



Division of TennCare

TennCare II Demonstration

Project No. 11-W-00151/4

Amendment 40

DRAFT FOR PUBLIC REVIEW

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Amendment 40 to the TennCare II Demonstration

I. Description of the Amendment

Amendment 40 to the TennCare II Medicaid Section 1115 Demonstration proposes to establish a new “Katie Beckett” program within the TennCare demonstration. This amendment is submitted as directed by a new state law—Public Chapter No. 494 (see attachment A), passed by the Tennessee General Assembly during the 2019 legislative session. This law directs TennCare to submit a demonstration amendment to CMS to establish a new Katie Beckett program for children under age 18 with disabilities and/or complex medical needs who are not Medicaid eligible because of their parents’ income or assets.

The program is the result of a grassroots advocacy effort led by parents who have children with significant disabilities and/or complex medical needs, coordinated by the Tennessee Disability Coalition and others in the disability advocacy community, and championed by state lawmakers who were committed during the 2019 legislative session to prioritizing services for these children and their families within the constraints of a constitutional requirement to balance the State’s budget.

Included in the program’s goals are to:

- Help address inequities in Medicaid eligibility between institutionalized children and children with comparable needs who live at home with their families;
- Provide services in the most integrated setting appropriate in a manner consistent with the Americans with Disabilities Act;
- Support children with disabilities and complex medical needs to grow and thrive in their homes and communities;
- Plan and prepare the child for transition to employment and community living with as much independence as possible;
- Support and empower families caring for a child with disabilities or complex medical needs at home;
- Provide services these families say they need most to attain financial, physical, and emotional relief;
- Keep families together, sustain family caregiving;
- Assist families in purchasing and maintaining private insurance;
- Help fill gaps between the child’s needs and what private insurance will cover, including essential wraparound services;
- Delay the need for Medicaid eligibility where possible; and
- Provide services in the most cost-effective manner possible in order to serve as many children as possible within approved program funding.

Tennessee's new Katie Beckett program will have two parts:

- **Katie Beckett – Part A** will be a more "traditional" Katie Beckett program, providing full Medicaid eligibility by waiving the deeming of the parents' income and assets to the child, as well as essential wraparound home and community based services (HCBS) to children with the most significant disabilities or complex medical needs who meet institutional level of care. Children enrolled in Part A will be entitled to full Medicaid benefits provided under the federal *Early Periodic Screening, Diagnosis and Treatment (EPSDT)* program¹, regardless of whether the State elects to cover those benefits in its Medicaid State Plan², as well as case management and essential wraparound HCBS not otherwise covered by the Medicaid program, including respite.
- **Katie Beckett – Part B** will be a Medicaid diversion program, offering a capped package of essential wraparound services and supports, as well as premium assistance on a sliding fee scale to a broader group of children with disabilities, including those "at risk" of institutionalization. Part B is an innovative new approach—the first of its kind in the country that would leverage federal Medicaid funds to help divert children from becoming Medicaid eligible by helping their families purchase private insurance and providing essential wraparound services and supports to meet the child's health care and related needs. Part B is a critical component of the program, and key to achieving the statutory goal of serving as many children and families as possible within available state funding.

Both Parts A and B are subject to the availability of state appropriations, and will enroll as many children as can be served within approved program funding.

In addition, Amendment 40 proposes to establish a new hypothetical demonstration Katie Beckett Continued Eligibility Group that will provide continuity of coverage, benefits, and providers for children under age 18 with significant disabilities and/or complex medical needs who are currently enrolled in Medicaid but have been determined to no longer qualify for Medicaid in any other eligibility category and who would qualify to enroll in Part A, but for whom there is not a Part A program slot available.

Table 1 below provides an overview of proposed Katie Beckett Amendment components.

¹ *Early Periodic Screening, Diagnosis and Treatment* – the mandatory Medicaid program for all eligible children under age 21. States are required to provide comprehensive services and furnish all specified Medicaid, appropriate and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guidelines.

² A Medicaid State Plan is the **official document developed by each state that describes the nature and scope of a state's Medicaid program**, as required under Section 1902 of the Social Security Act, and which must be approved by the federal Department of Health & Human Services, Centers for Medicare and Medicaid Services (CMS).

Table 1: Overview of Katie Beckett Amendment Components

	Katie Beckett – Part A	Katie Beckett – Part B	Katie Beckett – Continued Eligibility
Target population	Children under age 18 not currently eligible for Medicaid with the most significant disabilities or complex medical needs	Children under age 18 with significant disabilities or complex medical needs who are not currently Medicaid eligible and do not qualify for Part A or for whom there is not a Part A program slot available based on the state’s prioritization criteria	Children under age 18 currently enrolled in Medicaid determined to no longer qualify for Medicaid in any other eligibility category who meet Part A eligibility criteria but for whom there is not a Part A program slot available
Level of Care	Qualify for care in a medical institution <u>and</u> for SSI (and Medicaid) if in an institution	Qualify for care in a medical institution <u>OR</u> at-risk of institutional placement	Qualify for care in a medical institution <u>and</u> for SSI (and Medicaid) if in an institution
Benefits	Medicaid, including EPSDT; specified wraparound HCBS up to \$15,000 per child per year	Specified HCBS up to \$10,000 per child per year	Medicaid, including EPSDT (<u>no</u> wraparound HCBS)
Medicaid appeal rights?	Yes	Yes	Yes
Program premium requirement?	Yes, if the family’s MAGI ³ exceeds 150% of FPL, based on sliding scale; offset by cost of child’s portion of employer-sponsored or private insurance	No	No
Requirement to obtain/maintain employer-sponsored or private insurance?	Yes, with hardship exception	No	No

³ MAGI or Modified Adjusted Gross Income – as defined in 42 CFR § 435.603. In general, the MAGI methodology is defined by the following characteristics: a) financial eligibility is based on current monthly household income and household size; b) taxable income is countable income; c) non-taxable income is excluded income; and d) household size is determined by the principles of tax dependency.

	Katie Beckett – Part A	Katie Beckett – Part B	Katie Beckett – Continued Eligibility
Premium assistance for employer-sponsored or private insurance?	Yes, at the state’s discretion if hardship exception requested and would otherwise be approved	Yes	No
Delivery system	Managed care program	DIDD ⁴	Managed care program

Overview and Background of “Katie Beckett” Medicaid Eligibility Mechanism

Under federal law, when a child is in a medical institution for at least 30 days, the parents’ income is not counted in determining the child’s eligibility for Medicaid.⁵ Once the child leaves the institution, the parents’ income is counted, which for parents with higher incomes, may mean that the child no longer qualifies for Medicaid.

Often referred to as “Katie Beckett waivers or programs,” “Katie Beckett” more appropriately refers to a Medicaid eligibility mechanism states can elect across several different Medicaid program options and authorities on behalf of children whose families have income above current Medicaid eligibility thresholds, allowing parents’ income (and in some cases, assets) to not be counted in determining the child’s eligibility for Medicaid. The child can then qualify for Medicaid when they otherwise would not because of their parents’ income (or assets).

Originally designed for children with complex medical conditions who would otherwise require care in a medical institution⁶ but living at home with their families, various Medicaid authorities now permit the Katie Beckett eligibility provision to be extended to children who would not qualify for care in a medical institution, but are “at risk” of institutional placement.

The Katie Beckett Eligibility Provision in Tennessee

Tennessee originally had a Katie Beckett children’s waiver. Like many states, Tennessee folded that program into a Statewide Section 1915(c) HCBS waiver program established in 1986 for individuals of all ages with intellectual disabilities. For many years, Tennessee applied the Katie Beckett eligibility option in each of its three Section 1915(c) HCBS waivers for individuals with intellectual and developmental

⁴ DIDD – The Tennessee Department of Intellectual and Developmental Disabilities. DIDD will partner with TennCare in the administration of the Katie Beckett program.

⁵ This refers to “institutional deeming rules”—meaning, in the case of children, the parents’ income is not “deemed” to the child in determining the child’s eligibility when the child is institutionalized.

⁶ A hospital, nursing home, or Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID)

disabilities⁷ operated by the Department of Intellectual and Developmental Disabilities (DIDD). While the target populations served in the waivers included individuals with intellectual disabilities of all ages and children with a developmental disability up to age six, parents' income was not counted when determining children's financial eligibility for Medicaid when enrolling in these waivers. The 1915(c) waivers closed to new enrollment on June 30, 2016.⁸ Importantly, however, due to limitations on funding, enrollment into these waivers had for many years been largely limited to people in certain "crisis" circumstances in which services were eminently required.⁹ Because children rarely met these conditions, very few children were enrolled.

Effective July 1, 2016, Tennessee has exercised the Katie Beckett eligibility provision as part of the Employment and Community First CHOICES program, operated under the authority of TennCare's 1115 demonstration waiver. Since the program's inception, hundreds of children have been enrolled into the program, with a significant percentage of those children eligible in a category based on higher institutional income standards where the parents' income is not counted to determine the child's financial eligibility for Medicaid. For these children, enrollment in Employment and Community First CHOICES provides not only home and community based services, it also allows the child to become eligible for Medicaid when he or she might not otherwise qualify financially. Prioritization criteria for enrollment into the program are largely employment-related (although employment planning and preparation for transition-age youth are included), and reserve capacity groups have, of necessity, prioritized those in the most emergent circumstances, which generally favors adults.

Accordingly, like all states that use one of the "Katie Beckett Waiver" options, Tennessee's ability to enroll children with disabilities into Medicaid whose parents have income above Medicaid limits has been limited by available funding. In order for the parents' income to not count when determining the child's eligibility for Medicaid, there must be an open program slot into which the child will be enrolled. In the proposed new Katie Beckett program, all program funding and program slots will be specifically designated to serve children with significant disabilities and/or complex medical needs that do not otherwise qualify for Medicaid. Sliding scale premiums in Part A to help offset program costs and the innovative new Medicaid diversion approach in Part B will allow state and federal funds to be used more cost-effectively to serve even more children and their families.

Public Chapter No. 494 specifies that Tennessee's program will be established under Section 1115 of the Social Security Act, as a Medicaid demonstration. This is because none of the other Medicaid program

⁷ The Comprehensive Aggregate Cap Waiver (Control # TN.0357); Statewide Waiver (Control # TN.0128); and Self-Determination Waiver (Control # TN.0427)

⁸ There is a limited exception for persons institutionalized in the Harold Jordan Center for a period of 90 days or more to be enrolled into the Comprehensive Aggregate Cap Waiver.

⁹ Homelessness; death, incapacitation, or loss of primary caregiver; serious/imminent danger of harm to self or others; multiple urgent issues likely to result in crisis and two or more of following: aging/failing health of caregiver, living situation presents significant risk of abuse/neglect, increasing behavioral risk to self or others, stability of current living situation severely threatened due to extensive support needs or family catastrophe, or imminent discharge from alternative service system (DCS, RMHI)

options or authorities would provide the flexibility needed to implement the program in accordance with the intent of the General Assembly, as reflected in the statutory language.¹⁰

While much of the proposed new program's structure is dictated by state law, TennCare and the Department of Intellectual and Developmental Disabilities (DIDD) share a commitment to ensuring that families of children who would be served by the new program have an important role in helping to inform the design of the new program. Accordingly, TennCare and DIDD worked quickly to schedule in-person stakeholder input meetings across the state and to provide an opportunity for people to share input online as part of crafting the proposed waiver amendment. A conversation with family leaders was also held to gather more in-depth personal perspective and feedback regarding the program's design. Written recommendations were also received from the Children's Hospital Alliance of Tennessee¹¹ with whom TennCare has a strong working partnership.

Stakeholder input sessions were conducted in each of Tennessee's three grand divisions during May and July of 2019. With the assistance of The Arc Tennessee, the first session was in Nashville at the annual Tennessee Disability Mega Conference on May 23, 2019. By taking advantage of this annual event which draws self-advocates and families from across Tennessee, the State was able to gather input from the largest number and most diverse group of stakeholders. At the request of the advocacy community, additional sessions were held in Knoxville (East Tennessee) on July 1, 2019, and Jackson (West Tennessee) on July 2, 2019.

The stakeholder input sessions consisted of two parts. First, TennCare and DIDD collaborated on a presentation about the proposed program, including program goals; requirements set forth in the new

¹⁰ Medicaid State Plan authorities (*TEFRA* and *Family Opportunity Act*—see below) would obligate the State to enroll all children who qualify into Medicaid; there is no ability to limit enrollment based on state appropriations. Tennessee's constitutional requirement to balance the state budget would not permit a new open-ended entitlement program that could grow far beyond the state's financial capacity and result in the program not being sustainable. Tennessee's law specifies that it "*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.*" The *TEFRA* option would further limit eligible children to those who would qualify to receive care in a medical institution. Tennessee's new law requires that Part B is available to children who have medical needs that "*[w]ould qualify the child for institutionalization...or place the child at risk of institutionalization*" [emphasis added]. The Medicaid buy-in option for children with special health care needs, implemented as part of the *Family Opportunity Act*, would limit qualifying children to those with family incomes up to 300% of the federal poverty level. Under Section 1915(c) waiver authority, the State could not require parents of disabled children to purchase or maintain employer-sponsored insurance or establish buy-in requirements by charging a premium (using a sliding fee scale, based on parents income) to help offset program costs and ensure the program's sustainability as provided in the new law. Importantly, the ability to include a Medicaid diversion component as part of the Katie Beckett program in order to serve more children would only be possible as part of an 1115 demonstration, as these children will not qualify for Medicaid. Part B is a critical component of the program as defined in the new law, and key to achieving the statutory goal of serving as many children and families as possible within available state funding. (*TEFRA* stands for the *Tax Equity and Fiscal Responsibility Act of 1982* (PL No. 97-248, Section 134); the *Family Opportunity Act* was part of the *Deficit Reduction Act of 2005* (PL No. 109-171, Section 6062)).

¹¹ Member hospitals include Monroe Carell Jr. Children's Hospital at Vanderbilt, East Tennessee Children's Hospital, Children's Hospital at Erlanger, Le Bonheur Children's Hospital, and Niswonger Children's Hospital.

state law; program funding, eligibility, and benefits; expected timeline; where to go for additional information as the program is developed; and program design areas where stakeholder input was needed. The second part of each session included small group breakout sessions where structured feedback was solicited on four main questions:

- What services should the program offer that are not covered by insurance and will help you and your family?
- What are the kinds of things the State should consider when deciding how to prioritize enrollment into Part A?
- What questions do you have about the proposed program?
- What concerns do you have about the proposed program?

For purposes of reviewing the feedback, attendees were asked to self-identify as either a parent with a child under age 18, a parent with a child over age 18, a self-advocate, or other. Where possible, participants were placed in a small group for the breakout session with others who were in the same category. Individuals were asked to write their answers to the above questions on notecards, discuss their answers in the small group, identify the most popular answers to each question, and report out to the larger group.

A total of 99 people participated in one of the three meetings: 59 in Nashville, 28 in Knoxville, and 12 in Jackson. Of the total, 29 identified themselves as parents of a child under age 18, six were parents of children over age 18, one was a self-advocate, and 63 attendees listed themselves in the “other” category.

According to the feedback collected, the most heavily-requested services that the program should offer are as follows:

- Private duty nursing
- Medical equipment
- Traditional therapies (occupational therapy, physical therapy, speech therapy) and non-traditional therapies (applied behavior analysis or ABA, nutritional therapy, aquatic therapy, animal therapy, horseback riding)
- Respite (in and out of home)
- Insurance (assistance with co-pays, deductibles, and premiums)
- Supplies (diapers, under pads, wipes, gloves, and diaper creams)

As expected, for children with disabilities and complex medical needs, these benefits are largely included in the comprehensive EPSDT program for Medicaid-eligible children (with the exception of respite, certain medical equipment or supply items, and most non-traditional therapies).

The feedback also indicated the kinds of things TennCare and DIDD should consider when deciding how to prioritize enrollment into part A:

- Level of care needed;
- Complexity of family needs (single parent, multiple children with disabilities);
- Location of family (rural areas where access to care is more difficult); and
- Rarity of child’s condition (genetic condition not specified for SSI eligibility).

Families expressed particular concern regarding reliance on diagnosis for prioritizing enrollment into Part A, and wanted consideration to be given not just to the child’s presenting needs at the time of application, but also over the course of time. Continuity of eligibility and benefits was also an important concern, including when the child’s needs change (increase or decrease), intermittent and/or episodic changes in condition, turning age 18, losing Medicaid eligibility, and no longer qualifying for one or more parts of the program.

In addition to gathering in-person input, TennCare and DIDD posted the presentation online and an online survey form was posted for families to submit their input electronically. TennCare received 85 responses to the online survey, including respondents from 26 of Tennessee’s 95 counties and all three grand divisions of the state. There was remarkable alignment between the responses submitted online and those gathered during the in-person meetings. Primary needs identified in the online surveys included medical equipment and supplies, traditional therapies (occupational, physical, and speech therapy), respite, ABA and non-traditional therapies, assistance with insurance premiums and co-pays, specialized formulas and food, nursing, and medications, followed by cognitive behavioral therapy, diapers and incontinence supplies, family counseling, and personal attendant services.

TennCare and DIDD also responded to a request from “family leaders”—primarily those who led the legislative advocacy effort—for an afterhours call in order to provide more in-depth perspective and feedback regarding the program’s design. This was held on July 3, 2019. State leadership from TennCare and DIDD listened to stories shared by or on behalf of seven children and their families, along with their specific concerns and recommendations. While most of this information reiterated and reinforced feedback already received, the context of how these concerns specifically impact their individual families and the ability to hear their personal stories was particularly powerful.

A consistent theme is that families want a program that is family-focused and family-centered.¹²

Family leaders reinforced the importance of benefits that would offset costs not covered by private insurance—nursing, therapies (without yearly limits), medical equipment and supplies, ABA, medications, specialized food and formulas, respite, and availability of caregiving supports (nursing, personal assistance, respite) when school is out. Families also noted the importance of training for staff, including with routine health care tasks such as tube feeding. There was consensus among the families

¹² A *family-centered* approach includes working with family members to understand their strengths, needs, preferences, goals, and challenges; developing a collaborative relationship with the family; and providing support in a way that helps to engage, strengthen, support, and build the capacity and confidence of the family in order to help ensure safety, well-being, and permanency.

that the services Medicaid covers generally “hit the boxes”; the issue is who qualifies for Medicaid coverage.

A second focus of the conversation thus centered on determining who would qualify for the new Katie Beckett program—in particular who would qualify to enroll in Part A. Family leaders advised that criteria should be individualized and needs based—not solely based on diagnosis—and take into account needs that may not be present every day, but occur upon illness. Families recommended that hospitalization (or other institutionalization) should not be required as a condition of eligibility. There was also concern that families who have managed the care for their children on their own for some time not be penalized in the prioritization process. Family leaders recommended that a professional with pediatric complex care expertise make or be involved in making these determinations.

Family leaders generally requested a simplified application process and asked that families be assigned a case manager for intake to help gather relevant information for an individualized determination of the child’s needs, and to assist in gathering relevant medical and related information. Family leaders also asked for a simplified eligibility redetermination process that does not require the child to apply again or “requalify” every year. While both federal and the new state law require periodic redeterminations of financial and level of care eligibility, there are ways these processes can be streamlined to help ensure continuity of eligibility and benefits.

This led to the third key theme of the discussion with family leaders: transitions and continuity of eligibility and benefits. Parents wanted to be able to celebrate their children’s developmental milestones and achievements without risk of losing eligibility. They also wanted to ensure that the program recognize how widely a child’s medical stability and functional needs may vary over the course of time. A child may seem “healthy” one week and be very ill the next, and the entire course of the child’s condition should be taken into account. Families do not want to live in fear of losing coverage during periods when their child’s condition may be more stable. At the same time, they want to know that if their child’s condition declines, there is potential and process for transition from Part B to Part A. Another critical transition is for families who may have foregone employment opportunities or otherwise made difficult decisions (including divorce) in order to access Medicaid assistance for their child. They requested the ability to transition from Medicaid to the Katie Beckett program without gaps in coverage in the event their child loses Medicaid eligibility, and to seamlessly transition from the Katie Beckett program to Medicaid when their child turns age 18.

With regard to premium requirements, families expressed concerns regarding the affordability of sliding scale premiums, requested assistance in paying for private insurance in some cases, and wanted assurance that program premiums will be offset by the cost of private insurance premiums.

The Children’s Hospital Alliance of Tennessee (CHAT),¹³ with whom TennCare has a strong working partnership, also provided written recommendations regarding program design which generally echoed those communicated by families, and emphasized the importance of access to assistance that “*wrap[s] around services that are either not fully funded or provided at all,*”—in particular at-home nursing care.

Proposed Amendment 40 reflects input received from families and other stakeholders, as well as a commitment to their ongoing engagement in program operations and improvement through the establishment of a Stakeholder Advisory Group.

Comment [TENNCARE1]: TennCare is committed to ongoing engagement of families of affected children and other stakeholders as part of the advisory group.

Eligibility for Katie Beckett – Part A

Part A will target (and prioritize enrollment of) children with the most significant disabilities or complex medical needs who meet institutional level of care. These children will qualify for TennCare in a new hypothetical demonstration “Katie Beckett Institutional Level of Care Group.” As required by state law, in order to be eligible for the new eligibility group and to enroll into Part A, a child must:

- Be under age 18¹⁴;
- Have medical needs that:
 - Are likely to last at least twelve months or result in death; and
 - Result in severe functional limitations based on medical eligibility criteria developed specifically for children;
- Qualify for care in a medical institution—a hospital, nursing facility, or ICF/IID (even though services will be provided at home); and
- Qualify for supplemental security income (SSI) due to the child’s disability—except for parents’ income and/or assets.

Additionally, a licensed physician must agree and certify that in-home care will meet the child’s needs, the cost of providing the child’s care at home (including traditional Medicaid benefits and wraparound HCBS) cannot exceed the estimated Medicaid cost of institutional care, and the child cannot be Medicaid-eligible or receiving long-term services and supports in another Medicaid program.

Comment [TENNCARE2]: The eligibility criteria listed for Part A are dictated by Public Chapter No. 494.

In order to help offset program costs and ensure program sustainability and as a condition of eligibility for and enrollment into Part A, the child’s parents must purchase and maintain minimum essential coverage¹⁵ private or employer-sponsored insurance for primary coverage. The State may grant a hardship waiver of this requirement if the cost of the child’s portion of all available employer-sponsored or private insurance would exceed 5 percent of the family’s MAGI, provided that consideration of the child’s portion of the cost would take into account any coverage the parent would be required to

¹³ Member hospitals include Monroe Carell Jr. Children’s Hospital at Vanderbilt, East Tennessee Children’s Hospital, Children’s Hospital at Erlanger, Le Bonheur Children’s Hospital, and Niswonger Children’s Hospital.

¹⁴ While a child must be under age 18 to enroll in Part A, a child may remain enrolled in Part A for up to 12 months following the 18th birthday to allow time for an SSI eligibility determination, and continuity of Medicaid eligibility and benefits as further described below.

¹⁵ As defined under the Affordable Care Act.

purchase in order for him or herself in order to obtain coverage for the child (it would not take into account the cost of covering other family members). The State may also grant a hardship waiver of this requirement if a child whose family MAGI is less than 400 percent of the federal poverty level does not have access to employer-sponsored insurance through either parent's employer, since the child would not be eligible for premium assistance tax credits for insurance purchased through the Health Insurance Marketplace after approval for Katie Beckett Part A. Alternatively, in either instance, the State could elect to offer premium assistance to help cover the child's portion of employer-sponsored or private insurance.

Comment [TENNCARE3]: This paragraph reflects specific input from families regarding the affordability of program premiums and the need for premium assistance in some instances.

In addition, children whose families have MAGI above 150 percent of the federal poverty level (taking into account household size) will be required to pay a sliding scale monthly premium based on the family's MAGI, as further described in the *Cost Sharing* section below. Premium payments must be made both as a condition of initial enrollment and continued eligibility for Katie Beckett Part A. A child for whom premium payments are not made timely is not eligible for enrollment in the program.

Because the new Katie Beckett program is subject to the availability of state appropriations, all eligible children may not be able to enroll in Part A (and thereby qualify for Medicaid). In order to comply with the specific statutory and budget authority provided, the State proposes to establish an enrollment target for Part A based on the availability of state appropriations to provide assistance. The enrollment target will include both upper limits and lower limits, with the actual target number to be made publicly available on the program's website and in informational materials. This will allow flexibility to adjust the actual enrollment target based on utilization. (For example, if the average cost of providing service is lower than projected in the program's approved budget, the enrollment target can be increased.) The State will never adjust the enrollment target below the program's current enrollment. Any waiting list for Part A will be maintained by TennCare on a statewide basis.

Comment [TENNCARE4]: This flexibility reflects specific input from families and advocates regarding the potential to serve more people in Part A if utilization is lower than budgeted program costs.

Children will be prioritized by DIDD for enrollment into an available Part A program slot in accordance with objective, needs-based criteria developed or identified by the State and made publicly available through administrative rules. These criteria will not be based solely or even primarily on diagnoses, but rather on each child's specific functional and developmental limitations (as compared to the child's chronological age); the impact of the child's diagnoses, including the frequency, intensity, and duration of functional, medical, and behavioral supports required; and the degree of caregiver burden entailed in providing such supports; as well as other factors which impact a family's ability to meet the child's support needs. Importantly, prioritization will take into account not just the current or most recent spell of the child's condition, but also the course of the child's condition, including intermittent or episodic needs, and the long-term prognosis for the child's condition(s). Hospitalizations (or other institutionalizations) will be considered, but not required as part of the prioritization process.

Comment [TENNCARE5]: The language in this paragraph reflects specific concerns and recommendations received from families of children with disabilities and complex medical needs.

Prioritization criteria will be applicable only for purposes of enrollment. Once a child is determined eligible and enrolled into Part A, financial and medical (level of care) eligibility will be reevaluated at least annually. The child must continue to meet the criteria for an institutional level of care to remain enrolled in Part A. If a child's condition improves to the point that the child no longer meets

institutional level of care criteria, and in accordance with due process pertaining to such determination, the child will be disenrolled from TennCare, but only upon also being determined ineligible for all open categories of TennCare coverage. The child may transition to Part B if there is an open program slot available. Likewise, a child found to no longer qualify for Part A due to non-payment of premiums will be disenrolled from TennCare only after also being determined ineligible for all open categories of TennCare coverage and could transition to Part B if there is an open program slot available.

Comment [TENNCARE6]: Clarification that prioritization criteria will be applicable only for purposes of initial enrollment. This clarification reflects specific concerns expressed by stakeholders regarding continuity of enrollment and benefits.

The requirement for periodic review of eligibility is in the new state law and in federal regulations; both the state law and the federal regulations also require a review of Medicaid eligibility before any disenrollment would proceed.

Eligibility for Katie Beckett – Part B

Children in Part B will qualify in a new demonstration “Katie Beckett Diversion Group.” In order to be eligible to enroll into Part B, a child must:

- Be under age 18;
- Have medical needs that:
 - Are likely to last at least twelve months or result in death; and
 - Result in severe functional limitations based on medical eligibility criteria developed specifically for children; and
- Qualify for care in a medical institution—a hospital, nursing facility, or ICF/IID (even though services will be provided at home), or be “at risk” of institutional placement.

In addition, the child cannot be TennCare-eligible or receiving long-term services and supports in another Medicaid program.

Comment [TENNCARE7]: The eligibility criteria listed for Part B are dictated by Public Chapter No. 494.

As with Part A, because the program is subject to state appropriations, all eligible children may not be able to enroll in Part B. The State proposes to establish an enrollment target for Part B based on the availability of appropriations to provide assistance. Children will be enrolled into an available Part B program slot on a first come, first served basis.

A child who is eligible for, but not enrolled into Part A, due to the lack of availability of an open program slot, may be enrolled into Part B. Objective, needs-based criteria used to prioritize enrollment into Part A will take into account any additional needs that are not being met in Part B.

Katie Beckett – Part A Benefits

Children enrolled in Part A will be entitled to full Medicaid benefits provided under the federal Early Periodic Screening, Diagnosis and Treatment program, regardless of whether the State elects to cover those benefits in its Medicaid State Plan,¹⁶ as well as essential wraparound HCBS, as follows:

1. Self-directed respite and/or supportive home care, using the services of the State’s contracted fiscal employer agent; and/or

¹⁶ Home health, private-duty nursing, durable medical equipment and supplies, occupational therapy, physical therapy, speech therapy, audiological services, and non-emergency transportation (NEMT) are all covered Medicaid benefits for children.

2. Agency-based HCBS – specified HCBS delivered by a qualified HCBS provider, as follows:
 - a. Respite
 - b. Supportive home care
 - c. Assistive technology, adaptive equipment and supplies (up to \$5,000 per calendar year)
 - d. Minor home modifications (up to \$6,000 per project; \$10,000 per calendar year; and \$20,000 per lifetime)
 - e. Vehicle modifications (up to \$10,000 per calendar year and \$20,000 per lifetime)
 - f. Community integration support services
 - g. Family caregiver education and training (up to \$500 per calendar year)
 - h. Health insurance counseling/forms assistance (up to 15 hours per calendar year)

The total cost of wraparound HCBS cannot exceed \$15,000 per child per calendar year.

Katie Beckett Part A benefits are summarized in Table 2 below.

Comment [TENNCARE8]: This expenditure cap aligns with that for children enrolled under the current Katie Beckett eligibility mechanism in Employment and Community First CHOICES Group 4.

Table 2: Katie Beckett Part A Benefits Chart

Benefit	Amount, Duration and Scope
State Plan- and EPSDT-covered services	Covered as medically necessary, no limitations
Self-directed respite and/or supportive home care	Total cost of self-directed respite and/or supportive home care and agency-based HCBS cannot exceed \$15,000 per calendar year
Agency-based HCBS <ul style="list-style-type: none"> – Respite – Supportive home care – Assistive technology, adaptive equipment and supplies (up to \$5,000 per calendar year) – Minor home modifications (up to \$6,000 per project; \$10,000 per calendar year; and \$20,000 per lifetime) – Vehicle modifications (up to \$10,000 per calendar year and \$20,000 per lifetime) – Community integration support services – Family caregiver education and training (up to \$500 per calendar year) – Health insurance counseling/forms assistance (up to 15 hours per calendar year) 	Individual benefit limits as specified; the total cost of self-directed respite and/or supportive home care and agency-based HCBS cannot exceed \$15,000 per calendar year

Katie Beckett – Part B Benefits

Benefits in Part B will encompass a menu of five distinct program components.

1. Health insurance premium assistance – assistance in paying the eligible child’s portion only of employer-sponsored or other private family health insurance
2. Automated health care and related expenses reimbursement (a “Flexible Spending Arrangement-like” approach) – payment (or reimbursement) of qualified medical and related expenses, including private insurance deductibles and co-payments for physician and nursing services, therapies, prescription drugs, etc.; medical equipment and supplies; dental and vision, medical mileage; and other eligible medical expenses as determined by the Internal Revenue Service (see Publication XX);
3. Individualized therapeutic support reimbursement – reimbursement of therapeutic supports determined to be medically necessary for the child but not eligible for automated reimbursement, including non-traditional therapies;
4. Self-directed respite and/or supportive home care, using the services of the State’s contracted fiscal employer agent; and
5. Agency-based HCBS – specified HCBS delivered by a qualified HCBS provider, as follows:
 - a. Respite
 - b. Supportive home care
 - c. Assistive technology, adaptive equipment and supplies (up to \$5,000 per calendar year)
 - d. Minor home modifications (up to \$6,000 per project; \$10,000 per calendar year; and \$20,000 per lifetime)
 - e. Vehicle modifications (up to \$10,000 per calendar year and \$20,000 per lifetime)
 - f. Community integration support services
 - g. Family caregiver education and training (up to \$500 per calendar year)
 - h. Health insurance counseling/forms assistance (up to 15 hours per calendar year)

A child may receive benefits in any or all program components, based on the needs of the child, subject to a combined maximum total of \$10,000 in program expenditures per child per year. Only payments actually made with program dollars will count against the annual expenditure cap, regardless of any billed amounts for services.

Katie Beckett Part B benefits are summarized in Table 3 below:

Comment [TENNCARE9]: This maximum amount is driven by budgeted program funding. It could be amended over time if experience indicates that beneficiaries tend not to use the maximum funding budgeted.

Comment [TENNCARE10]: This clarification reflects questions and concerns raised by stakeholders.

Table 3: Katie Beckett Part B Benefits Chart

Benefit	Amount, Duration and Scope
Health insurance premium assistance (for the eligible child’s portion of the premium <i>only</i>)	Individual benefit limits as specified; the combined maximum total of benefits received cannot exceed \$10,000 per calendar year
Automated health care and related expenses reimbursement	
Individualized therapeutic support reimbursement	
Self-directed respite and/or supportive home care	
Agency-based HCBS <ul style="list-style-type: none"> – Respite – Supportive home care – Assistive technology, adaptive equipment and supplies (up to \$5,000 per calendar year) – Minor home modifications (up to \$6,000 per project; \$10,000 per calendar year; and \$20,000 per lifetime) – Vehicle modifications (up to \$10,000 per calendar year and \$20,000 per lifetime) – Community integration support services – Family caregiver education and training (up to \$500 per calendar year) – Health insurance counseling/forms assistance (up to 15 hours per calendar year) 	

Due Process

Persons applying to or enrolled in either Part A or Part B will have all due process rights applicable to Medicaid programs (see 42 CFR Part 431, Subpart E and 42 CFR Part 438 *et seq.*), as well as assistance navigating the appeals process utilizing the beneficiary supports system required pursuant to 42 CFR §438.71 (Tennessee’s current beneficiary supports system contractor is Disability Rights Tennessee, the State’s Protection and Advocacy organization).

Program Administration

The population expected to be served in Part A are primarily children with complex medical needs. The kinds of benefits these children will most need—including private-duty skilled nursing care, expensive medical equipment, and therapies—are currently provided under the Medicaid program as part of the

federally required EPSDT program, and delivered through managed care under the authority of TennCare’s 1115 demonstration waiver. Thus Part A of the program will be administered by TennCare through the existing managed care demonstration. Wraparound benefits that will be covered under the proposed new program will also be provided by the MCOs under the CHOICES and/or Employment and Community First CHOICES programs, using a network made up largely of providers also serving individuals with intellectual or developmental disabilities (I/DD) in the Section 1915(c) HCBS waivers operated by DIDD.

Because Tennessee’s Katie Beckett program will be new and the population will be small, TennCare will not have sufficient program experience to establish an actuarially sound rate. All children in Part A will be assigned to TennCare Select, a PIHP¹⁷ that currently serves most TennCare-eligible children with chronic disabilities and the most complex special health care needs. These children will be enrolled in a special component of TennCare Select called SelectCommunity, developed specifically for individuals with I/DD. Person- and family-centered planning will be conducted for children enrolled in SelectCommunity in a manner consistent with CFR §441.301(c)(1) , using SelectCommunity Nurse Care Managers who have specialized training in developmental disabilities, and in a family-centered approach. Tennessee will leverage the leadership of the Tennessee Department of Intellectual and Developmental Disabilities (DIDD) and the Tennessee Council on Developmental Disabilities in the *Supporting Families Initiative* to train Nurse Care Managers, and to embed a *Supporting Families* approach within the program’s policies and procedures.¹⁸

DIDD will play an important role in administering Part A of the program, including:

- Providing input regarding program design;
- Conducting outreach and intake for children who might qualify to enroll in the program, including working with the family to gather relevant information for an individualized determination of the child’s needs and to assist in gathering relevant medical and related information;
- Application of prioritization criteria and determination of prioritization for enrollment into Part A based on objective criteria established by the State;

Comment [TENNCARE11]: This language reflects stakeholder input and concerns.

¹⁷ Prepaid inpatient health plan, a health plan similar to an MCO, except PIHPs generally do not operate at full financial risk like MCOs.

¹⁸ The *Supporting Families* approach involves actively carrying out a comprehensive and coordinated set of strategies designed to ensure that family members who have a key role in the provision of support and guidance of their family member with intellectual or developmental disabilities (I/DD) have access to person-centered and family-centered resources, supports, services, and other assistance to address the emotional, physical and material well-being of the entire family. These strategies are directed to the family unit, but ultimately benefit the individual with I/DD. The overall goal of *Supporting Families*, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members. More information about the approach and the *Supporting Families* project is available at: <http://supportstofamilies.org/>.

- Providing intermittent case management contacts/assistance for children not able to enroll immediately (based on program capacity);
- Conducting individualized reevaluations based on significant changes in the needs and/or circumstances of a child enrolled in Part B, including potential eligibility for Part A and information pertaining to the child’s prioritization for enrollment into Part A;
- Serving as the licensure entity for wraparound services (such as respite or personal assistance) as applicable;
- Conducting annual quality monitoring surveys for specified agency types providing wraparound HCBS;
- Assisting with critical incident management and investigation; and
- Providing assistive technology evaluation or assistance where needed.

Comment [TENNCARE12]: This language reflects stakeholder input and concerns.

In addition, DIDD will directly administer Part B, the Medicaid diversion component of the program.

Transitions and Continuity of Enrollment and Services

Helping to ensure seamless transitions and continuity of TennCare enrollment and services is critical to meeting the needs of children in the target population and their families. This includes transitions between Parts A and B based on significant changes in a child’s needs and/or circumstances or as Part A program slots become available; transition from Medicaid to Part A when a child no longer qualifies for Medicaid in other open eligibility categories; and transition from Part A to other Medicaid eligibility categories upon the child turning age 18. While some of these transitions are discussed within sections above, they are reiterated here for purposes of clarity.

Transitions from Part A to Part B

Once a child is determined eligible for and enrolled into Part A, financial and medical (level of care) eligibility will be reevaluated at least annually. The child must continue to meet the institutional level of care criteria to remain enrolled in Part A. (Prioritization criteria will no longer apply.) If a child’s condition improves to the point that the child no longer meets institutional level of care criteria, and in accordance with due process pertaining to such a determination, the child will be disenrolled from Medicaid, but only upon also being determined ineligible for all open categories of TennCare coverage. The child could transition to Part B if there is an open program slot available. Likewise, a child found to no longer qualify for Part A due to non-payment of premiums will be disenrolled from Medicaid only after also being determined ineligible for all open categories of TennCare coverage and could transition to Part B if there is an open program slot available. (Note, however, as described in *Cost Sharing* below, that Part A benefits may be suspended during this review and/or transition period.)

Comment [TENNCARE13]: Clarification that prioritization criteria will be applicable only for purposes of initial enrollment. This clarification reflects specific concerns expressed by stakeholders regarding continuity of enrollment and benefits.

Transitions from Part B to Part A

The requirement for periodic review of eligibility is in the new state law and in federal regulations; both the state law and the federal regulations also require a review of Medicaid eligibility before any disenrollment would proceed.

As required by state law, Part A will target (and prioritize enrollment of) children with the most significant disabilities or complex medical needs who meet institutional level of care criteria. A child who does not qualify for Part A but qualifies for Part B may be enrolled into Part B, subject to availability of program slots and the State's first come, first served approach for enrollment into Part B.

A child who is eligible for Part A but not enrolled into Part A due to the lack of availability of an open program slot may also be enrolled into Part B, subject to availability of program slots and the State's first come, first served approach for enrollment into Part B. Objective, needs-based criteria used to prioritize enrollment into Part A will take into account any additional needs that are not met in Part B.

One of DIDD's contracted responsibilities as it relates to administration of Part A will be conducting individualized reevaluations based on significant changes in the needs and/or circumstances of a child enrolled in Part B, including potential eligibility for Part A and information pertaining to the child's prioritization for enrollment into Part A.

[Transition from Medicaid to Part A and Continuity of Medicaid Eligibility](#)

Children with significant disabilities and/or complex medical needs who are losing Medicaid eligibility and their families face myriad potential challenges, including disruptions in essential services and in longstanding patient/provider relationships, delays in accessing needed care, increased risk of institutionalization, lapses in provider payment (for which parents are likely responsible), and resultant financial hardship that may endure long past any effective date of new coverage. Although these children will likely be re-enrolled into Medicaid in a Medically Needy ("spend down") category once sufficient medical expenses are incurred to offset monthly income, the negative consequences of these gaps in coverage may be long felt. In order to avoid this "churn" and ensure continuity of coverage, benefits, and provider relationships, TennCare thus proposes the following:

For purposes of program eligibility, a Medicaid-eligible child who has been determined to no longer qualify for Medicaid in any open eligibility category shall be considered "not Medicaid eligible." The child could thus qualify for enrollment (and seamless transition) into Part A, if the child meets all other applicable eligibility criteria for Part A (including institutional level of care) and if there is an available program slot for which the child has been prioritized, in accordance with the prioritization criteria and process established by the State. (A child losing Medicaid eligibility should neither be advantaged nor disadvantaged over a child who does not have Medicaid coverage at the time of application.) Medicaid eligibility will be continued for a reasonable period pending the review of the child's Part A application, determination of the availability of a slot for the child, and seamless transition to Part A without a gap in coverage if a slot is available and the child meets program requirements.

In addition, as part of Amendment 40, TennCare proposes to apply the Katie Beckett *eligibility mechanism* (the waiving of the deeming of parents' income and assets to the child) to a child under age 18 who is currently Medicaid-eligible but has been determined to no longer qualify for TennCare in any other eligibility category, and who would qualify for enrollment into Part A, but for the lack of

Comment [TENN CARE14]: This is responsive to concerns from families whose children are currently on Medicaid because their parents have previously foregone employment opportunities or otherwise made difficult decisions in order for their child to qualify for Medicaid. These families requested assurances that there will be a pathway for these children to qualify for Medicaid if those circumstances change, without gaps in coverage.

availability of a program slot for that child. These children would be enrolled in a new demonstration “Katie Beckett Continued Eligibility Group.” Table 4 below summarizes each of the new eligibility groups proposed as part of Amendment 40, including income and level of care requirements.

Table 4: TennCare Katie Beckett Eligibility Chart

Eligibility Group	Income/Resource Standard	Level of Care Standard
<p>“Katie Beckett” Institutional Level of Care Group – children described in Section 1903(e)(3) with the most significant disabilities and/or complex medical needs.¹⁹ This group is subject to the enrollment target for Part A.²⁰</p>	<p>Income no more than 300% SSI/FBR; resources \$2,000 (Only the child’s income and resources are counted)</p>	<p>Qualify for care in a medical institution and for SSI if in an institution</p>
<p>“Katie Beckett” Diversion Group – children under age 18 with medical needs that are likely to last at least 12 months or result in death and that result in severe functional limitations based on medical eligibility developed specifically for children. This group is subject to the enrollment target for Part B.</p>	<p>Income no more than 300% SSI/FBR; resources \$2,000 (Only the child’s income and resources are counted)</p>	<p>Qualify for care in a medical institution OR at risk of institutional placement according to criteria established by the State</p>
<p>“Katie Beckett” Continued Eligibility Group – children who are enrolled in Medicaid but are no longer eligible in any category, and who are described in Section 1903(e)(3) but for whom there is not an available slot in Part A²¹</p>	<p>Income no more than 300% SSI/FBR; resources \$2,000 (Only the child’s income and resources are counted)</p>	<p>Qualify for care in a medical institution and for SSI if in an institution</p>

¹⁹ While a child must be under age 18 to qualify in the Katie Beckett Institutional Level of Care Group and enroll in Part A, a child who has filed an SSI application may remain enrolled in this Group and in Part A for up to 12 months following the 18th birthday to allow time for an SSI eligibility determination, and continuity of Medicaid eligibility and benefits.

²⁰ Children in the Continued Eligibility Group shall not count against the enrollment target for Part A.

²¹ Like children in Katie Beckett Part A and the Katie Beckett Institutional Level of Care Group, a child must be under age 18 to qualify in the Katie Beckett Continued Eligibility Group. However, a child who has enrolled in the Katie Beckett Continued Eligibility Group prior to age 18 and has filed an SSI application may remain enrolled in this Group for up to 12 months following the 18th birthday to allow time for an SSI eligibility determination, and continuity of Medicaid eligibility and benefits.

Children whose Medicaid eligibility is continued by enrollment in the Katie Beckett Continued Eligibility Group will remain enrolled in their current MCO, and will be accounted for in separate reporting to CMS and the General Assembly, but will not technically be “enrolled” in Part A. They will not be counted against the Part A enrollment target; nor will their expenditures be counted against the newly appropriated funding for Parts A and B. Accordingly, they will not have access to the wraparound HCBS that are available to children enrolled in Part A. It is only through transition to the new Part A program (in accordance with the prioritization criteria established by the State) that the child could access the additional wraparound benefits available to children enrolled in that program component.

A child must remain continuously eligible and enrolled in TennCare to qualify in the Katie Beckett Continued Eligibility Group. If a child enrolled in this group loses TennCare eligibility, the child will have to reapply for Katie Beckett Part A and could enroll subject to the availability of an open slot. Enrollment will proceed in accordance with prioritization criteria for available Part A program slots. The child could not re-enroll in the Katie Beckett Continued Eligibility Group (unless the disenrollment was the result of an administrative error made by the State).

Table 5 below provides a comparison of benefits that will be available to children in the Katie Beckett Continued Eligibility Group, versus children enrolled in Katie Beckett Parts A and B.

Table 5: Comparison of Katie Beckett Program Benefits

Benefits	Katie Beckett Part A	Katie Beckett Part B	Katie Beckett Continued Eligibility
State Plan- and EPSDT-covered services	Covered	Not covered	Covered
Health insurance premium assistance	Not covered ²²	Covered	Not covered
Automated health care and related expenses reimbursement	Not covered	Covered	Not covered
Individualized therapeutic support reimbursement	Not covered	Covered	Not covered
Self-directed respite and/or supportive home care	Covered	Covered	Not covered
Agency-based HCBS <ul style="list-style-type: none"> – Respite – Supportive Home Care – Assistive Technology, Adaptive Equipment and Supplies (up to \$5,000 per calendar year) – Minor Home Modifications (up to \$6,000 per project; \$10,000 per calendar year; and \$20,000 per lifetime) – Vehicle Modifications (up to \$10,000 per calendar year; and \$20,000 per lifetime) – Community integration support services – Family caregiver education and training (up to \$500 per calendar year) – Health insurance counseling/forms assistance (up to 15 hours per calendar year) 	Covered	Covered	Not covered

Transition from Part A to other Medicaid Eligibility Categories

Because a child enrolled in Part A must qualify for supplemental security income (SSI) due to the child’s disability—except for parents’ income and/or assets—these children will be expected to qualify for SSI upon turning age 18 (when the parent’s income and/or assets are no longer counted for purposes of determining SSI eligibility). As noted above, a child who has applied for SSI but whose application is pending or in appeal status may remain enrolled in Part A for up to 12 months following the 18th birthday to allow time for an SSI eligibility determination, and to provide continuity of Medicaid

²² Health insurance premium assistance may be provided at the State’s discretion if a hardship exception to the requirement obtain/maintain employer-sponsored or private insurance is requested and would otherwise be approved. In such cases, the premium assistance would not count against \$15,000 per calendar year expenditure cap for self-directed respite and/or supportive home care and agency-based HCBS.

eligibility and benefits. The child's health plan (TennCare Select) will be contractually required to assist the family in the SSI application process.

Eligibility Redeterminations

Children enrolled in any component of the Katie Beckett program will be required to verify continued financial and level of care eligibility for the program at least annually, as required under federal law. While providing timely proof of continued eligibility for TennCare is the beneficiary's (or in this case, parent's) responsibility, for children enrolled in Katie Beckett Part A or in the Katie Beckett Continued Eligibility Group, the child's health plan will be contractually required to provide reminders and other assistance as requested, assisting the family in completing the eligibility redetermination process. If in spite of the availability of such assistance, a child in Katie Beckett Part A or the Katie Beckett Continued Eligibility Group is disenrolled from TennCare, including for failure to respond to and/or complete the redetermination process timely, the child will have to reapply for Part A and could re-enroll subject to the availability of an open program slot. The child's previous Part A slot will not be held. Nor could a child whose eligibility has ended qualify again in the Continued Eligibility Group. Enrollment will proceed in accordance with prioritization criteria for available Part A program slots.

For children enrolled in Katie Beckett Part B, DIDD will be responsible for completing the annual verification that the child continues to meet financial and level of care eligibility. This will include obtaining attestation that the child's income (on which the financial eligibility determination is based) has not changed, or assisting the family in submitting verification to TennCare of any income changes that have occurred in order to ensure the child's income limit is not exceeded; and completing a continued eligibility review for level of care. Documentation of these annual verifications shall be maintained by DIDD or as otherwise directed by TennCare.

Cost Sharing

Premiums

As noted in *Part A Eligibility* and contemplated under state law, as a condition of enrollment and continued eligibility in Part A, children whose families have MAGI above 150 percent of the federal poverty level (FPL) (taking into account household size) will be required to pay a monthly premium, as set forth in Table 6 below.

The family's FPL percentage is determined based on their MAGI and household size. The amount of the monthly premium for each applicable FPL range is set to the percentage of the income of a household of two (the smallest potential household size for the applicable population) at the lower end of the range. For example, for households with incomes in the range between 150 percent and 250 percent of the FPL, the monthly premium is slightly less than 1.5 percent of the monthly income of a family of two with income at 150 percent of the FPL.

Table 6: Part A Premiums

Household Income (MAGI)	Premium % of income for a household of two	Monthly premium
>150% - 250% FPL	1.5%	\$25
>250% - 300% FPL	2.5%	\$75
>300% - 400% FPL	3%	\$125
>400% - 500% FPL	4%	\$225
>500% FPL - No limit	5%	\$350 + \$70 for every 100% above 500% FPL

Part A premiums as described above will be reduced by the eligible child's portion only of employer-sponsored or other private family health insurance. The State will establish a methodology for calculating the child's portion of employer-sponsored or other private family health insurance to be set forth in administrative rule. For ease of administration, the State may elect to establish a standard amount that will be deducted from the child's Part A premium obligation when a child has employer-sponsored or other private family health insurance coverage (i.e., when a hardship exception is not requested or is requested but not approved) rather than verifying premium amounts for this coverage and applying the deduction on an individual basis. If the child's portion of employer-sponsored or other private family health insurance (determined using the established methodology) is more than the child's monthly premium for Katie Beckett Part A, the child will not have premium obligations in Katie Beckett Part A.

At the State's discretion, premium amounts may be adjusted every year to account for changes in the FPL as determined by HHS, or alternatively, may continue to base premium obligations on 2019 FPL percentages for the duration of this demonstration.

Families of children enrolled in Katie Beckett Part A will be required to report changes in income within ten business days in order to make any needed adjustments in Katie Beckett Part A premiums. Premium changes will be effective the first day of the month following the month in which the adjustment is made, provided that a one-time payment to account for any delays in reporting income changes could be assessed. In that case, the one-time payment shall be due within no more than 30 days of notice of the payment obligation and if not paid timely, could result in suspension of Part A benefits and/or termination of eligibility as described in *Premium Payments and Arrearages* below.

Katie Beckett Part A will not assess co-pays and deductibles for Medicaid services provided under the program. The aggregate total of premium and cost sharing obligations will not exceed 5 percent of the family's annual gross income.

[Premium Payments and Arrearages](#)

Premiums for beneficiaries with MAGI above 150 percent of the FPL will be charged on a monthly basis and will not be pro-rated. Premium payments will be assessed effective the first full month the child is enrolled into Part A. The first two months' premium payments are due before the child can be enrolled

into the program, along with election of payment arrangements for subsequent premiums. Ongoing premium payments must be made via automatic bank draft. The effective date of eligibility for Katie Beckett Part A will be the date that the first two months premium payments are received in full, along with payment arrangements for subsequent bank drafts. If the two months advance premiums are not paid within 60 days following notice of the premium obligation amount, the Part A program slot will be released to another child. The child would need to reapply again for Part A, subject to the availability of another open program slot. The Part A program slot will not be held. Enrollment will proceed in accordance with prioritization criteria for available program slots.

If all or part of a premium payment is more than 30 days in arrears, program benefits for Part A will be suspended. If all or part of premium payments are more than 60 days in arrears, an advance notice of program disenrollment for non-payment of premiums will be sent.

An appeal may be filed regarding any valid factual dispute pertaining to premiums, including the premium amount and/or payments received. Benefits would remain in suspended status during the pendency of any appeal, but would be retroactively reinstated if resolved in favor of the enrollee (based on an error in calculating the premium amount or premium payments received).

If the premium payments in arrears are made in full at any point prior to the effective date of disenrollment, program benefits will return to active status retroactive to the date they were suspended.

If the premium payments in arrears are not made in full prior to the effective date of disenrollment, the child will be disenrolled from Part A, pending resolution of any hearing regarding any valid factual dispute pertaining to such payments.

If the arrearages are paid after the child is disenrolled, the child will have to reapply for Part A and could re-enroll subject to the availability of an open program slot. The Part A slot will not be held. Enrollment will proceed in accordance with prioritization criteria for available program slots. All premium arrearages and the first two months premiums must be paid in advance in order to qualify for re-enrollment.

NOTE: For reference purposes only, Table 7 below provides FPL percentages based on households of up to 8 persons. Note that \$4,420 multiplied by the applicable FPL percentage is used to account for each person in the household above 8.

Table 7: 2019 FPL Percentage by Household Size

Persons in Household	100% FPL	150% FPL	200% FPL	250% FPL	300% FPL	400% FPL	500% FPL
1	\$12,490	\$18,735	\$24,980	\$ 31,225	\$ 37,470	\$ 49,960	\$ 62,450
2	\$16,910	\$25,365	\$33,820	\$ 42,275	\$ 50,730	\$ 67,640	\$ 84,550
3	\$21,330	\$31,995	\$42,660	\$ 53,325	\$ 63,990	\$ 85,320	\$106,650
4	\$25,750	\$38,625	\$51,500	\$ 64,375	\$ 77,250	\$103,000	\$128,750
5	\$30,170	\$45,255	\$60,340	\$ 75,425	\$ 90,510	\$120,680	\$150,850
6	\$34,590	\$51,885	\$69,180	\$ 86,475	\$103,770	\$138,360	\$172,950
7	\$39,010	\$58,515	\$78,020	\$ 97,525	\$117,030	\$156,040	\$195,050
8	\$43,430	\$65,145	\$86,860	\$108,575	\$130,290	\$173,520	\$217,150

Estate Recovery

Because Tennessee Code Annotated Section §71-5-116 prohibits liens on real property on account of medical assistance and recovery of payments for medical assistance for individuals under age 55, estate recovery shall not be applied to benefits provided under Tennessee’s Katie Beckett program.

Proposed Waiver and Expenditure Authorities

To implement Amendment 40, the State requests the necessary expenditure authorities to establish the Katie Beckett Institutional Level of Care Group, the Katie Beckett Diversion Group, and the Katie Beckett Continued Eligibility Group as eligibility categories within the TennCare demonstration and to provide members of those groups with Part A and Part B benefits and services as described above.

Specifically, the State requests the following expenditure authorities under Section 1115(a)(2) of the Social Security Act:

- **“Katie Beckett” Institutional Level of Care Group.** Expenditures for children under age 18 who (1) have medical needs that are likely to last at least 12 months or result in death, and which result in severe functional limitations based on medical eligibility criteria developed specifically for children; (2) qualify for care in a medical institution; and (3) but for the parents’/guardians’ income would qualify for supplemental security income (SSI) on the basis of disability. These expenditures are limited to those necessary to provide:
 - “Part A” or “Part B” services, as described in this amendment, and as appropriate based on the component of the program (Part A or Part B) in which the beneficiary is enrolled.
- **“Katie Beckett” Diversion Group.** Expenditures for specified services for children under age 18 who (1) have medical needs that are likely to last at least 12 months or result in death, and

which result in severe functional limitations based on medical eligibility criteria developed specifically for children; (2) qualify for care in a medical institution or are at risk of institutional placement. These expenditures are limited to those necessary to provide up to \$10,000 annually of:

- Premium assistance
 - Reimbursement for specified items and services, as described in the amendment
 - Home and community based “Part B” services, as described in the amendment
- **“Katie Beckett” Continued Eligibility Group.** Expenditures for children under age 18 who are enrolled in Medicaid but are no longer eligible in any category, and who meet the criteria for enrollment in the “Katie Beckett” Part A group, but for whom there not an available Part A slot. These expenditures are limited to those necessary to provide:
 - All TennCare Medicaid services as presented in Table 2a of the TennCare II STCs
 - **“Katie Beckett” Part A Home and Community-Based Services.** Expenditures for the provision of home and community-based waiver-like services, as specified in the amendment, up to \$15,000 annually, that are furnished to children under age 18 who (1) have medical needs that are likely to last at least 12 months or result in death, and which result in severe functional limitations based on medical eligibility criteria developed specifically for children; (2) qualify for care in a medical institution; and (3) but for the parents’/guardians’ income would qualify for supplemental security income (SSI) on the basis of disability.
 - **“Katie Beckett” Part B Benefits.** Expenditures for the provision of benefits, up to \$10,000 annually, for premium assistance, reimbursement for specified items and services, and specified home and community-based waiver-like services, as described in the amendment, that are furnished to children under age 18 who (1) have medical needs that are likely to last at least 12 months or result in death, and which result in severe function limitations based on medical eligibility criteria developed specifically for children; (2) qualify for care in a medical institution or are at risk of institutional placement.

Medicaid Requirements Not Applicable to these Expenditure Authorities:

Other than Title XIX requirements already waived for the TennCare demonstration, all Medicaid requirements apply, except the following:

Cost Sharing	Section 1902(a)(14) insofar as it incorporates Section 1916	To enable the State to charge a sliding scale monthly premium, up to 5 percent of income, to custodial parent/guardian(s) of eligible children with annual household income above 150 percent of the federal poverty level.
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Reasonable Promptness	Section 1902(a)(8)	To enable the State to limit enrollment in “Katie Beckett” Part A and Part B to the enrollment targets established by the State. To enable the State to implement periods of enrollee ineligibility for failure to pay applicable monthly premiums.
Comparability of Eligibility	Section 1902(a)(17)	To enable the State to require parents with access to private coverage for a child to obtain or maintain such coverage, subject to a hardship exception To the extent necessary to permit the state to limit enrollment in the Katie Beckett continued eligibility group to those losing Medicaid eligibility

II. Expected Impact on Budget Neutrality

Implementation of Amendment 40 is projected to result in an increase in aggregate annual expenditures of \$77 million. A spreadsheet illustrating the anticipated impact of Amendment 40 on expenditures under the TennCare demonstration is appended to this amendment request.

III. Expected Impact on CHIP Allotment Neutrality

Amendment 40 will not result in any changes to Tennessee’s CHIP allotment neutrality.

IV. Modifications to the Evaluation Design

As discussed in detail in Section I, the goal of the State’s proposal is to demonstrate that a targeted package of tailored services and supports for individuals with significant medical needs can improve quality of life and delay the need for institutionalization.

The table below presents an overview of the state’s preliminary plan for evaluating the provisions outlined in Amendment 40. This evaluation plan is subject to change and will be further refined to reflect operational details as the program is implemented.

Hypothesis	Methodology	Data Sources and Metrics
Children enrolled in the Katie Beckett program will receive services and supports in the most integrated setting appropriate, avoiding the need for long-term institutional placement.	Number and percentage of children enrolled in the Katie Beckett program (by Part and in total) who require long-term institutional placement	Administrative data
Children receiving targeted supportive services and their families will maintain an improved quality of life, as compared to before the Demonstration.	Number and percentage of individuals in Part B program who report improvement on key quality of life indicators.	To be identified in conjunction with the state’s evaluation partner
Providing a targeted package of essential wraparound services and supports as well as premium assistance to children in Part B will delay the need for Medicaid eligibility.	Number and percentage of children who transition from Part B to Part A and the length of time in Part B prior to transition	Administrative data

The evaluation design of the TennCare demonstration will be modified to incorporate these hypotheses and metrics.

V. Documentation of Public Notice and Input

As discussed in detail in Section I, Amendment 40 is a direct outgrowth of a transparent, public legislative process involving a variety of stakeholders and culminating in the enactment of a new state law (Public Chapter No. 494) on May 24, 2019. Since the passage of Public Chapter No. 494, TennCare and its partner organization, the Tennessee Department of Intellectual and Developmental Disabilities, have actively sought to engage a variety of individuals, advocacy organizations, and other stakeholders to inform the development of Amendment 40. The State’s formal compliance with the requirements of 42 CFR § 431.408 is detailed below.

Public Notice

The State has implemented multiple mechanisms for notifying interested parties about Amendment 40 and for soliciting public input on Amendment 40. These public notice and input procedures are informed by—and comply with—the requirements specified at 42 CFR § 431.408.

The State’s public notice and comment period began on August 5, 2019, and lasted through September 6, 2019. During this time, a comprehensive description of the amendment to be submitted to CMS was made available for public review and comment on an amendment-specific webpage on the TennCare

website. An abbreviated public notice—which included a summary description of Amendment 40; the locations, dates, and times of three public hearings; and a link to the full public notice on the State’s amendment-specific webpage—was published in the newspapers of widest circulation in Tennessee cities with a population of 50,000 or more. TennCare disseminated information about the proposed amendment, including a link to the relevant webpage, via its social media (i.e., Twitter, Facebook). TennCare also notified the members of the Tennessee General Assembly of Amendment 40 via an electronically transmitted letter.

The state held three public hearings to seek public comment on Amendment 40, which took place as follows:

East Tennessee

Location: John T. O’Connor Senior Center, 611 Winona Street, Knoxville, Tennessee

Date: Tuesday, August 20

Time: 1:00 p.m. Eastern Time

West Tennessee

Location: STAR Center, 1119 Old Humboldt Road, Jackson, Tennessee

Date: Wednesday, August 21

Time: 1:00 p.m. Central Time

Middle Tennessee

Location: Bordeaux branch of Nashville Public Library, 4000 Clarksville Pike, Nashville, Tennessee

Date: Thursday, August 22

Time: 2:00 p.m. Central Time

Members of the public also had the option to submit comments throughout the notice period by mail and/or email. Documentation of the state’s public notice process is included as Appendix B.

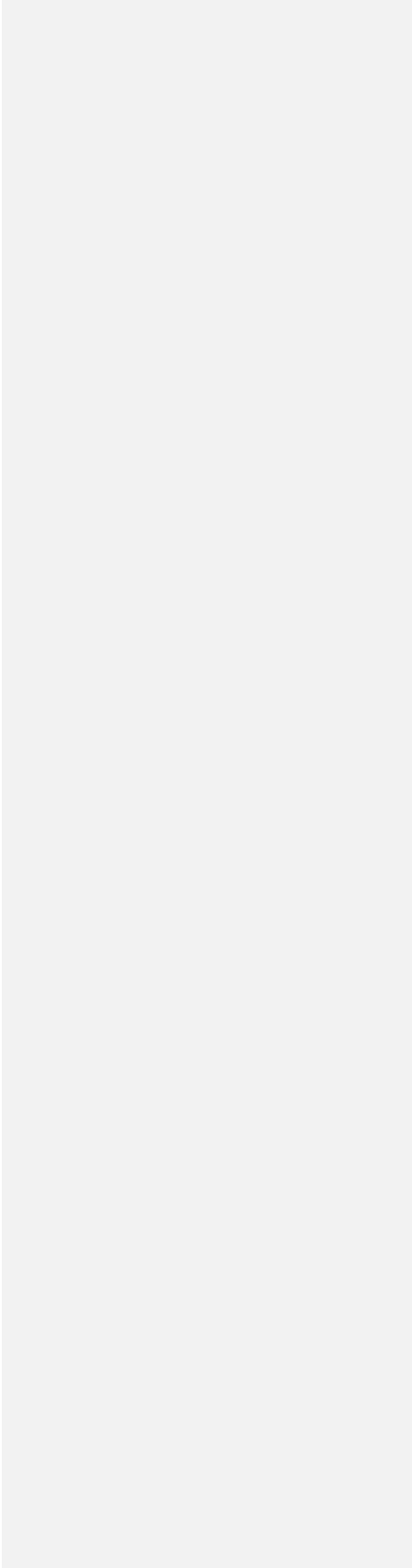
Public Comments

[RESERVED]

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Appendix A

Tennessee Public Chapter No. 494





State of Tennessee

PUBLIC CHAPTER NO. 494

HOUSE BILL NO. 498

By Representatives Whitson, Tillis, Rudd, Timothy Hill, Smith, Matthew Hill, Jernigan, Cameron Sexton, Curcio, Mr. Speaker Casada, Freeman, Daniel, Powell, Byrd, Hawk, Littleton, Van Huss, Gant, Hodges, Staples, Terry, Thompson, Cepicky, Sparks, Miller, Hicks, Hall, Clemmons, Love, Hakeem, Potts, Beck, Travis, Williams, Windle, Keisling, Towns, Dixie, Sherrell, Powers, Faison, Hurt, Lafferty, Eldridge, Zachary, Curtis Johnson, Wright, Shaw, Howell, Carr, Leatherwood, Coley, Farmer, Rudder, Helton, Moon, Calfee, Garrett, Lamar, Camper, Cochran, Ramsey, Stewart, Russell, Carter, Hazlewood, Haston, Dunn, Griffey, White, Marsh, Hardaway, Moody, Crawford, Kumar, Gloria Johnson, Parkinson, Weaver, Holsclaw, Baum, Bricken, Ogles, Ragan, Chism, Mitchell, Todd, Vaughan, Doggett

Substituted for: Senate Bill No. 476

By Senators Roberts, Lundberg, Stevens, Dickerson, Massey, Crowe, Bailey, Akbari, Haile, Yarbro, Gilmore, Bowling, Hensley, Powers, Reeves, Rose, White, Briggs, Yager

AN ACT to amend Tennessee Code Annotated, Title 4; Title 33; Title 56; Title 68 and Title 71, relative to healthcare benefits for disabled children.

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 be administered in accordance with this section. It is the intent of the General Assembly, that subject to approval by the centers for medicare and medicaid services, the Katie Beckett program

be composed of two (2) parts as described in subsections (b) and (c); provided, however, if the centers for medicare and medicaid services only approves one (1) part of the program, either Part A or Part B as described in subsections (b) and (c) respectively, then the approved part may be administered without the other part.

(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.

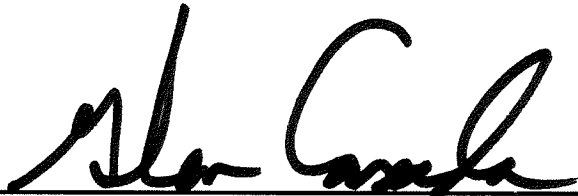
(f) The bureau of TennCare and the department of intellectual and developmental disabilities are authorized, as necessary, to promulgate rules to effectuate the purposes of this section. Rules must be promulgated in accordance with the Uniform Administrative Procedures Act, compiled in title 4, chapter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

HOUSE BILL NO. 498

PASSED: May 1, 2019



GLEN CASADA, SPEAKER
HOUSE OF REPRESENTATIVES



RANDY MCNALLY
SPEAKER OF THE SENATE

APPROVED this 24th day of May 2019

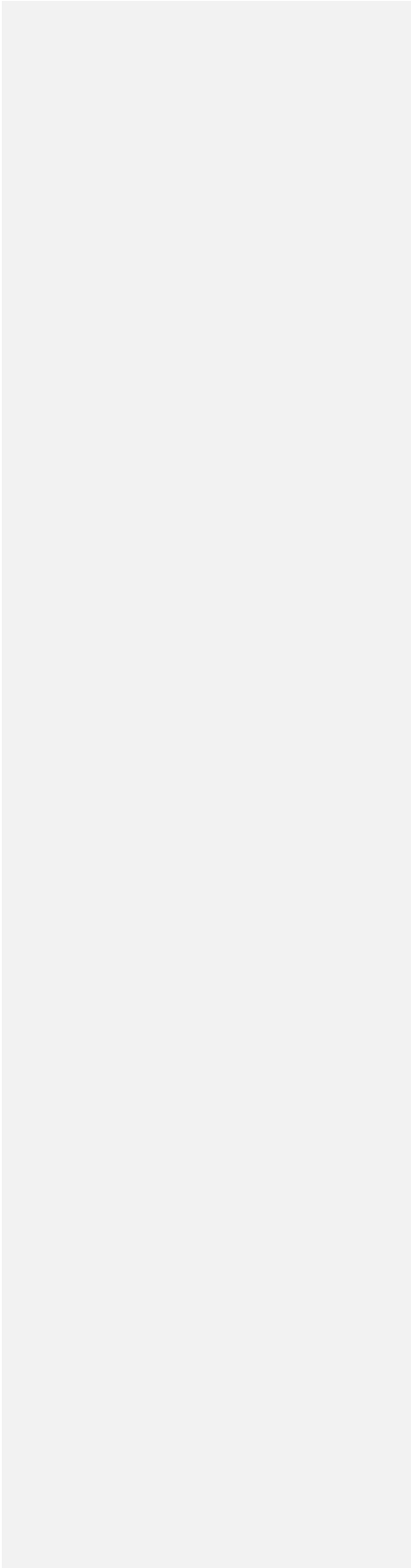


BILL LEE, GOVERNOR

Appendix B

Updated Demonstration Financial Model

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Baseline Budget Neutrality - Budget Impact Analysis

Amendment 40 - Katie Beckett Waiver Parts A & B

II. Actual Expenditures

Group 1 and 2

	Projected	
	2020	2021
1-Disabled (can be any ages)	\$ 2,240,280,696	\$ 2,326,818,716
2-Child <=18	\$ 2,030,046,662	\$ 2,119,368,715
3-Adult >= 65	\$ 2,050,556	\$ 2,120,275
4-Adult <= 64	\$ 1,683,574,455	\$ 1,771,120,327
Duals (17)	\$ 1,295,028,885	\$ 1,342,944,954
Total	7,250,981,253	7,562,372,986

Group 3

	2020	2021
1-Disabled (can be any ages)	\$ 20,206,534	\$ 21,014,796
2-Child <=18	\$ 1,441,401	\$ 1,504,823
3-Adult >= 65	\$ 107,786,964	\$ 111,451,721
4-Adult <= 64	\$ 596,207	\$ 627,210
Duals (17)	\$ 326,829,889	\$ 338,922,595
Total	456,860,996	473,521,144

Projected Pool Payments and Admin

	2020	2021
Total Pool & Admin	1,078,246,950	1,110,594,358

Total Net Quarterly Expenditures

\$ 8,786,089,199 \$ 9,146,488,488

III. Surplus/(Deficit) - Per change in CMS policy

Annual With Am 40 Changes
Cumulative With Am 40 Changes

	2020	2021
Annual With Am 40 Changes	\$ (19,207,555)	\$ (19,207,555)
Cumulative With Am 40 Changes	\$ 27,901,344,184	\$ 30,524,056,113

Annual Before Am 40 Changes
Difference

	2020	2021
Annual Before Am 40 Changes	\$2,475,220,262	\$2,622,711,929
Difference	\$ (19,207,555)	\$ (19,207,555)

Cumulative Before Am 40 Changes
Difference

	2020	2021
Cumulative Before Am 40 Changes	\$27,920,551,739	\$30,543,263,668
Difference	(19,207,555)	(19,207,555)

IV. Amendment 40 On-Off Switch

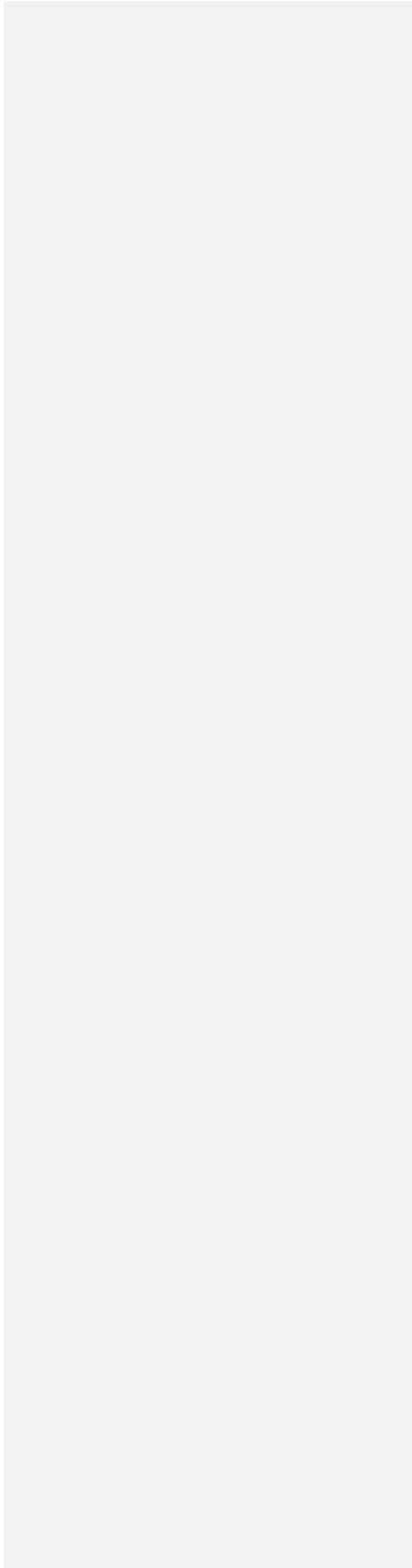
Amendment 40 (1 = yes,
0 = no)

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Net FFP Impact of Amendment 40	\$52,690,165	\$52,690,166
FFP with Amendment 40	\$5,786,342,625	\$6,023,694,389

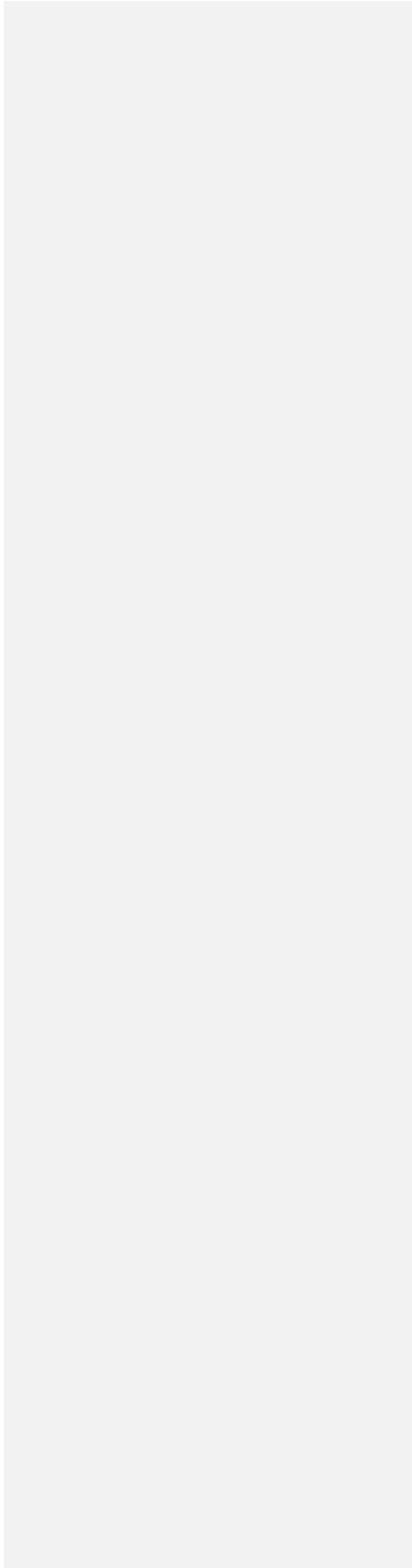
Appendix C
Documentation of Public Notice

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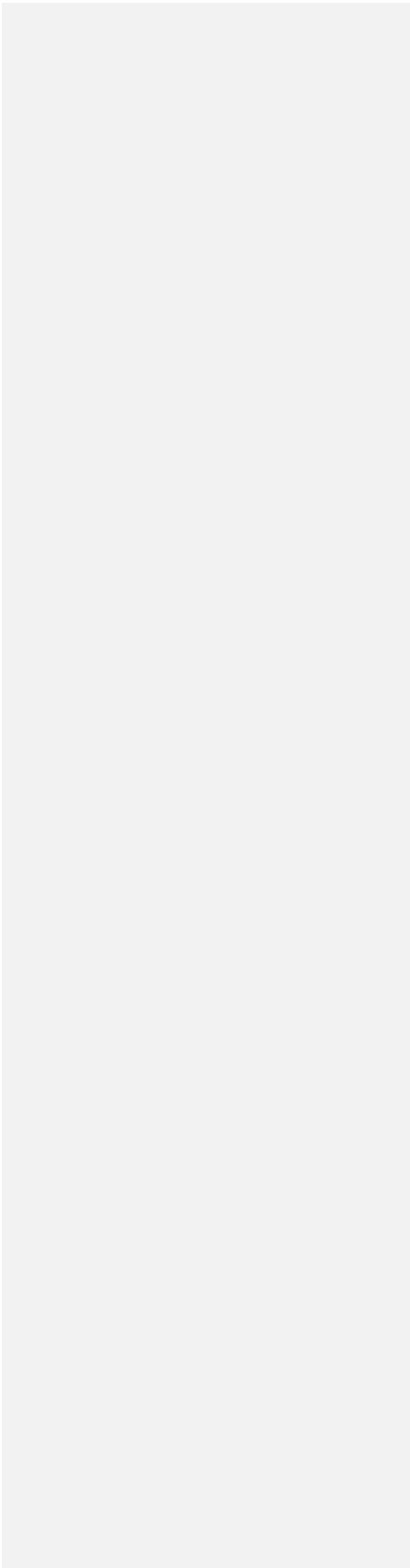
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Appendix D
Public Comments Received

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