House TennCare Subcommittee Am. #1

Amendment No._____

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Date _____
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Clerk _____
Comm. Amdt. _____
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Signature of Sponsor

AMEND Senate Bill No. 476 **House Bill No. 498***

by deleting all language after the caption and substituting instead the following:

WHEREAS, families caring for a child with disabilities or complex medical needs at home are often burdened with the excessive financial and personal costs of providing continuous care; and

WHEREAS, private insurance companies rarely cover essential, long-term medical care, specialized equipment and therapies, and respite services needed by these children and their families, and often establish monetary limits that are well below the level required by a severely disabled child; and

WHEREAS, these children would qualify for Medicaid if institutionalized, but their families may not meet the income or resource thresholds for government assistance if they choose to care for a severely disabled child at home; and

WHEREAS, private insurance premiums may be unaffordable for low and middle income families and may not cover essential wraparound benefits such as respite care; and

WHEREAS, assisting these families in purchasing and maintaining private insurance can help delay the need for Medicaid eligibility and services and allow more children and their families to be served with available appropriations; and

WHEREAS, providing essential wraparound services for children with disabilities and their families may help to sustain family caregiving, plan and prepare the child for transition to employment and community living with as much independence as possible, and delay the need for Medicaid eligibility and services; now, therefore,

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Title 71, Chapter 5, Part 1, is amended by adding the following new section:

(a) The commissioner of finance and administration is directed to submit, no later than one hundred twenty (120) days after the effective date of this act, to the federal centers for medicare and medicaid services a waiver or waivers pursuant to Section 1115 of the Social Security Act for the purpose of establishing a distinct Katie Beckett program. The Katie Beckett program must be designed in consultation with the commissioner of intellectual and developmental disabilities and must, subject to approval by the centers for medicare and medicaid services, be composed of two (2) parts as described in subsections (b) and (c), and be administered in accordance with this section.

(b) Part A of the Katie Beckett program:

(1) Must be designed to provide a pathway to eligibility for medicaid services and essential wraparound home- and community-based services by waiving the deeming of the parents' income and resources as applicable to a child who is under eighteen (18) years of age and:

(A) Has medical needs that:

(i) Result in severe functional limitations that meet criteria established specifically for children;

(ii) Would qualify the child for institutionalization in an acute care hospital, nursing facility, or intermediate care facility for individuals with intellectual disabilities; and

(iii) Are likely to last at least twelve (12) months or result in death;

(B) Is not receiving long-term services from any alternative waiver program established under this title;

(C) Would otherwise qualify for supplemental security income due to the child's disability but for the income or resources of their parent;

(D) For whom a licensed physician has certified that in-home care is an appropriate way to meet the child's needs; and

(E) For whom the cost of care outside of the institution does not exceed the estimated medicaid cost of appropriate institutional care;

(2) Must offer an integrated program that:

(A) As funding permits, provides children meeting the criteria in subdivision (b)(1) with treatment and support, including, but not limited to:

(i) Respite care;

(ii) Care coordination; and

(iii) Medically necessary medical care and supportive services;

(B) Accepts applications for the program during periods of open enrollment;

(C) Prioritizes for enrollment into the program children with the most significant disabilities or complex medical needs;

(D) Delivers medically necessary care and essential wraparound services and supports in the most integrated setting appropriate and cost-effective way possible in order to utilize available funding to serve as many children as possible; and

(E) If approved by the federal centers for medicare and medicaid services:

(i) Requires periodic reevaluations of an enrolled child's eligibility based upon eligibility criteria for all open categories of TennCare coverage; and

(ii) At the time of reevaluation, allows the bureau of TennCare to disenroll a child who no longer meets the eligibility criteria for any open category of TennCare coverage;

(3) Must provide children applying for or enrolled in Part A of the program with the same appeal rights accorded all other TennCare applicants and enrollees; and

(4) May require parents of children enrolled in Part A of the program to purchase and maintain available private or employer-sponsored insurance that offers coverage for the child, and establish buy-in or premium requirements, using a sliding fee scale based on parent income, to help offset state costs and ensure program sustainability. Any premiums must take into account any amounts paid by a family for private insurance also provided for the child.

(c) Part B of the Katie Beckett program:

(1) Must be administered by the department of intellectual and developmental disabilities;

(2) Must be designed as a medicaid diversion plan and offer a capped package of essential wraparound services and supports as well as premium assistance, using a sliding fee scale based on parent income, for a child who is under eighteen (18) years of age and:

(A) Has medical needs that:

(i) Meet the level of care criteria established specifically for children;

(ii) Would qualify the child for institutionalization in an acute care hospital, nursing facility, or intermediate care facility for individuals with intellectual disabilities or place the child at risk of institutionalization; and

(iii) Are likely to last at least twelve (12) months or result in death; and

(B) Is not medicaid eligible and is not receiving long-term services from any alternative waiver program established under this title;

(3) Must provide services in the most integrated setting appropriate and cost-effective way possible in order to utilize available funding to assist as many children and families as possible; support and sustain child health; utilize, support, and sustain family caregiving; plan and prepare the child for transition to employment and community living with as much independence as possible; and delay the need for medicaid eligibility and services;

(4) Must determine eligibility for services based solely upon medical necessity; and

(5) Must provide children applying for or enrolled in Part B of the program with the same appeal rights accorded all other TennCare and department of intellectual and developmental disabilities applicants and enrollees.

(d) If the bureau of TennCare finds it cost-effective and all necessary federal waivers are obtained, then parents or guardians of a child meeting the criteria in subsection (b) or (c) may be authorized to hire and manage care providers for specified wraparound services using a consumer direction model.

(e) Beginning February 1, 2020, and no later than February 1 of each year thereafter, the bureau of TennCare and the department of intellectual and developmental disabilities shall issue an annual joint report to the insurance committee of the house of representatives and the health and welfare committee of the senate on the status of the Katie Beckett program that includes, but is not limited to, the following information:

(1) Total spent on program funding, including state and federal funds;

(2) The amount of administrative costs to operate the program;

(3) The costs of Part A and Part B, individually;

(4) The number of children served through the program;

(5) The services provided by and through the program; and

(6) The income range of the parents of children participating in the program.

(f) The bureau of TennCare and the department of intellectual and developmental disabilities are authorized, as necessary, to promulgate rules to effectuate the purposes of this section. Rules must be promulgated in accordance with the Uniform Administrative Procedures Act, compiled in title 4, chapter 5.

(g) This section does not create an entitlement to services through the provisions of a Katie Beckett program, and the services provided and the number of individuals served are subject to appropriations made for that purpose.

SECTION 2. This act shall take effect upon becoming a law, the public welfare requiring it.