

# Avoiding Cruel Choices

A guide for policymakers and family organizations on Medicaid's role in preventing custody relinquishment



**Bazelon Center for Mental Health Law**

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# Introduction

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Nationally, the public mental health system for children is in crisis. As a result of its sorry state, many children are placed in the custody of child welfare or juvenile justice systems because that is the only way they can gain access to care that should have been available to them through a healthcare delivery system. Failings in public policies and private practices have led to this situation.

However, public-policy alternatives do exist that could rescue families from the awful choice of giving up custody to the state or seeing their child go without needed care. And most of these policy alternatives are state issues. The federal government gives states several ways for these families to access services through the federal-state Medicaid program, but to date most states have failed to take advantage of them

This guide is designed to assist advocates in educating policymakers about the problem and potential policies that could significantly alleviate it. It describes the causes of the problem and its devastating consequences. It details the federal policy options that could be used to fill the gaps in private insurance coverage. We report which states are taking advantage of these programs and which are not, and discuss the issues that state officials say prevent them from implementing these solutions. We also provide recommendations for advocates and policymakers who want to encourage their states to do more.

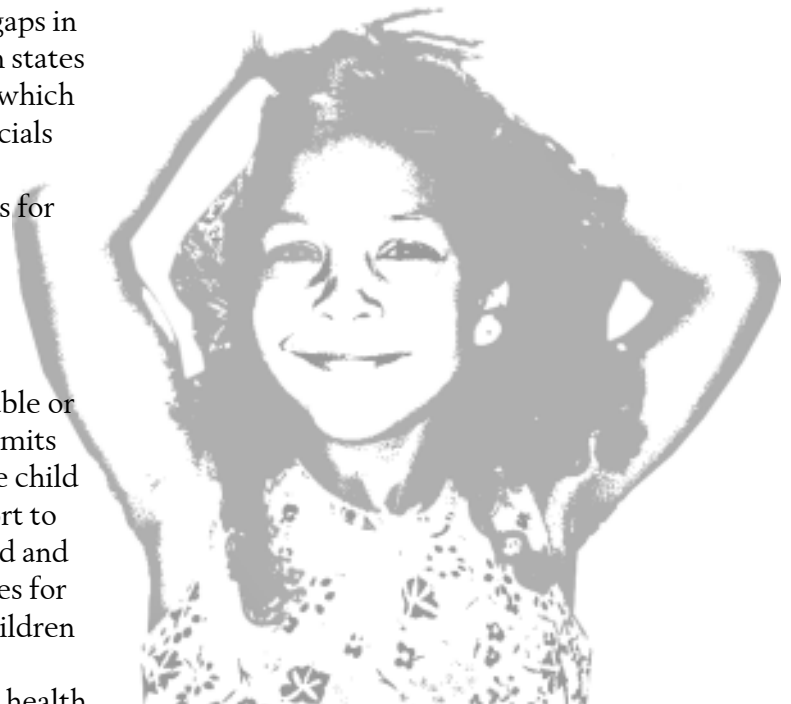
## The Problem

When private insurance coverage is unavailable or inadequate and family income exceeds the limits for public programs, children often enter the child welfare or juvenile justice systems in an effort to access treatment. This practice is widespread and has long-lasting and devastating consequences for families. Unfortunately, large numbers of children in this country are either uninsured or have insurance with minimal coverage for mental health care.

A significant number of children are uninsured. The Kaiser Commission on Medicaid and the Uninsured, which compiles these data, estimated the uninsured rate for children at 15.6 percent in 1998. With the slowdown in the economy, this rate has likely risen since then. The uninsured rate is slightly higher for adolescents than for younger children. Nearly a third of uninsured children live in families where both parents work and 85 percent live in families with at least one working parent. These children have no coverage for mental health care—either private insurance or Medicaid.

Children who do have private health insurance almost always encounter caps on their mental health coverage. Both inpatient and outpatient services are limited. Data show that 94 percent of health maintenance plans and 96 percent of other plans have restrictions on mental health benefits, such as the number of outpatient sessions and inpatient days covered. And these limits have risen over time.

Moreover, private insurance plans do not cover the full array of intensive, community-based rehabilitative services that children with the most severe mental or emotional disorders need. In this



respect, coverage of mental health services is similar to coverage for physical health care, where rehabilitation or services designed to maintain an individual's functioning are often not covered. However, children with the most severe mental and emotional disorders require a range of community services usually offered only through public child-serving systems, such as intensive in-home services, day treatment, behavioral aides or mentors, structured services and activities after school and during the summer, and independent-living skills training.

The major public program covering mental health care for children is the federal-state Medicaid program for low-income individuals. Medicaid is

supplemented by the State Child Health Insurance Program (S-CHIP), which covers children up to a slightly higher level of family income. The federal government shares in the cost of Medicaid and S-CHIP services, at a slightly higher rate for S-CHIP than for Medicaid. States may provide S-CHIP children with either Medicaid coverage or coverage under a health plan based on a private insurance plan in the state. To date, about half the states have chosen Medicaid (either putting all their S-CHIP children into Medicaid or having a mix of Medicaid for some children and a private plan for others). States that choose a private-plan approach give children policies that have the same restrictions as other private insurance.

## ***What Is Medicaid?***

**M**edicaid finances health and mental health care for eligible low-income people. As a means-tested program, children and adults must have low income to qualify. Medicaid is run and financed jointly by the federal government and the states. Thirty-seven million people, including one quarter of all children, are covered by Medicaid. Children normally qualify either because they live in a family with very low income or because they have a disability severe enough to qualify them for federal disability benefits and live in families who are financially eligible for SSI (generally, SSI financial eligibility standards are somewhat higher than the state's ceiling for other low-income families).

Once on Medicaid, children are eligible for a significant range of mental health services: inpatient hospital care, residential treatment center services, outpatient clinical care (including therapy, medications and visits to a physician), crisis services, intensive in-home services, day treatment, substance abuse counseling, social and daily living skills training, case management, behavioral aide services and other intensive community-based care. This broad array provides more comprehensive, and more appropriate, coverage than a typical private insurance plan.

The federal government requires that states cover certain individuals on Medicaid, including children, pregnant women and caretaker adults with the lowest incomes, those with low incomes who also have a disability and elderly individuals who meet certain financial-eligibility criteria. In addition, the federal law permits but does not require states to expand Medicaid eligibility to certain other groups. The TEFRA option discussed in this report is one of those eligibility groups. Finally, states have the ability to apply to the federal government to alter their Medicaid program in certain ways, provided the federal government approves of the changes. This authority to "waive" federal rules can be used to expand the use of managed care in the state, to try out and evaluate new approaches to health care coverage or to provide home- and community-based services to individuals who would not otherwise be able to access them. The home- and community-based waiver for children with mental disorders discussed in this report operates only when a state has permission to waive federal rules in this manner.

## **Medicaid Coverage of Institutional Services for Children with Higher Incomes**

Even for families who are not normally eligible for Medicaid, hospital and other medical institutions' services are a covered Medicaid service when a child with a mental or physical disability resides there for more than 30 days<sup>10</sup>. This is because, once 30 days of care have elapsed, the income and resources of the child's family are no longer considered. As a result, many children with disabilities from higher-income families become eligible, but only as long as they reside in an institution.

Families soon find that only Medicaid offers the comprehensive array of intensive services needed by a child with a serious mental or emotional disorder. However, since Medicaid is a program designed to cover low-income individuals, its rules on financial eligibility keep many families from qualifying. Their family income- while far short of the level needed to pay for their child's care- is still above the very low levels required for Medicaid eligibility.

Families who do not qualify for Medicaid or S-CHIP due to their income and resources have no alternative but to try to pay out-of-pocket for services not covered through their private insurance. However, these children generally have a long-term and consistent need for services and some of those services can be prohibitively expensive. Eventually, many families reach the end of their resources.

In at least half the states, such families are told to place their children in state custody in order to access the services covered through the public programs. The National Alliance for the Mentally Ill reported that approximately one of every five families of children with mental or emotional disorders were advised to give up custody to get help. When they do, the families risk losing their children altogether, since under federal law states must work to place children who are in custody in adoption or back with their families within strict time limits.

Other parents are told to call the police and turn their children over to the juvenile justice system to

get mental health care. Thirty-six percent of families surveyed reported that their children were in the juvenile justice system because mental health services were not available.

This reliance on the child welfare and juvenile justice systems tears families apart and misuses public funds. The Federation of Families for Children's Mental Health lists the following consequences of such policies:

- Children are led to believe they have been abandoned by their family. This irreparably damages the bond between child and family.
- Parents are forced to make an unthinkable choice between retaining the responsibility for and relationship with their child or giving over decision-making authority and control to a state agency in order to get the help their child desperately needs.
- Public funds are wasted by keeping children as wards of the state when the families who love them could provide for their basic needs.
- Children are forced into expensive residential placements rather than living in supportive families and receiving less costly community-based services.

# State Options for Providing Access to Care

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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).

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, 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.

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



# 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 to 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.

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-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, 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 described above, 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). The state can also use waiver funds to make 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 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.

# 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 14 states use either approach to improve access to services for families whose children have a serious mental or emotional disorder. Even in these states, very few children benefit from these policies.

## 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:

- black 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;
- 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. 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

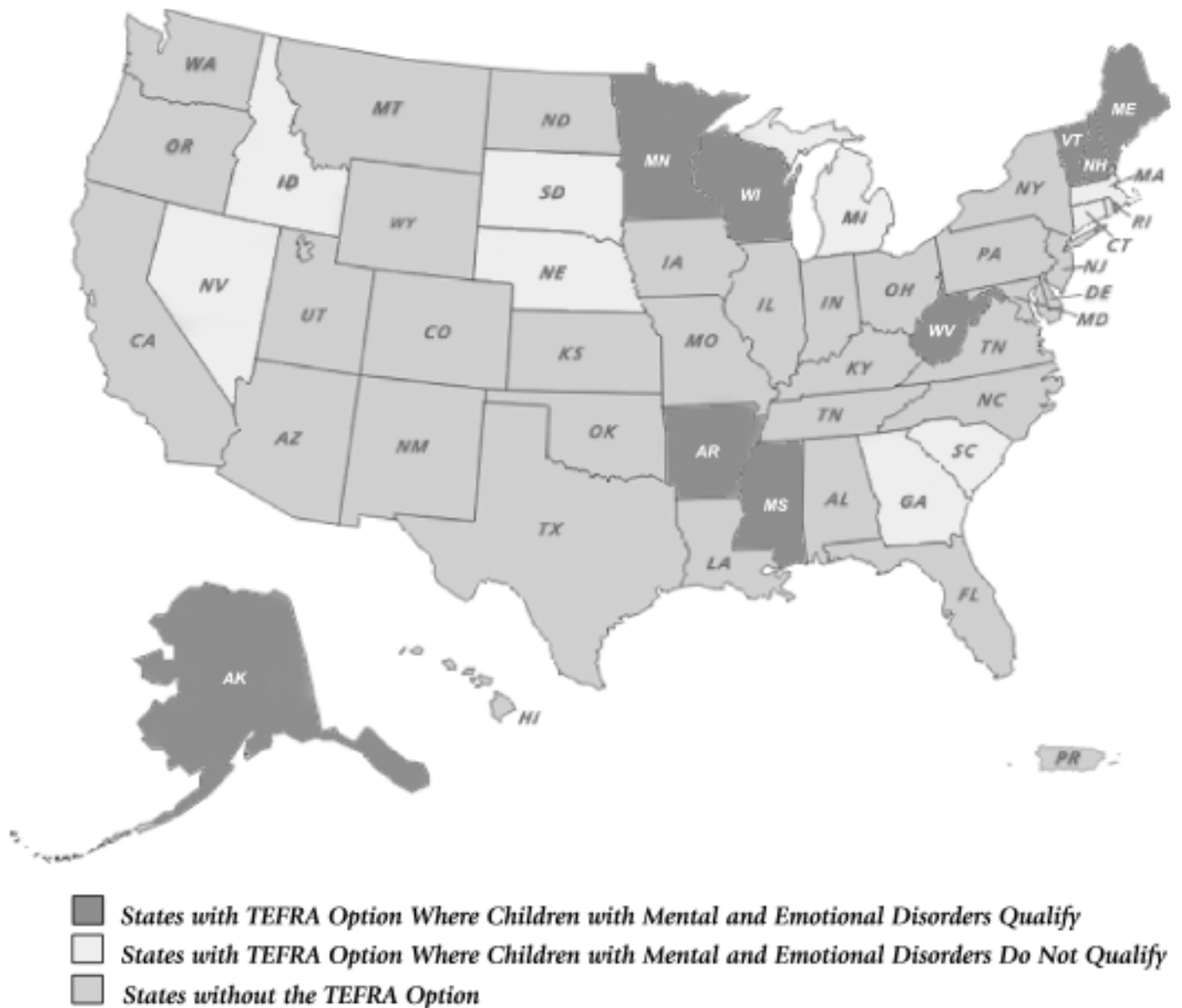
### Experience of States with Home- and Community-Based Waivers: Per-Child Costs\*

**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 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, *Information for States Interested in Adopting TEFRA Option*, 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](http://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, lower right).

### **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 for 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 one 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 six of these states 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. 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, a majority 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. 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 XX) , 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 states 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 states 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.



# Improving State Systems

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TEFRA and the home- and community-based waiver are underused resources for helping families of children with mental disorders avoid having to relinquish custody or place their children in institutions far from home.

State officials contacted for the Bazelon Center study confirm the importance of TEFRA. Officials in seven of the 10 states where children with mental or emotional disorders qualify for TEFRA said that availability of the option has reduced the number of parents relinquishing custody to the state. The experience in Vermont shows the potential: More than half of TEFRA children in Vermont are children with mental or emotional disorders.

Advocates for families of children with mental or emotional disorders should therefore review their state's policies with respect to TEFRA and the home- and community-based waiver. State policymakers should be urged to make the changes needed to help families keep their child with a mental disability at home. Table 1, which can be found on page XX, shows details of state policies on TEFRA and the home- and community-based waiver for children with mental disorders. Using data in that table, advocates should:

- Urge adoption of either the TEFRA option or the home- and community-based waiver in the 29 states that have adopted neither of these approaches.
- In the 10 states that have the TEFRA option but where no children with a primary diagnosis of mental disorder are qualifying, urge changes to state TEFRA rules and criteria and greater effort to publicize the option to potentially eligible families.

- In states with the TEFRA option that do include children with a primary diagnosis of mental disorder, check the number of these children currently qualifying. If it seems low, urge state officials to make greater efforts to publicize the option to potentially eligible families.

- In states without the home- and community-based waiver, urge policymakers to review the practicality of this waiver for children with mental and emotional disorders.

If the state already has the TEFRA option for children with mental or emotional disorders, advocates may wish to find ways to get the word out to families. In addition to developing appropriate parent materials, it is important to give this information wide circulation. Both the state and parent groups should work to ensure that families are aware of their options.



# Advocating for TEFRA and the Home- and Community-Based Care Waiver

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To accomplish these goals, advocates will need to present information to legislators and other policymakers in the state. The attached fact sheets will help begin this process. Policymakers will want:

- information that explains the federal rules on TEFRA and the home- and community-based waiver, the advantages to a state of adopting one of these approaches and the impact on families and children of failing to act (see Fact Sheet, Families Need Choices: Lack of Access Results in Custody Relinquishment to the State);
- information on why the TEFRA option is a good policy choice, including data from states with the option (see Fact Sheet Information for States Interested in Adopting TEFRA Option);
- explanations of specific TEFRA rules that states need to adopt to ensure appropriate eligibility for children with mental and emotional disorders (see Fact Sheet TEFRA (Katie Beckett) Medicaid Option: State Policies); and
- information regarding why the home- and community-based waiver is a good policy choice, including data from states with the waiver (see Fact Sheet, Rules on Home- and Community-Based Waivers for Children with Mental and Emotional Disorders).

Advocates will have to overcome inertia at the state level in adopting either of these Medicaid policies. Although lack of funding is often cited as a major impediment, states are already paying a high cost for services to children with mental health needs in their child welfare and juvenile justice systems. Moreover, both the waiver and the TEFRA option are more extensively used for children with developmental or other disabilities. The real issue is priority-setting, not an overall lack of funds.

Children with mental health care needs are victims of the continued stereotypes that their disorders are not real or that they will outgrow their behavior problems. Parents continue to be blamed, children's needs remain ignored and services are denied. This pattern inevitably leads both to bad outcomes for the children and to high costs in other sectors of the state system. Advocacy and education are essential to overcome the stereotypes and encourage states to fill the gaps in mental health care coverage with a healthcare delivery system (Medicaid), instead of through the punitive systems of child welfare and juvenile justice. Some strategies to do this are presented below.

# Strategies for Advocacy

## TEFRA Option

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- In states without the TEFRA option, advocates for children with mental disorders may find that other organizations representing children with developmental or physical disabilities would be interested in joining with them to urge the state to adopt this option.
- Additional allies may be community mental health providers and their state association. These organizations will understand the problem and the impact of current policy on families, and may have sophistication of cost and other data policymakers will want, such as how the state's rules need to be written and how much the alternative community services would cost.
- Other mental health and child advocacy groups may also join with families in making the case for keeping children at home.

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## Home- and Community-Based Waiver

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Kansas was successful in securing a home- and community-based waiver in 1997, and it now has the largest such waiver program for children with mental and emotional disorders, with 1,150 children. This success was the result of several factors:

- cooperation between state policymakers, children's advocates, families, service providers and Medicaid officials;
- inclusion on a task force that planned and designed the waiver of parents, providers, state agencies, research and policy experts and state Medicaid staff;
- use of a consultant experienced in writing waiver applications;
- the experience of state staff in successfully securing a home- and community-based waiver for individuals with developmental disabilities;
- conducting a review of waiver applications from other states.

The application process was not costly or unduly burdensome and federal CMS staff were helpful and encouraging. The waiver was approved about three months after its submission.



## Conclusion

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States can use policy options under Medicaid to alleviate the problems for families of children with mental and emotional disorders who cannot obtain the services they need to keep their child at home. However, these tools—the TEFRA eligibility option and the home- and community-based waiver—are greatly underutilized.

Many more states could utilize the home- and community-based waiver and state concerns about implementation of such a waiver are not borne out in practice by the three states that have them. Waiver costs can be modest and controlled, and can easily offset alternative institutional costs, while helping families who might otherwise be forced to give up custody of their child to the state.

The TEFRA option provides another important tool to avoid custody relinquishment. It could benefit even more families than a home- and community-based waiver because it is an entitlement for all eligible children. Yet few states have the TEFRA option and even those that do could improve their policies to help more families. Few children benefit from TEFRA and children with mental or emotional disorders benefit even less, whether because of state rules, omissions in state policy, deficient parent-education materials or misinformation from state officials who do not understand the program.

The purpose of this guide is to give family advocates and policymakers the information they need to change this bleak picture. We hope they will use this report, and the attached fact sheets and other information, to educate state decision-makers on how TEFRA or a home- and community-based waiver can benefit many children and families while still being a cost-effective approach for the state.

Federal Medicaid law offers the states options that could greatly alleviate the inhumane practice of sending parents and children to court and putting them on trial for their inability to get help for a mental health problem. Children and their families should not be punished for having a mental health condition. Instead, states should make full use of federal Medicaid options and waivers to serve children with mental and emotional disorders in their homes and communities.

# Notes

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1. Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States' Public Mental Health Systems*. Washington, D.C. 2001; and *State Mental Hospital Continuity of Care Study: Preliminary Report*, Louis de la Parte Florida Mental Health Institute, University of South Florida. Tampa. 2002.
2. Kaiser Commission on Medicaid and the Uninsured (May, 2000). *Uninsured in America: A Chart Book, Second Edition*.
3. P. Peele, J. Lave, Y. Xu, Benefit Limitations in Behavioral Health Carve-Outs: Do They Matter? *Journal of Behavioral Health Services and Research*, 26(4): 430-441 (1999).
4. Generally, up to 200 percent of federal poverty level.
5. Generally, up to 200 percent of federal poverty level.
6. S-CHIP plans can be based on the state employees' health plan, the federal employees' Blue Cross/Blue Shield plan or the plan of the largest commercial HMO in the state, or they can be private plans that are created especially for S-CHIP but are the actuarial equivalent of any one of the above plans. However, states may limit the mental health benefit under these options to only 75 percent of the actuarial value of the mental health benefit in the plan on which the state has modeled its S-CHIP plan. Thus, mental health benefits in S-CHIP private insurance plans are generally quite limited.
7. *Avoiding Cruel Choices*, a report on TEFRA by the Bazelon Center for Mental Health Law produced for the Center for Mental Health Services. 2002.
8. National Alliance for the Mentally Ill, *Families on the Brink* (1999) at 10.
9. *Relinquishing Custody to Obtain Necessary Treatment, Fact Sheet*, Federation of Families for Children's Mental Health, November 1999.
10. TEFRA, the Tax Equity and Fiscal Responsibility Act of 1982 created this option. This replaced a previous authority for state waivers which had accomplished the same goal. The TEFRA option is sometimes known as the Katie Beckett option after the child whose plight came to the attention of President Reagan.
11. These levels are set by the state, but will only exclude children with significant assets or who have income. However, sometimes child support payments can exclude a child from TEFRA eligibility.
12. Some children who qualify due to a physical disability may also have a serious mental disorder, and so may be receiving TEFRA health and/or mental health services.
13. Massachusetts has a rule that defines a hospital level of care as addressing only the needs of children with physical disabilities, thus making it impossible for a child with a mental or emotional disorder to qualify.
14. Nevada, Rhode Island, Georgia, Idaho, Michigan and South Carolina.
15. Three other states also fail to identify any children due to their mental disorder, but two (Nebraska and Connecticut) did not share copies of their rules for review and one (South Carolina) reported that children can only qualify if they have a physical disability.
16. These seven states are: Connecticut, Georgia, Idaho, Massachusetts, Michigan, Nevada and Rhode Island. In South Carolina and South Dakota there is mention of mental health issues for TEFRA children in the parent materials, but the state identifies no children based on their mental or emotional disorder.
17. Arkansas, Connecticut and Idaho.
18. Minnesota, Mississippi, New Hampshire, South Carolina, South Dakota, Vermont and Wisconsin.

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# **Appendices**

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**Table 1: TEFRA and Home- and Community-Based Waivers by State**

State	Eligibility Expansion	Total number of TEFRA children	Children Qualify for TEFRA Based on Mental Disorder	Number of Children with Primary Mental Diagnosis	% of Children on TEFRA with Primary Diagnosis of Mental Disorder	Level of Care Criteria Includes Psychiatric Hospitals	Information Materials Refer to Mental Disorder
Alabama							
Alaska	TEFRA	272	x	16	6%	x	
Arizona							
Arkansas	TEFRA	3,334	x	700	21%		
California							
Colorado							
Connecticut	TEFRA	125		--	--	not available	
Delaware	TEFRA	1500	x	not available	not available	x	
District of Columbia							
Florida							
Georgia	TEFRA	4,086		--	--		
Hawaii							
Idaho	TEFRA	887		--	--		
Illinois							
Indiana							
Iowa							
Kansas	H&CB waiver						
Kentucky							
Louisiana							
Maine	TEFRA	1,157	x	not available	not available	x	
Maryland							
Massachusetts	TEFRA	250		--	--		
Michigan	TEFRA	10		--	--		
Minnesota	TEFRA	3,603	x	581	16%	x	x
Mississippi	TEFRA	708	x	123	17%		
Missouri							
Montana							
Nebraska	TEFRA	42		---	--	not available	not available
Nevada	TEFRA	204		--	--		
New Hampshire	TEFRA	1,125	x	165	15%	x	x
New Jersey							
New Mexico							
New York	H&CB waiver						
North Carolina							
North Dakota							
Ohio							
Oklahoma							
Oregon							
Pennsylvania							
Rhode Island	TEFRA	800		--	--		
South Carolina	TEFRA	2,012		not available	not available		x
South Dakota	TEFRA	49		--	--		x
Tennessee							
Texas							
Utah							
Vermont	TEFRA H&CB waiver	309	x	160	52%		x
Virginia							
Washington							
West Virginia	TEFRA	164	x	5	3%	x	
Wisconsin	TEFRA	4302	x	262	6%	x	x
Wyoming							

<sup>1</sup> States that specify the standard level of care—hospitals, nursing facilities, and intermediate care for the mentally retarded.



## Fact Sheet

# Access to Services for Children with Serious Mental Disorders

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### Families Need Choices:

#### Lack of Access Results in Custody Relinquishment to the State

Families of children with mental and physical disabilities are often unable to obtain the specialized and intensive services their children need through their private insurance policy. Most policies limit coverage of the rehabilitative and other care needed by individuals with disabilities and chronic illnesses, and few families can afford to pay out-of-pocket.

This problem is especially acute for children with mental and emotional disorders. Insurance coverage of mental health services is extraordinarily limited. Coverage of acute hospital and physician care is generally far below what these children require and private insurance does not pay at all for many essential rehabilitative services. The result is that most children with mental or emotional disorders have no access to the services they need. Their families then face the choice whether to leave their child untreated—with horrible, even fatal, consequences—or give up custody to the child welfare system so their child can access services through Medicaid.

Medicaid can be a lifesaving resource for these families because it covers the range of services that children with disabilities need. Families whose children with physical or mental disabilities are on Medicaid are much more satisfied with their child's care than are families with only private insurance coverage. Seventy-one percent of families rated Medicaid good or excellent and 54 percent had no problems getting the mental health services their child needed. In contrast, only 51 percent of families with private insurance thought their plan was good or excellent and only 38 percent reported no problems getting mental health services for their child.<sup>1</sup>

Federal Medicaid law gives states two policy options that allow children with a mental or physical disability to be enrolled in Medicaid even when their family income would normally exclude eligibility. These children can qualify if the state adopts either:

- the eligibility option authorized by the Tax Equity and Financial Responsibility Act of 1988, TEFRA (also known as the Katie Beckett option) Sect. 1902(a)(ii)(VI) of Medicaid law; or
- a Home- and Community-Based Services waiver under Section 1915(c).

The Medicaid TEFRA eligibility option permits states to enroll children with disabilities who live at home and need extensive care but who would not otherwise qualify for Medicaid due to their family income and resources.<sup>2</sup> In order to be eligible:

- The child must be a child with a disability as defined in federal disability rules (Supplemental Security Income, SSI, program).
- The child must need the level of care normally provided in a medical institution.
- Home care for the child must be appropriate and the cost of home care must not exceed the cost of the alternative institutional care.

Compared to the total enrollment in the Medicaid program, the TEFRA option covers a small number of children and enrollment varies widely between states. The average number of children qualifying under TEFRA per state is 1,230 (the range is from 10 to 4,300 children). The average

### Issue

### Medicaid's Role

### State Options

### TEFRA

## Access to Services for Children with Serious Mental Disorders: The Problem

**TEFRA (cont'd.)** number of children with a primary diagnosis of mental or emotional disorders is 250, or between 3% and 21% of total TEFRA enrollment, except in Vermont, where 52% of the TEFRA children are estimated to have a primary diagnosis of serious emotional disturbance.<sup>3</sup>

A study of Minnesota's TEFRA option<sup>4</sup> found that, while costs for children with physical disabilities averaged \$43,000, costs for children with mental health diagnoses averaged only \$17,900. Since TEFRA is the payer of last resort and many children have other insurance, the cost per child for Medicaid was only \$8,100.<sup>5</sup> Children on TEFRA with a mental disorder come from families with lower incomes and were also less likely to have supplemental insurance than other TEFRA children.

### Home & Community-Based Waiver

The home- and community-based waiver, authorized under Section 1915(b), allows states to cover under Medicaid children who would otherwise be excluded because of their parents' income and resources and to expand services beyond those listed in federal law. For a child to be eligible under this 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 excluding residential treatment centers).
- Home- and community-based services must be an appropriate option for the child.

Families in states with these waivers are very pleased with the array of community services available to them. For example, Kansas offers respite care, independent living skills services and parent training and support. Vermont offers various flexible supports, include respite and other services. New York provides individualized care coordination, respite and family support services.

Although federal rules require that states show the waiver to be budget neutral for the Medicaid program, federal rules are not onerous. States need only show that the average cost of community care for all children in the waiver will not exceed the average cost of the alternative institutional care otherwise payable by Medicaid. It is not necessary for the state to require such a showing for every waiver child.

Federal rules also provide another level of flexibility for states, in that children need not be placed in an institution to qualify under the waiver. The costs of institutional care for children at risk of placement may also be used to offset the costs of community services.

One limiting factor for home- and community-based waivers for children needing mental health care is that federal rules do not allow states to consider the costs of institutionalizing the child in a residential treatment facility. In many states children with mental or emotional disorders are at risk of long-term placement in residential treatment centers. But because these facilities are not considered a medical institution under the law, home- and community-based waivers cannot be used to divert children from such a placement.

States may limit the number of children in the waiver in order to reduce their costs. Funding for the waiver may also be linked to state appropriations for services. As result, states can control the number of children in a home- and community-based waiver and costs are readily controlled.

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<sup>1</sup> *Your Voice Counts! The Health Care Experiences of Children with Special Health Care Needs*, Brandeis University, Center for Child and Adolescent Health Policy, MassGeneral Hospital for Children and Family Voices, Boston, MA. 1999. • <sup>2</sup> The Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 created the TEFRA state option. This replaced a waiver authority that had accomplished the same goal (and was known as the Katie Beckett waiver after a child whose plight came to the attention of President Reagan). • <sup>3</sup> Bazelon Center for Mental Health Law (2002) Report to the Center for Mental Health Services on the Implementation of the TEFRA Option. • <sup>4</sup> Chan, Benjamin., Jahnke, Lola., Thorson, Sarah., Vanderberg, Nancy (1988). *Caring for Our Children: A Study of TEFRA in Minnesota. Minnesota Children with Special Health Needs*. St. Paul, MN: Minnesota Department of Health. • <sup>5</sup> Chan, Benjamin., and Vanderburg, Nancy. (1999). *Children with Disabilities, Managed Care Plans, and Medicaid TEFRA Option in Minnesota- Implications for Patients' Rights*. Paper presented at the 16<sup>th</sup> Annual Meeting, Academy for Health Services Research and Health Policy, Washington, DC.

## Fact Sheet

# States' Use of the TEFRA Option for Children with Serious Mental Disorders

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## TEFRA Option for Children with Serious Mental Disorders

Twenty state Medicaid programs use the eligibility option known as TEFRA or Katie Beckett to expand eligibility to certain children with physical and mental disabilities. **Issue**

In other states, policymakers have indicated that more information on TEFRA implementation would help them make a decision about whether to adopt this option.

The TEFRA option permits children with physical or mental disabilities (as defined in SSI regulations) to be offered home-based services instead of placement in an institution. Under current law, these children are covered under Medicaid while in the institution after the first 30 days; at that time their family's income and resources are no longer counted and so the child becomes financially eligible. If these children meet the federal definition of disability, they then become Medicaid-eligible. **TEFRA**

A 2002 survey of states without the TEFRA option by the Bazelon Center for Mental Health Law identified the following as the major reasons why the state had not considered or had not adopted this option: **State Concerns**

- lack of information on implementation of TEFRA by states with the option;
- concern over raising funds for the state match
- overall costs, concern over budget-neutrality and ability to control the number of children who would become eligible;
- mistaken belief that other Medicaid options will address this need;

The Bazelon Center for Mental Health Law recently conducted a study of the implementation of TEFRA in the 20 states with the option. Data from this study show: **TEFRA Implementation**

- The overall number of children who qualify is low.
- The costs per child on TEFRA are low. A Minnesota study of TEFRA found that TEFRA only pays 23% of total health care costs for the children (private health insurance, families and schools pay the rest).
- Half the states with the option have rules that enable children with serious mental and emotional disorders to qualify; the other 10 states have rules or practices that create barriers for these children.

Other Medicaid options that state officials believe may meet the needs of these children do not, in fact, address the same issues. The Medicaid options cited by state officials as alternatives to TEFRA were: **Other Medicaid Options**

- Medically needy option: This requires a family to spend down into poverty for their child to be eligible. But these families are seeking home- and community-based services only available through the public sector—services that cannot be purchased—and so they will not be able to “spend down” by accessing community care. Instead, the families are forced into paying for residential services in order to meet medically needy standards. In addition, families must frequently re-establish eligibility under the medically needy option. For these reasons the

## States' Using the TEFRA Option for Children with Serious Mental Disorders

### Other Medicaid Options (cont'd.)

medically need option is impractical as a means of covering the community care these children need.

- Home- and community-based waivers: A home- and community-based waiver could be an alternative to TEFRA for these children. However, only three states have home- and community-based waivers for children with mental and emotional disorders; in no other state does this alternative Medicaid eligibility approach exist.

### Costs

States had concerns over both the cost of the TEFRA option and the budget-neutrality of its implementation. These concerns were heightened by a fear that the state could not control the number of children who might be eligible (as it can with a home- and community-based waiver), and that this too would drive up overall costs to the state.

- Data from Minnesota (the only state that has studied this issue) show that the actual costs of providing home- and community-based services to TEFRA children are not high. Moreover, the costs for children with mental disorders were less than for other children.
- Budget-neutrality is a federal requirement for TEFRA, and states make the essential calculations themselves. Concern over budget neutrality can be addressed by states by ensuring accurate assessments of the costs of institutional care and accurate assessments of whether the child truly needs the level of care provided in an institution. These are state decisions, controlled by the Medicaid agencies.
- Overall, few children qualify. First, all children must meet the stringent SSI definition of disability and second, they must need the level of care furnished in an institution. This greatly reduces the total number of potential eligibles, and the data confirm this.

### State Match

Mental health officials were concerned about the need for state matching funds for services to these children. In most states, mental health authorities provide the Medicaid match for community-based mental health services. Accordingly, this is of concern. However, when parents of these children are forced into giving up custody to the state, the costs of their care will still fall on the state and the Medicaid match must still be paid. In these situations, the child becomes the responsibility of child welfare (not mental health), but the service furnished will be residential care, that is far more expensive for the state than the TEFRA community-based services. Thus, while the mental health system “saves” the match, the state itself pays an even higher match.

State policymakers need to examine the full impact of policies designed to “save” the match. More effective would be to offer these families family-friendly community based services that are available through the public mental health system by ensuring that the child becomes Medicaid-eligible through TEFRA.

The advantage of TEFRA for the child is obvious. Families on TEFRA in Minnesota (the only state with data) have incomes that are average for the state. If they have private insurance, mental health coverage is limited and the intensive community services their children need are typically not part of an insurance policy benefit package. The options facing these families are to place their child in an institution (Medicaid will pay after 30 days), give up custody to child welfare (child welfare will pay the Medicaid match and the costs of residential care), or continue to struggle along until their child will, most likely, enter the juvenile justice system and become a state responsibility. Families want their children to have access to services before such dire outcomes occur. TEFRA is an obvious policy option for states that wish to address these families' needs.

## Fact Sheet

# For States Interested in Using the TEFRA Option for Children with Serious Mental Disorders

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### TEFRA (Katie Beckett) Medicaid Option: State Policies

Families of children with serious mental or emotional disorders are often unable to obtain the specialized and intensive services their children need through their private insurance policy or by paying out-of-pocket. Medicaid provides the range of services children with disabilities require and can be a life-saving resource for these families. However, many such families have incomes too high to be covered under normal Medicaid rules.

#### Issue

Under federal law, states have the option to cover children with physical and mental disabilities in the community if the child would be eligible for Medicaid institutional services but can be cared for at home. This option was authorized by the Tax Equity and Financial Responsibility Act of 1982 (TEFRA); it is sometimes called the Katie Beckett option after the child whose situation inspired it.

#### State Option

In half the 20 states that have the TEFRA option, no children with mental or emotional disorders have qualified for the program. While federal law does not permit states to exclude qualified children based on their disability, these states' policies have effectively done just that. The states are: Connecticut, Georgia, Idaho, Massachusetts, Michigan, Nebraska, Nevada, Rhode Island, South Carolina and South Dakota.

#### Children Who Are Not Covered

State rules in these 10 states may be causing children with mental disorders to be inappropriately excluded under TEFRA. When states set policy for their TEFRA option they must do the following:

#### State Policy Issues

- clarify the definition of a medical institution that the child would need to be admitted to without the community services of TEFRA;
- define the level of care the state considers to be “normally provided” in these institutions;
- clarify how the state will decide that home care is appropriate for the child; and
- explain how the state will calculate that home care does not cost more than the alternative care in the medical institution.

In setting these policies, states can affect the degree to which children with mental disorders access the program. For example, state rules defining a medical institution and the level of care a child needs in order to be at risk of placement in such an institution can be problematic for children with mental and emotional disorders. A number of states include reference to “psychiatric hospitals” in their definition of medical institution. These states have children with mental disorders on TEFRA, while most of those that do not reference psychiatric hospitals do not. (See the box on the next page for more details on the TEFRA rules as they relate to children with mental disorders.)

Parents need information about TEFRA and assistance in applying. States where children with mental and emotional disorders qualify under TEFRA have parent booklets and other materials that reference the eligibility of children with mental and emotional disorders. Often this information is also featured on a web page. Materials need to be short and easy to read, but must include appropriate information on the option and how to apply.

#### Parent Information

## Fact Sheet for States Interested in Using the TEFRA Option for Children with Serious Mental Disorders

### State TEFRA Rules Relevant for Children with Mental Disorders

None of the 10 states with the TEFRA option where no children with mental disorders qualify explicitly cite psychiatric hospitals in their definition of a medical institution. Most of the states that do include children with mental disorders refer to psychiatric hospitals in their rules.

Level-of-care criteria may also be inappropriate for children with mental disorders. For example, one state explicitly defines a hospital level of care as addressing only the needs of children with physical disabilities and another requires a child to need nursing home level of care, an inappropriate standard for a child with a mental disability.

The way states calculate the cost of home care versus the cost of institutional care may also be a barrier. The methods used by states vary widely, and in some states it is the counties that make these calculations.

In contrast, none of the states reviewed have rules that appear to exclude children with mental disorders from being considered appropriate for home care instead of institutional care. In fact, in most states children are able to qualify for TEFRA while still at home because they are found at risk of institutional placement. Accordingly, this aspect of state rules is not a barrier to including children with mental disorders.

From: *Avoiding Cruel Choices, Report of a Study on TEFRA* for the Center for Mental Health Services, Rockville, MD, Bazelon Center for Mental Health Law, Washington, D.C. 2002

### Parent Information (Cont'd.)

Materials, while useful, are not sufficient to ensure that families learn of TEFRA. Families in states with the TEFRA option complain of:

- difficulty 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 time intervals;
- denials resulting from missing information when the parent was unaware of this fact;
- difficulty finding assistance to help them complete the application.

Several states have engaged in outreach and other educational efforts to overcome these barriers, such as:

- outreach to family organizations;
- in-service training on TEFRA for community mental health program staff and training and orientation about TEFRA for Medicaid eligibility workers;
- distribution programs to provide materials to pediatricians offices, children's hospitals, county offices and other places where families may pick them up.

Some states also designate individuals to help families fill out TEFRA applications. For example, Wisconsin has regional Katie Beckett consultants.

## **Fact Sheet**

# **For States Interested in Creating a Home- and Community-Based Waiver for Children with Serious Mental Disorders**

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## **Rules on Home- and Community-Based Waivers for Children with Mental and Emotional Disorders**

Despite the value of the home- and community-based services waiver under Section 1915(c) for children with mental and emotional disorders whose families might otherwise be forced into giving up custody to the state because they can no longer manage their child at home without supports, only three states have such waivers in their Medicaid programs. In contrast, 49 have waivers for individuals with developmental disabilities.

A home- and community-based waiver permits children with mental disabilities (as defined in SSI) to be offered home-based services in lieu of placement in an institution. The waiver allows the state to expand the number of children eligible for Medicaid because children may be included regardless of family income if they would otherwise require care in an institution.

The waiver also allows the state to offer these children and their families an expanded package of home- and community-based services that may include the all-important service of respite care for the family, along with other family-support services that enable the child to remain at home. This is a far better option for the child and family and less expensive for the state. With support services, the children's own family is able to care for the child. Without such services, costly therapeutic foster care or institutional services are the only option.

One potential problem in the federal rules for home- and community-based waivers is the definition of the institutions from which the covered child would be discharged or diverted. Federal law defines these institutions as only "hospitals, nursing homes and Intermediate Care Facilities for Mental Retardation." The federal Centers for Medicare and Medicaid Services (CMS) has made it clear that a residential treatment center for a child with a mental or emotional disorders does not fall within this definition. This makes it more difficult for states to use the waiver. However, states can still estimate the number of children with serious mental disorders whose condition requires the level of care provided in a hospital and use cost estimates of hospital care to document their potential savings through a waiver.

A recent survey of selected states without the home- and community-based services waiver found that more than half of states had considered developing a waiver for children with mental or emotional disorders, but faced barriers in doing so.<sup>1</sup> These states identified the following

as the most significant barriers (percentage of states where officials cited these barriers in parentheses):

- lack of state funds to furnish the state's share of Medicaid costs (65%);
- the federal rule which does not permit children in or at risk of placement in a residential treatment center to be eligible (59%);
- the requirement that community services be no more expensive than the alternative institutional placement (47%).

Experience in the three states that have these waivers shows that the cost-related concerns of other states can be addressed. In fact:

## **Issue**

## **Home- and Community-Based Waiver**

## **State Concerns**

## **Modest Cost**

## **Fact Sheet For States Interested in Creating a Home- and Community-Based Waiver for Children with Serious Mental Disorders**

### **Modest Cost (Cont'd.)**

- The costs of a home- and community-based services waiver for children with mental or emotional disorders are quite low per child, e.g. \$9,300 per child for the home- and community- based services in Kansas (1998-99), \$18,376 in Vermont (1998) and \$40,000 in New York (2002). In comparison, per child institutional costs in these states were: \$25,600 in Kansas, \$52,988 in Vermont and \$77,429 in New York.
- 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.

The three states with these waivers did not find the state match difficult to raise. All started small and expanded the waiver after the state had some experience. In New York, the legislature was supportive of increasing access to community care. In Vermont, total costs are low and several agencies contribute funds for the match. In Kansas, tobacco settlement resources were initially used for the match and experience with waivers for individuals with developmental disabilities encouraged state officials to apply for a waiver for children with mental disorders.

These three states have had little trouble meeting the cost-neutrality requirements. The high costs of institutional care easily offset the average waiver costs. Each state found it had an adequate level of funding and none have average costs that approach the institutional costs. States also did not find it difficult to gather the data to demonstrate cost neutrality to the federal government. They used existing data systems, and one supplemented this through a survey of providers.

### **Other Barriers**

The states with the waiver found it a helpful source of funding for home- and community-based services and a catalyst to build the necessary infrastructure. However, states needed to address the issue of workforce development and training. One state provided incentives for participating agencies by providing start-up funds for new services.

Federal rules on the institutions to which children are at risk of placement are a more serious barrier. Only hospitals, nursing homes and Intermediate Care Facilities for Mental Retardation are included in the federal definition. In some states very few children on Medicaid are placed in a psychiatric or other hospital settings, but are instead in residential treatment centers (RTCs). In these states, a home- and community-based waiver can still be developed but the state will have to prepare documentation showing that a significant number of children have conditions that require a hospital level of care (even if the child is not placed in a hospital) and the costs of such care. A home- and community-based waiver can be developed in this manner.

Legislation to include RTCs within the definition of institution under Section 1915(c) is pending in Congress and CMS has announced plans to develop a demonstration program along these lines. However, pending federal action some states may not be able to use the home- and community-based waiver to help parents of children with mental or emotional disorders.



States can also control the size of the population covered (and thus the costs) and the home- and community-based services families need to keep their child at home are significantly less expensive than the costs of alternative institutional care.

All 47 states<sup>2</sup> without the waiver should examine the pattern of institutional placements for children with mental and emotional disorders to determine whether a home- and community-based services waiver can help families struggling to find services for their child.

## **Action Needed**

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<sup>1</sup> Survey conducted in 2001 by the Bazelon Center for Mental Health Law, Washington, D.C. • <sup>2</sup> And the District of Columbia

