjoy the limelight. She's more comfortable, she says, when she's anonymous, like when she's by herself reading in her favorite bookstore back home in Cedar Rapids.

"I'm the girl they see drinking a latte at Barnes & Noble," she says. "I'm not the girl from the newspaper or from the television station."

Katie still relies upon nurses who, for an hour every night, give her treatments. She still needs the ventilator to breathe, up to 15 hours a day. She's taking classes at a local community college in counseling. But what she really wants to do is write children's literature. She's taking a writing class, too, and hoping to sign up for a graduate program in fine arts next year.

It's a pretty normal life, she says. She wants the same things as other 32-year-olds.

"Living at home," she told her audience in Washington, "is where we learn to be a part of the larger picture of life."

“

Just because you reach a certain age does not mean that you are miraculously cured of all the things you have endured.

”

- Katie Beckett