

# **Katie Beckett Program Update**

## **A Joint Report to the Tennessee General Assembly**

January 26, 2023

## Overview and Context

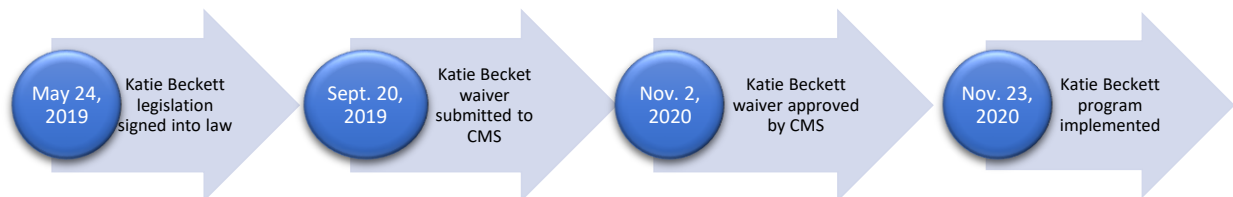
Tennessee’s current Katie Beckett Program, which serves children with significant disabilities and/or complex medical needs who are not Medicaid eligible because of their parents’ income or assets, was established pursuant to Public Chapter No. 494, passed by the Tennessee General Assembly during the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

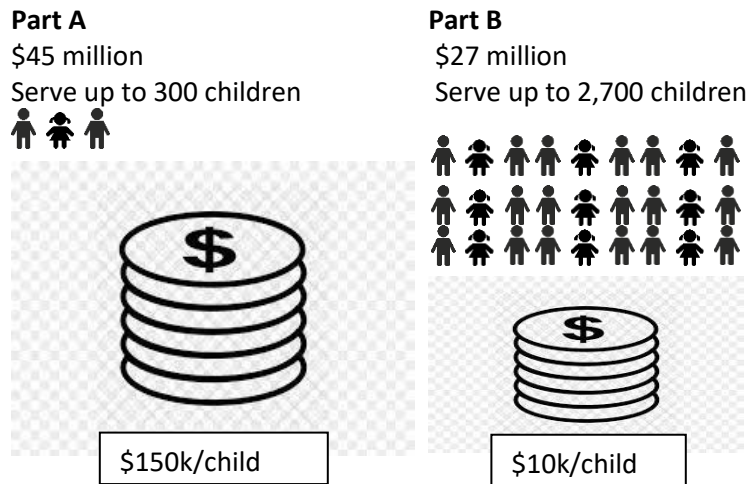
### Katie Beckett Program Timeline



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).<sup>1</sup>

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 higher than projected in the budget—currently \$204,000 based on plans of care developed for each child, as well as actual expenditures to date. As expected, the most significant portion of medical expenses (more than 65%) are attributable to nursing care in the home. The implication of the higher per child average cost is that fewer children may be able to enroll in Part A—currently 220 slots at the current projected average per child cost, rather than the 300 originally expected.

### 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 \$31.2 million. As noted above, nursing care accounts for more than 65% of medical costs. Other services include durable medical equipment, medical supplies, and occupational, and physical and speech therapies.

The annualized cost of currently enrolled Part B members is \$19.7 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 is Automated Health Care and Related Expenses Reimbursement. Of the \$18,821,373 in Katie Beckett Part B authorizations, \$18,131,340 are Automated

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

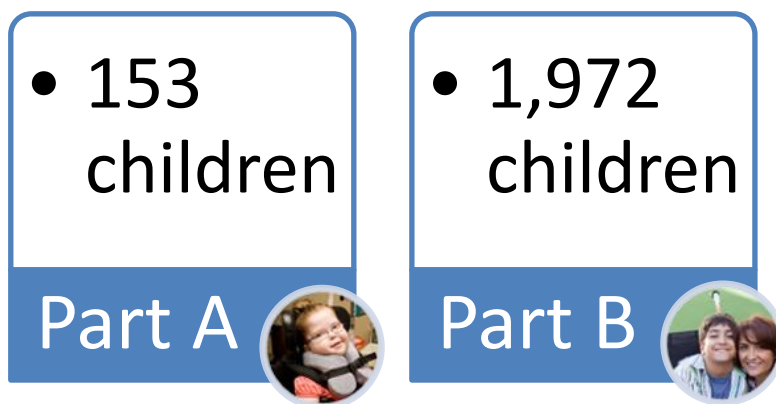
Health Care and Related Expense Reimbursement authorizations. This is a flexible benefit unique to Katie Beckett Part B that is designed to “mimic” a Flexible Spending Account (FSA) or Health Reimbursement Account (HRA), as defined in federal law, except that contributions to the account are made using 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**

During CY 2022, DIDD has \$4,658,129 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 16, 2022, there are 2,125 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. A listing of these experts and a brief biographical sketch of their experience is attached hereto as Appendix A.

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. There is no waiting list for any part of the program. Everyone who has applied and who has qualified is currently being served.

## 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 40% 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 7, 2022. The data reflects parents' monthly income, using MAGI<sup>2</sup> budgeting, multiplied by 12 months to determine annual income.

Annual income ranges	# of Individuals	% of Total
<= \$50,000	127	5.95%
Between \$50,000 - \$100,000	866	40.54%
> \$100,000	1143	53.51%
Total	2136	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 continued with outreach efforts to educate families and other stakeholders about

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<sup>2</sup> 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.

the program. This included presenting to staff and social workers at LeBonheur Children’s Hospital and Monroe Carell Children’s Hospital at Vanderbilt. DIDD also held two presentations at the Building Best Practice Conference for Tennessee Early Intervention System (TEIS) service coordinators and community providers to improve collaboration and coordination of benefits across programs. DIDD 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.

TennCare and DIDD have continued to meet with the Katie Beckett Technical Advisory Group (TAG) to gather feedback in order to inform program opportunities and improvements. Throughout 2022, based on the feedback received from the TAG, TennCare and DIDD made a number of programmatic improvements. For example:

- The Katie Beckett Program TN Anytime Eligibility one pager was developed to help providers with understanding how the Katie Beckett program works specifically related to Part B. The one pager provided an overview on how to interpret TN Anytime regarding the Katie Beckett program.
- Based on the recommendations of the TAG, TennCare has developed an Employment and Community First (ECF) CHOICES v. Katie Beckett Flow Chart that will be used to help with outreach to families. TAG members shared that families are sometimes unsure of which program they are eligible for and this chart will be used to support families in understanding the differences between the programs and provide guidance on which program they are eligible for. The flow chart will provide families with a description of both programs, qualifications overview, benefits, and how to apply.
- Streamlined and improved processes and communication, revising letters and forms, and creating new tools to help parents understand certain aspects of the program. As examples, TennCare and DIDD created a high-level process flow to help families understand how applications move through the process and an FAQ (Frequently Asked Questions) document that assists with transition from Part B to Part A. These examples are provided in Appendix B.
- TennCare and DIDD collaborated to make adjustments in the service definition for the Automated Health Care and Related Expenses Reimbursement benefit. Previously, families specified an amount each year to be available for payment or reimbursement through Automated Health Care and Related Expense Reimbursement, and once established, the amount could not be changed for the year. TennCare sought a correction to this definition to clarify that the amount designated for Automated Health Care and Related Expense Reimbursement can be changed during the year so long as the individual’s maximum benefit limit is not exceeded. This correction will provide for greater flexibility for members in Medicaid Diversion (Part B).

Additional improvements are always in process as TAG meetings yield great conversation and new, innovative ideas for programmatic improvements to better serve Katie Beckett members.

## **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).

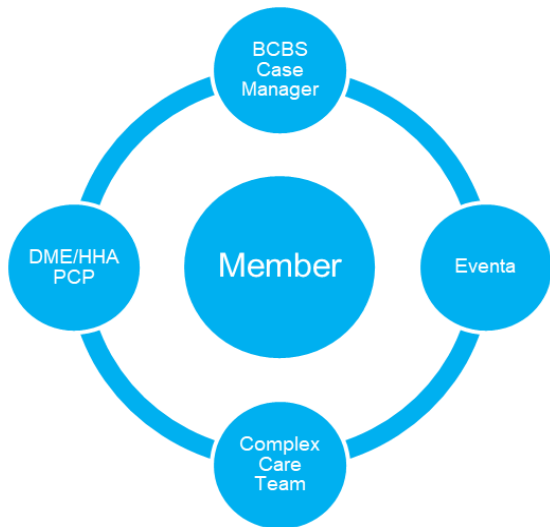
### **Katie Beckett Part A Telehealth Pilot**

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.

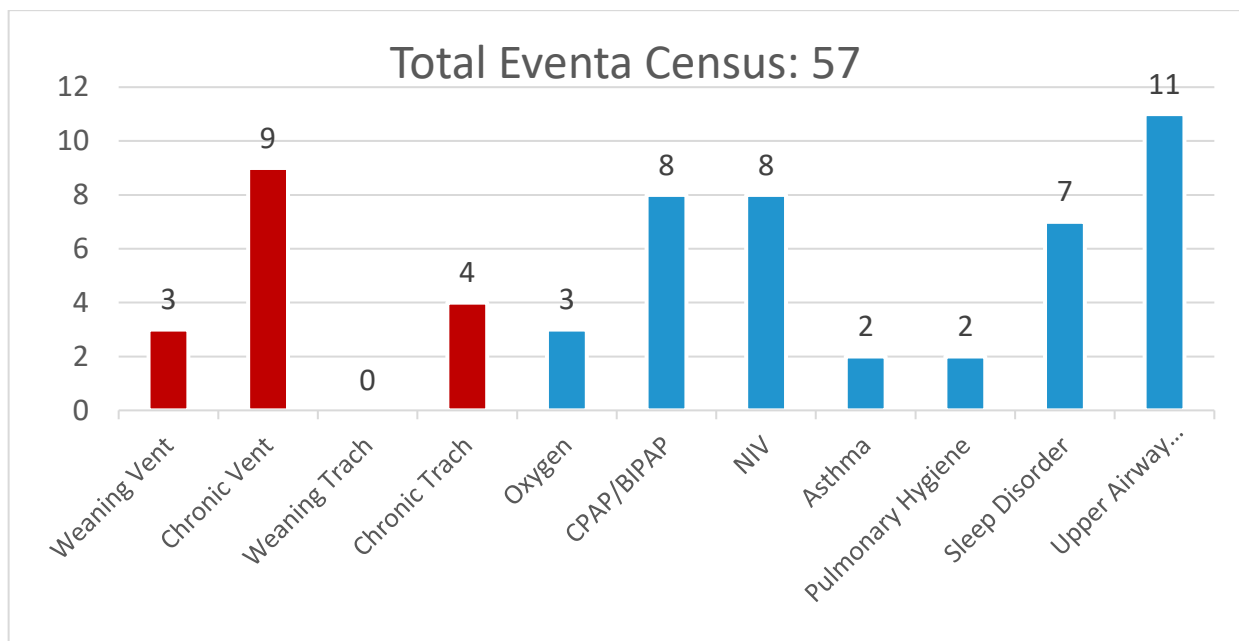
Working with Eventa, LLC, internationally recognized experts in respiratory care, selected members with the most complex respiratory care needs, at high risk of hospitalization, and/or weaning from the ventilator are monitored closely with the goal of early intervention due to change in respiratory status 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.

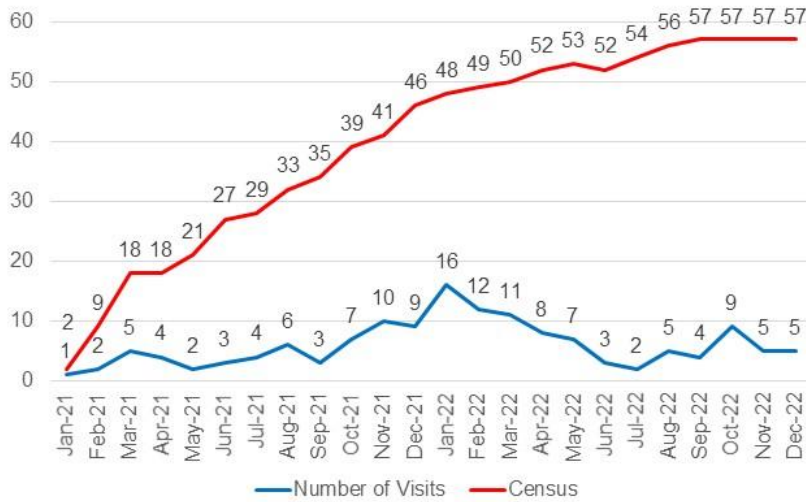
The total number of children enrolled in the pilot program through CY 2022, Quarter 4 is 57. The chart below provides a breakdown:



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



## Reported ER Visits with Census



2021 Quarterly Utilization:

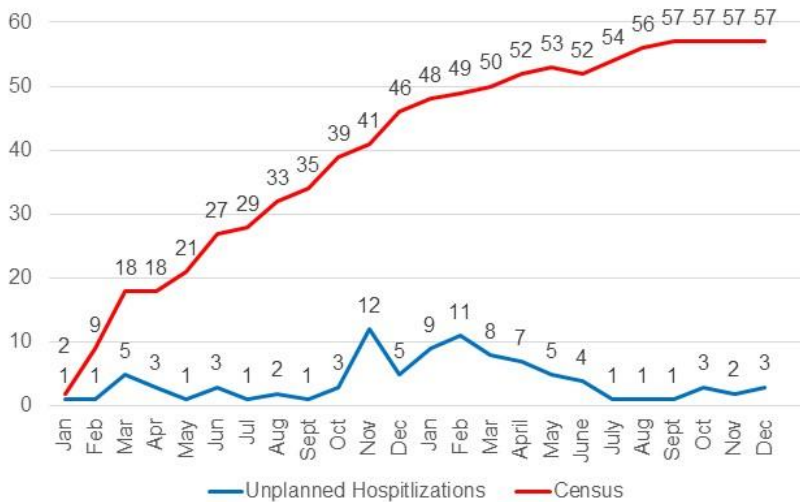
- Q1 – 28%
- Q2 – 13%
- Q3 – 12%
- Q4 – 20%

2022 Quarterly Utilization:

- Q1 – 27%
- Q2 – 11%
- Q3 – 6.5%
- Q4 – 11%

\*Reported by Member's Caregiver

## Reported Unplanned Hospitalization with Census



2021 Quarterly Utilization:

- Q1 – 24%
- Q2 – 10%
- Q3 – 4%
- Q4 – 15%

2022 Quarterly Utilization:

- Q1 – 19%
- Q2 – 10%
- Q3 – 1.7%
- Q4 – 4.6%

\* Reported by Member's Caregiver

### Eventa Success Stories

**Quality of Life Impact:** Eventa supports a member who is 2.5 years old with a complex medical history requiring a tracheostomy as well as ventilator dependency. Eventa was able to build rapport with the mother of the member. With frequent communication, remote monitoring, respiratory recommendations and support, the member was able to safely tolerate vent weaning sprints with success. The member can now successfully remain off invasive ventilation during the day. The member

was liberated from the ventilator during the day and only has to use ventilation at night. The member is an energetic and active toddler who is no longer tethered to invasive ventilation during the day. The member's favorite game is hide-n-seek. Eventa also recommended the utilization of a speaking valve with the assistance of Speech Therapy. The member can now verbalize and is tolerating the utilization of the speaking valve throughout the day and it is the first-time family has heard him speak their names.

**Utilization Management:** Eventa supports a member who is 7-year-old diagnosed with multimorbidity's that included Congenital Brain Abnormalities, Blood Disorders, and Asthma. The mother reported prior to the Katie Beckett Program, they had routine and frequent ER, Hospital, and Antibiotic utilization for Asthma and Pneumonia occurrences. Eventa assessed the member's respiratory regimen in November 2021. Their team collaborated with both the primary care physician and BCBST care team to develop a plan of care change, which included remote monitoring, change in inhaled medications and delivery device, implementing pulmonary hygiene techniques with HFCWO via Vest Therapy, training on proper suctioning for airway patency, and providing education to increase CPAP compliance. With the implementation of these changes in the member's plan of care, the member experienced a reduction in ER and Hospital admissions, improved overall compliance with treatment, and improved quality of life. The member has only had one Asthma exacerbation requiring hospitalization and has not required any antibiotics for pulmonary infections since the implementation of the new respiratory regimen in November 2021. The member has also increased CPAP compliance from 10% to 60%.

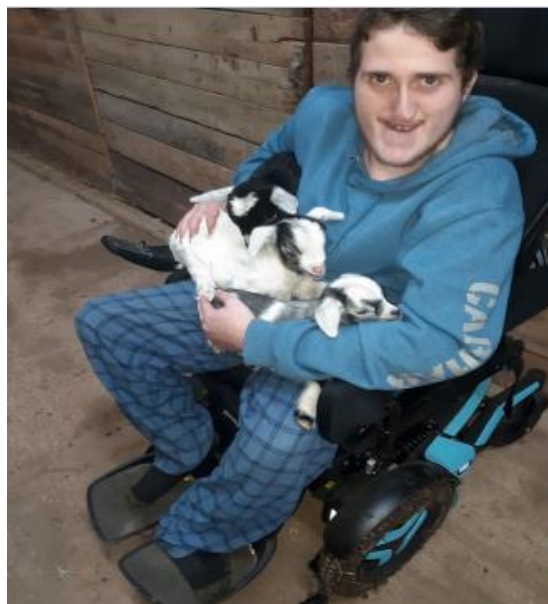
**Advanced Technology/Remote Monitoring:** Eventa supported a member that was a 13-year-old male with Progressive Muscle Weakening with Hypoventilation. The member utilized continuous BIPAP for respiratory support. Eventa identified the need to utilize remote monitoring to determine adequate level of respiratory support. Within 24 to 72 hours of the system set up, the member was observed with several desaturation episodes. With the assistance of BCBS, Sleep Medicine was notified, and the member was able to complete a sleep study within a short period of time. The sleep study indicated that the member's hypoventilation had progressed and required an increase in settings. With the member's setting changes from the sleep study and within 30 days of implementation of remote monitoring, the member experienced zero desaturations on reports. With this intervention, the member was able to avoid a hospital/ER admission and have an improved quality of life. The member reported more energy and being more alert and stated that he thought being tired was normal for his disease process and forgot how good it feels to sleep at night and be rested during the day!

### **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. Nurse Care Managers, Utilization Management team, Medical Directors, home health providers, and TennCare work together. They meet frequently and try to problem solve as it relates to providing home health care to Part A members. Even though there are still some members that do not have home health in place, BCBST has been able to significantly close several gaps in care this year regarding home health.

In 2022, BCBST had two Katie Beckett Advisory meetings with Part A families in June and November 2022. Families were able to use this time to voice any concerns or ask any questions they had about the program. In 2022, there were 4 successful transitions to ECF CHOICES when the member turned 18 years old and aged out of the Katie Beckett program. Looking forward for 2023, TennCare will be adding two stakeholder meetings per year for Katie Beckett Part A parents to attend virtually.

### Mission Moments – Part A Member Success Stories



***Caden's Story*** Caden was born with Myelomeningocele from lumbar 1 to lumbar 4 of his spine. We found out he also had hydrocephalus as well, at birth he required a shunt and closure of his spine. Caden has a few other congenital malformations like cleft lip and palate, club feet, and hip dysplasia to name a few. Caden had more than 10 procedures by the age of 1 years old, and a few more by age 2. Caden is now wheelchair independent, trying to do all he can by himself. He does have a few memories of being able to walk when he was younger. At times this does get him a little down. Most of the time, he is full of smiles, laughter, kindness, and hospitality. Caden was brought into our family to provide us what we needed in life- which is to know the true meaning of strength, the value of love, and the art of dedication. Caden loves fiercer and cares more

deeply for those that he accepts into his inner circle. He has taught me so much, and for that I want to give him the world. Caden's ultimate goal in life is to help others, other people, animals, anyone or anything, at any opportunity. I am so grateful for the compassion others have shown to help Caden and our family. The ramp and chair lift for transportation has been a blessing for Caden and for us as his providers. Transporting Caden just to the doctors was very difficult, typically requiring two people to help with lifting. Caden also has a job and works every weekend. Now, anyone can take Caden to work without a struggle. Caden is even working on his permit to be able to drive himself one day! Caden's new shower and stair lift has provided Caden more independence within our home, helping him feel more competent and maintain his dignity. The small things usually taken for granted have made a huge difference in Caden's daily life. Much Appreciation and Thanks to the Katie Beckett Program!





***Hank's Story*** My name is Cari Kent, and I am a Nurse Care Manager for the Katie Beckett Waiver in Tennessee. I am writing to share how Katie Beckett has positively impacted my member, John "Hank" Hardwick.

Hank is a three-year-old who was born with many genetic medical conditions. He required a tracheostomy early on and now requires a nighttime ventilator. Hank has dysphagia and receives all medications and nutrition via a g-tube. Hank also has severe developmental delays. These delays require ongoing physical and occupational therapy.

Hank was recently approved for a wheelchair, his primary source of mobility. His mother states that this wheelchair has made such an impact on how he can access the community.

The wheelchair allows him to safely attend pre-school at High Hopes and into the community to participate with his family. Hank has a private duty nurse that attends pre-school with him. This gives Hank the opportunity to participate with children his age, while having his medical needs met.

Hank's mother is also very grateful for the items they have received through Home and Community Based Services. Hank has received several items through Assistive Technology. The Ladybug chair allows Hank to sit at tables and at circle time with his peers while keeping him safely supported. The sensory toys allow him to have his sensory needs met and play with other children. The floatation device allows Hank to safely access the pool with his family. His mother states the other children at High Hopes love his sensory items. So, while it seems they are playing with the toys, they are also engaging with Hank. Hank's parents are truly grateful for how Hank's quality of life has improved thanks to TennCare and the Katie Beckett program.





***Katy Mae's Story*** The Katie Beckett program has been a lifesaver for our family. Katy Mae was born in 2008 with “the most severe birth defect still compatible with human life.” She was born with cloacal exstrophy, spina bifida, OEIS complex, a left club foot, short gut syndrome, and an omphalocele. We knew from that moment that she’d require a lot of medical care. We lived in Mississippi and there they had a medical waiver for special needs kids to get them Medicaid to help cover medical supplies, doctor visits, therapies, surgeries, etc. We moved to TN and there wasn’t a waiver. There was NO HELP for families who make above the poverty level. We were out over two thousand dollars a month just to provide our child with the medical supplies she needed for daily life. As you can imagine that didn’t leave much extra for anything to help her live a more “normal” life. The system needed some changes for these kids! These families don’t deserve to spend all they have just to give their medically complex child a better life! The Katie Beckett program came along and we were so excited to apply. We got all of our forms

filled out and doctors to sign off on all of her needs, and submitted in hopes for an approval. We got approved, and it has changed our lives! Katy Mae is now able to live a much more normal life! She gets all of her medical supplies every month! She gets the therapy she needs, and we even got approval for a walk-in/roll in shower so when she has surgery she can still get into her own bathroom! The KB program has provided her with so many small and big things to improve her daily life and help her achieve so much more independence!! We are so thankful for this program!

## **Katie Beckett Part B**

The Department of Intellectual and Developmental Disabilities (DIDD) continues to make progress in improving the user experience in Part B. With nearly 100 percent of the families utilizing the Healthcare Reimbursement Account (HRA), DIDD has worked with its vendor, PayFlex, to make processes more efficient and user-friendly for families. This includes:

- Having PayFlex establish a dedicated team to review Katie Beckett Claims
- Streamlining the Letter of Medical Necessity (LOMN) process to allow for one LOMN for the duration of a child’s enrollment in the program. Previously LOMNs were to be resubmitted on an annual basis.
- Developing reimbursement templates for popular items and such as respite and mileage
- Developing an HRA user guide to provide a “one-stop-shop” for families about the HRA benefit specific to the Katie Beckett Program
- Holding a WebEx with PayFlex for families to ask questions and learn more information about how to successfully use the HRA benefit.
- Worked with TennCare to submit a technical amendment to allow a family to change its HRA allocation amount throughout the year. This is pending approval from CMS.

## Mission Moments – Part B Member Success Stories

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.



***Lucas' Story*** Lucas is loving his new bike that he got with the support of the Katie Beckett program. He brings along an iPad and portable speaker so he and his family can dance and sing along to their favorite Disney songs while they ride.

Lucas Bussell is a 12-year-old in West Tennessee and primarily uses a speaking device to communicate. When his mom asked what he thinks about his bike, he responded by making his tablet say, "Lucas bike, happy, dance, sing Disney". His mom, Tonia, says the bike makes him very happy. "When Lucas was smaller, we used a bike seat or a bike trailer to go on family bike rides. Lucas outgrew all of those options a couple of years ago and we could no longer enjoy that time together. The Katie Beckett program gave that back to us because we were able to use the funds allocated to Lucas to buy this specialized bike for him. To

hear Lucas's giggle and to see his smile in the mirror while we are riding together as a family again is priceless," Tonia said. "We are blessed to be a part of this program!" The bike is not only fun for Lucas and the entire family, but it is also helping Lucas strengthen his core, his trunk control, and balance with motion. He has been working very hard over the years to learn how to sit up on his own and maintain his balance. The shape of the seat and the transition to get in the chair are also supporting his work in physical therapy. Tonia says their case manager has been very helpful assisting their family to navigate the Katie Beckett program to get the bike and other medical supplies.





***Cosette's Story*** Two-year-old Cosette Smith loves to be on the move! After her mom, Nicole, picks her up out of a swing at Pinkerton Park in Franklin, Cosette squeals excitedly and points toward the big green slide. She gets into her new walker, grabs her mom's hand, and then she's on the go again. These are the moments her mom doesn't take for granted. "[When] I realized I had held her hand for the first time, it was just a

very deeply impactful moment," said Nicole. "She's a mover and a shaker. We come here all the time. She likes to try to climb and slide and swing just like any other kiddo." Cosette's walker was purchased with the support of the Katie Beckett Program Part B to replace another pre-used walker that was donated to their family. They were appreciative of the older equipment, but it wasn't functional for the developmental challenges Cosette was facing with Cerebral Palsy and buying a new one came at a big price tag. Nicole says she would've had to wait for another donated walker if it wasn't for Katie Beckett funds, which would have delayed some of her daughter's progress to meet her goals and gain the independence she desired. Now her new walker is allowing Cosette to move herself across the playground, interact with other children with and without disabilities at daycare, and participate in classroom events that she wasn't able to before. "Katie Beckett was a game changer for us," Nicole added. "With medical costs as high as they are and Cosette's ever-changing condition and needs, it has made a huge difference with what we're able to do with her."

The program is also allowing their family to purchase other medical equipment and participate in non-traditional therapies recommended by their primary care physician. Combined with services provided through Tennessee Early Intervention System (TEIS), Nicole believes Cosette has a solid team of support around her child that is improving Cosette's quality of life and setting her up for success.

