

## People with IDD Wait To Be Served!

### Caseload Forecast DDA Services!



## Medically Fragile Children Fall Through the Cracks! 1115 Demonstration Waiver

Medically fragile children have complex medical and functional support needs. These children may have complex medication regimens, frequent monitoring, or assessment of medical issues and frequent hospitalizations. Children that are hospitalized for thirty days or more can be eligible for Medicaid for up to one year without consideration of family income or resources. When Medicaid coverage ends, this creates a gap in care as children lose access to the Medicaid coverage and in-home services.<sup>1</sup>

Parents whose household income is above minimum income standards can't get needed services for their medically fragile child once their private health insurance caps out. If a child does not meet eligibility for Developmental Disabilities Administration (DDA) services, family income has to be counted. This can make Medicaid unavailable and the child can end up being placed in a hospital, unless the family can provide 24-hour care.

As a state plan program, Tax Equity and Fiscal Responsibility Act (TEFRA) coverage for a child needing services could target specific medical conditions. Currently, 18 states and the District of Columbia have implemented the TEFRA state plan option. A few states have chosen to implement TEFRA look-alike programs using state statutes or other state plan amendments. These programs have the flexibility to extend Medicaid eligibility to a broader group of children with disabilities. The most popular alternative to the TEFRA state plan option has been the home and community-based services (HCBS) waiver. Unlike the TEFRA option, HCBS waivers allow states to target specific diagnoses or conditions, cap enrollment in the program, and offer additional Medicaid benefits, including HCBS services.

Gaining knowledge through an 1115 demonstration waiver is recommended. Following the example of other states establishing an 1115 demonstration waiver for medically fragile children would permit the state to gain experience and understand the numbers of children needing access to Medicaid. After gaining experience through a demonstration option, a determination could then be made as to whether to implement a TEFRA state plan option or one of the waiver options available.

State	Program Name	Program Type	Ages Served	Level of Care	Income Waiver	Populations
<a href="#">Alaska</a>	TEFRA	TEFRA	0 – 18	All	Yes	All
<a href="#">Arkansas</a>	Arkansas TEFRA-like	1115	0 – 18	All	Yes	All
<a href="#">Connecticut</a>	Katie Beckett	1915(c)	0 – 22	All	Yes	PD
<a href="#">District of Columbia</a>	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
<a href="#">Georgia</a>	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
<a href="#">Idaho</a>	TEFRA/Katie Beckett	TEFRA	0 – 18	All	Yes	All
<a href="#">Maine</a>	Katie Beckett Waiver	TEFRA	0 – 18	All	Yes	All
<a href="#">Massachusetts</a>	Kaileigh Mulligan TEFRA Waiver	TEFRA	0 – 18	All	Yes	All
<a href="#">Michigan</a>	TEFRA	TEFRA	0 – 18	All	Yes	All
<a href="#">Minnesota</a>	MA-TEFRA	TEFRA	0 – 18	All	Yes	All
<a href="#">Nebraska</a>	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
<a href="#">Nevada</a>	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
<a href="#">Oklahoma</a>	TEFRA Children	TEFRA	0 – 18	All	Yes	All
<a href="#">Rhode Island</a>	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
<a href="#">South Carolina</a>	Katie Beckett TEFRA Children	TEFRA	0 – 18	All	Yes	All
<a href="#">Vermont</a>	Disabled Children's Home Care - Katie Beckett Program	TEFRA	0 – 18	All	Yes	All
<a href="#">Wisconsin</a>	Katie Beckett Program	TEFRA	0 – 18	All	Yes	All

For the program evaluation component of an 1115 demonstration waiver, ensuring that enrollment in the demonstration increases beneficiaries' access to health care services and satisfaction in the quality of this specialized care received in the home would likely provide a meaningful purpose for the program design. Stakeholders have expressed a desire to have access to the Medicaid program as their priority and access to personal care and nursing will be sufficient to close the existing gap in HCBS services.

**Don't force parents to quit jobs, divorce or go bankrupt to have their child's medical needs met.**

**Create an 1115 Demonstration Waiver for Medically Fragile Children**

<sup>1</sup> The information on this page is excerpted from the Engrossed Substitute Senate Bill 6168 Report to the Legislature, [Tax Equity and Fiscal Responsibility Act \(TEFRA\) and Katie Beckett waivers](#)

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