



The TEFRA Medicaid State Plan Option and Katie Beckett Waiver for Children – Making It Possible to Care for Children with Significant Disabilities at Home

The Chartbook Indicator: “TEFRA Medicaid State Plan Option/ Katie Beckett Waiver for children”

The Catalyst Center’s online State-at-a-Glance Chartbook offers a comprehensive array of data from a variety of different sources on the coverage and financing of care for children and youth with special health care needs (CYSHCN). One of the data indicators found in the Chartbook under the topic area “Factors Influencing Health Insurance Coverage” tells users whether or not a specific state offers Medicaid eligibility to children either under the TEFRA state plan option or under a Katie Beckett home and community-based services waiver. There are differences between state plan options and waivers but we’ve grouped these two pathways to Medicaid coverage together as a single indicator because they both serve a group of children whose complex care needs are similar, at least on paper. In this article we provide an introduction to the two options and how they came into existence.

Katie Beckett and the Waiver Named After Her

The Katie Beckett waiver was created first, in the early 1980s. Katie Beckett was a three-year-old girl who contracted encephalitis, a viral brain infection, when she was just five months old.¹ Katie was in the hospital when she had her first seizure and went into severe respiratory distress. Another seizure five hours later sent her into a coma and onto life support. At this point, the encephalitis attacked Katie’s central nervous system and paralyzed her diaphragm, permanently affecting her ability to breathe and swallow without medical support. In the beginning, the Beckett’s private insurance covered Katie’s medical expenses, but during her extended hospitalization she became eligible for Supplemental Security Income (SSI) which meant she also became eligible for Medicaid coverage.¹ When the

¹ In 209(b) states, SSI does not confer automatic Medicaid eligibility; people with disabilities must submit a separate application for Medicaid benefits and are generally required to meet stricter income, asset, or disability criteria. The 209(b) states are: CT, HI, IL, MN, MO, NH, ND, OH, OK and VA.

Becketts reached their million dollar private insurance cap, Medicaid began covering Katie in full. After nearly three years in the hospital, her condition improved to the point where she was ready to go home with her parents.

Improvements in medical technology meant more children, like Katie, with complex needs could be safely cared for at home. However, a substantial barrier still stood in their way. In the early 1980s, if a child with disabilities who lived at home needed Medicaid coverage, the family income and assets were considered as part of the eligibility determination process, and the child had to be living in a household with very low income to receive Medicaid benefits. However, if the same child were institutionalized in a hospital, nursing home, or an intermediate care facility for people with intellectual disabilities for 30 days or more, the parent's income was not counted under Medicaid eligibility requirements.² This meant that parents who did not financially qualify for Medicaid but could not afford their child's medical care had to place their child with a disability in an institutional setting in order to qualify for Medicaid.³ The only other ways to qualify for Medicaid were to become impoverished or relinquish custody.⁴

All this changed in 1981 after Katie Beckett's story got the attention of then president Ronald Reagan. The Reagan Administration created the Katie Beckett waiver which changed the Medicaid rules to make an exception (the rules were "waived", hence the term) that allowed Katie, and children like her, to receive their care at home, while retaining their Medicaid coverage.^{1,3} Iowa, where the Becketts lived, was the first state to offer the Katie Beckett waiver. It provided long-term care services to children with significant disabilities in a less restrictive and more cost-effective way.

TEFRA Expands the Katie Beckett Waiver

In 1982, Congress expanded what had been accomplished by the Katie Beckett waiver by creating a new state plan option under section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA), also referred to as the Katie Beckett provision.^{2,4} To qualify for Medicaid under either the TEFRA state plan optionⁱⁱ or Katie Beckett waiver, a child must meet all of these criteria:

- Be 18 years old or younger
- Meet the state's definition of institutional level of care;
- Have medical care needs that can be safely provided outside of an institutional setting; and
- The cost of care in the community must not exceed the cost of institutional care.^{2,4}

ⁱⁱFor TEFRA only, the child must be 18 years of age or younger.



Most states converted their Katie Beckett waivers to TEFRA programs but “Katie Beckett” remains a general umbrella term that is often used interchangeably between the two types of programs. In states where either the Katie Beckett waiver or the TEFRA state plan option are in effect, children who meet the above criteria can be enrolled in Medicaid even if their family income is higher than the Medicaid income eligibility limit for their state.

About the Institutional Level of Care

The institutional level of care (ILC) requirement is the most important criteria. This means the child’s needs must be intensive enough that the child would typically be expected to receive care in a pediatric nursing home, a hospital, or an intermediate care facility for persons with intellectual disabilities.

It is important to note that each state has different criteria for defining an institutional level of care; thus the number of CYSHCN who qualify for either option varies from state-to-state. Currently 18 states and the District of Columbia have implemented the TEFRA state plan option.⁵ A few states have chosen to implement TEFRA look-alike programs using state statutes or other state plan amendments. These programs have the flexibility to extend Medicaid eligibility to a broader group of children with disabilities.

But Wait, There’s More: the Home and Community-Based Services Waiver

Since its implementation, states have experienced significant increases in TEFRA enrollment which has created budgetary pressures.⁵ Many states have sought alternative pathways to provide Medicaid coverage to children in higher income families who meet an institutional level of care. The most popular alternative to the TEFRA state plan option has been the home and community-based services (HCBS) waiver.⁵ Unlike the TEFRA option, HCBS waivers allow states to target specific diagnoses or conditions, cap enrollment in the program, and offer additional Medicaid benefits such as case management and home modifications.^{2,5}

What the Chartbook Indicator Means

Checking the Catalyst Center Chartbook indicator for “TEFRA Medicaid state plan option/Katie Beckett waiver for children” will tell you in a broad sense if your state offers Medicaid eligibility to children who meet the institutional level of care requirement at higher income levels than traditional Medicaid. This indicator does not include states that provide coverage through a HCBS waiver. A good resource for information on all types of waivers is found on the official Centers for Medicare and

Medicaid Services' website at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html>. The Catalyst Center website offers additional information about TEFRA and TEFRA look-alike programs (<http://cahpp.org/project/the-catalyst-center/financing-strategy/tefra/>) and includes a chart listing states that offer the TEFRA state plan option specifically.

Endnotes

¹Shapiro, J. (2010). Katie Beckett: Patient turned home-care advocate. Retrieved October 20, 2011 from the National Public Radio website: <http://www.npr.org/templates/story/story.php?storyId=131145687>

²Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., ... Williams, L. (2000). Understanding Medicaid home and community services: A Primer. Retrieved October 18, 2011 from U. S. Department of Health and Human Services website: <https://aspe.hhs.gov/basic-report/understanding-medicaid-home-and-community-services-primer>

³Musumeci, M. (2011). Modernizing Medicaid eligibility criteria for children with significant disabilities: Moving from a disabling to an enabling paradigm. *American Journal of Law and Medicine*, 37(2011):81-127.

⁴Semansky, R.M. & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *The Journal of Behavioral Health Services and Research*, 31(3);334-342.

⁵Catalyst Center. (2010). TEFRA and TEFRA look-alike programs. Retrieved from <http://cahpp.org/project/the-catalyst-center/financing-strategy/tefra/>



About the Catalyst Center

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