

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

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*, page 21);
- information on why the TEFRA option is a good policy choice, including data from states with the option (see Fact Sheet, *States Using the TEFRA Option for Children with Serious Mental Disorders*, page 23);
- 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*, page 25); 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*, page 27).

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 on the facing page.

Strategies for Advocacy

TEFRA Option

- 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 special knowledge 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.

Home- and Community-Based Waiver

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 of parents, providers, state agencies, research and policy experts and state Medicaid staff on a task force that planned and designed the waiver;
- 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.