



## For Florida’s Medically Fragile Children, their Families, and the State, the “Katie Beckett” Option is the Best Solution

### Background

- HB 391 (2023) was designed to allow families with medically fragile children to be paid for the care they provide to their children.
- HB 391 was enacted to address the pediatric nursing shortage, decrease hospitalization/institutionalization of medically fragile children, reduce state expenditures, and provide training and employment opportunities for family caregivers.
- In Florida, medically fragile children are currently evaluated for Medicaid eligibility under the same income standards as all other children (*e.g.*, \$43,000/family of 4).
- Thus, an unintended consequence of HB 391 is that the income earned by the family caregiver will typically place the medically fragile child over the Medicaid income limit, causing the child to lose Medicaid eligibility (and the resultant nursing coverage) altogether.
- To address this unintended consequence, at the Health Care Facilities & Systems Subcommittee meeting on 1/15/25, AHCA’s Deputy Secretary of Medicaid, Brian Meyer, identified a possible solution: treat the medically fragile child as a household of one, thus disregarding the parents’ income in determining the child’s Medicaid eligibility.

### Recommendation

- We respectfully urge implementation of AHCA’s “household of one” option.
- Officially termed “TEFRA”, also known as the [“Katie Beckett” Option](#) — Katie Beckett was a 3-year-old child from Iowa whose life depended on a ventilator. To receive the Medicaid coverage necessary to live, Katie was forced to remain hospitalized because living at home with her family rendered her financially ineligible for Medicaid coverage. In 1982, President Ronald Reagan signed the Tax Equity and Fiscal Responsibility Act (TEFRA) into law, which gave all states the option to have Medicaid cover at-home care for children like Katie, regardless of their parents’ income. See [42 U.S.C. s. 1396a\(e\)\(3\)](#); [42 C.F.R. s. 435.225\(a\)](#).
- This option has been adopted by [many other states](#) including Alaska, Georgia, Idaho, Mississippi, Louisiana, and West Virginia.
- Florida has not implemented the Katie Beckett Option (the [Model Waiver](#) is not the same as a Katie Beckett option).

### **How the Katie Beckett Option Works**

- The state adopts an optional eligibility group in its Medicaid program: medically fragile children requiring an institutional level of care that can be provided at home at lower cost than if forced to live in an institutional setting.
- State adoption will require: (1) amending [409.904, F.S.](#) and (2) AHCA to submit a State Plan Amendment (SPA) to the Centers for Medicare and Medicaid Services (CMS).
- The medically fragile child is evaluated as a household of one, meaning that any income received by their parents does not negatively impact their Medicaid eligibility.

### **Advantages**

- Promotes families' economic potential by removing the dilemma of having to choose between gainful employment and healthcare coverage for their medically fragile child (*See 1/15/25 testimony of Cynthia Gonzalez and Kelly Olive*).
- Helps Medicaid-enrolled families participate in Family Home Health Aide services, and also extends to other families caring for medically fragile children who are currently over-income for Medicaid (*e.g., Ms. Gonzalez*).
- Because the option enables parents to earn income without rendering their medically fragile child Medicaid ineligible, those children will also often have access to employer-sponsored insurance. Thus, Medicaid will often act as the secondary insurer and pay only a portion of the health care costs.
- The state plan option ensures that all eligible families will be able to access Medicaid and Family Home Health Aide services, eliminating the possibility of a yearslong waitlist to participate in the program.