



Katie Beckett Program Update

A Joint Report to the Tennessee General Assembly

January 29, 2021

Overview and Context

Public Chapter No. 494, passed by the Tennessee General Assembly during the 2019 legislative session, directed TennCare to submit a demonstration amendment to CMS to establish a new distinct 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 new law also requires that TennCare and the Department of Intellectual and Developmental Disabilities (DIDD) issue an annual joint report to the Insurance Committee of the Tennessee House of Representatives and the Health and Welfare Committee of the Tennessee Senate on the status of the Katie Beckett program, including:

- (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.

The purpose of this joint report is to provide an update on TennCare and DIDD's collaborative efforts to implement the new program and to meet statutory reporting requirements.

Federal Approval

Amendment 40 to the TennCare II Demonstration, requesting authority for the Katie Beckett Program, was submitted to the Centers for Medicare and Medicaid Services (CMS) on September 20, 2019. Following more than a year of conversations with CMS, TennCare received CMS approval on November 2, 2020.

Program Launch

Once federal approval was received, TennCare and DIDD were able to implement the program quickly (less than a month later on November 23, 2020) because so much planning and preparation had already been completed. This included an integrated eligibility determination system with capability to fully manage the Katie Beckett Program. Typically, TennCare would wait until federal approval is received before investing significant information technology (IT) resources in preparation for a new program. However, given the complexity of the Katie Beckett program (multiple program components, multiple new financial eligibility categories, completely new medical (level of care) eligibility and prioritization criteria for children, and premium requirements), this would have likely delayed implementation for at least a full year following CMS approval. In the interest of preparing to serve these children and their families as soon as possible and based upon extensive conversations with CMS which indicated that the state would ultimately receive approval for the program, TennCare and DIDD had cautiously proceeded.

Outreach to Children and Families

Upon CMS approval, letters were sent by DIDD to each of the 734 individuals on the Katie Beckett "interest list" that had been maintained by DIDD and by TennCare to each of the 158 non-Medicaid eligible children on the referral list for Employment and Community First CHOICES, advising them of the program's approval, when the program would begin accepting applications, how to apply, and how to request assistance in applying, if needed. DIDD and TennCare promoted the program rollout on social media and

collaborated to conduct a family-focused information session about the application process, develop frequently asked questions and guidance documents, and create animations and videos. The agencies' partnership with the Tennessee Council on Developmental Disabilities was extremely beneficial in reviewing and adjusting educational materials to meet families' needs. In addition, DIDD continues to utilize its Developmental Disabilities Planning and Policy Council (DDPPC) to provide recommendations and feedback on outreach efforts.

As we continue our efforts to engage with families and other stakeholders and to respond to their questions and concerns, TennCare and DIDD have created a high-level process flow to help families understand how applications move through the process (see Attachment A). Once the program has been operational for at least a quarter, we are also planning to reconvene the Katie Beckett Technical Advisory Group (made up of complex care pediatric experts, representatives from advocacy groups, and parents of children with complex medical needs) to review key learnings to date, and discuss potential recommendations for improvement.

Number of Referrals Received and Children Enrolled

Families began submitting self-referrals on November 23, 2020. As anticipated and based on TennCare and DIDD's collaborative outreach efforts, nearly six hundred referrals were received the first day. TennCare and DIDD began immediately processing the applications, working to enroll children in the program as expeditiously as possible.

As of January 28, 2021, TennCare has received 849 referrals for the Katie Beckett Program. In just over two months, 290 children have been enrolled in the program.

Income Range of Parents

A breakdown of parents' income ranges for children applying for the program is below. The data is based on Katie Beckett applications for which financial eligibility processes had run as of the date the query was completed. The data reflects parents' monthly income, using MAGI¹ budgeting, multiplied by 12 months to determine annual income.

Annual income ranges	# of Individuals	% of Total
<= \$50,000	147	22%
Between \$50,000 - \$100,000	254	39%
> \$100,000	252	39%
Total	653	100%

¹ 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.

Services and Expenditures

Services and expenditure data is not yet available. This is because the program was just launched in late November, and while TennCare and DIDD have worked quickly to enroll nearly 300 children, many are still in process of developing person-centered support plans to identify the services they need. This information will be provided in the next annual report, and can be made available as requested by the General Assembly, as the program is implemented.

Administrative Costs

Through December 31, 2020, TennCare has incurred just over \$9 million in implementation-related expenditures, the vast majority (\$8.9 million) for costs related to development of the new information system to support the program and eligible for enhanced (90/10) administrative funding from the federal government for new eligibility and enrollment systems, such that the state cost for these expenditures to date is less than \$1 million.

In FY 2020, DIDD incurred \$772,676 in administrative expenditures related to start-up costs for the Katie Beckett program—most associated with payroll and benefits for case management staff, with lesser amounts for travel, supplies, etc. To date for FY 21, DIDD has incurred just over \$1 million in administrative expenditures for the Katie Beckett program. Most of these expenditures are associated with the payroll and benefits for the Regional Office Katie Beckett staff, including directors and case managers, with a small amount for utilities, supplies and other administrative expenses.
