

State Options for Providing Access to Care

Medicaid is a safety-net program for children and adults with disabilities who have no other means to obtain the specialized, long-term services they require. This role is enhanced by eligibility rules designed to allow children with mental or physical disabilities to become eligible in certain circumstances without regard to their family's income.

For children whose family income makes them ineligible under standard Medicaid rules, certain institutional services are nonetheless covered in all state Medicaid plans (see box, page 3).

Most families do not wish to place a child with a serious mental disorder in an institution for a long time. Their child needs community-based services and if they had access to these services the family would be able to keep the child at home. To help these families, federal law gives states two options:

- The TEFRA option,¹⁰ also sometimes known as the Katie Beckett option after the child whose situation led to this policy, and
- The home- and community-based services waiver under section 1915(c) of Medicaid law.

TEFRA

The TEFRA option allows states to cover home- and community-based services for children with disabilities living at home. These are children who would otherwise need the kind of skilled care provided in a medical institution. Eligibility for TEFRA is based on the child's disability and care needs, not on family income. For the child to be eligible, certain conditions must be met:

- The child must be a child with a disability, as defined in federal disability policy under

Supplemental Security Income (SSI) or the Social Security Disability Insurance (SSDI) program.

- The child must need the level of care normally provided in a hospital, nursing home or Intermediate Care Facility for Mental Retardation (ICF-MR).
- The child must be able to be cared for at home instead of in the institution.
- The cost of care in the community must not be more than the estimated cost of the institutional care.
- The child, without regard to family income, must not have income or assets in his or her own name that exceeds the state's financial eligibility standards for a child living in an institution.¹¹

Children who qualify under TEFRA will be given a Medicaid card and all state Medicaid program rules will apply. For example, these children are eligible for the same array of services as other Medicaid-eligible children.

Home- and Community-Based Services Waiver

Generally, states must follow all federal Medicaid rules in order to receive federal Medicaid funds. However, Medicaid law allows certain federal rules to be waived, or set aside, so that states can have the flexibility to make changes to their Medicaid programs. To do this, states need to submit a request to the federal Centers for Medicare and Medicaid Services (CMS) central office in Baltimore and have it approved before operating a waiver program.

One of the waivers permitted under federal law allows an expanded array of home- and community-based services to be furnished to children or adults with physical or mental disabilities as an alternative to institutional care that would otherwise be paid for by Medicaid. In addition to offering an expanded array of services, these waivers, known as home- and community-

How TEFRA Works

Families interested in applying for TEFRA should contact the local agency responsible for Medicaid (generally the social or human services agency). They should make clear they are applying through TEFRA, not through the regular Medicaid eligibility categories.

To complete the application, families will need to:

- present evidence documenting the child's disability (from treating physicians, psychologists or others who work with the child; information from school and other sources is also often helpful);
- provide information on the child's income and resources, if any; and
- furnish other information the state may request, such as their willingness and ability to care for the child at home.

Once the child is approved, the child will be on Medicaid and all state Medicaid rules will apply:

- The child will be eligible for all community-based clinical, rehabilitative and case management services covered by Medicaid law (this includes in-home services, day treatment, therapy, medications, case management and other services).
- The child has the right to appeal if a request for a service is denied.
- Medicaid will pay for services only as the last payor. This means if the family has private health insurance that covers a service their child needs, their insurance will be billed first. Medicaid will only pay for what is not covered in the child's insurance plan.
- The child must use providers who are certified by Medicaid in order for Medicaid to pay.
- States are not permitted to charge parents co-payments for services their child receives.

Some states have systems to help families as they apply for TEFRA. For example, in Wisconsin there is a "Katie Beckett consultant" who will talk with the family about the program and help them apply. Check with your local Medicaid agency. In many states with TEFRA, parent groups representing children with physical and/or mental disabilities have information and can assist parents with TEFRA issues.

Children who have received services in the three months prior to applying for TEFRA may be eligible for retroactive payment for those services. Check with the Medicaid agency.

Children must be re-certified every year as being eligible for TEFRA, as they must for any other Medicaid eligibility category.

Additional Services Offered to Families Under Home- and Community-Based Waivers

Kansas: Wraparound facilitation, parent support and training, respite care and independent living services

Vermont: Flexible supports, including respite care, home supports, family supports, community/ social supports and crisis supports, and transportation, environmental modification and adaptive equipment

New York: Individualized care coordination, respite care, skill building, intensive in-home services, crisis-response services and family support services

based care waivers, permit states to provide Medicaid coverage to some children who would not otherwise be eligible for Medicaid.

The waiver gives states considerable flexibility. States can open the program to children who would otherwise be excluded because of their parents' income and resources and can expand the array of services these children receive. However, states are also allowed to limit the number of children in the waiver. They can restrict services to parts of the state, target certain populations, such as children with mental disorders, and set overall limits on the number of children who are included. As a result, many of these waivers have very small numbers of children enrolled.

For a child to be eligible under a home- and community-based waiver, certain conditions must be met:

- The child must require care in a medical institution (a hospital, nursing home or institution for mental retardation, but not a residential treatment center), and
- home- and community-based services must be an appropriate option for the child.

As with the TEFRA option, children are eligible for home- and community-based waivers without regard to family income.

In order to receive federal approval for a home- and community-based waiver, the state must show that the average cost of community care for all children in the waiver will not exceed the average cost of the institutional care that would be paid by Medicaid. In making this calculation, the state must use the costs of institutions defined in federal law— psychiatric or general hospitals, nursing homes and ICF- MRs— and show that children will be diverted from these institutions into community care that is, on average, no more expensive.

A significant advantage of a home- and community-based waiver is that the state may expand the array of services for the children in the waiver. In the three states that now have home- and community-based waivers for children with mental or emotional disorders, these services include respite care for the families caring for these children at home, other family support services and skill building (*see box, above*). The state can also use waiver funds to pay for one-time setup expenses for the child to transition from the institution to home.

Unfortunately, in many states the home- and community-based waiver is not a practical option for children with mental or emotional disorders. The problem is the federal definition of a "medical institution". In many states children with mental or emotional disorders are at risk of long-term placement in a residential treatment center, but these facilities are not referenced in the federal

definition. As a result, home- and community-based waivers cannot be used to divert children from a residential treatment center placement. In some states, where Medicaid-eligible children are rarely placed in a psychiatric hospital for any substantial length of time, the waiver may not be a practical possibility.

Differences Between TEFRA and Home- and Community-Based Waivers

The TEFRA option has an important advantage over the home- and community-based waiver. TEFRA creates an entitlement for all children who qualify, while under the home- and community-based waiver the state may limit the number of children who benefit. No one can be excluded from the TEFRA option based on limited state resources, diagnosis or for any other arbitrary reason.

The advantage of the waiver over the TEFRA option is that the state can expand the array of services available to children and families. The waiver may also be more attractive to states because they

can accurately estimate its costs and can limit costs to funds available for their match of federal Medicaid dollars.

The process of developing a waiver application involves public input, so there is greater awareness around the state of the waiver's availability. In contrast, parents are often totally unaware of TEFRA.

States selecting the TEFRA option can receive federal approval promptly through their CMS regional office. Obtaining approval for a home- and community-based waiver, on the other hand, can be more time-consuming and complicated because it involves demonstrating to the CMS central office that the proposed community services will, on average, cost the same or less than institutional care for the targeted population.

The differences between these two approaches are summarized in the box below.

Comparing TEFRA and Home- & Community-Based Waivers

TEFRA Option

- Children qualify without regard to family income.
- All children who qualify are eligible regardless of whether their disability is physical or mental.
- Children are covered for the same array of Medicaid services as all other Medicaid-eligible children.
- Children from all parts of the state are eligible.
- The TEFRA option can be approved by the federal regional office.

Home- and Community-Based Waiver

- Children qualify without regard to family income.
- The waiver can be limited to children with certain disabilities, such as serious emotional disturbance. The state can establish a limited number of slots.
- Children can receive additional services as well as those covered in the regular Medicaid program.
- Eligibility can be limited to particular geographic area.
- The CMS Central Office in Baltimore must approve the waiver.