

Katie Beckett Program Update

A Joint Report to the Tennessee General Assembly

February 1, 2024

Overview and Context

Tennessee’s current Katie Beckett Program, which serves children with significant disabilities and/or complex medical needs who are not Medicaid eligible because of their parents’ income or assets, was established pursuant to Public Chapter No. 494, passed by the Tennessee General Assembly during the 2019 legislative session. 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 disability advocacy community, and championed by state lawmakers who were committed to prioritizing services for these children and their families within the financial constraints of state government.

The law 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 in working with stakeholders to continually improve the new program and to meet statutory reporting requirements.

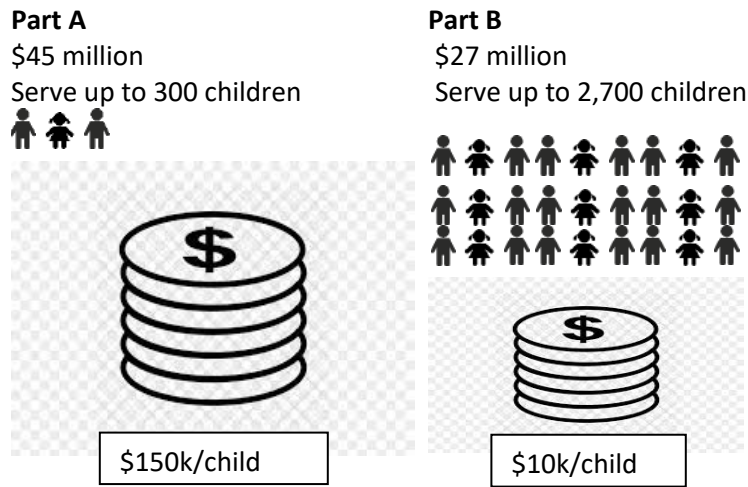
Katie Beckett Program Timeline



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. 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.

Katie Beckett Program Budget and Costs

Program Funding/Original Fiscal Review Committee Cost Estimate:



Program funding was based on cost projections of the Fiscal Review Committee as depicted above: \$45 million to serve up to 300 children in Part A (a projected average of \$150,000 per child) and \$27 million to serve up to 2,700 children in Part B (a projected average of \$10,000 per child).¹

As depicted below, in August 2023, as a part of budget rebalancing, \$13 million in budget authority was transferred from TennCare for the Part A program to DIDD for the Part B program, allowing 1,300 additional Part B slots and totaling 4,000 slots, while still preserving enough funding for the 300 Part A slots.



¹ The Appropriations Act also included \$4,828,200 for DIDD administrative expenses related to the Katie Beckett program.

In Part A, which is statutorily required to serve children with the most complex medical needs and disabilities, the per child costs to date are lower than projected in the budget—currently \$106,000 per year based on plans of care developed for each child, as well as actual expenditures within the State fiscal year. As expected, the most significant portion of medical expenses (more than 67%) are attributable to nursing care in the home.

Services and Expenditures

Based on currently approved plans of care and actual expenditures to date, the annualized cost of currently enrolled Part A participants is just over \$18.2 million. As noted above, nursing care accounts for more than 67% of medical costs. Other services include durable medical equipment, medical supplies, and occupational, physical, and speech therapies.

The annualized cost of currently enrolled Part B members is just over \$28.4 million. This is based on the budgeted cost of \$10,000 per child per year. Children enrolled in Part B receive a home and community-based services (HCBS) benefit package capped at \$10,000 per child per year. Most families seek to maximize the available benefit.

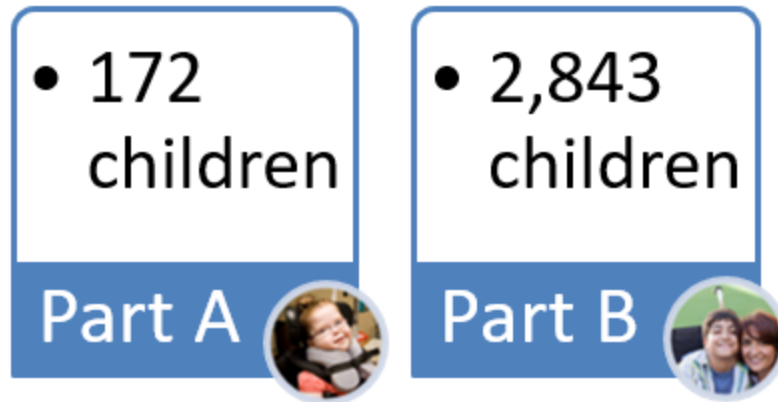
By far, the most widely used benefit in Part B continues to be Automated Health Care and Related Expenses Reimbursement. Of the \$29,295,736 in Katie Beckett Part B authorizations, \$28,376,744 are Automated Health Care and Related Expense Reimbursement authorizations. This is a flexible benefit unique to Katie Beckett Part B that is designed to “mimic” a Flexible Spending Account (FSA) or Health Reimbursement Account (HRA), as defined in federal law, except that contributions to the account are made using state and federal Medicaid funds, rather than pre-tax contributions from an employee’s paycheck or employer contributions. Families may then utilize a debit card to pay directly for eligible medical expenses (or have such expenses reimbursed). Assistance with [private insurance] Premium Payments is the second most widely used benefit, followed by Supportive Home Care, Individualized Therapeutic Supports Reimbursement (primarily for non-traditional therapies), Assistive Technology, Adaptive Equipment and Supplies, and Minor Home Modifications.

Administrative Costs

There was an increase in administrative expenditures for Part B as a result of the allocation of the 1,300 additional Part B slots. During CY 2023, DIDD has \$6,129,036.40 in administrative expenditures related to Part B of the Katie Beckett program—most associated with payroll and benefits for case management staff, with a small amount for utilities, supplies and other administrative expenses.

Katie Beckett Program Enrollment

As of December 28, 2023, there are 3,015 children are enrolled in the Katie Beckett Program, as depicted below:



When TennCare and DIDD began implementing the Katie Beckett program, we had many unknowns. We did not know how many children were going to apply, how many of those children would qualify, or what the average cost of providing the needed services would be. All of these factors are significant in light of a fixed budget allotment for the Katie Beckett program.

We were specifically directed by the Katie Beckett law to establish new eligibility requirements for children and to make sure that the children with the most complex medical needs and disabilities were enrolled in Part A. To that end, we worked with parents of children with complex medical needs and disabilities and physicians who provide their care, as well as advocates and other stakeholders, setting up a Katie Beckett Program Technical Advisory Group (TAG) representing all relevant perspectives.

One of the biggest concerns expressed by the TAG was that so many children would apply in the first weeks and months that it would take up all the room in the program, and that children with the most complex medical needs and disabilities might not be enrolled. None of the stakeholders wanted to be in a position where we had to tell a family with a child with one of the most complex medical needs that applied in the sixth month "sorry, but there is no room for you."

To follow the law, and based specifically on the recommendations of the TAG, TennCare decided to *initially* limit enrollment in Part A to children with the most complex medical or behavioral health needs. These are children who require very complex skilled nursing care and use medical equipment to sustain life, and children with such severe behavioral health needs accompanying their disability that there is imminent risk of serious physical harm—children at risk of needing inpatient care in a medical or psychiatric hospital unless in-home care is available.

To be clear, **every** child who applied and qualified for the Katie Beckett program was enrolled. However, children with less significant needs were *initially* enrolled into Part B. After working through the large volume of applications received upon program implementation, in the first quarter of 2021, TennCare reconvened the TAG and upon their recommendation, opened up enrollment into Part A to all eligible children. Any child eligible for Part A but initially enrolled into Part B has been offered the opportunity to transition to Part A, although some children have elected to remain in Part B. Everyone who has applied for Part A and who has qualified is currently being served. However, due to high demand, a waiting list had to be established for Part B in June 2023. As noted earlier, additional slots were approved for Part B in August 2023. While children on the waiting list are being actively enrolled, families continue to apply for the program. Therefore, there continues to be a waiting list that is being actively worked to enroll eligible individuals.

Income Range of Parents

A breakdown of parents' income ranges for children applying for the program is below. More than half of the children's families have combined income of more than \$100,000 per year. Another 38% of families have annual income between \$50,000 and \$100,000, with a small percentage less than or equal to \$50,000 per year. The data is based on Katie Beckett applications for which financial eligibility processes had run as of the date the query was completed — December 18, 2023. The data reflects parents' monthly income, using MAGI² budgeting, multiplied by 12 months to determine annual income.

Annual income ranges	# of Individuals	% of Total
<= \$50,000	144	4.70%
Between \$50,000 - \$100,000	1186	38.67%
> \$100000	1737	56.63%
Total	3067	100%

Program Outreach and Improvements

DIDD and TennCare have worked together to continue to provide outreach to educate families about the program, assist them in applying for the program, and provide guidance on how to use their benefits in the program. DIDD's outreach efforts included several presentations to hospitals and other stakeholders about the program. In addition, DIDD continued to educate Tennessee Early Intervention System TEIS Service Coordinators and early interventionists about the program at the Building Best Practice Conference in April. DIDD Commissioner Brad Turner and DIDD leadership also spoke with educators and families in 75 school districts across the state and presented to the West Tennessee Special Educators Conference about DIDD programs for children, with a heavy emphasis on the Katie Beckett Program.

DIDD also includes Katie Beckett families and stakeholders in its planning and policy councils. Its Developmental Disabilities Planning and Policy Council has provided recommendations and feedback on outreach materials as part of its focus area, which has led to the development of guidance for families on various program components including transition from Part B to A, the Redetermination Process, and fact sheets on the Healthcare Reimbursement Account (HRA) and Premium Assistance benefits.

Additional initiatives and improvement efforts for 2023 have included:

- Holding quarterly Katie Beckett Technical Advisory Group (TAG) meetings to gather feedback to identify program needs and inform improvement initiatives.
- Completing an overhaul of the TennCare Katie Beckett website. Feedback from TAG members as well as other stakeholders was obtained. The website was reorganized and streamlined to help provide a more family friendly experience.

² 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.

- Developing an Employment and Community First (ECF) CHOICES vs. Katie Beckett Flow resource document to help with outreach to families. This resource was designed with TAG and other stakeholder input to help support families in understanding the differences between the programs and to provide guidance on which program may be more appropriate for their child.
- Assisting Katie Beckett Part A and Part B families with the transition to a new fiscal employer agent (FEA), effective July 1, 2023. TennCare and DIDD worked with the previous FEA as well as the incoming FEA, Consumer Direct Tennessee (CDTN) to address transition related needs. Beyond the transfer of member information, resources were made available and informational sessions were put in place to assist with this process.
- Holding a Katie Beckett Part A Stakeholder Meeting with Katie Beckett Part A family members and BlueCare, the Managed Care Organization (MCO), for all Katie Beckett Part A families. This meeting was to obtain feedback on what is working well as well as recommendations for improvement.
- Participating in Katie Beckett Part A Advisory Group Meetings held by BlueCare semi-annually with select families.
- Conducting several community/stakeholder Katie Beckett program presentations, upon request.
- Developing a Katie Beckett brochure to provide an overview for families wanting to know more about the program.
- Expanding the number of Part B slots from 2,700 to 4,000.
- Identifying current mental and behavioral health support options available for Katie Beckett members and exploring potential areas for improvement.

Program Innovations, Impacts, and Success Stories

Without question, the most important measure of the program’s success is the impact it is having on the lives of children enrolled in the program and their families.

Katie Beckett Part A

Children in Part A are enrolled in TennCare Select, which is operated by Volunteer State Health Plan, a subsidiary of BlueCross BlueShield of Tennessee (BCBST).

Katie Beckett Part A Telehealth Pilot

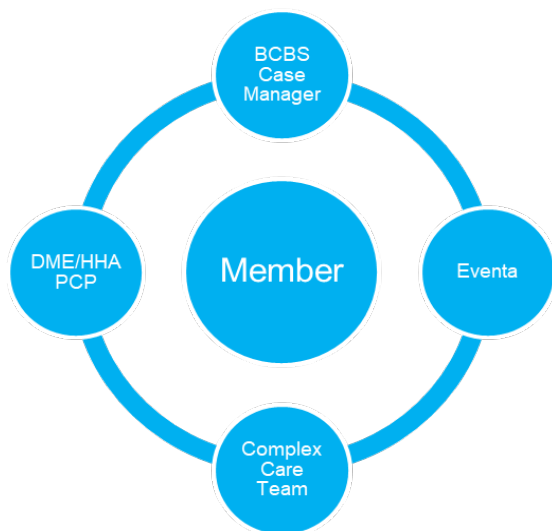
As part of planning for the implementation of the Katie Beckett Program, TennCare established contractual requirements for a Telehealth Pilot with specific requirements related to telehealth. For children enrolled in Katie Beckett Part A, TennCare Select is required to ensure that telehealth options are utilized to expand access to specialty care in rural areas, reduce travel burden on children with significant medical needs or disabilities and their families, build capacity of primary (in particular, rural) care providers to serve children with medical or behavioral complexity, improve monitoring and management of unstable or high-risk conditions—with a primary focus on children with complex respiratory care needs, reduce unnecessary emergency department visits or inpatient utilization, and improve care management and coordination.

As a telehealth pilot for the Katie Beckett Part A population with the most complex medical needs and disabilities, reimbursement is provided for medically necessary services when the TennCare provider is at

a qualified site other than where the patient is located and the patient is at a site appropriate to receive healthcare services (which may include the Katie Beckett member’s home).

In addition, a special Telehealth Pilot for Katie Beckett Part A children with enhanced respiratory care needs offers these children onsite clinical assessment, oversight and onsite and remote monitoring, including the opportunity for teleconsultation with a family member or paid caregiver in the home, and/or with the treating physician, as needed. Clinical experts in respiratory care ensure that the child is using state-of-the art equipment that supports remote monitoring (when applicable) for purposes of improved clinical management of enhanced respiratory care needs, such as pulse oximetry and end-tidal capnography devices to monitor pertinent vitals (oxygen saturation, heart rate, end-tidal carbon dioxide, and respiratory rate) and portable mechanical ventilators that support opportunities for family, school, and community participation, as appropriate. Additional technology such as heated, high flow molecular humidification devices are used to reduce the need for suctioning and risk of infection. The clinical support team responsible for onsite and remote monitoring for the Katie Beckett Part A telehealth pilot is available and engaged to provide onsite training and education for family members and/or paid caregivers, as needed, including nurses or those who will be performing self-directed enhanced respiratory health care tasks.

Working with Eventa, LLC, internationally recognized experts in respiratory care, selected members with the most complex respiratory care needs, at high risk of hospitalization, and/or weaning from the ventilator are monitored closely with the goal of early intervention due to change in respiratory status and to assist in improving quality and overall improved member outcomes. The Katie Beckett Program is pioneering this unique monitoring program and is the first to launch such a program in the home environment with the expansive reporting and data analysis being developed. The remote monitoring system is not designed to replace the bedside nurses or family caregivers for the member in emergency situations. However, the remote monitoring system provides crucial data to the medical providers, inclusive of more data points over additional periods of time. For weaning members, the recorded and reported data will allow the medical providers to make more informed decisions regarding the weaning process.

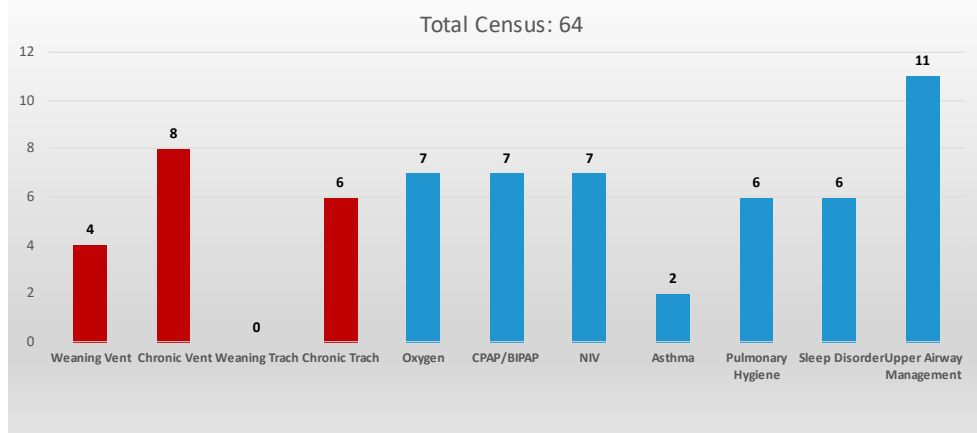


With the implementation of Remote Monitoring, we’re achieving:

- Improved Physician/DME/HHA involvement in care plans as a result of the collaborations and trending reports
- Assess and make recommendations for more appropriate home devices to assist in successfully supporting the member at home
- Identify clinical opportunities with early detection and intervention as a result of remote monitoring
- Improved QOL and member satisfaction with increased clinical support, including access after hours.

The total number of children enrolled in the pilot program through CY 2023, Quarter 4 is 64. The chart below provides a breakdown:

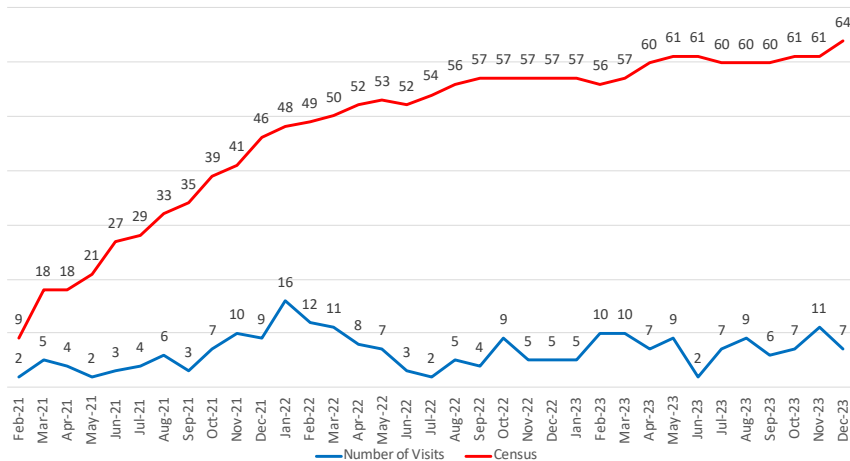
2023 Q4 – Katie Beckett by Care Type



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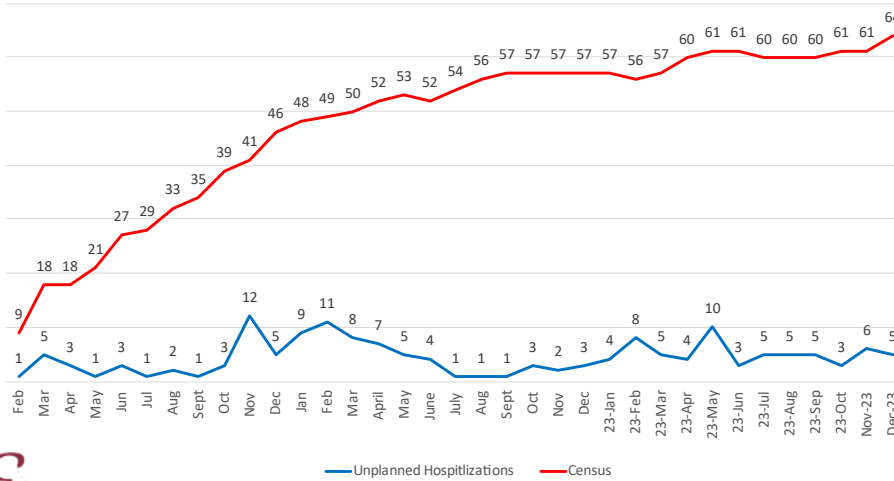
To date, the pilot has been successful in limiting Emergency Department visits and unplanned hospitalizations, even as the number of children enrolled in the program increased.

2023 - KBP ER Utilization



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2023 - KBP Unplanned Hospitalizations



2023 Quarterly Utilization:

- Q1 – 10%
- Q2 – 9%
- Q3 – 8%
- Q4 – 9%



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Eventa Success Stories

Quality of Life Improvement: Eventa supports a member who is 1 year old with a diagnosis of Chromosome 12 Abnormality which resulted in trach and ventilator dependence. The child required frequent ER and hospital utilizations for respiratory infections during his first year of life. Eventa began supporting the child in September 2022. Eventa recommended the utilization of high molecular heated humidification for secretion management and ventilator weaning purposes. The child received an Airvo device, which drastically improved secretion management. He began tolerating ventilator weaning trials and is now utilizing PMV twice daily! The child has had a significant decrease in ER and hospitalizations, with only one ER visit since being admitted to the Katie Beckett program. He now has an increased energy level and can participate in tummy time!

Competency of Care: Eventa supports a member who is 3.5 years old diagnosed with Hypoxic Ischemic Encephalopathy, Cerebral Palsy, and Developmental Delays secondary to a traumatic birth. The mother of the child reported increased episodes of lethargy as well as difficulty maintaining oral secretions with the concern of possible aspiration. Eventa identified the child as a candidate for remote monitoring as the child did not have a pulse oximeter to assess the episodes of lethargy or any possible desaturation events connected with possible aspiration. The child has been placed on remote monitoring with his current baseline still being determined. However, the reports are not indicating any acute events with stable vitals. The mother of the child now has peace of mind on her child’s clinical status.

Remote Monitoring: Eventa supports a member that is an 18-month-old with concerns of intermittent hypoxemic episodes requiring supplemental oxygen as needed. The mother of the child was concerned with hypoxemic episodes resulting in frequent ER visits leading to hospitalizations for observation – locally and out of state. The child’s mother reported twice weekly visits. Eventa worked collaboratively with the Nurse Care Manager and Medical Director to identify the child as a candidate for remote monitoring to determine how frequent and how severe the hypoxemic episodes were. The child was set

up with remote monitoring on 8/20/2023. Remote Monitoring was utilized as a tool to provide education on “true events” and physical assessments to determine child’s episodes. Since implementation, the child has decreased ER/hospitalizations by 100% and has gone more than 60 days without an occurrence.

BlueCare Updates

BCBST supports Katie Beckett Part A members and is committed to making a positive difference in their lives. Nurse Care Managers listen to families, encouraging not only proper care and support of the child, but also the whole family. Nurse Care Managers support and teach families how to recognize signs that require medical intervention. Families have received information and support to make difficult decisions such as when to request hospice, palliative care for pain management, or when more intense treatment may be needed. BCBST’s Nurse Care Managers have strongly advocated with members’ commercial insurance (primary insurance), and others to be collaborative partners in these children’s care and have helped families navigate the broader health care system.

This year has provided opportunities to improve BlueCare’s Katie Beckett Part A processes to benefit members. The greatest improvement was related to facilitating redetermination for continuing participation in the program. Parents were supported by the Nurse Care Managers who were able to answer questions, assist with document submissions, and help ensure that the redetermination process was completed timely.

Obtaining necessary medications can be a particularly difficult challenge for Katie Beckett Part A members, and the BlueCare Katie Beckett Part A team has continued to work closely with the Pharmacy Benefits Manager (PBM) liaisons to reduce the related stress and optimize this process. The Third-Party Liability (TPL) rules can be confusing, and liaisons are pharmacists who work closely with the Nurse Care Managers in obtaining prior authorizations for members.

The BlueCare Katie Beckett Part A team has also spent time educating office managers and advocating on behalf of Katie Beckett Part A members when offices refuse to see them due to them having Medicaid benefits. Many offices tell parents that they cannot see them because they would then be required to take all Medicaid patients. The Nurse Care Managers provide the Katie Beckett Program TN Anytime Eligibility document (from the Division of TennCare) and review it with the staff. This has reduced the instances in which members are required to find new primary care providers.

Mission Moments – Part A Member Success



Peyton's Story Peyton Hickman is a 15-year-old Katie Beckett member with Duchenne Muscular Dystrophy. Peyton is a spirited young man who begins each day with a positive and optimistic outlook. He is always smiling and loves to laugh. Peyton is limited in his mobility being wheelchair bound but doesn't let that stop him in pursuing his interests. In his free time away from specialist visits and school, Peyton is a LEGO builder extraordinaire and enjoys cooking and baking.

Peyton was able to attend two local cooking classes during 2023 using his CISS SS funds. Peyton attended a class entitled Family Steakhouse as well as another called French Croissants & Danish Pastries Made Simple. Peyton stated, "The cooking classes helped me get out of the house and taught me some new recipes that I am cooking for my family at home." Peyton enjoys being able to participate in integrated activities with his family as well as his typical peers. These classes not only provide him with activities now but prepare him for more independence as he ages.

Katie Beckett Part B

Part B experienced significant growth this past year, reaching its original capacity of 2,700 slots by early 2023. Because of the increased demand, TennCare and DIDD allocated an additional 1,300 slots to Part B.

This year also brought about several important changes to Katie Beckett Part B services. The most important was the decision to move to a calendar year expenditure timeframe for the program. Before, the program relied on tracking a child's \$10,000 annual cap along both a calendar year and the child's Independent Support Plan (ISP) year. Moving to a calendar year timeframe streamlined the process for both families and DIDD's program contractors. In addition, the department updated the Healthcare Reimbursement Account (HRA) guidelines after receiving family feedback and revised the Letter of Medical Necessity (LOMN) form to help ensure adequate documentation is provided upfront to ensure a

successful HRA (Health Reimbursement Account) approval process. The department also developed a mailing list to provide direct and timely communications to families from DIDD leadership.

In Part B of the program, the HRA continues to be the most popular service, with nearly all children having at least a portion of their funding going to the HRA. Satisfaction has also increased in the Katie Beckett Program. DIDD conducted a survey of Part B families in January. 92% of families indicated they were satisfied or very satisfied with their Katie Beckett Case Manager. 84% indicated they were either very satisfied, satisfied or neutral about their overall experience with PayFlex. Overall, 90% of families were very satisfied or satisfied with the Katie Beckett program, with almost all families saying that it had improved their child's quality of life.

Mission Moments – Quotes from Part B Families

A major benefit of Katie Beckett Part B is the flexibility built into the program structure to allow families to maximize funds to meet their child's individual needs.

"This program has truly changed my daughter's life. Being able to access the services she needs without having to worry whether we can afford them has been a huge blessing to us. She has experienced positive changes and growth more in the time we have been part of the program than at any other time of life. I'm so thankful for this program."

"This has allowed our son to participate in camps, baseball and other activities he would not have been able to. It also has allowed him to continue with private speech therapy. The respite is wonderful for us as parents to know we can get a few hours away occasionally. "

"Thank you for this program! It has allowed us to pursue respite, special therapies for autism and autism and sensory equipment that has improved my son's quality of life, improved our relationships and eased the financial burden of expensive therapies! Thank you so much!"

"We can't share enough how amazing and helpful this program is. We are extremely grateful."