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CATALYST CENTER
IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities

What is TEFRA?

Medicaid is the publicly funded health insurance program for people with low income. In general, income is the foundation for Medicaid eligibility and children's eligibility is based on their family income.[1] Typically, children with disabilities who receive care **outside of institutional settings** must meet their state's income eligibility criteria to qualify for Medicaid; however, when a child receives extended care **in an institutional setting,** such as a hospital, pediatric nursing home, or other long-term care facility, family income is disregarded as a qualification for Medicaid. For families who cannot otherwise afford their child's care, this policy can push parents towards choosing institutional placement. The Tax Equity and Fiscal Responsibility Act (TEFRA) [Pub. L. 97-248, Sec. 134], passed by Congress in 1982, includes an option for states to create an additional pathway to Medicaid for children, birth to age 18:

- Who have family incomes that are too high to qualify for Medicaid and;
- Whose medical, mental, and emotional health needs are described by the childhood listing of impairments on the Social Security website,*[2] and;
- Who also require an institutional level of care, but can be cared for at home, rather than in an institution.

The TEFRA option allows family income to be disregarded for children who meet the above criteria so that they qualify for Medicaid to cover the services they need to grow and thrive while living at home.[3]

In addition to the TEFRA state plan option, there are also Medicaid waivers for home- and community-based services (HCBS), which provide a similar option to families.[3] Both TEFRA and HCBS waivers allow states to change their Medicaid eligibility policies to cover more children. The table below highlights the similarities and differences between the TEFRA state plan option and Medicaid HCBS waivers.

*This listing can be found at http://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

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The TEFRA state plan option and Medicaid HCBS waivers, a comparison

	TEFRA state plan option	HCBS waivers
Who qualifies?	Children, birth to age 18 who: • Meet their state's definition of requiring an institutional level of care • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care[3,4]	Children (and others as defined by age, diagnosis, or other criteria established by the state) who: • Meet their state's definition of requiring an institutional level of care • Have medical needs that can safely be provided outside of an institution • Receive care in the community that does not exceed the cost of institutional care[3,4]
What authority do states use to offer these programs?	State plan option (a.k.a. state plan amendment or SPA): • Allows states to change their individualized state plan, which outlines the way their Medicaid program operates. States may use this to add optional services or change eligibility requirements • States must still follow federal Medicaid rules (e.g., a state cannot use a state plan option to cut mandated services) • All services in the state plan option must be available to all children who qualify for Medicaid in the state • **No waiting lists are allowed**[5,6]	Home- and community-based service waivers: • Allow states to request that certain Medicaid guidelines be waived. States can use this to provide additional services not usually covered by Medicaid to help individuals remain in the community • With federal approval, states do not have to comply with federal Medicaid rules (i.e., Medicaid regulations are "waived" to make an exception) • Services can be provided to specific groups (e.g., based on diagnosis and/or age and/or other criteria) • **Waiting lists are allowed**[5,6]

How does TEFRA affect children with disabilities?

Adoption of a TEFRA state plan amendment provides four main benefits to children with disabilities and their families:

1. TEFRA pays for services under Medicaid which allow children with disabilities to remain at home with their families and receive care in the community.

One of the most important benefits of TEFRA for children with disabilities is their ability to remain in their own homes. In states without a TEFRA state plan option, children with disabilities who do not meet their state's income eligibility criteria for Medicaid can generally access Medicaid only if they enter an institution, enter the foster care system, or qualify for a waiver program (which often has long waiting lists).

2. TEFRA provides more children with disabilities access to Medicaid's comprehensive Early and Periodic Screening, Diagnostic and Treatment (ESPDT) benefit.

Access to Medicaid is important for children with disabilities because of the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit that federal Medicaid regulations require states to provide. EPSDT requires that Medicaid cover all services that are medically necessary for enrollees under age 21, even if the service is not part of the state's list of mandatory and optional services under the state plan.[9] Because there are no copays, deductibles, or coinsurance associated with Medicaid, TEFRA provides children with disabilities access to more robust benefits at a much lower cost than private insurance.

3. TEFRA allows families greater employment flexibility.

The TEFRA state plan option allows families greater employment flexibility by disregarding income eligibility limits. This disregard allows families to continue to work without their child losing Medicaid benefits. Only the child's income and assets are considered in determining whether the child qualifies for Medicaid coverage.[6] (Note the entire family does not qualify for Medicaid, only the child with a disability.) Without the family income disregard, family members may choose to cut down on hours worked, turn down raises or promotions, or stop working completely to keep their family's income low enough to ensure that their child with disabilities remains eligible for the comprehensive health benefits Medicaid provides. In 2010, a quarter of families of children with special health care needs (CSHCN), including children with disabilities, reported that they cut back on hours worked or stopped working because of their child's health condition.[9] For some families, these decisions may have been made in order to access Medicaid. Because TEFRA does not count family income in determining a child's Medicaid eligibility, it allows parents of children with disabilities to continue working while still accessing Medicaid coverage for their child.

4. **TEFRA provides wrap-around coverage to supplement private health insurance.**
   As of 2010, about half of CSHCN had private insurance;[6] however, even among CSHCN who are insured, inadequate benefits and high out-of-pocket cost-sharing often creates financial hardship for families. In the same year, 21.6% of families of CSHCN reported that their child's health condition caused financial hardship for the family.[9] Many services that children with disabilities need may not be covered by private insurance or may require significant cost-sharing (copays, coinsurance, deductibles, etc.).[8] In these cases, the TEFRA option can allow families to use Medicaid as a secondary form of insurance for their child with a disability to help with the costs associated with covered services or to access services that their private insurance does not cover. As noted above, family members can continue to work and use their employer-sponsored insurance coverage for themselves, their children with disabilities, and other family members.

What's next for TEFRA?

Data from the 2009/10 National Survey of Children with Special Health Care Needs shows that 36.9% families with household income between 200% and 399% of the federal poverty level (FPL) and 31.9% of families with income of 400% FPL or higher whose CSHCN are insured report their insurance is inadequate. In addition, the survey shows that as a child's number of functional difficulties increases, so does the percent of families who report the child's insurance is not adequate to meet their needs (26.5% for 1 functional difficulty; 44.6% for 4 or more functional difficulties). TEFRA provides an excellent opportunity for states to improve inequities in coverage and access to care for children with the most significant functional disabilities whose family income is too high to qualify for Medicaid.

Additional improvements that could provide further support

While there are federal guidelines that states have to follow in implementing their Medicaid programs, there is also broad latitude in what options states can choose, which means that Medicaid looks different in every state.[8] This variation is also true for TEFRA for two main reasons:

1. **TEFRA is a state plan option, not a federally mandated requirement. Not every state has chosen to amend its Medicaid program to cover additional children with disabilities through this pathway.**
   Geographic disparities exist in access to Medicaid for children with disabilities because some states have expanded Medicaid through a TEFRA state plan option, while other states have not. While states that have not chosen a TEFRA state plan option may use other pathways to improve access to Medicaid, such as HCBS

waivers, large geographic variation still exists in the proportion of moderate- to higher-income children with disabilities who have access to Medicaid coverage.[8] If more states create a TEFRA state plan option, it may help close existing between-state variation in access to Medicaid for children with disabilities.[8] This has a particular impact on where families feel they can afford to live and raise their children with disabilities.

2. Even among states that have chosen to use the TEFRA state plan option, what constitutes an "institutional level of care" differs from state to state.[8]

Even in states that have enacted the TEFRA option, several barriers still exist. Accurate and widespread information about the program may be scarce.[8] Improving knowledge about TEFRA among families, caregivers, family leaders, and policymakers in states that have adopted it would help increase access to the program. Additionally, while TEFRA is federal legislation and all states who use the TEFRA state plan option expand Medicaid eligibility to children with disabilities who meet the definition of an "institutional level of care," this definition varies from state to state.[8] A child may meet one state's definition of an "institutional level of care" and be eligible for Medicaid under TEFRA but fail to meet this level of care eligibility requirement in another state. Thus, a standardized definition of "institutional level of care" may help reduce geographic disparities in access to Medicaid for children with disabilities.

If children with disabilities cannot gain access to Medicaid through income eligibility or TEFRA (or other HCBS waiver options), some families may have no other option than to give up custody of their children with disabilities so they will qualify for Medicaid. It appears to be more difficult for children to qualify for Medicaid through TEFRA because of a mental health diagnosis than because of a physical disability,[6,8] due to difficulty establishing a need for an institutional level of care or statutory exclusions for children with primary mental or emotional health diagnoses.[8] This disparity may mean that children with mental health diagnoses face a higher likelihood of being placed in an institution or other out-of-home placements to get the care they need. This may widen inequities among children with disabilities based on diagnosis if families choose to go without coverage for their child rather than give up custody or place the child in an institution. Thus, improvements in the TEFRA state plan option to include more children with mental health as well as physical disabilities would be an important improvement for children with disabilities in general.

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About the Catalyst Center

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