

Katie Beckett Program Update

A Joint Report to the Tennessee General Assembly

January 31, 2022

Overview and Context

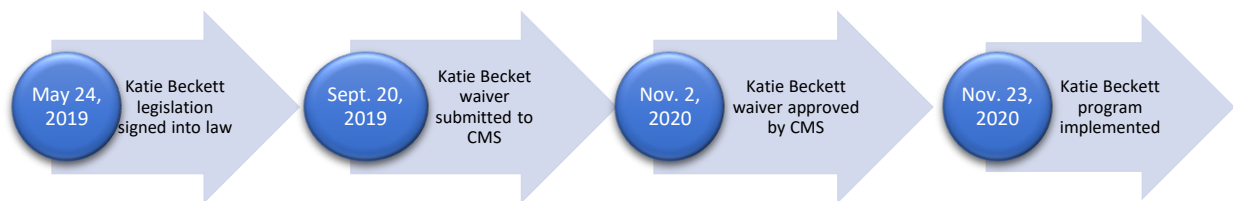
Tennessee’s current Katie Beckett Program, which serves children with significant disabilities and/or complex medical needs who are not Medicaid eligible because of their parents’ income or assets, was established pursuant to Public Chapter No. 494, passed by the Tennessee General Assembly during the 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 during the 2019 legislative session to prioritizing services for these children and their families within the constraints of a constitutional requirement to balance the State’s budget.

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.

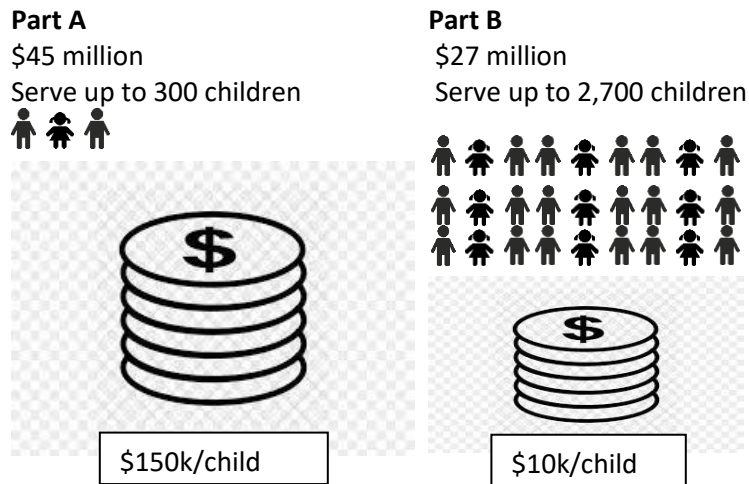
Katie Beckett Program Timeline



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).¹

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 \$184,000 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 70%) 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 245 slots at the current projected average per child cost, rather than the 300 originally expected.

If the higher than funded per child costs continue, funds could be moved from Part B to Part A to cover the full 300 slots originally contemplated for Part A in the budget. An additional 55 slots would be expected to ensure availability of Part A for children with the most complex needs through at least June 2023. It would reduce total Part B capacity to around 1,700 children, which at the current projected rate of enrollment, should be sufficient through at least January 2023.

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 under \$23.7 million. Because these children were enrolled throughout the course of CY 2021, TennCare CY 21 obligations for the partial year roll-out are \$5.3 million. Children enrolled in Part A receive full Medicaid benefits as well as a \$15,000 per year home and community-based services (HCBS) capped benefit package. As noted above, nursing care accounts for more than 70% of medical costs. Other services include durable medical equipment, medical supplies, and occupational, and physical and speech therapies.

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

The annualized cost of currently enrolled Part B members is \$10.3 million. This is based on the budgeted cost of \$10,000 per child per year. Because these children were enrolled throughout the course of CY 2021, DIDD CY 21 service obligations for the partial year roll-out are \$3.8 million. Once sufficient actual experience can be obtained across a full calendar year of enrollment, DIDD may be able to adjust projected per child costs. 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.

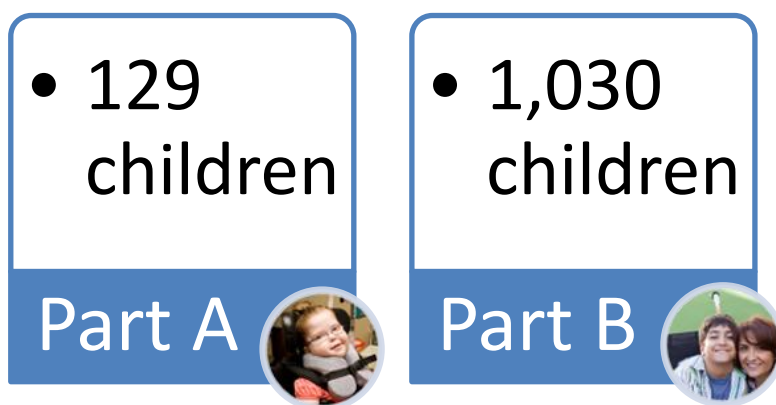
By far, the most widely used benefit in Part B is Automated Health Care and Related Expenses Reimbursement. This is a flexible new benefit unique to Katie Beckett Part B that is designed to “mimic” a Flexible Spending Account (FSA) or Health Reimbursement Account (HRA), as defined in federal law, except 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 2021, DIDD has \$2.8 million 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 January 21, 2022—14 months after implementation, 1,159 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—January 11, 2022. 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	67	5.9%
Between \$50,000 - \$100,000	454	40%
> \$100,000	614	54.1%
Total	1135	100%

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.

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. To ensure families are aware of the Katie Beckett Program, DIDD and TennCare have provided presentations to groups around the state who support young children with disabilities and complex medical needs including:

- East Tennessee Children’s Hospital Social Workers
- Vanderbilt University Medical Center’s Developmental Medicine Department
- Metro Nashville Public School families
- Tennessee Early Intervention System (TEIS) Service Coordinators and State Interagency Coordinating Council (SICC)
- Community Advisory Boards

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. To further assist families in using its benefits, DIDD has held two webinars with PayFlex, its HRA provider, to answer questions and explain the reimbursement process.

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 2021, based on the feedback received from the TAG, TennCare and DIDD made a number of programmatic improvements. For example:

- As described above, based on the recommendations of the TAG, TennCare opened enrollment into Part A to all eligible children upon completing the initial volume of applications and ensuring capacity to enroll children with the most complex medical needs and disabilities.
- A number of adjustments and clarifications were made in the Katie Beckett Level of Care criteria and guide to ensure that all eligible children can enroll in the program. These include (but were not limited to) clarifying communication deficits associated with a diagnosis of Autism, adjustments to mobility criteria, and working with DIDD to ensure alignment of functional limitations with the developmental disability definition in State law and regulation. This change specifically led to DIDD reassessing over 300 records with many more children determined to qualify for the program and enroll into Part B.
- 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.

Additional improvements are in process for 2022. For example, TennCare and DIDD are collaborating to make adjustments in the service definition for the Automated Health Care and Related Expenses Reimbursement benefit to allow flexibilities not available in a more traditional FSA or HRA account—specifically allowing the annual amount designated for the benefit to be adjusted mid-year.

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

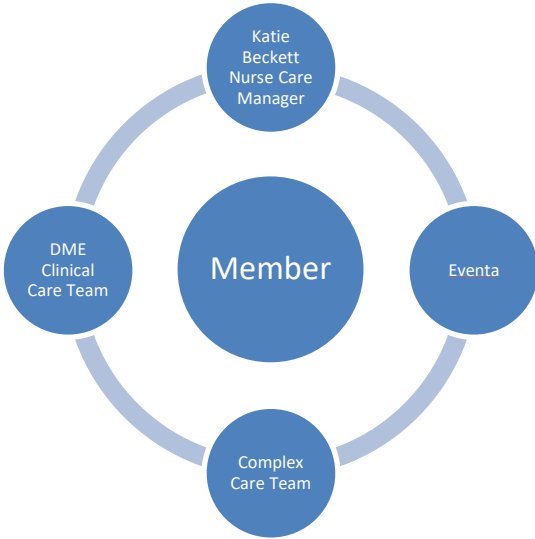
As part of planning for the implementation of the Katie Beckett Program, TennCare established contractual requirements for a Katie Beckett Telehealth Pilot. For children enrolled in Part A, TennCare Select is required to ensure that telehealth options are utilized to expand access to specialty care in 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

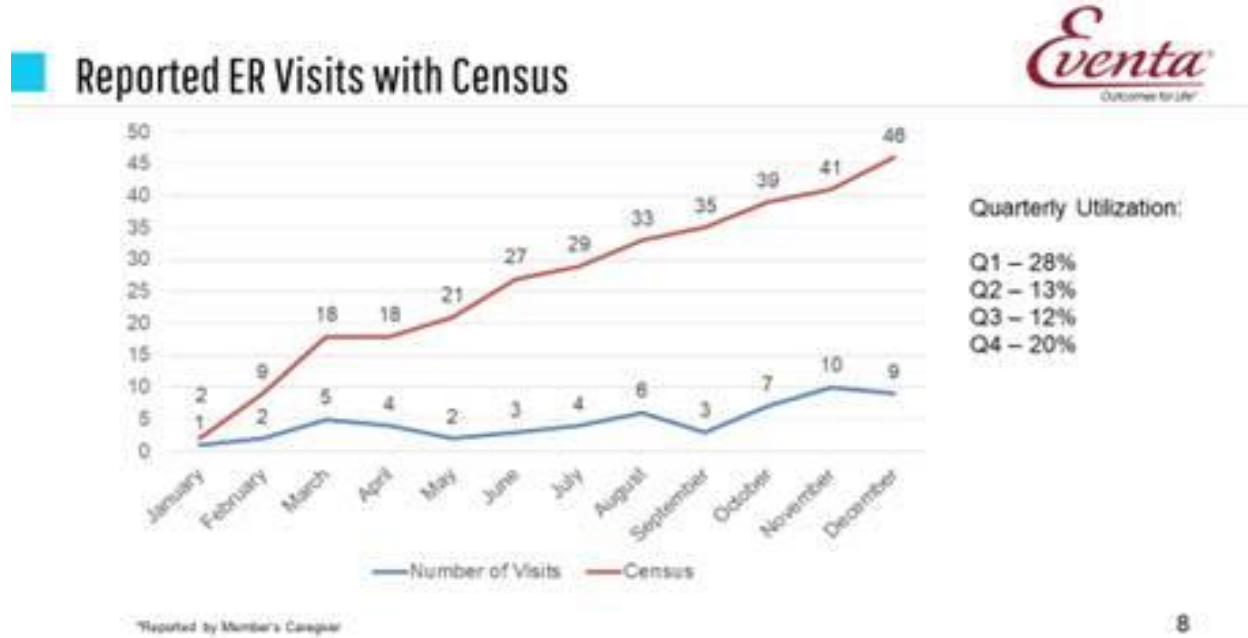
situations. The remote monitoring system provides crucial data to the medical providers, inclusive of more data points over additional periods of time. For weaning members, the recorded and reported data will allow the medical providers to make more informed decisions regarding the weaning process.



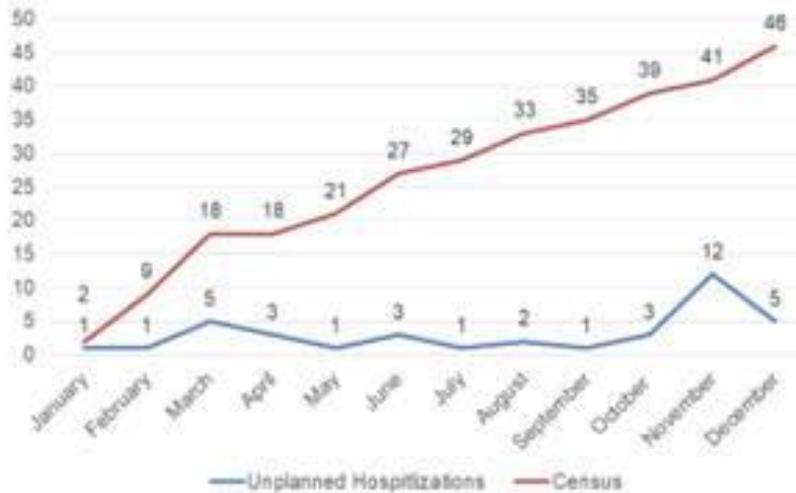
Demonstrated program benefits include:

- Improved physician involvement in care plans
- Assessments with recommendations for more appropriate home devices to assist in successfully supporting the member at home
- Recommendation and implementation of state-of-the-art devices “generally” not covered by insurance and would otherwise be unavailable
- Early detection and intervention as a result of remote monitoring
- Improved QOL and member satisfaction with increased clinical support, including access after hours

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 as referenced in the charts below.



Reported Unplanned Hospitalization with Census



Quarterly Utilization:

Q1 – 24%
 Q2 – 10%
 Q3 – 4%
 Q4 – 15%

* Reported by Member's Caregiver

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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. Examples include:

- Arranging transportation for out-of-state services
- Obtaining customized medical orders as needed
- Communicating with the child's physician to identify how to best meet identified needs (e.g., properly fitting diapers not typically stocked)
- Specialized connections for drain or feeding tubes
- Member/Family was paying as much as \$10,000 per month for special bandages due to the member's skin condition. As a result of advocacy efforts, the child's family now has no out-of-pocket expense
- Acquisition of adaptive car seats
- Worked with Servpro to identify possible environmental issues related to water damage for a child who was having repeated respiratory infections
- Worked with families and schools to develop appropriate IEPs (Individualized Education Plans)

Mission Moments – Part A Member Success Stories



Carson's Story Carson is an 11-year-old child who has a diagnosis of microcephaly, intractable seizures, chronic respiratory failure with tracheostomy, chronic hypoxia, developmental delay, metabolic syndrome, and a feeding tube. He is on a ventilator 16 hours a day which requires transporting a lot of medical equipment anywhere he goes. The previous mode of transportation came with a very long process to get Carson ready for a community outing or doctor's appointment and always required two-person assistance. The family had to manually lift Carson into their vehicle and then pull him into his car seat. Carson weighs 76 pounds, and this had started to cause physical pain for his parents.

Upon enrolling in the Katie Beckett program, the member's family was in desperate need of a newer van that could be modified to meet Carson's needs. His parents searched months for a van that would last them for years to come and found it in late December. TennCare Select then approved coverage of a Vehicle Modification on the family's newly purchased vehicle.

This came at a perfect time for this family, and they were able to pick up their new van on December 30, 2021. It was such a huge blessing for them. Carson's mom was in tears—but HAPPY tears as she told the Nurse Care Manager how she was able to take her son to multiple appointments without assistance. She also made it a point to let the Nurse Care Manager know what an amazing program that Katie Beckett is and how thankful she is for it. This vehicle modification alone has truly changed this family's life.



Enoch's Story Enoch is a 10-month-old child who was born at 34 weeks with two major gene mutations. Since birth, doctors diagnosed him with Juvenile Idiopathic Osteoporosis after discovering multiple fractures. Enoch is physically delayed due to hypotonia and lack of physical therapy due to his fractures. His mother asked to purchase adaptive equipment items to allow him to be positioned in ways other than lying flat. A Firefly Playpak, Splash bath seat, and Tumbleforms chair were ordered through the Assistive Technology benefit. His mother recently sent pictures saying, *"The Playpak and the Tumbleform seat are life changing quality of life wise. Enoch wants to play with more age-appropriate toys (i.e., not rattles) and cognitively he's there, but being stuck on his back limits how he can play and what he can engage with. Now that we have these, he's able to practice fine motor skills on cause-and-effect type toys that are more consistent with his actual and cognitive age since his body is so far behind his brain. Forever grateful for this program and the ability to get these items that so increase our kiddos' quality of life."*

Katie Beckett Part B

Families enrolled in the Part B program are reporting a high level of satisfaction. DIDD sent out a survey to families in Part B in June 2021 to gauge family satisfaction with their case managers. 95 percent of families reported satisfaction with their case manager.

Mission Moments – Part B Member Success Story

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.

Asa's Story



On a nice day in Alcoa, you might find Asa and her mother on the greenway. Her mother likes to jog, and Asa has no problems keeping up in her adaptive tricycle. In fact, if you ask Asa what she likes about her bike, she'll tell you, *"I like that it goes fast!"*

Asa was diagnosed with Kabuki syndrome and Rhabdomyosarcoma years before. Her parents say they exhausted all other resources and that the Katie Beckett Program arrived at just the right time for their family. Case managers, Asa's family, and physical therapists worked together to identify and purchase the custom tricycle with funds provided through Part B of the program. Now, Asa's bike is not only helping her work on her physical therapy goals and increase her strength and mobility, it's also connecting her in an activity her family enjoys and providing her with opportunities to explore her community.

Appendix A

Katie Beckett Technical Advisory Group

Katie Beckett Technical Advisory Group Members

Family Experts

1. Brianna MacEachern
2. Jennifer Aprea
3. Jessica S. Fox
4. Melanie Preston
5. Rondi Kauffmann (also a physician)
6. Tori Goddard
7. Teri Fought

Clinical Experts:

1. Dr. Jana Dreyzehner, MD
Child and Adolescent Psychiatrist, Founder and CEO of Life Connect Health LLC
2. Dr. Deanna Bell, MD
Section Head of the Program for Children with Medical Complexity at Monroe Carell, Jr. Children's Hospital at Vanderbilt, Associate Professor of Clinical Pediatrics at Vanderbilt University School of Medicine, and chair of the Council of Past Presidents of the Tennessee Chapter of the American Academy of Pediatrics (TN AAP)
3. Dr. David E. Hall, MD
Professor of Clinical Pediatrics at Vanderbilt and Director of the Program for Children with Medically Complex Needs at Monroe Carell Jr Children's Hospital at Vanderbilt (Retired)
4. Dr. Beth Ann Malow, MD
Burry Chair in Cognitive Childhood Development and Professor of Neurology and Pediatrics at Vanderbilt University Medical Center
5. Dr. Arie Nettles, PhD, NCSP, HSP
Associate Professor of Clinical Pediatrics; Director of the Office of Inclusion and Health Equity at the Vanderbilt University Medical Center

Stakeholders

1. Brian Keller (Disability Rights Tennessee)
2. Carol Westlake (Tennessee Disability Coalition)
3. Heidi Haines (The Arc Tennessee)
4. Janet Shouse ([Vanderbilt Kennedy Center](#))
5. Lauren J. Percy (Tennessee Council on Developmental Disabilities)
6. Mary Nell Bryan (Children's Hospital Alliance of Tennessee)

State Representatives:

1. Angela Turner (TennCare Member Services)
2. Timothy ("Bo") Hickman (DIDD)
3. Cara Kumari (DIDD)
4. Dr. Bruce Davis (DIDD)
5. Jordan Allen (DIDD)
6. Jordan Hall (TennCare Member Services)
7. Karen Gonzales ([TennCare LTSS](#))
8. [Katie Moss \(TennCare LTSS\)](#)
9. [Kim Hagan \(TennCare Member Services\)](#)
10. Kristeena I. Ashby ([TennCare LTSS](#))
11. Patti Killingsworth ([TennCare LTSS](#))
12. [Tabitha Satterfield \(TennCare LTSS\)](#)

Katie Beckett Technical Advisory Group Members

Family Experts:

Aprea, Jennifer lives with her family in Arrington and has two children who are 9 and 7 years old. Her youngest, Ryan, was born at 25 weeks and is profoundly deaf, visually impaired, intellectually/developmentally delayed, and was recently diagnosed with Autism. She currently works as the Family Engagement Project Coordinator at The Arc Tennessee. Before her son was born, she taught elementary school for 12 years but went into "early retirement" from teaching after he spent 7 months in the NICU and came home needing 24/7 care.

Fought, Terri is the mother of three children, two of which are on the Autism Spectrum.

My two boys are on opposite ends of the spectrum. I have one that took honors classes in high school and is attending college while the other is in functional skills classes and will require care for the rest of his life. Prior to living in Tennessee, we received services through the TEFRA program in Arkansas. Through this experience, I understand how the families use programs such as Katie Beckett and the impact this program can have on a family's quality of life. My volunteer activities include being a legislative advocate for Autism Resources of the Midsouth, completing the Partners in Policymaking class in 2018, and participating in the Reimagining Long-Term Services and Supports in Tennessee group for the Tennessee Justice Center. With my family, we started a ministry at our church for families that have children or adult children with disabilities. Professionally, I've worked in higher education for the past 8 years, earning my Masters in Education with an emphasis in Student Personnel Management from ETSU in 2018. Prior to this, I was an Event Planner for 20 years.

Fox, Jessica is a full time working mother of three children. She and her husband, Sean, live in Johnson City, Tennessee. She is in her 17th year of her career as a Registered Nurse, providing direct patient care. Jessica's middle child, Claire, is a bright, loving 5 year old little girl. Claire was born with Cri Du Chat Syndrome (a chromosome deficiency), resulting in numerous medical complexities. Jessica has become an advocate for her daughter and other disabled and medically complex children in the state. She will be able to provide valuable insight to the group from a personal and professional perspective.

Goddard, Tori is mom to Zoey Jones- a medically fragile child with a severe congenital heart defect that can't be corrected. After navigating Zoey's numerous hospital stays and surgeries spanning 22 months, Tori discovered a passion for helping other families navigate the healthcare system. Tori has served on several special needs non-profits, most recently as the Vice President of the Pediatric Congenital Heart Association's Advocacy committee, and the Family Delegate for the TN Health Department completing the LEND program at Vanderbilt University in 2019. She excels in grant writing and fund raising/building awareness, and advocated for the Katie Beckett Bill passed in Tennessee in 2019. In addition to her board positions, Tori and Zoey have been vocal advocates for children with special health care needs- both in Washington FC and the State of TN, Tori has a BS in Health Promotion and Education from the University of Georgia, and moved back to Nashville to start her career in 2005. Zoey was born in 2012 and became the catalyst for Tori's passion to help all special need families.

Kauffmann, Dr. Rondi M, MD, MPH, FACS is a surgical oncologist at Vanderbilt University Medical Center. She is board-certified in both general surgery and complex surgical oncology, and has been on faculty at Vanderbilt for 4 ½ years. She is mom to a 21 month old, medically complex child with Spinal Muscular Atrophy Type 1, and has been deeply involved in advocacy efforts surrounding the Katie Beckett program for Tennessee.

MacEachern, Brianna is a Wife, Mom of two (with one on the way) living in Nashville. Former Neonatal ICU nurse, now stay at home parent caring for medically complex son. Son was diagnosed with brain tumor at two months old, now 3 years old with global developmental delay, right hemiplegia, optic nerve damage, seizure disorder, hydrocephalus, and many more health issues. Son is currently in active treatment for brain tumor. Participates as a Katie Beckett family member on the Developmental Disabilities Planning and Policy Council (DDPPC).

Preston, Melanie is a mom of 5 and resides in Knoxville, TN with her husband and 4 younger children. Melanie works PRN as a nurse at a busy eye surgery center in Oak Ridge. Melanie has 2 children with disabilities. Elliott, 7 was born with Down syndrome and Emory, 5, (who is also an identical twin) was born with Spina bifida and many other challenges. She has been very excited to see the passing of the Katie Beckett program and thrilled to be a member of committees and subgroups to help make the process smoother and more efficient for other families.

Clinical Experts:

Bell, Dr. Deanna, MD is the Section Head of the Program for Children with Medical Complexity at Monroe Carell, Jr. Children's Hospital at Vanderbilt, Associate Professor of Clinical Pediatrics at Vanderbilt University School of Medicine, and chair of the Council of Past Presidents of the Tennessee Chapter of the American Academy of Pediatrics (TN AAP). She completed her medical doctorate at East Tennessee State University College of Medicine, completed her pediatrics training at Vanderbilt University Medical Center, and is board certified in both general pediatrics and pediatric hospital medicine. Dr. Bell focuses her career on improving care of medically complex and socially disadvantaged children. She served as Chief Medical Officer of Mercy Community Healthcare where she developed a specialized system of comprehensive care for children with medical complexity which accepts referrals from across the southeast. Dr. Bell served as Senior Medical Director of Quality Improvement for Cigna/HealthSpring where she practiced executive oversight of quality improvement for Cigna's Medicare/dual-eligible special-needs population across 27 states. She served as the Medical Director of the Division of Pediatric Hospital Medicine for HCA TriStar Centennial prior to returning to the Division of Hospital Medicine at Vanderbilt to serve as Section Head of the Program for Children with Medical Complexity. She has been active in her state AAP chapter where she led multiple advocacy, quality improvement, and educational initiatives. Dr. Bell has become known as an expert in systems and processes of care for medically complex and socially at-risk children and has held many leadership and consultative roles in that capacity. She received multiple awards from the American Academy of Pediatrics for her work in understanding and improving care systems for medically complex youth and their families.

Dreyzehner, Dr. Jana, MD has focused her child psychiatry career of more than 25 years primarily on understanding and providing for the care of medically underserved and special populations including persons with IDD and persons who are deaf. She has a strong interest in systems of care integrating behavioral health in primary care improving access to and quality of specialized care. She pioneered telepsychiatry services for the deaf in Appalachia in the late 1990s and developed a consultative team model that later served as a model for development of specialized behavioral health and crisis prevention services. She has served as the Behavioral Health Medical Director for Anthem in TN and during that time, worked with TennCare leaders to support development of crisis stabilization and prevention services for persons with IDD and challenging behaviors. She gained direct care experience with these services working as the Chief Medical Officer for the implementation provider of the TennCare Systems of Support benefit before founding a new company, Life Connect Health, focused on provision of ECF Specialized Consultation and Training, specialized psychiatric and behavioral health services for organizations serving individuals in ECF Group 7 and 8, and development of a specialized IDD Health Home all leveraging Telehealth to be accessible statewide even in rural areas. In addition, Life Connect Health provides the bridge needed between institutional care and community based residential services, supporting both the individuals and their support teams before, during and after the transition. She is also the proud aunt of a special olympics bowling champion in California. Her nephew, Donnie, who has had challenges with IDD and expressive communication, also works at Taco Bell and has bowled a 300 game.

Hall, Dr. David, MD is the retired Professor of Clinical Pediatrics at Vanderbilt and Director of the Program for Children with Medically Complex Needs at Monroe Carell Jr Children’s Hospital at Vanderbilt. This program is designed to assist families of children with multisystem chronic disease who have frequent hospital admissions and see multiple subspecialists. Care provided to enrolled children have led to a decrease of 72 % in days in the hospital, 44% in admissions, 58 % in readmissions after hospital discharge, and 52% in Emergency Department visits within 6 months of enrollment.

Malow, Dr. Beth, MD is Burry Chair in Cognitive Childhood Development and Professor of Neurology and Pediatrics at Vanderbilt University Medical Center. She is the parent of two adult children on the autism spectrum. She conducts research in the medical aspects of developmental disabilities including novel provider-training aspects, such as Project ECHO. She has worked on the IDD Toolkit and related projects to enhance provider and patient/family knowledge of developmental disabilities in Tennessee.

Nettles, Dr. Arie L., PhD, NCSP, HSP, is an Associate Professor of Clinical Pediatrics; Director of the Office of Inclusion and Health Equity (OIHE) at the Vanderbilt University Medical Center (VUMC); and Chair, Statewide Planning and Policy Council (SPPC), TN Department of Intellectual and Developmental Disabilities. She is a licensed psychologist; nationally certified school psychologist; and nationally registered health service provider. Her clinical practice includes school age children to young adults with developmental disabilities, autism, and cleft-craniofacial. Nettles serves as child advocate to the SPPC.

Stakeholders:

Bryan, Mary Nell has worked as an advocate for non-profit organizations, primarily for health care non-profits, since 1991. She began her advocacy work at a lobbying firm. Later, she served as Director of Communications and subsequently as Director of Government Relations for a TennCare MCO. Following that, Mary Nell served as Director of Government Relations at what was then Nashville's largest law firm. In 1998, Mary Nell established a private consulting practice, representing the now-defunct TennCare MCO association, and working as an advocate and consultant for myriad groups, including health care providers and health care advocacy organizations, mental health organizations, an anti-tobacco coalition, and March of Dimes. Since 2004, Mary Nell has served as President of the Children's Hospital Alliance of Tennessee.

Haines, Heidi is the Executive Director at The Arc Tennessee. Before joining The Arc Tennessee, Heidi served as the Director of Advocacy at The Arc Colorado. In addition, Heidi is a council member of the Tennessee DDPPC. Heidi also serves as an Advisor to the National Self Advocacy organization Self Advocacy Becoming Empowered. Heidi has long demonstrated a passion for disability rights with an understanding of the critical issues and the desire to collaborate with a wide range of advocacy and community groups. Heidi has a B.S. in Human Services from Colorado State University and has completed graduate course work in Disability Studies from the City University of New York (CUNY).

Keller, Brian is the public policy and voting attorney at Disability Rights Tennessee. He focuses on following legislation and regulation through the process and educating policy makers on the impact proposed legislation would have on Tennesseans with disabilities. He also works with state and county election officials to ensure the election process is accessible for all voters. Brian graduated from Belmont University College of Law in 2016 where he served as president of the health law society. A native of Fayetteville, AR, Brian lives in Nashville with his wife and puppy.

Pearcy, Lauren is the Executive Director of the TN Council on Developmental Disabilities. Prior to this role, Lauren served as the Council's public policy director for 5 years. Before joining the Council, Lauren has worked in leadership roles at Tennessee's Medicaid Agency, TennCare, and at the National Governors Association in Washington, DC. Lauren has a Master's in Public Policy from the George Washington University and a Bachelor's degree from the University of California, Davis.

Shouse, Janet is the program coordinator at the Vanderbilt Kennedy Center for the IDD Toolkit, www.iddtoolkit.org, an online resource for medical providers to better serve adults with intellectual and developmental disabilities. She is also the parent of a young adult with autism, who has very limited communication skills and has intermittent, but intense, behavioral challenges. Although her son was diagnosed at age 2, her family struggled for 19 years to secure appropriate services and supports for him. Her son did not qualify for TennCare until he was 18, and thus despite being on the DIDD waiver waiting list since he was 8, he was not accepted into the Statewide Waiver until he was 19. Finding an agency willing to support his needs took two additional years. Janet also is connected to hundreds of families of children with disabilities across the state through her work with Autism Tennessee, TennesseeWorks, The Arc Tennessee and the IDD Toolkit.

Westlake, Carol is a nationally recognized leader in the disability community and a lifelong advocate for vulnerable people. She is the founding executive director of the Tennessee Disability Coalition. The Coalition led the effort to establish a new “Katie Beckett” program this year. Carol’s background and training are in special education, disability, and public policy. Her doctoral training was funded as an early intervention leadership trainee, giving her a strong background in services and supports for children with disabilities. Carol regularly serves on state boards and commissions that affect people with disabilities, especially those that promote access to health care, long-term supports and services, and economic self-sufficiency. She has helped to establish a number of disability advocacy programs and agencies in Tennessee.

State Representatives

Allen, Jordan is the Deputy Commissioner of Program Operations for DIDD. He has career experience spanning nearly 25 years, within multiple state service delivery systems, supporting persons with intellectual and development disabilities as well as persons with behavioral health diagnosis. These experiences include direct supports, development and implementation of quality assurance and improvement strategies across multiple service systems, executive leadership within the private sector, and senior and executive leadership within State Government. Deputy Commissioner Allen has been a champion of community integration strategies, vocational training, integrated employment supports and enabling technology for persons with disabilities.

Davis, Dr. Bruce PhD, is a Licensed Professional Counselor and Senior Psychological Examiner in Tennessee and works as the Deputy Commissioner of Clinical Services for the Tennessee Department of Intellectual and Developmental Disabilities. Throughout his 33 years in the field of intellectual and developmental disabilities Dr. Davis has served in several different roles in the TN Department of Intellectual and Developmental Disabilities and held positions as an associate psychologist at Poplar Bluff Regional Center, as the Behavior Analysis Director for the Middle Tennessee Region at the Team Evaluations Center, and Director of the Behavioral Health and Intellectual Disability Clinic, an interdisciplinary program at the Vanderbilt Kennedy Center. Dr. Davis earned his Ph.D. in Educational Psychology from the University of Georgia. He has presented 33 professional papers and served as the Subject Matter Expert on 5 Relias trainings in circulation. Currently, Dr. Davis serves as the President of the National Association for the Dually Diagnosed (NADD) and is a national Advisory Council member for the Center for START services.

Gonzales, Karen currently serves as the Assistant Deputy of Clinical Operations for TennCare Long Term Services and Supports. Her work involves the programmatic development, implementation, and ongoing service delivery of Medicaid programs designed to serve the elderly as well as individuals with physical, intellectual, and/or developmental disabilities. Prior to her state service, she worked as a certified pediatric nurse at Vanderbilt Children’s Hospital. In her 27- year nursing career, she has been both a clinical consultant and hands on caregiver for individuals and families across the age continuum. She has also worked as a foster care social worker, specializing in the coordination of services for medically complex children. She is an honors graduate of Wheaton College and Rush University. Karen is also the parent of a teenage son with autism and a rare neurological disorder, who inspires her daily to advocate for individuals and families with special needs.

Hagan, Kim is the TennCare Director of Member Services, a role she has held since 2016. Over the past 20 years she has also worked in various eligibility policy roles and as an attorney in the Office of General Counsel for TennCare. Kim is responsible for the TennCare application, renewal, and case maintenance processes, as well as the TennCare Connect call center and the eligibility appeals process and the internal and external technology used by state staff and Tennessee clients. She graduated from Emory University and American University's Washington College of Law.

Hall, Jordan is the Eligibility Policy Director for TennCare. She has worked with TennCare Member Services Eligibility Policy for the past 7 years. In her current role, Jordan is responsible for researching and implementing eligibility policy for all TennCare categories of eligibility. Jordan has worked in partnership with LTSS and DIDD to implement the financial eligibility portion of the Katie Beckett program. Prior to working with TennCare, Jordan worked with Mercy Community Healthcare as a Social Service Case Manager where she helped connect families with different resources in their community, including health insurance.

Hickman, Timothy ("Bo") is DIDD's Deputy Director of Intake and Case Management and has served the Department in multiple capacities, crossing the working aspects of virtually every unit within DIDD, for twenty-two years. During that time he has excelled in the areas of quality assurance, system design, and customer focused government. Prior to his current role as a statewide director, he served in additional roles of Regional Monitor, Intake Coordinator and as the Intake and Case Management Director for the East Tennessee Regional Office. Previous to working for DIDD, Bo worked with both the Community Mental Health system and within the DIDD Provider Network. He is a graduate of East Tennessee State University and the Tennessee Government Executive Institute.

Killingsworth, Patti is an Assistant Commissioner for TennCare and the Chief of Long-Term Services & Supports (LTSS). She has worked in Medicaid programs for over two decades, advocating on behalf of people with disabilities and their families, and leading system redesign initiatives in multiple states. She is also the parent of a young man who had lifelong significant physical disabilities and complex medical needs and for a time had health insurance only by virtue of another state's Medicaid program. His memory continues to fuel her passion for this work. Her commitment is to changing systems to better meet the needs of individuals and family members, promoting the development and expansion of HCBS, and ensuring that the voice and perspective of people who need LTSS, their family members, and other key stakeholders is brought to bear in policy and program decision-making processes

Kumari, Cara is the Assistant Commissioner of Communications and External Affairs for DIDD. In this role, she has oversight of all internal and external communications, including media requests, DIDD web properties, social media, video production, special events, family, legislative and stakeholder outreach, and the department's planning and policy councils. She joined DIDD in 2013 after a decade in television news, where she served as the state government reporter for WSMV-TV in Nashville and television stations in Kansas and Arkansas.

Moss, Katie Evans is the Deputy Chief of LTSS with TennCare. Prior to joining LTSS in 2021, Katie was an attorney in the TennCare Office of General Counsel. From 2008 to 2015, she was an attorney with the Legal Aid Society of Middle Tennessee focusing on health, benefits, elder law and children's issues and was involved in significant federal litigation with the aim of keeping individuals with disabilities in their homes and communities.

Satterfield, Tabitha is the Assistant Deputy Chief of Programs, Policy, Contracts and Compliance with Long-term Services and Supports at TennCare. Tabitha joined TennCare in October 2021 after over 18 years of serving older adults and adults with disabilities at the Tennessee Commission on Aging and Disability. She is a graduate of Langston University with a degree in Gerontology. Her experience ranges from development of health promotion projects, Title V – Senior Employment, social work in a nursing facility, service and supports for family caregivers, Older Americans Act program oversight, to provision of home and community-based services for older adults and adults with disabilities.

Turner, Angela is a Deputy Director for TennCare Member Services and is responsible for the Compliance and Policy Group (CPG). Angela has worked with TennCare for over 20 years. She began as a TennCare advocate with the Mental Health Association developing and managing their outreach and education program for community mental health centers. She joined TennCare in 2005 as a Member Communications Specialist and remained a liaison with the TennCare advocacy community for many years. Angela's current responsibilities include work with community and partner organizations on applications, renewals, and access to care, member communications, eligibility policy, training, and eligibility system functionality.

Wilson, Kristeena is the Assistant Deputy Chief of Operations, Long term services and supports with the Division of TennCare. Kristeena is responsible for oversight of medical eligibility through enrollment for all TennCare LTSS programs as well as Appeals and Business Operations, including management of the eligibility systems required for PAE and PASRR submissions. She is considered a PASRR national expert. She is a Registered Nurse with over 25 years' experience working with primarily adults with Intellectual and physical disabilities as well as the geriatric population. Her experience ranges from Primary Care physician office, to both medical and psychiatric inpatient care, hospital nursing care and Community Living Supports for persons in 1915(c) waivers.

Appendix B

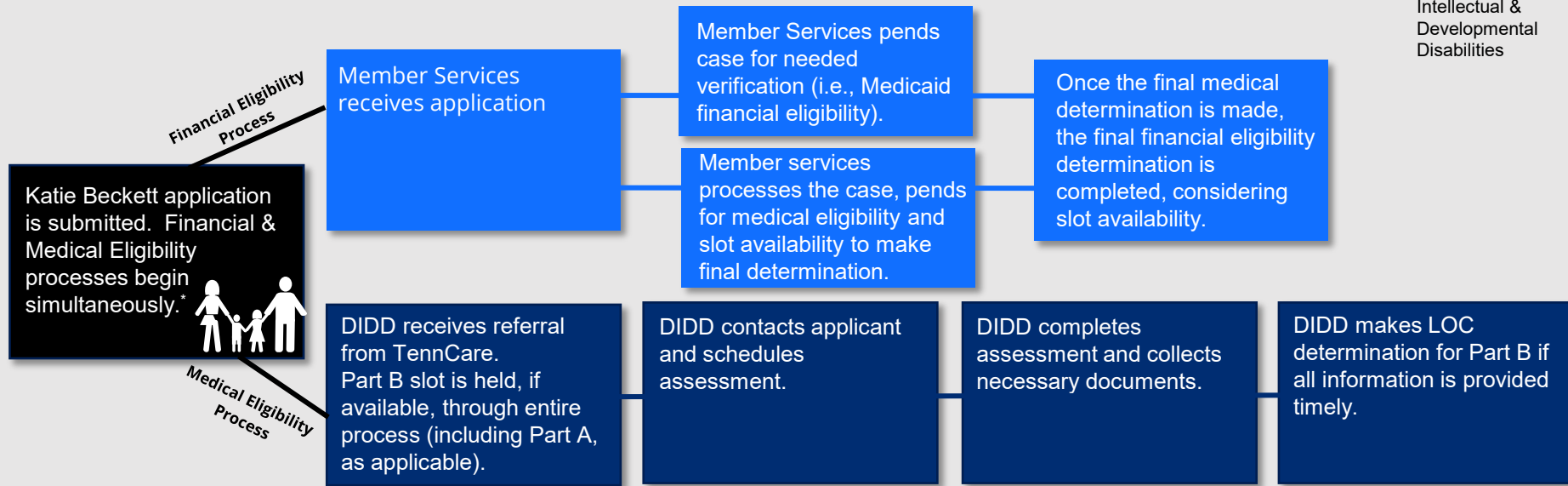
Katie Beckett Program Education and Outreach Material Examples

Katie Beckett Application/Referral Process Flow

High Level Process Flow



Step 1: Part B Application Process



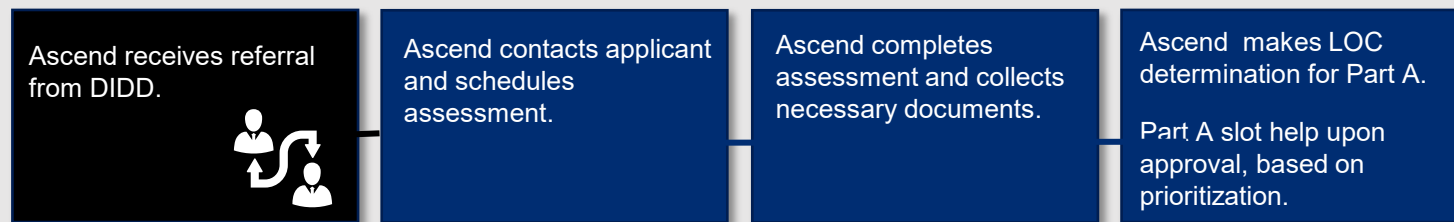
Key Terms
 LOC: Level of Care
 DIDD: Department of Intellectual & Developmental Disabilities

Potential Outcomes

- If Part B LOC approved**, financial process is completed. If approved and applicant does not trigger or request Part A, applicant is enrolled in Part B, if slot was available at referral.
- If Part B LOC approved and applicant triggers or requests Part A**, Part B slot remains held, and the referral is sent to Ascend. **Proceed to Step 2*
- If applicant is denied**, applicant will receive notice, including appeal rights.

*Both processes *begin* at the same time, but the financial process cannot be *completed* until after the medical eligibility determination is completed. This is because a child can only be approved financially for Katie Beckett if the child also qualifies medically, there is a slot available, and the child will be enrolled in the program upon approval.

Step 2: Part A Application Process (if triggered or requested)



Medical Eligibility Process

Potential Outcomes

- If Part A LOC approved**, Part A slot is held (if available). If financial eligibility is approved, the applicant must pay premium payment (if applicable) to be enrolled in Part A. If not paid in 60 days, Part A enrollment denied; applicant enrolled in Part B if slot was available at referral.
- If Part A LOC approved and no Part A slot available** (including based on prioritization), the applicant will be placed on the Waiting List for Part A and enrolled in Part B if a slot was available at referral. **If no Part B slot available, Member will be placed on Waiting List for Part B*
- If Part LOC denied**, the applicant will receive notice, including right to appeal the Part A determination. Applicant will be enrolled in Part B, if slot was available at referral. **If no Part B slot available, applicant will be placed on Waiting List for Part B*

Katie Beckett Program

Transitioning from Part B into Part A:

What to Expect

Introduction:

Tennessee's Katie Beckett Program has 3 parts: Part A, Part B, and Part C. Each part has different services, different yearly limits, and different providers. [You can read more about the 3 parts here.](#)

Due to limited funding, some children who qualify for Part A were not enrolled in Part A right away. That's because children with the highest needs were enrolled in Part A first. Children—who qualify for Part A but couldn't enroll in Part A right away—were enrolled in Part B while they waited.

Now, ALL of those children can move to Part A. This tells parents what to expect when their child moves from Part B to Part A.



How You Know When Your Child Can Move to Part A

When your child can transition to Part A, TennCare will send a letter that says your child can enroll in Part A. To move to Part A, there are a few things you may have to do first.

Provide proof of your income

Did you provide proof of your income when you applied for Katie Beckett? If not, you'll have to provide that proof now. This allows TennCare to set your Katie Beckett premium payment (if your income is above certain limits). If we need proof of income from you, you'll get a letter from TennCare. You can upload the proof in TennCare Connect (<https://tenncareconnect.tn.gov/services/homepage>). The faster you provide the proof, the quicker we can see if you'll have a premium and if so, tell you how much it is.

If you have a Katie Beckett Part A premium, you must pay the first month **before** your child can enroll. If you do not pay your premium within 60 days, the slot will be given to another child.

Your child's Part A enrollment date will be the date the money is drafted from your bank account.

Things to Consider When Moving from Part B to Part A:

There are many differences between Part A and Part B of the Katie Beckett Program. Some of those are shown below. To find out more, [read these Katie Beckett pages](#).

	Katie Beckett Part A	Katie Beckett Part B
Medicaid benefits for children?	Yes	No
Extra help paying for things insurance doesn't cover?	Yes, up to \$15,000 per year, but the services in each Part are different	Yes, up to \$10,000 per year, but the services in each Part are different
Is private insurance required?	Yes. If you don't have it now, you must get it during the next open enrollment	No
Is there a Katie Beckett premium payment?	Yes, if your income is above a certain limit. To find out more, read the Katie Beckett pages . You can find examples here: https://www.tn.gov/content/dam/tn/tenncare/documents/UnderstandingKBCostSharing.pdf .	No

After your child is enrolled in Part A

Once your child is enrolled in Part A, a Nurse Care Manager with TennCare Select, the health plan for your child, will call to set up a time to meet with you. The Nurse Care Manager will help develop your child's support plan based on your child's needs and the benefits in Part A. If you don't hear from them within a week after your child enrolls in Part A, you can call TennCare Select at **1-800-263-5479**.

Once you are enrolled in Part A, your child's Part B benefits will end. You can't use any more Part B services.

Any services that were part of your child's approved Part B Support Plan that your child received before your Part A enrollment date will still be paid. This includes services that your child received while in Part B that were approved for payment through the Healthcare Reimbursement Account. You will have up to 90 days to submit any documentation or receipts for reimbursement of those services.

Declining Part A

You may choose for your child to stay in Part B. However, your child's enrollment into Part A is not guaranteed if you later change your mind.

If you decline enrollment in Part A when a slot is offered, your child will be removed from the Part A waiting list. If you change your mind, you can ask for your child to be assessed again for Part A. Enrollment would depend on whether there is an open slot in Part A and whether your child has the highest priority score for that slot.

If you receive a notice that your child can move to Part A, but you want your child to stay in Part B, please tell your DIDD case manager or TennCare right away.