

PATHWAYS TO MEDICAID FOR CHILDREN AND YOUTH WITH DISABILITIES:

The TEFRA State Plan Option and Home and Community-Based Services Waivers



For most people, low income is the primary pathway to Medicaid coverage. This means that the eligibility of children and youth (including that of children and youth with disabilities) for this important public benefit is based on their family's income. However, the Centers for Medicare & Medicaid Services (CMS), the federal agency that oversees Medicaid, allows states to use other eligibility criteria, such as age and disability status, to create alternative pathways to Medicaid for defined populations. Two of these pathways to Medicaid eligibility for children and youth with disabilities are the so-called TEFRA state plan option (sometimes referred to as the Katie Beckett option)¹ and Home and Community-Based Service (HCBS) waivers.

When a child or youth with a disability receives extended care in an institutional setting, such as a hospital, pediatric nursing home, or other long-term care facility, family income is disregarded as a qualification for Medicaid.² However, if the child or youth is cared for at home and in the community, Medicaid eligibility is based on his or her family's income. Prior to 1981, a family that could not afford to cover the medical expenses of a child or youth with disabilities, but did not financially qualify for Medicaid, had to place their child or youth in an institutional setting, become impoverished so as to qualify for Medicaid, or relinquish custody of the child.

The Katie Beckett option created an exception to the Medicaid income-qualification rules that allowed families, regardless of income, to obtain Medicaid coverage to care for a child with disabilities at home. Congress then expanded this waiver by creating a new state plan option under Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982. This option allows children and youth with disabilities who require an institutional level of care, but whose families have incomes that are traditionally too high to qualify for Medicaid, to receive comprehensive services



TEFRA refers to a provision of the **Tax Equity and Fiscal Responsibility Act (TEFRA)** of 1982 that created a state plan option to allow children with disabilities who require an institutional level of care, but who live in families with incomes that are traditionally too high, to qualify for Medicaid so they can receive comprehensive services in their homes instead of in an institution.

1. This option is commonly referred to as the Katie Beckett provision because the original waiver program was created to serve a medically fragile child named Katie Beckett. For more on the background of TEFRA and the Katie Beckett provision, please see: Catalyst Center. (2012). The TEFRA Medicaid state plan option and Katie Beckett waiver for children. Retrieved May 12, 2021, from <https://ciswh.org/resources/tefra-medicaid-state-plan-option-katie-beckett-waiver-children/>

2. Medicaid and CHIP Payment and Access Commission (MACPAC). Managed long-term services and supports. Retrieved May 12, 2021, from <https://www.macpac.gov/topics/long-term-services-and-supports/>

at home instead of in an institution. If the child with disabilities has other health insurance (e.g., commercial insurance), that payer is the primary insurer and Medicaid will cover remaining expenses such as deductibles, co-pays, and co-insurance.

One of the most important Medicaid benefits that the TEFRA state plan option provides to children and youth with disabilities is the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit, which requires that all medically necessary services be covered under a state's Medicaid program for children and youth under age 21. (See Section 12.) The TEFRA option, therefore, ensures that not only do more children and youth with special health care needs (CYSHCN) qualify for Medicaid, but also that they are eligible to receive all of the services they need.

TEFRA STATE PLAN OPTION ELIGIBILITY CRITERIA

A child or youth must meet the following eligibility criteria to enroll in Medicaid under the TEFRA state plan option:^{3,4}

- Be under age 18;
- Live in a family whose income exceeds the state's Medicaid eligibility level;
- Meet the state's definition of institutional level of care;
- Have medical care needs that can safely be provided outside of an institutional setting; and
- Have medical, mental, and emotional health needs that are described by the [listing of childhood impairments on the Social Security website](#).

In addition to covering children and youth with medically complex health care needs or who require medical technology to maintain their physical health, the TEFRA state plan option also covers care in intermediate-care facilities for children and youth with intellectual disabilities. It therefore provides a way for children and youth with a variety of physical, mental, behavioral, and developmental health



The TEFRA/Katie Beckett option provides a way for children and youth with a variety of physical and mental, behavioral, and developmental health conditions to qualify for Medicaid coverage, when family income exceeds the state's Medicaid income eligibility limits for children.

3. O'Keefe, J., Saucier, P., Jackson, B., Cooper, R., McKenny, E., Crisp, S., & Moseley, C. (2010). Understanding Medicaid Home and Community Services: A Primer, 2010 Edition. U.S. Department of Health & Human Services. Retrieved April 27, 2021, from <http://aspe.hhs.gov/understanding-medicare-home-and-community-services-primer-2010-edition>

4. Semansky, R.M., & Koyanagi, C. (2004). The TEFRA Medicaid eligibility option for children with severe disabilities: A national study. *Journal of Behavioral Health Services & Research*, 31(3), 334-342. doi: 10.1007/BF02287295

conditions to qualify for Medicaid coverage when their family's income exceeds their state's Medicaid income eligibility limits.

Because each state sets its own criteria for determining what qualifies as an institutional level of care,⁵ eligibility for Medicaid under the TEFRA state plan option may differ from state to state. As of 2018, 20 states have adopted state plan options under TEFRA and two states have adopted TEFRA "look alike" programs⁶ to expand Medicaid to children and youth who meet the above eligibility criteria.

HOME AND COMMUNITY-BASED SERVICE WAIVERS

Another pathway to Medicaid eligibility for children and youth with disabilities is the HCBS waiver, sometimes known as the Katie Beckett waiver. (See Section 4 for more information on waivers in general and HCBS waivers in particular). Though both the HCBS waiver and the TEFRA state plan option may carry Katie Beckett's name, they are distinct programs that provide different advantages to families.

States with HCBS waivers have received permission from CMS to make changes to their state Medicaid programs such as offering additional benefits, targeting specific populations, and changing income eligibility levels. In addition, among other requirements, they must demonstrate that providing services under an HCBS waiver will not cost more than providing these services in an institution.⁷

By contrast, the TEFRA state plan option is implemented through a state plan amendment (SPA; see Section 2 for more information about SPAs). States that have chosen this option have received CMS approval to make changes to their state's Medicaid program's income eligibility criteria for children and youth with disabilities.⁸ These states do not have to prove that their program is cost-neutral and they cannot maintain a waiting list; all children and youth who qualify for Medicaid through the TEFRA state plan option based on the eligibility criteria described above are entitled to enrollment in Medicaid.⁹

The table on the next page compares the two pathways to Medicaid for children and youth with disabilities: the TEFRA state plan option and the HCBS waiver program.

5. Musumeci, M. (2011). Modernizing Medicaid eligibility criteria for children with significant disabilities: Moving from a disabling to an enabling paradigm. *American Journal of Law & Medicine*, 37, (1), 81-127. doi: [10.1177/009885881103700103](https://doi.org/10.1177/009885881103700103)

6. Musumeci, M., Chidambaram, P., & Watts, M.O. (2019, June 14). Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey. Retrieved May 12, 2021, from <https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-appendix-tables/>

7. Centers for Medicare and Medicaid Services. Home & Community-Based Services 1915(c). Retrieved May 12, 2021, from <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html>

8. For more about the differences between the TEFRA state plan option and an HCBS waiver, please see: Wilson, K., Dworetzky, B., Comeau, M. (2015). Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities. Catalyst Center. Retrieved May 12, 2021, from <https://ciswh.org/resources/expanding-access-medicaid-coverage-tefra-option-children-disabilities/>

9. Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., & Williams, L. (2000). Understanding Medicaid Home and Community Services: A Primer. U.S. Department of Health & Human Services. Retrieved May 12, 2021, from <https://aspe.hhs.gov/basic-report/understanding-medicaid-home-and-community-services-primer>

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	TEFRA State Plan Option	HCBS Waiver Program
Who qualifies?	<p>Children and youth from birth to age 18 who:</p> <ul style="list-style-type: none"> • Meet their state’s definition for an institutional level of care • Have medical needs that can safely be provided outside of an institution 	<p>Children (and others as defined by age, diagnosis, or other criteria established by the state) who:</p> <ul style="list-style-type: none"> • Meet their state’s definition for an institutional level of care • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care
What authority do states use to offer these programs?	<p><i>State plan option (a.k.a. state plan amendment or SPA)</i></p> <ul style="list-style-type: none"> • With approval from CMS, states may change their individualized state Medicaid plan by adding optional services or changing eligibility requirements. • States must still follow federal Medicaid rules (e.g., a state cannot use a state plan option to cut mandated services). • All services provided under the state plan option, including EPSDT, must be available to all children who qualify for Medicaid in the state • No waiting lists allowed^{10,11} 	<p><i>Home and Community-Based Service waiver</i></p> <ul style="list-style-type: none"> • States may request that certain Medicaid guidelines be waived to allow them provide additional services not usually covered by Medicaid to help individuals remain in the community (e.g., home/vehicle modifications). • With federal approval, states do not have to comply with certain federal Medicaid rules (i.e., certain Medicaid regulations are waived). • Services can be provided to specific groups of people (e.g., based on diagnosis or age) • Children and youth under age 21 who are enrolled in Medicaid under an HCBS waiver receive the EPSDT benefit in addition to any unique benefits offered under the waiver program. • Waiting lists allowed

10. Families USA. (2012). State Plan Amendments and Waivers: How States Can Change Their Medicaid Programs. Issue Brief. Retrieved May 12, 2021, from <https://www.sfdph.org/dph/files/CBHSdocs/QM2017/4Families-USA-IssueBrief2012StatePlanAmendmentsWaivers.pdf>

11. Ghandour, R. M., Comeau, M., Tobias, C., Dworetzky, B., Hamershock, R., Honberg, L., Mann, M. Y., & Bachman, S. S. (2015). Assuring Adequate Health Insurance for Children With Special Health Care Needs: Progress From 2001 to 2009–2010. *Academic Pediatrics*, 15(4):451–60. doi: 10.1016/j.acap.2015.02.002



TEST YOUR KNOWLEDGE

- 1. True or False: TEFRA is a waiver program, so states can maintain waiting lists for enrollment.**
- 2. Which of the following is *incorrect* about state TEFRA programs?**
 - a. TEFRA allows children who qualify to receive care in the community.
 - b. TEFRA institutional level of care criteria are the same in every state.
 - c. Family income is not a factor in determining eligibility for TEFRA programs.
 - d. All of the above.
- 3. True or False: The TEFRA state plan option covers services not usually provided by Medicaid.**



FIND OUT IN YOUR STATE

- 1. Does your state have a TEFRA state plan option? If so, how many children with disabilities are enrolled in Medicaid through this pathway to coverage?**
- 2. What are your state's criteria for determining an institutional level of care?**

ANSWER KEY

1. False 2. b 3. False

This document is part of Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN). The document is available in its entirety at <https://ciswh.org/resources/Medicaid-CHIP-tutorial>

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