

Fact Sheet

Access to Services for Children with Serious Mental Disorders

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.¹

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.² 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

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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.³

A study of Minnesota's TEFRA option⁴ 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 \$8,100.⁵ 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 a result, states can control the number of children in a home- and community-based waiver and costs are readily controlled.

¹ *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. ² 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). ³ Bazelon Center for Mental Health Law (2002) Report to the Center for Mental Health Services on the Implementation of the TEFRA Option. ⁴ 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. ⁵ 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 16th Annual Meeting, Academy for Health Services Research and Health Policy, Washington, DC.