

## Pediatric Home Care loses a Hero

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Every now and then you find someone who truly makes a difference in history. I wanted to share this article about a young, disabled woman who TRULY made a difference in the much needed care of disabled children. God Bless you Katie!

Katie Beckett, a pioneer for health reform for children with disabilities, died last month in her home town of Cedar Rapids, Iowa

Katie's story began in 1978 when at four months old she contracted viral encephalitis and suffered multiple complications. The illness left her partially paralyzed, with swallowing difficulties and unable to breathe on her own. Although she made great strides towards recovery, Katie remained with residual deficits and ventilator dependent. Nevertheless, in 1981, after spending three years in a pediatric intensive care unit, Katie and her parents were ready to go home, and this is where their remarkable journey for health care reform began.

While hospitalized, Katie exhausted her private health insurance coverage, and she began to receive Medicaid to cover her health care costs. Unfortunately, Katie would not be eligible to receive Medicaid if her care continued at home since her parent's income would be taken into account when determining Medicaid eligibility.

In order for Katie to continue to receive Medicaid coverage for her health care, she would have to remain institutionalized, even at six times more the cost than providing care at home. It was this irrationality in the Medicaid rules that brought Katie's ordeal to the national stage, and eventually would lead then Iowa Congressman Tom Tauke, President Ronald Reagan and many others to intervene on Katie's behalf.

Provisions in the Medicaid law were waived to allow Katie to receive care at home under the Medicaid program. The waiver program became known as the "Katie Beckett" waiver.

The Katie Beckett option was enacted permanently into law in 1982 through the Tax Equity and Fiscal Responsibility Act. The option enables states to provide Medicaid to certain children with disabilities living at home, but who would, without the option, be unable to qualify because their parents' income or resources put them above the level of financial eligibility.

Julie Becket, Katie's mother, was a guest speaker at the NAHC Annual Conference in 1984. She spoke about the progress Katie had made in the short time she had been at home, and how grateful she was for the home care Katie was receiving.

Katie would eventually graduate from college, learn to live on her own, and became a tireless advocate for children with disabilities.

In 1981 when Katie's ordeal began it was estimated that only several hundred disabled children would benefit from the Katie Beckett waiver. Today that number is over 500,000. Advances in medical technology and disease management has made it possible for even the most severely disabled child to be care for at home rather than institutionalized.

The National Association for Home Care & Hospice (NAHC) salutes its pediatric home care members for their dedication in caring and supporting our most vulnerable members of society. The Pediatric Home Care Association of America, a NAHC affiliate, will continue to fight to ensure Medicaid and CHIP dollars are adequate to care for the children in the community and to ensure that federal regulations do not prevent pediatric home care agencies from adequately caring for these medically fragile children.

*Source: National Association for Home Care & Hospice*