

Mary Katherine “Katie” Beckett

1978 – 2012



Her name may not be a household word, but thanks to Katie Beckett and her mother, more than a half million American children with disabilities have been able to live in their own homes and participate in their communities.

Shortly after her birth, Katie contracted viral encephalitis, leaving her partly paralyzed, unable to swallow and barely able to breathe. Under the Medicaid law at that time, Katie could only receive care through Medicaid if she remained in the hospital even though her family could care for her at home with a ventilator.

Her mother, Julie, began lobbying politicians and bureaucrats including an Iowa Congressman who convinced the Reagan Administration that the system should be changed to allow states to provide Medicaid to children receiving care in their homes. Ultimately President Reagan intervened, citing the case as an example of “hidebound regulations” and marking a shift in policy toward government support for home health care. Shortly after, Congress passed the *Tax Equity and Fiscal Responsibility Act of 1982*, often called the Katie Beckett Waiver, under which Medicaid pays for home care for disabled children.

On May 18, 2012, Katie Beckett died in the same Cedar Rapids, Iowa, hospital where she was born 34 years ago. The cause was a digestive disorder not related to her respiratory disability. According to her wishes, her body was donated to the University of Iowa.

“I think she just wore out,” her mother said. “Katie was doing a lot of public speaking – she loved the banter of questions and answers. She had found her niche. She did more in her 34 years than most people do in a lifetime.”

Katie was trached and used a ventilator 16 to 18 hours a day when she finally moved home from the hospital as a toddler. Gradually she was able to breathe

on her own and only required the ventilator at night.

She traveled to Washington numerous times to testify before Congressional committees and to serve on national disability policy panels. She graduated from Mount Mercy College in 2001 with a bachelor’s degree in English and a creative writing minor. She was working on a novel and had completed 10 chapters. “I found it on a flash drive when I was closing her apartment,” Julie Beckett said. “I haven’t read it, but I know the heroine had a disability, although that isn’t the focus of the book.”

Her disability was not the focus of Katie’s life either: Advocacy was. As she wrote about herself at age 22, “It was not my choice but rather a path chosen for me. Whatever and wherever my career takes me, I know that I will always be an advocate for people with disabilities. You can count on that.”

Katie was the first co-chair of Kids As Self-Advocates (KASA), a project of Family Voices, the organization co-founded by her mother that aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. KASA is a national, grassroots organization created by youth with disabilities that encourages teens and young adults with disabilities to speak out, make choices and advocate for themselves.

“Katie was remarkable,” Julie said. “She didn’t mince words. She understood her situation and her ability to change minds. We had so much fun together; I feel like she’s still here. I will keep on going. That’s what we planned to do.” ▲