

What Ever Happened to Katie Beckett?
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In the Section on Home Health Newsletter – Fall 2002

The Early Years

People in the disability community are aware that my journey down the disability path began at six months of age. I contracted viral encephalitis and after a grand mal seizure, which sent me into a coma, the encephalitis attacked my central nervous system and caused nerve damage to various parts of my body. Most significantly affected was my ability to breathe. I was placed on a ventilator and later a tracheotomy was performed. I required multiple medical procedures even after awoke from the coma. I was totally paralyzed and could not even handle my own secretions. This paralysis resolved itself in the first few years, but I did not breathe at all until I was almost two years old. At this time the medical community and the insurance companies believed only medical professionals could perform the care that I needed. However, after three years in a pediatric intensive care unit and my parent's active participation in my day to day routine, it became clear that I needed to come home. But the government was not so easily convinced. Rules and regulations prohibited my family from safely taking me home. The government had to create a new standard so I could come home. The home and community-based waiver program, often called the Katie Beckett Waiver program was the new standard. It allowed kids who were forced to be institutionalized or hospitalized, many on assistive technology, to be treated at home by keeping them eligible for Medicaid by waiving the income deemed to them by their parents, since that income could not or would not cover the cost of their care at home and would be waived if they remained in an institutional setting. This new program helped over a half a million people with disabilities especially kids to live in their homes and communities.

School and Work

I've been able to do so many things since my release from the hospital. I was able to be off the ventilator for more than 6 hours before discharge. I started school on time and was never required to be in a special education classroom. My fellow students considered me different because of my disability throughout grade school and high school. This was not only because of my getting sick numerous times during school hours but also because while other kids were being kids I was speaking in front of Senators, Congressman, Governors and even Presidents. I helped in trainings for medical professionals and even parents of children with special health care needs. I worked as an intern at Exceptional Parent Magazine between my sophomore and junior years in high school living with my friend Betsy Anderson in Boston, MA. There I had to direct my own medical care. I monitored the nurses that provided my treatments and cared for my ventilator.

I started my advocacy career at age ten. It was not my choice but rather a path chosen for me. It was not until I was twelve or thirteen that I realized the important work I was able to do because I was who I was and how much this work helped other kids. I realized that this was something I was born to do so I was willing to take on the extra attention given to me by other students and teachers when I returned home even if it was embarrassing at times. Being single out even for

doing something so rewarding is uncomfortable and can create tension with other students. It made it difficult sometimes to fit in and just be normal.

My first job was at a music store at the mall. I felt like I had a “normal” job where the subject of my disability would only come up on occasion. As a matter of fact, I was offered the job because I would bug them about when new releases were supposed to be out and fill the manager in on new information about music performers. It was a great job with a good discount of CD’s and other musical related materials. I could have stopped my advocating because of the added responsibility of a job but I did not. Advocacy is in my blood and in my soul. I care too much about the people I help, to push them aside. For me, it’s not about the attention I’ve gotten over the years, it’s about the kids and families I have helped by being a role model of sorts. They see me succeed and that helps them to do the same.

I wanted a job helping people even though the music store was great. I had been volunteering at the YWCA in the second hand shop that supports the only homeless shelter for woman and children in Eastern Iowa. I learned many things about the challenges these young children and their families face. I wanted to make their lives better. I applied for a receptionist’s job at the YWCA. The job title receptionist does not begin to cover what the job entailed. I was a first responder to our sexual assault and domestic violence victims. I helped get them in touch with our counselors. I assisted in the neutral exchange program, which allows divorced and separated couples a drop off site for their children with a third party so that the couples need not see one another. I also helped with the supervised visitation program, which allows parents who have abused their partner to visit their children in a neutral site under the watchful eye of an abuse counselor. I am now the assistant to the supervisor for this program having graduated from the receptionist desk.

KASA

While this job is very rewarding, what I find is my most rewarding work is a program started by Family Voices, who speak on behalf of children with special health care needs. This organization with 40,000 members was founded by my mother, Julie Beckett, Polly Arango and Josie Woll. The program I am referring to is KASA-Kids As Self-Advocates. KASA teaches kids with disabilities how to be an active participant in their health care. It helps them to talk to their doctors, nurses, therapists, home health care providers, teachers and their parents about how they feel about their disability. Kids need to teach these adults that as kids they can have input into decision-making about their lives. Expressing what they need to be independent. A young person’s idea of what they can do is often far different from these well-meaning people. For instance, while I still require the ventilator at night few people can tell I need it. But the trach is a dead give away that I have some very special needs. Most people accept me for who I am but some treat me cautiously, believing I cannot or should not do everything. I have to teach people everyday, as do so many of my KASA friends. We want to live a normal life but normal to us has a few different meanings.

KASA helps kids through our website at www.FUKASA.org. We provide articles on how to talk to parents and other professionals about health care decision-making. For example, sample questions are provided and listening tips to help assure the messages they are receiving are clear.

We have developed information on how to create a contract with your doctor before a hospitalization or medical procedures is done which allows a patients input on decisions made. We also teach kids how to file their own complaints. The site has a list of disability-related organizations, which kids can contact about specific issues. The seven, youth board members who run KASA also present to parent groups, medical professionals and organizations who serve people with disabilities on the advantages of using KASA services for themselves and their constituents. KASA is 400 members strong and has recently received a grant from the United States Diana Princess of Wales Memorial Fund. We will be using this grant to reach out to more and more young people with disabilities.

I am proud of the work I have done with KASA, but I am even prouder of the fact that I graduated from Mount Mercy College in Cedar Rapids this last spring with a Bachelors Degree in English and a creative Writing minor. I am currently enrolled in the paralegal/Legal Assistants program at our local community college. 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.

Update

Katie has recently been appointed to the Advisory Panel for the Ticket to Work and the Work Incentives program. She is still enrolled at Kirkwood Community College, living in her own apartment and searching for a job. She is still actively involved in the KASA Project.