Katie Beckett Program Update

A Joint Report to the Tennessee General Assembly

January 31, 2025

Overview and Context

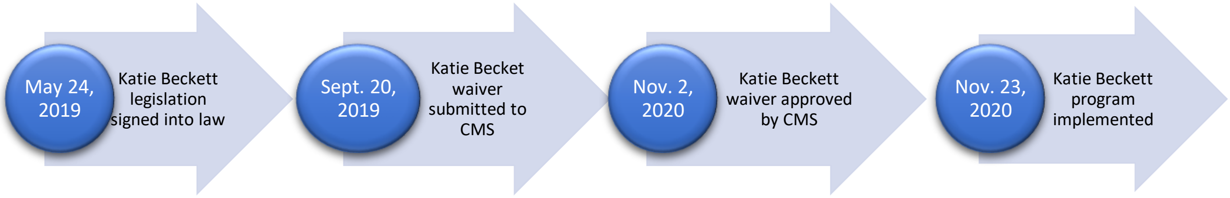
Tennessee's Katie Beckett Program, which serves children with significant disabilities and/or complex medical needs who are not Medicaid eligible because of their parents' income or assets, was established pursuant to Public Chapter No. 494, passed by the Tennessee General Assembly during the 2019 legislative 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 Disability and Aging (DDA) (formerly 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 DDA's collaborative efforts in working with stakeholders to continually improve the new program and to meet statutory reporting requirements.

Katie Beckett Program Timeline

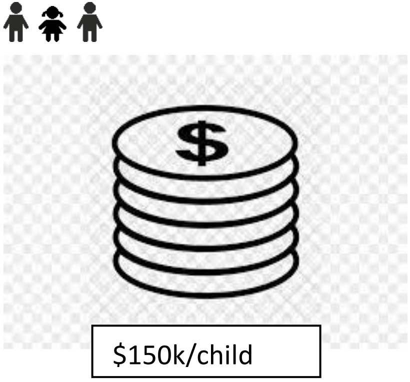


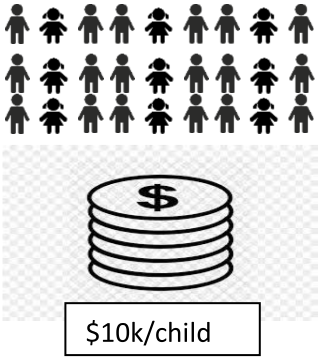
Amendment 40 to the TennCare II Demonstration, requesting authority for the Katie Beckett Program, was submitted to the Centers for Medicare and Medicaid Services (CMS) on September 20, 2019. Following more than a year of conversations with CMS, TennCare received CMS approval on November 2, 2020. Once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

Part A	**Part B**
$45 million	$27 million
Serve up to 300 children	Serve up to 2,700 children





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 DDA 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.

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

In October 2024, as a part of another budget rebalancing, $7 million in budget authority was transferred from TennCare for the Part A program to DDA for the Part B program, allowing 700 additional Part B slots and totaling 4,700 slots, while still preserving enough funding for the 300 Part A slots.

Part A	Part B
$100k Yearly Per Child	4,700 Capacity
$25 M Program Funding	$47 M Program Funding

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 $100,000 per year as of December 6, 2024 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 (nearly 70%) 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 $22.3 million. As noted above, nursing care accounts for nearly 70% 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 approximately $45.5 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 $36,582,483 in Katie Beckett Part B authorizations, $35,676,235 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 additional Part B slots. During CY 2024, DDA had $8,962,846 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 30, 2024, there are 4,411 children are enrolled in the Katie Beckett Program, as depicted below:

- 223 children

Part A

- 4,188 children

Part B

When TennCare and DDA 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, an additional 1,000 slots were approved for Part B in August 2023. While the children on the waiting list were being actively enrolled, families continued to apply for the program at a high rate. The additional 1,000 slots were filled by October 2024 in addition to newer applicants on the waitlist. In October 2024 an additional 700 slots were approved for Part B. The waiting list continues to be 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 37% 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 20, 2024. The data reflects parents' monthly income, using MAGI[2] budgeting, multiplied by 12 months to determine annual income.

Annual income ranges	**# of Individuals**	**% of Total**
<= $50,000	184	**3.96%**
Between $50,000 - $100,000	1742	**37.47%**
> $100000	2723	**58.57%**
Total	4649	**100%**

Program Outreach and Improvements

DDA 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.

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[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.

Initiatives and improvement efforts for 2024 have included:

- Holding quarterly Katie Beckett Technical Advisory Group (TAG) meetings to gather feedback to identify program needs and inform improvement initiatives.
- Conducting website review and updates.
- Refining the review/transition process for Katie Beckett members turning 18.
- 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.
- Expanding the number of Part B slots from 4,000 to 4,700.
- Continued focus and conversation with TAG members on identifying current mental and behavioral health support options available for Katie Beckett members and exploring potential areas for improvement.
- The National Core Indicators (NCI) Family Survey was released and highlighted that Tennessee is making a profound difference in the lives of Katie Beckett Members and their families. Tennessee ranked 1st in 29 indicators (46.8% of the 62 indicators) and is the only state that scored a perfect 100% on the indicator "Do you feel that services and supports have made a positive difference in the life of your child?"
- The KB TAG making the decision to reduce the number of reserved slots that have to meet Tier 1 criteria (most complex medical needs and disabilities) for Part A from 50 to 25 to provide flexibility to also allow more children to enroll that meet Tier 2 criteria (meet institutional level of care but needs are not as significant as Tier 1).

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).

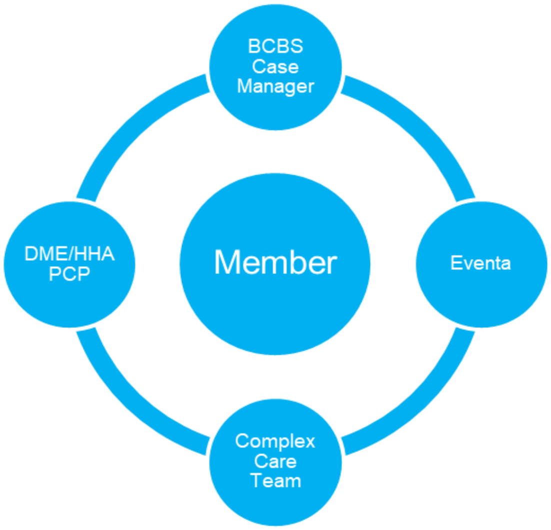
Katie Beckett Part A Telehealth Pilot

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.

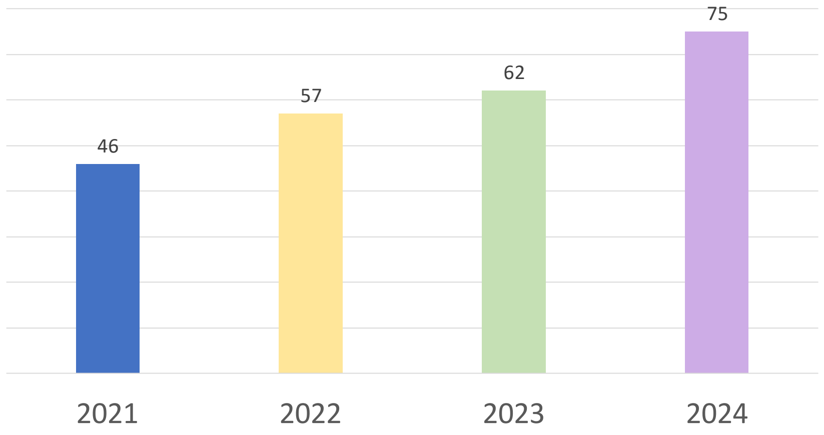


With the implementation of Remote Monitoring, we’re achieving:

- 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.

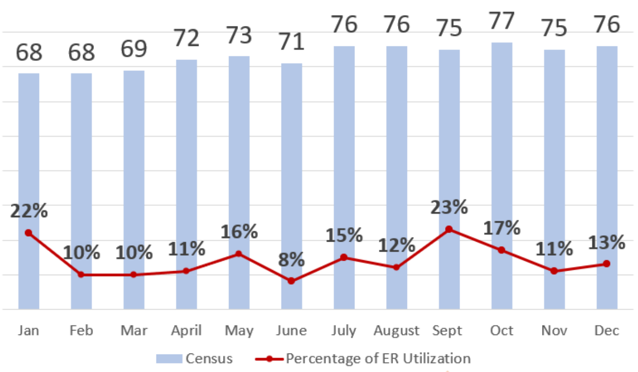
The total number of children enrolled in the pilot program through CY 2024, Quarter 4 is 75. The chart below provides a breakdown:

Average Annual Census



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:

2024 - KBP ER Utilization Percentage vs Census

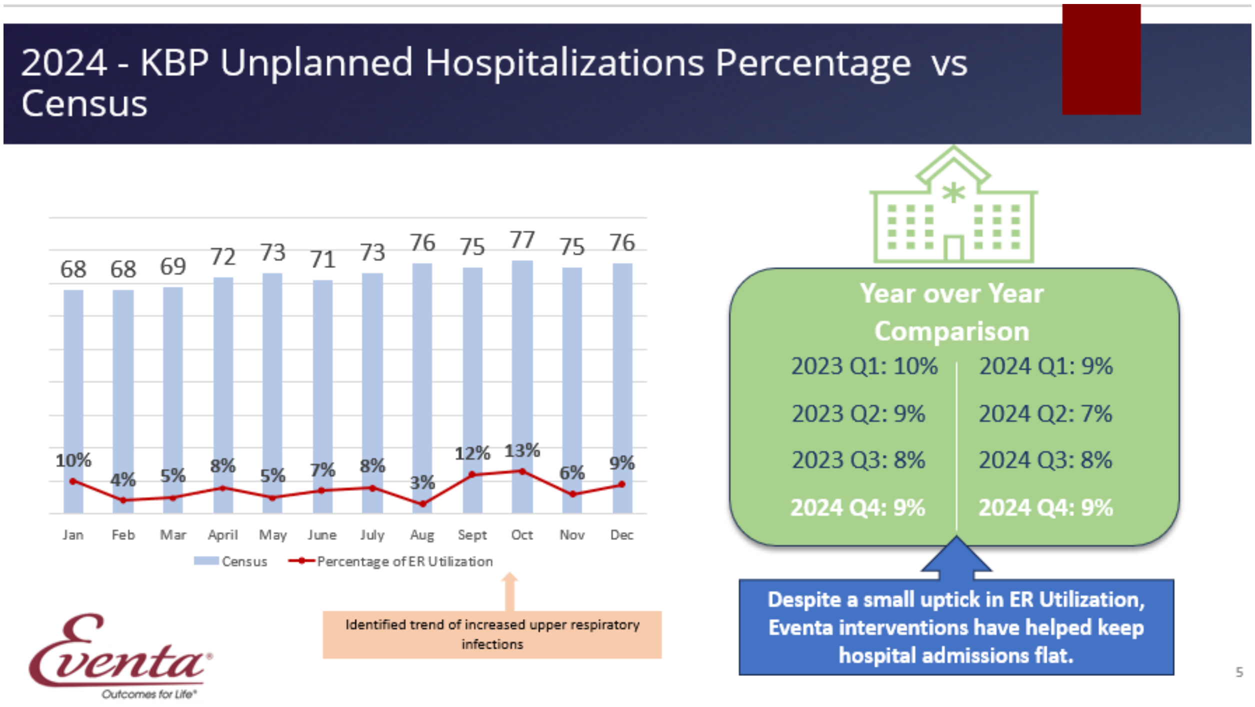


*New member to Eventa with frequent utilization for sepsis

Year over Year Comparison

2023 Q1: 15%	2024 Q1: 14%
2023 Q2: 10%	2024 Q2: 12%
2023 Q3: 12%	2024 Q3: 16%
2023 Q4: 13%	**2024 Q4: 13.59%**

Despite an aggressive respiratory season, Eventa interventions have helped keep utilization at just under a 1% increase



2024 - KBP Unplanned Hospitalizations Percentage vs Census

Identified trend of increased upper respiratory infections

Year over Year Comparison

2023 Q1: 10%	2024 Q1: 9%
2023 Q2: 9%	2024 Q2: 7%
2023 Q3: 8%	2024 Q3: 8%
2024 Q4: 9%	2024 Q4: 9%

Despite a small uptick in ER Utilization, Eventa interventions have helped keep hospital admissions flat.

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<u>Eventa Success Stories</u>

Decreased Hospital Utilization: Eventa supports a member who is 5 years old diagnosed with Pfeiffer Syndrome and has been trach dependent since birth with noted frequent ER and readmissions. Eventa identified frequent desaturation events resulting from mucus plugging. Eventa recommended the use of high molecular heated humidification for secretion management and provided education to the family and Private Duty Nurse (PDN) on pulmonary hygiene. Along with providing education, Eventa also followed up on supply ordering for all devices supporting pulmonary hygiene. The member's father has increased participation in the member's care and care competency has improved with caregivers and PDN. As a result, the member has required only one hospitalization with a decreased length of stay for respiratory illness in the last 6 months.

Decannulation: Eventa has supported a member who is 12 years old with multiple cardiac complications and trach dependency due to narrow airway since March 2023. The member had required a trach since 1 year of age. Eventa identified decannulation potential and collaborated with ENT to obtain an order for Speech Therapy and PMV with the goal of decannulation. Eventa provided ongoing support and encouragement to the family on the use of Prolonged Mechanical Ventilation (PMV)_while also relaying concerns with the ENT provider for additional oversight. The member underwent a successful capping trial in May 2024 which then led to successful decannulation in July 2024.

Weaning Progress: Eventa supports a member who is 5 years old born with congenital abnormalities. This member required trach, continuous ventilation, g-tube, and colostomy 2 months after birth. Eventa began evaluating the member in 2021. The member required continuous ventilation and the member's mother was informed that the member would most likely require invasive ventilator until at least puberty. Eventa provided support with monthly evaluations, ensuring that the member remained stable and that their respiratory needs were being met. The member began to attempt vent weaning in August

2023. The member underwent a successful sleep study to determine if noninvasive ventilator (NIV) would be sufficient with a capped trach. The member was able to tolerate capping for short periods of time. Eventa began educating the member's caregiver on capping and utilizing PMV to help ensure the member's success. The member progressed to only requiring mechanical ventilation while sleeping and comfortably capping or using a speaking valve throughout the day. The member recently underwent a scope and was determined ready to begin progression towards decannulation. The physicians report that member's weaning progress is exponentially ahead of projected care plan goals.

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 provided opportunities to improve BlueCare's processes to benefit members. The greatest improvement was related to transitioning members from Katie Beckett Part A to ECF CHOICES for those members that met the Reserve Capacity population. This year BlueCare had 10 members aging out of the Katie Beckett program and 5 have successfully transitioned to ECF CHOICES with 2 currently in process.

TennCare, like all Medicaid agencies, is required to renew every member's coverage once a year. Renewals, also known as redeterminations, mean TennCare must review members' information to make sure they still qualify for coverage. BlueCare has continued to work closely with families in Katie Beckett regarding the redetermination process. This includes notifying them as soon as BlueCare sees that they are coming up for redetermination and assist with submitting documentation when needed.

The BlueCare team spent time educating families on the use of the $15,000 wraparound service to their Third-Party Liability (TPL) and Medicaid. They also provided education to families to assist in better understanding the Assistive Technology (AT) benefit. AT and how those items are reviewed have been discussed on each of the BlueCare Advisory Meetings this year.

BlueCare has also realized the benefit of having quarterly meetings with Eventa to discuss members receiving Enhanced Respiratory Care (ERC) services in Katie Beckett Part A. This allows BlueCare to discuss any issues, successes, and upcoming transitions.

Mission Moments – **Part A Member Success Stories**

Henlee's Story Henlee was born with a 12th chromosome abnormality. He spent the better part of his first year in and out of the hospital and experienced respiratory and digestive issues that ultimately led to a trach, ventilator, feeding tube, and a now-reversed ostomy. While inpatient, Henlee went into cardiac arrest and received CPR numerous times. His parents were given all the possible side effects of repeated episodes of resuscitation; and at times, were told to expect the worst. Despite all of this, Henlee has proven himself to be one tough and resilient little boy.

When enrolled in Katie Beckett Part A, Henlee was completely ventilator and G-Tube dependent. Henlee, however, didn't let any of that hold him back. Henlee and his parents have endured many hours of therapies, private duty nursing, doctors' appointments, procedures/surgeries, and hospital stays. Henlee turned 3 in November and is now walking independently, completely off the ventilator, and is taking all foods/formula by mouth. If all continues to go well, there are plans to have the trach removed in the next year. Henlee has very minor developmental delays and is expected to start preschool in Spring 2025.

"We are extremely grateful for the Katie Beckett program and all the support we have received. This program has allowed us to care for Henlee in our own home without concern of how we will afford the services he needs to thrive." -Christin and RJ Oliver

Mason's Story Three years ago, Mason went from a very compliant child with Autism to a moody, withdrawn child with a new onset of aggression. He also had an increase in OCD and anxiety which lead to other behaviors and a decrease in activities of daily living. With such a dramatic change in behavior, his pediatrician made a referral for Applied Behavior Analysis (ABA) therapy. After 2.5 years of trying to find a center that had an opening and 2 hospitalizations related to behavior, he finally received services. He has now been in therapy for 7 months with a new increase in hours from 3-hour sessions 5 days a week to 4-hour sessions 5 days a week. With the help of his behavior tech and Board-Certified Behavior Analyst (BCBA), he has charted a major change from being aggressive on a daily basis to having 1-2 less intense episodes a month. He has also had a decrease in his PICA to the point he will now give his parents objects instead of eating them. His Obsessive-Compulsive Disorder (OCD) does still cause problems with transitioning but, with the medication change and therapy, his family has seen improvement . His parents also receive training in the center every other week for 30 minutes to an hour per session. In these sessions they go over skills that have worked at the center so that his parents can implement them at home. This school year is the first in 3 years that he hasn't been overly aggressive with staff. Mason has been able to increase his time at school from 1-2 hours per day to now attending full time.

Katie Beckett Part B

The Katie Beckett Program completed its 4th full year of operation in 2024 and continued to experience rapid growth through the year. Due to the popularity of the program and the beneficial impacts on Tennessee families, an additional 700 slots were allocated in the fourth quarter of 2024. By the end of the 2024, enrollment in Part B of the program was at 4,188, an increase of over 1,300 children from the previous year.

This year also brought about an important change to case management within the program. Beginning in March 2024 the Department of Disability and Aging began contracting with independent support coordination agencies to provide the ongoing case management to children enrolled in Katie Beckett Part B. The transition to independent support coordination has allowed for more rapid enrollment of children into the program without waiting for request and approval of authorized positions and has substantially reduced the waiting period from eligibility approval to enrollment.

In Part B of the program, the Health Reimbursement Account (HRA), which allows parents to utilize an HRA debit card or receive reimbursement for qualified medical expenses, continues to be the most popular service, with nearly all children having at least a portion of their funding going to the HRA. The second most popular service, Health Insurance Premium Assistance, allows parents to offset the cost of their child's private health insurance and has further reduced the financial burden on families as they support children with disabilities in Tennessee.

Mission Moments – **Part B Member Success Stories**

Walter's Story Walter has been enrolled in Katie Beckett Part B since January of 2023, and has made many strides in his journey through the assistance and support that he and his family receives from the program. Diagnosed with autism and Mixed Receptive-Expressive Language Disorder at age two, Walter's family struggled with navigating some challenges in Walter's world. They were concerned about his refusal to use the toilet and worried he would have to remain in diapers for the foreseeable future. Through the use of HRA service, they were able to enroll in a potty training "boot camp" intensive offered through Mindful Voices Autism Consulting and Walter is now using the toilet on his own!

Throughout the process, Walter was able to gain a sense of independence and self-worth while building a lasting relationship with the team at Mindful Voices. The family was also afforded the opportunity to increase his weekly hours at ABA, thereby supplementing Walter with various methods to express himself such as the use of Picture Exchange Communication (PECs) choice cards and learning to use his Augmentative and Audio Communication (AAC) device.

Last year the family was able to utilize the Adaptive Equipment service offered through Katie Beckett to purchase a wagon, an adaptive car seat, and a step stool for getting into his car seat independently. All these items have increased Walter's autonomy and safety in the community, which his family is most proud of. Although Walter is still learning and growing, he has accomplished so many of his and his family's goals ever since enrolling in Katie Beckett Part B. They look forward to seeing Walter thrive in his home and community as he continues to make breakthroughs with the help of his circle of support!

Archer's Story Archer Maple is a very social kid. He enjoys spending time with other kids and playing outside. The Katie Beckett Program is giving him more opportunities to do just that.

"Katie Beckett has just improved our quality of life so much."

Archer was born with Peroxisome Biogenesis, a rare genetic disorder that impacts his bone and teeth development. Archer is also deaf and blind with low muscle tone and poor balance.

The Katie Beckett program is providing support to the Maples in a variety of ways.

“We were never able to get a good dental exam because he needed to be sedated,” says Ashley Maple, Archer’s mom. “That was a big expense that we were able to use the Katie Beckett [program] for, and such a relief for us that we were finally able to get the dental care that we knew he needed.”

In addition, the Maples were able to pay for Archer to attend a summer camp to ensure he was able to interact with other kids during the summer and avoid isolation. They also used Part B funds to purchase an advanced mobility adaptive stroller to take him on walks and other community outings. The respite availability has also been tremendously helpful to the Maples to sustain caregiving. The program has been life-changing for the entire family.

“It just has given him more access to his world, taken some burden off of us financially, emotionally,” says Maple. “I just know that if he could, he would thank the organization that is providing this for him.”