



Katie Beckett Waiver Brings Home Care to Kids with Serious Disabilities

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In many states, the Medicaid program can generally be seen as having a strong institutional bias when it comes to coverage of long-term care, forcing many families to place loved ones in skilled care facilities or similar institutional settings, despite longstanding efforts to serve individuals with disabilities in mainstream settings. As reported in a recent [SNA blog post](#), even when there are waiver programs in place to provide community-based services, waiting lists tend to be daunting. The “[Katie Beckett Medicaid Waiver](#),” which has been enacted in some form in 24 states, provides an alternative for many individuals under 19 who have serious conditions related to their disabilities which, but for the Katie Beckett Waiver, might cause them to be placed in an institutional setting.

For those meeting the requirements, Katie Beckett Medicaid Waivers cover “institutional level” care in a home setting when it would cost no more than a nursing home or hospital. I have never encountered a situation in which the cost of home care became a disqualifying factor, although I’ve seen instances where medically necessary treatment couldn’t be adequately delivered outside a nursing home or other institutional setting, typically based on the physical (rural) location of the family. Financial eligibility is based only on the child’s income and assets, without regard for the parents’ financial status. Unlike Home and Community- Based Services (HCBS) waiver programs, states cannot limit the number of “Katie Beckett” participants, so there are no waiting lists.

Among the states that have implemented this waiver, the definition of “institutional level of care” differs, and as is the case with many programs that have the “institutional level or care requirement,” we have found that it can be difficult to determine who is medically eligible. The precise services available differ by state, as well. Some programs even include respite services, enabling family members to run errands or take needed breaks while skilled professionals watch over their child.

The advantages to home care are significant. Most notably, home care keeps families intact, enabling a child with special needs to live alongside loved ones who are usually far more attuned to their individual needs than institutional caregivers can be. Therapists and other professionals who serve them often develop close, long-lasting relationships with the entire family, contributing to a tight circle of support.

Needing “institution-level care” doesn’t necessarily mean a child can’t participate in community activities, so living at home presents greater opportunities for social inclusion. In fact, Katie Beckett, for whom the waiver is named, eventually attended college, lived in her own apartment and became an influential self-advocate.

The waiver originated in the early 1980s, when Katie Beckett’s parents fought to overturn a Medicaid regulation that would have forced her into a nursing home. After she was hospitalized for several years due to encephalitis, her doctors determined that she could be treated at home, given appropriate supports. By that time, her parents’ personal insurance had been tapped out and, given their financial resources, Medicaid would only cover institution-based treatment – even though the cost would be six times that of home care.

Katie’s mother argued that this was bad policy, and the story eventually reached President Reagan, who agreed and waived the Medicaid rule on a one-time basis. Congress subsequently passed the Katie Beckett Waiver, making it optional for states to make the same coverage available to others.

Since the eighties, the Katie Beckett Waiver has benefited over half a million children. On the other hand, state-by-state differences in availability, eligibility guidelines and services can be confusing. Even if a state doesn’t offer the Katie Beckett Waiver, it is possible that the state may have another Medicaid-funded program that can help provide needed services in the home, keeping the family unit intact. Families may find it helpful to consult a special needs attorney in order to evaluate their options.

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