

State Response

With few exceptions, states have failed to adopt the necessary policies to use either the TEFRA option or the home- and community-based services waiver. Only 12 states use either approach to improve access to services for families whose children have a serious mental or emotional disorder and even in these states, the number of children who benefit from these policies is very small.

Use of the Home- and Community-Based Waiver

Only three states have elected to seek a federal waiver to cover home- and community-based services for children with mental or emotional disorders. In contrast, 49 states have such waivers for people with developmental disabilities.

Many other states have considered, but rejected, applying for a home- and community-based waiver for children with mental or emotional disorders. According to a study by the Bazelon Center, more than half of states without these waivers considered developing a waiver but stopped when they faced barriers. The most significant barriers they cited were:

- lack of state funds to pay the state's share of Medicaid costs;
- the federal rule that prevents children in or at risk of placement in a residential treatment center from being eligible; and
- the requirement that community services be no more expensive than the alternative institutional placement.

However, experience from the three states that have the waiver shows that the other states' cost-related concerns can be addressed. In fact, per-child costs of a home- and community-based services waiver for children with mental or emotional disorders are quite low. Moreover, since the state can limit the number of slots, a home- and community-based waiver can be initiated with a relatively small state investment. For example,

first-year costs for the Kansas waiver were only \$1 million. Initially, New York began by serving 25 children (now up to 354). In addition, the costs of the waiver services can be offset by institutional savings. Kansas closed one of its psychiatric hospitals in coordination with the waiver.

Use of the TEFRA Option

Twenty states have the TEFRA option for children with disabilities. Yet half of these states have no children on TEFRA who qualified as a result of a mental or emotional disorder.¹² This means that the potentially very important TEFRA option is currently unavailable to children with mental disorders in 40 states and the District of Columbia.

Even in the states with the TEFRA option, very few children participate, and in most of these states children with mental or emotional disorders are a small percentage of these small numbers. Compared to total enrollment in the Medicaid program, TEFRA enrollment is minimal. It varies widely between states, ranging from extremely low (10 children in Michigan) to large (4,300 children in Wisconsin). Moreover, children with mental or emotional disorders are a small percentage of TEFRA enrollment—less than 21 percent, except

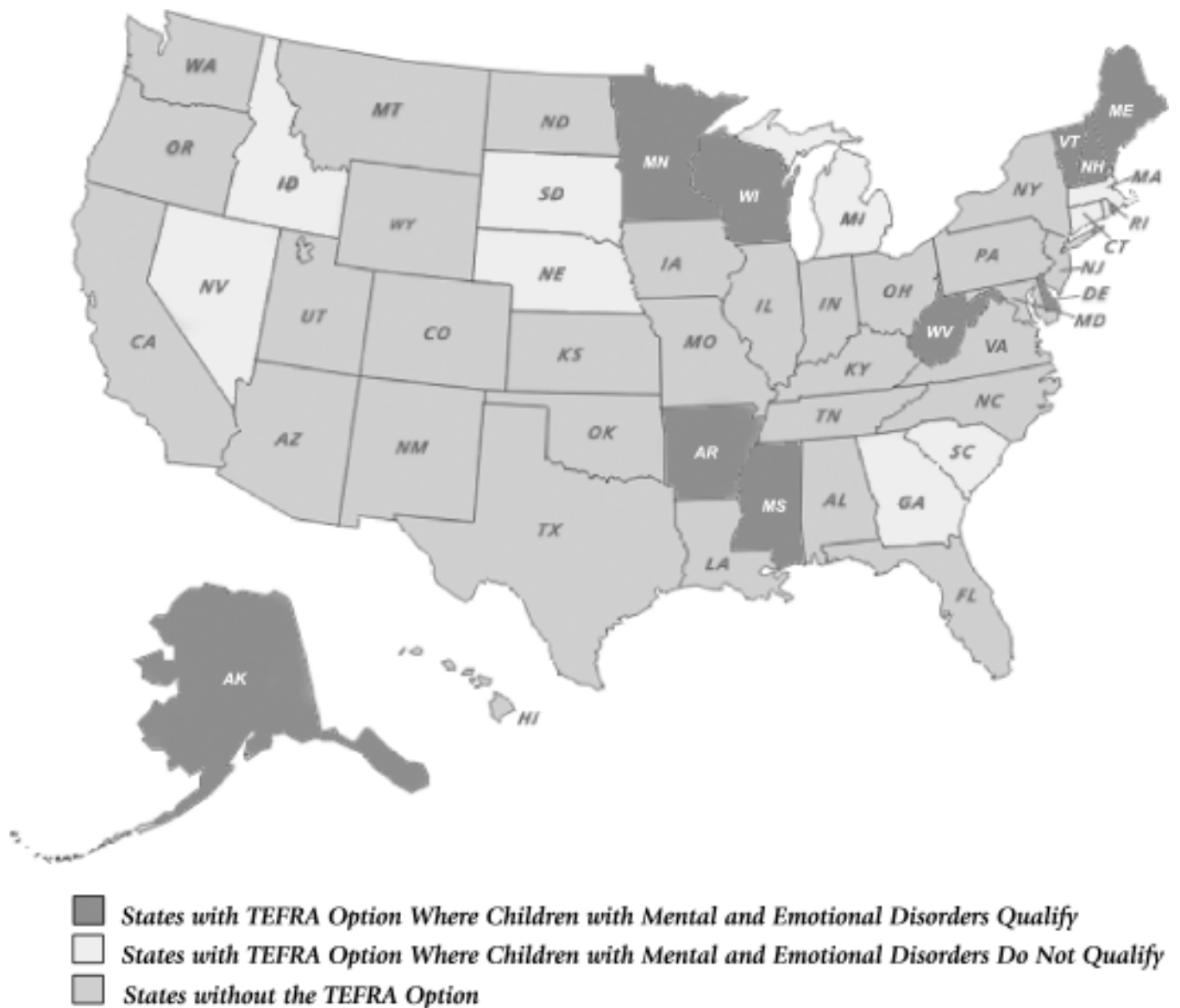
Experience of States with Home- and Community-Based Waivers: Per-Child Costs*

Kansas: Average annual per-child costs \$12,900, compared with institutional costs of \$25,600.

Vermont: Average annual per child costs \$23,344, compared with inpatient costs of \$52,988.

New York: Approximate annual per child costs \$40,000, compared with institutional costs of \$77,429.

*2001 data



in Vermont, where 52 percent of TEFRA children have mental or emotional disorders.

It is surprising that 30 states and the District of Columbia have not adopted the TEFRA option for children with disabilities, especially given the likelihood that in most states many of the families of children with mental or emotional disorders who could qualify will be faced with the option of giving up custody to the state. At that point the entire cost of the child’s care falls on the state, whereas if the TEFRA option is used the federal government will pay a substantial part of the cost.

Lack of knowledge about TEFRA may partially explain why so few states have adopted it.

Information collected by the Bazelon Center suggests that many state officials believe that additional information on implementation of TEFRA would help them determine whether or not their state should use this option. The information these state officials would like to have from states that already use the TEFRA option is:

- the number of children who have qualified;
- expenditures on services for these children;
- specific TEFRA rules used;
- characteristics of children who use TEFRA;

- source of funds for state match;
- plans and proposals developed in order to justify use of TEFRA.

The Fact Sheet, *States Using the TEFRA Option for Children with Serious Mental Disorders* (page 23), attached to this report provides a summary of some of this information. Further data are available to state officials and advocates in a Bazelon Center report prepared for federal officials that can be accessed at www.bazelon.org.

In some states with the TEFRA option, it is not meeting the needs of children with mental and emotional disorders. Among possible reasons:

- Families are unaware of the option and do not apply
- State rules are written in such a way that they either exclude children with mental or emotional disorders or discourage their inclusion.
- State practice emphasizes that only children with a qualifying physical disability can become eligible and other families are discouraged from applying.

Regardless of the cause, denying access to the TEFRA option to children with mental disorders is a direct violation of federal Medicaid policy, which specifically states that all qualified children must be eligible if the state takes this option (*see box, center*).

State TEFRA Rules Often Deny Access

Even in the 20 states that have the TEFRA option, children with mental or emotional disorders are often not included. Although federal law requires inclusion of all eligible children when the TEFRA option is adopted, families of children with mental

and emotional disorders do not believe TEFRA works for them.

One reason is the history of TEFRA. The option was initially developed in response to the publicized problems of Katie Beckett, a child with physical disabilities. From the first day, many state officials assumed that the option was designed to help only children like Katie, and the family groups publicizing the option were those focused on the needs of children with physical or developmental disabilities.

Federal Center for Medicare and Medicaid Services, Policy Manual for States

“If you elect this option you will need to provide coverage to all disabled children who meet the conditions. This is unlike the situation that exists for home- and community-based waivers, for which the law authorizes a waiver of the statewideness and comparability requirements.”*

* Centers for Medicare and Medicaid Services, State Medicaid Manual §3589

Another reason may lie in inappropriate or inadequate state rules. Federal rules for TEFRA implementation leave it to the states to develop many of the details of how the option will operate. For example, the federal government leaves to the states the development of rules that:

- clarify the federal definition of the medical institutions to which a child would otherwise need to be admitted without the community services of TEFRA;

- define the level of care considered “normally provided” in these institutions;
- clarify how the state will decide that home care is appropriate for the child;
- determine how the state will calculate that home care does not cost more than the alternative care in the medical institution.

It is important for these state rules to reflect policies that lead to the inclusion of children with mental or emotional disorders.

The Bazelon Center’s review of states’ TEFRA rules found that children with mental and emotional

disorders are qualifying in only 10 of the 20 states with the option. References to children with mental disorders or to psychiatric facilities or other programs relevant to them are an indication of whether these children will be able to qualify in the state.

Of the 10 states where children with mental and emotional disorders do not qualify under the TEFRA option, only one¹³ has an explicit provision in its rules that would tend to eliminate these children from its program. In the other nine, a combination of factors results in the exclusion of children with mental and emotional disorders. The rules in seven of these states¹⁴ have no reference to children with mental disorders and do not suggest that children who would otherwise be placed in a psychiatric hospital can qualify. These two omissions suggest that it is state policy to exclude these children—a conclusion strongly supported by the states' failure to enroll even one child with a mental disorder in TEFRA.¹⁵ In contrast, most of the states that do include children with mental or emotional disorders specifically cite psychiatric hospitals in their definition of medical institution.

In addition, many of the states where children with mental and emotional disorders do not qualify do not mention the fact that children with mental disorders can qualify for TEFRA in their materials for parents.¹⁶ This would discourage families with these children from applying.

State rules and criteria for measuring whether a child needs the level of care provided in an institution might also be problematic, as may rules on determining whether home care is appropriate and whether it is less expensive than institutional care. However, the Bazelon Center study did not find any specific problems in these parts of the TEFRA rules it reviewed. In the 10 states where children are qualifying, the approval rates for children with a primary diagnosis of mental or emotional disorder ranged from 50-100%, comparable to the approval rates for children with physical disabilities. This suggests that these aspects of state rules are generally not as problematic.

The Fact Sheet entitled *TEFRA (Katie Beckett) Medicaid Option: State Policies* (page 25), summarizes the issues in TEFRA rules that are important for children with mental disorders and presents information that can guide a state in developing appropriate TEFRA rules.

Information for Parents

The availability of information on the TEFRA option plays a critical role in whether parents of children with mental or emotional disorders apply. The Bazelon Center study found significant problems in the sample of parent materials it reviewed.

States have provided booklets with information on TEFRA and many have also included information on their web pages. In several states, parent organizations have produced materials. These materials generally describe the way the option works, the eligibility criteria, how to apply and the services for which a child may be eligible. Some include a copy of the application forms or forms for physician assessments.



The Bazelon Center was able to secure parent materials on TEFRA from 10 states. Nine others reported that they had no parent materials on TEFRA.

Parent materials in three states¹⁷ had no specific references to 1) the fact that children with mental or emotional disorders were eligible, 2) mental disability as a qualifying disabling condition, and 3) the availability of mental health services. Materials in seven states¹⁸ referenced at least one of these three elements.

Materials are useful, but without outreach and other educational efforts they will not ensure that families of children with mental or emotional disorders are aware of TEFRA. The study found that states where children with mental and emotional disorders qualify often conducted outreach to parent organizations or conducted training for the staff of community mental health programs or for their Medicaid-eligibility workers. In some states, materials on TEFRA were widely distributed to physician offices, children's hospitals, county offices and other places where families are likely to pick them up.

Some states designate individuals to help families fill out the application, while in others local mental health programs will provide such assistance. In addition, particularly in states with significant numbers of children with mental and emotional disorders on TEFRA, the family organization itself

plays a significant role in reaching potentially eligible families through workshops, educational materials and outreach.

Despite state efforts, parent groups in the states where children with mental or emotional disorders qualify for TEFRA report that parents still face several problems:

- difficulty in understanding how to provide the appropriate documentation of disability;
- long and complex application forms;
- significant delays before a decision is made on an application;
- requirements for re-application yearly or at other intervals; and
- denials of applications because of missing information of which the parent was unaware.

Parents also had a hard time finding help to complete the application. Given the problems parents face in dealing with the application process, it would seem important for the state to ensure they have this assistance.

Clearly, all states could do much more to make the TEFRA option more effective— even the states whose rules allow children with mental or emotional disorders to be covered.