

RESEARCH MEMORANDUM

To: Rep. Jillian Gilchrest, Connecticut House of Representatives

From: Center of Innovation, The Council of State Governments
Ashton Thompson, Research Associate
research@csg.org

Re: Your request of Sep. 20 for an analysis of ways states manage Katie Beckett waiver programs.

Date: Sep. 27, 2024

Note: The Council of State Governments (CSG) is a nonpartisan organization that provides its members with unbiased research using the available peer-reviewed evidence, reliable data, facts, and objective analysis. CSG takes no position on any pending legislation, enacted laws; proposed or enacted regulations, executive orders or agreements, or other executive actions; past or present court rulings or orders; nor any other governmental action or potential action; mentioned in this brief or in any linked material. Additionally, CSG does not endorse the viewpoints of any outside author, source, or third-party publications mentioned; sources cited are for informational purposes only.

Executive Summary

- The “Katie Beckett” waivers refer to Medicaid and state plan options that provide coverage to children with significant disabilities who require institutional-level care but can be cared for at home.
- States administer these programs through the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) state plan option or Medicaid waivers such as the 1915(c) Home and Community-Based Services (HCBS) waiver and the 1115 Demonstration waiver.
- Some states, including **Arkansas, Idaho, Maine** and **Tennessee**, charge premiums on a sliding scale based on income.
- **Tennessee** prioritizes enrollment by medical need and reimburses families for certain healthcare costs capped at a set annual limit.

Method of Research

CSG reviewed states with TEFRA and Medicaid waiver programs to evaluate the various ways these programs are managed. Sources include the Centers for Medicare and Medicaid Services (CMS), various state agency websites, the KFF Medicaid HCBS

Waiver Program Survey and the Center for Innovation in Social Work & Health at Boston University.

Findings and Analysis

Which Medicaid waiver does the program fall under?

The term “Katie Beckett” refers to Medicaid waivers and state plan options that allow children with significant disabilities who require institutional-level care to receive Medicaid coverage for home-based services. States have implemented these programs through either the [Tax Equity and Fiscal Responsibility Act of 1982](#) (TEFRA) state plan option or Medicaid waivers.

Under the [TEFRA option](#), states can extend Medicaid coverage to children with long-term disabilities or complex medical needs who are cared for at home instead of in an institution. Eligibility is determined by the level of institutional care the child requires and not by their diagnoses. In addition, only the child’s income and resources are considered, making it accessible for families with higher incomes. [Title 42 of the Code of Federal Regulations](#) outlines the criteria for eligibility.

Alternatively, Medicaid waivers like the [1915\(c\) Home and Community-Based Services](#) (HCBS) waiver and [1115 Demonstration waivers](#) allow states more flexibility to provide similar coverage. These waivers enable states to offer [additional benefits](#), including family support, care coordination, specialized equipment, medical supplies, respite care, medical daycare and home or vehicle modifications.

As of 2024, **44 states** have [reported](#) offering Katie Beckett coverage through TEFRA state plan options or Medicaid waivers. Of those states, **17** offer coverage through the state plan, **22** offer coverage through a waiver and **5** have both waiver and state plan options.

Which states have waiting lists, and which do not?

States utilizing the TEFRA state plan authority [cannot limit](#) the number of eligible participants, ensuring that all children who qualify receive coverage. This guarantees there are no waiting lists for these programs.

However, states operating under Medicaid waiver programs can [cap the number](#) of participants, often resulting in waiting lists for children needing services. A KFF [report](#) highlights how waiting lists vary by state based on populations served, services provided and available resources. Waiting list management approaches, such as prioritization and eligibility screening, also differ among states. The KFF Medicaid HCBS Waiver Program

Survey, FY 2023, provides additional [data](#) on the total number of individuals on waiver waiting lists by state and target population.

Do states have a sliding scale and provide different amounts of money to families based on income?

Under the TEFRA state plan option, [eligibility](#) is based solely on the child's income and assets. The income limit is generally 300% of Supplemental Security Income (SSI), about \$2,523 per month with a \$2000 asset limit. Parental income and assets are not considered for eligibility, similar to the rules for children with disabilities in institutions. Some states have introduced monthly premiums based on family income. For example, [Idaho](#) charges a premium up to 5% of household income, but this payment is considered voluntary and services cannot be stopped for non-payment. [Maine](#) also imposes a parental premium for families earning more than 150% of the federal poverty line (FPL).

Eligibility requirements for Medicaid waivers vary by state, some states impose premiums on a sliding scale based on family income. [Arkansas](#) and [Tennessee](#) charge premiums for families with incomes above 150% of the FPL, determining the amount by income and household size.

Do any states limit the types of healthcare they'll cover or provide a lump sum for healthcare costs?

TEFRA programs [provide](#) standard Medicaid coverage without additional services beyond each state's plan with covered services varying by state. For example, [Idaho's](#) Katie Beckett program imposes some limits on healthcare services and may require prior authorization from Medicaid before families can access certain services.

[Medicaid waivers](#) give states more flexibility to modify how Medicaid is administered, by allowing exceptions to federal rules, such as statewide availability, access to benefits and provider choice. The specific services covered by these waivers vary between states, reflecting different approaches to care.

[Tennessee's Katie Beckett program](#) provides an annual allowance to cover healthcare costs. It is divided into two parts, Part A and Part B, each offering different levels of coverage and support based on the child's needs. Part A provides up to \$15,000 annually for non-medical services alongside Medicaid coverage, while Part B offers up to \$10,000 per year for services such as premium assistance, health-care savings accounts, reimbursements for non-covered services, respite care, supportive home care and community-based services.

Do any states have families submit costs and reimburse them based on those costs up to a certain limit?

Tennessee's Katie Beckett program includes a [HealthCare Reimbursement Account \(HRA\)](#) that allows families to submit claims for eligible healthcare expenses such as co-pays, deductibles, medical equipment and other out-of-pocket expenses. Families can be reimbursed for up to \$10,000 per year, but any unused funds cannot be carried over to the next year.

Do any states tier illnesses or prioritize them based on life expectancy?

Eligibility for TEFRA is determined by the child's need for institutional-level care, not by specific diagnoses or life expectancy. Although, the definition of institutional care varies by state. All eligible children receive access to necessary healthcare services without being placed on a waiting list.

Medicaid waivers can target specific populations based on factors such as diagnoses, age or other criteria and may restrict eligibility accordingly. States have the flexibility to define the criteria and may limit the number of participants by capping available slots. For example, Tennessee's Katie Beckett program [requires](#) children to meet Tier-1 medical and Tier-1 behavioral levels of care for immediate enrollment into Part A. Children who meet the Tier-2 level of care are prioritized for enrollment in Part A if there is a slot available.

State	Program	State Plan/Waiver Type
Alabama	Alabama Home and Community Based Services (HCBS) Waivers	1915 (c)
Alaska	TEFRA	TEFRA
Arizona	Arizona Health Care Cost Containment System	1115
Arkansas	Arkansas TEFRA-like	1115
California	Medi-Cal Waivers	1915(c)
Colorado	Health First Colorado Buy-In Program for Children with Disabilities and Children's Home and Community-Based Services Waivers (CHCBS)	TEFRA and 1915(c)
Connecticut	Katie Beckett	1915(c)

Delaware	<u>Children's Community Alternative Disability Program</u>	TEFRA
Florida	<u>Florida Home and Community-Based Services (HCBS) Waivers</u>	1915(c)
Georgia	<u>TEFRA/Katie Beckett</u>	TEFRA
Hawaii	<u>QUEST Integration and Medicaid I/DD Waiver</u>	1115 and 1915(c)
Idaho	<u>Katie Beckett –TEFRA or Home Care for Certain Disabled Children</u>	TEFRA
Illinois	<u>Illinois Home and Community Based Services Waivers</u>	1915(c)
Indiana	<u>Medicaid HCBS Programs</u>	1915(c)
Iowa	<u>Iowa Home and Community Based Services</u>	1915(c) HCBS
Kansas	<u>Kansas Home and Community Based Services (HCBS)</u>	1915(c)
Kentucky	<u>Kentucky HCBS Medicaid Waiver Program</u>	1915(c)

Louisiana	Children's Medicaid Option	TEFRA
Maine	Katie Beckett Waiver	TEFRA
Maryland	Maryland Home and Community-Based Services	1915(C)
Massachusetts	Kaileigh Mulligan TEFRA Waiver	TEFRA
Michigan	Home Care Children's/TEFRA Program	TEFRA
Minnesota	MA-TEFRA	TEFRA
Mississippi	Disabled Children Living at Home	TEFRA
Missouri	Missouri Home & Community Based Services Waivers	1915(c)
Nebraska	Katie Beckett Program and Medicaid Waivers	TEFRA and 1915(c)
Nevada	Katie Beckett Program	TEFRA

New Hampshire	Home Care for Children with Severe Disabilities or Katie Beckett option	TEFRA
New Jersey	Medicaid Managed Long Term Services and Supports (MLTSS)	1115
New York	Children's Medicaid Waiver	1915(c) and 1115
North Carolina	Community Alternatives Program for Children (CAP/C)	1915(c)
North Dakota	North Dakota's current Medicaid 1915(c) Waivers	1915(C)
Oklahoma	TEFRA Children	TEFRA
Oregon	Medicaid Waivers	1915(c)
Rhode Island	Katie Beckett Program	TEFRA
South Carolina	Katie Beckett TEFRA Children	TEFRA
South Dakota	Disabled Children's Program	TEFRA

Tennessee	Katie Beckett	1115
Utah	Home and Community Based Services Waivers	1915(c)
Vermont	Disabled Children's Home Care - Katie Beckett Program	TEFRA
Washington	Medicaid Transformation Project (MTP)	1115
West Virginia	Children with Disabilities Community Service Program and West Virginia Medicaid Waivers	TEFRA and 1915(c)
Wisconsin	Katie Beckett Program	TEFRA
Source: KFF Survey of Medicaid Financial Eligibility & Enrollment Policies for Seniors & People with Disabilities, 2024 , Medicaid State Waivers List , and Various State Agency Websites		

Other Resources

- <https://www.kidswaivers.org/> - Provides information on Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs.