

# breaking ground

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## Get to Know the Council



Council on  
Developmental Disabilities

Dear Readers,

I am especially excited about this issue of *Breaking Ground* because we're doing something we have never done before: profiling our staff. This was an idea from our longtime leader, Wanda Willis, before she retired. Many of our staff were hired by Wanda and worked together for more than a decade. Wanda mentored each of us "newer" staff before she left, and I can say genuinely that our team feels like a family. You, our Council network, are part of this extended family. We hope the profiles help you get to know us a little bit better.

Every article on the following pages has a special place in my heart, as usual. Each article began with a conversation between us and a reader like you. Please keep sharing your stories with us. We hope you enjoy reading these as much as we enjoyed putting together this edition of *Breaking Ground*.



*Lauren Percy*  
*Executive Director, TN Council on Developmental Disabilities*



*Director of Leadership Development Cathlyn Smith is a certified Circle Facilitator and trained as a social worker. Last month, she led our team through our first circle exercise. We are setting aside time every month for team building and nurturing our team culture.*

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Learn more about the Tennessee Council on Developmental Disabilities.

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# Get to Know: Us

There are a lot of things that make the Tennessee Council on Developmental Disabilities special:

- Our role as the only state agency with the job of bringing positive change across the entire system.
- Our history of big changes that have shifted the path of disability services in Tennessee.
- Our ability to connect dots and bring people together around shared goals.
- Our broad lens on disability issues across the lifespan, from birth to aging.
- Our diverse Council members from every district in the state whose real-world experiences shape everything we do.

There is another thing just about everyone who knows the Tennessee Council on Developmental Disabilities will tell you is part of our magic: the Council staff.

We know we're not objective on this subject. So, we thought we'd give you the chance to get to know us. Some of you have been working with the Council for years and know many of our staff well. But there have been new additions in recent years. And some of our staff have fewer chances to share the public spotlight. In this issue, each staff member will get their highlight. Each person brings a unique set of skills and experiences to this work. There are also common threads across our 10-person crew:



- A deep commitment to the Council and its values of inclusion, independence, and self-determination for people with disabilities
- A team mindset that sets aside personal ego and works across areas to get the job done right
- A focus on practical problem solving
- A culture of kindness, gratitude, trust, and support
- An internal drive for excellence

An agency's culture always starts with leadership. The Council was lucky to have Wanda Willis as our Executive Director for 33 years, until her retirement last year. As Lauren Pearcy stepped into the role in January, she made it clear she would be building on Wanda's legacy. Her time so far has focused on fulfilling the clear vision of our work under the Council's state plan. She has also focused on growing our internal culture of close teamwork.

The proof of a strong team is in our results. We invite you to get to know us. Follow along with us to see change in progress. And most importantly, join us. As amazing as our team is, we know this work is bigger than us. It will take our entire community working together to build the future we want for people with disabilities in Tennessee. ■



Find contact information for any member of our team at [tn.gov/CDD](http://tn.gov/CDD).

# Get to Know: Alicia Cone

DIRECTOR, PROGRAM OPERATIONS



**Time with the Council:** 22 years

**Main areas of responsibility:**

Federal reporting - State Plan and PPR; Contracts - development, management, monitoring and payment; Quarterly reporting process; Program evaluation – strategies, data collection and monitoring; Title VI – monitoring and plan implementation.

**What brought you to this work in the disability field?**

I liked the idea of supporting Mississippians with intellectual disabilities to be employed in the community...so that was my first, full-time, real-world job after college.

**What one word/phrase best describes what you bring to the team?**

Problem solver

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?**

Creation of the Leadership Academy for Excellence in Disability Services (*Council note: This program is the only one of its kind in the nation! It offers expert training to employees who work in disability-related areas of state government.*)



*The training grows their leadership skills and knowledge of important disability issues.)*

**What is something you think makes the Council special?**

Being a systems improvement advocate from within the system.

**When should people contact you directly for help?**

Whenever they want, because if it is not my specific area, I will assist them to get to the person on staff with whom they need to speak. Any time they have a question in any of my specific work areas.

**What is your favorite way to spend a day off?**

Catching up on sleep while cuddling with one of my pets.

**What pets do you have/what is your favorite animal and why?**

I have three cats. I love cats because they love unconditionally and are very smart. Sabrina is my oldest



and a seal-point Siamese. Fitz is my middle child and a tabby-point Siamese. And Tiger is my youngest. He was once feral and is a domestic short-hair black and grey tabby. All are rescues from either Texas or Tennessee.

**What's something on your "bucket list" for the next few years?**

Planning some trips to places in the southeast and southwest United States.



# Get to Know: Ashley Edwards



ASSISTANT TO THE EXECUTIVE DIRECTOR

**Time with the Council:** 4 Years

**Main areas of responsibility:** Supporting the Executive Director’s desk and special projects as assigned; Meeting coordination & support.

**What brought you to this work in the disability field?** I earned my master’s in reading education, thinking I would teach high school social studies somewhere. I ended up at a school for kids who needed individualized learning plans, teaching reading and technology. It changed my entire life. I’ve learned from some of the most incredible young people (I hope I taught them something too!)-some who are working in the field with me today!

**What one word/phrase best describes what you bring to the team?** Creative problem solving sometimes just a little creative, sometimes we question whether Ashley is off her rocker...

**What is one accomplishment/contribution from your time at the Council that you’re especially proud of?** (with the help of all staff) Moving Council meetings from in-person, to virtual, to in-person again.

**What is something you think makes the Council special?** In a world where people notice gaps or obstacles in the services system, the Council suits up to get to work building bridges and connecting dots to close the gaps and eliminate obstacles. In my experience, we tackle problems or search for solutions



because of the people who have served on or are currently serving on the Council. We’re going into meetings with the faces and names of Tennesseans these programs impact regularly. Sometimes it takes time, but our track record is pretty great!

**When should people contact you directly for help?** If they need to set a meeting with the Executive Director, when they would like information about upcoming council meetings... or if they want board game recommendations!



**What is your favorite way to spend a day off?** Walking around Cheekwood without interruption, watching my kids playing baseball or performing on stage, or playing board games with my partner.

**What pets do you have/what is your favorite animal and why?** Iris is my fur baby. She’s a 6-year-old Brussels Griffon and is very grateful for remote work. She’s a very good (read: high-strung) guard dog.

**What’s something on your “bucket list” for the next few years?** Taking my mom to Harry Potter World in Orlando. My mom has spent her life taking care of other people and it’s been my dream to take her on some sort of vacation. She has been obsessed with Harry Potter since it came out 20 years ago. I can’t wait to enjoy down time together and watch her excitement when we go in October!

# Get to Know: Brian Keller

GENERAL COUNSEL AND DIRECTOR OF PUBLIC POLICY



**Time with the Council:** 6 months

**Main areas of responsibility:**  
Legislation and legal compliance

**What brought you to this work in the disability field?** I have a disability myself. The disability community has always been important to me, and I love to give back to it.

**What one word/phrase best describes what you bring to the team?** Innovation!

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?** I have a few that I'm still working on. Give me 3 more months! *(Council note: Brian answered this before the Tennessee legislature passed \$1 million in funding for adult-size changing tables – the Council's top policy issue!)*

**What is something you think makes the Council special?** What it can accomplish as an advocate inside the system.



**When should people contact you directly for help?** Any time they are having a problem with a state service or agency, or any time they have questions or ideas about legislation.

**What is your favorite way to spend a day off?** Walking my dog and eating at Taqueria Del Sol.

**What pets do you have/what is your favorite animal and why?** A 4-year-old boxer mix named Gunner

**What's something on your "bucket list" for the next few years?** Play catch with my son, who will be born in a couple of months. *(Council note: Jack Keller was born on May 14!)*



# Get to Know: Cathlyn Smith

DIRECTOR OF LEADERSHIP DEVELOPMENT



**Time with the Council:** 2 years

**Main areas of responsibility:**

Partners in Policymaking, Leadership Academy for Excellence in Disability Services (LAEDS), Scholarship Fund

**What brought you to this work in the disability field?**

I raised an amazing young woman who is Deafblind. Advocating for her over the years, along with caring for other family members who were disabled, made this transition a natural fit for me. Just because a person has a disability does not mean they shouldn't have access to services, employment, education, etc.

**What one word/phrase best describes what you bring to the team?** Flexibility

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?**

I am proud that in spite of the difficulties that COVID-19 posed, it provided an opportunity to present Partners in Policymaking in a new way (virtual). The virtual option also provided a way to connect for some that may not have been able to partake in the class otherwise.

**What is something you think makes the Council special?**

What makes the Council special is the staff. Each person brings unique gifts and skills that makes our team whole. Our Council members also bring their lived experiences and knowledge, which provides a perspective representing Tennesseans with disabilities.



**When should people contact you directly for help?** It is always the "right" time to reach out to me if one has a question, concern, or comment. If I don't know the answer offhand, I will seek an answer or get them to the appropriate person for their need.

**What is your favorite way to spend a day off?** When the weather is nice, I truly enjoy sitting outside in my garden, watching and listening to the birds, or taking a nice walk. I also enjoy spending time with my family.

**What pets do you have/what is your favorite animal and why?** I have two fabulous dog fur babies! I am a country girl, so I have always had pets and cannot imagine life without them.

**What's something on your "bucket list" for the next few years?** My husband and I would love to get a small RV and go on some National Park tours. There is still so much to see!





# Get to Know: Emma Shouse Garton



**PUBLIC INFORMATION SPECIALIST**

**Time with the Council:** 10 years full-time

**Main areas of responsibility:**

Communications work supporting the Chief Public Information Officer; tracking data and outcomes for storytelling and federal reporting; sharing information about Council priorities and news impacting the disability community; leading state-wide sibling support network TN Adult Brothers and Sisters

**What brought you to this work in the disability field?** I have a younger brother with autism and other disabilities. After his diagnosis, my family became very involved in the disability advocacy community. I became interested in how public policy impacted families with members with disabilities. This led me to the Council for a college internship and I was hired after I graduated.

**What one word/phrase best describes what you bring to the team?** Curiosity

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?** I led Tennessee's participation in a national learning community about supporting families of people with disabilities using the Charting the LifeCourse framework and tools ([www.lifecoursetools.org](http://www.lifecoursetools.org)). The LifeCourse framework continues to impact how the Council and other partners in Tennessee think about supports for families and public policy.

**What is something you think makes the Council special?** I think it is so special to see how many leaders in TN's disability community have been impacted by the Council's work.

**When should people contact you directly for help?** Contact me at [emma.shouse@tn.gov](mailto:emma.shouse@tn.gov) or 615-253-5368

- If you have success stories about Tennesseans with disabilities
- If you have questions about our communications
- If your organization wants training about the Charting the LifeCourse framework and tools
- If you want to learn about issues impacting siblings of people with disabilities
- If you are an adult sibling who wants to find support

**What is your favorite way to spend a day off?** Sitting outdoors with a good fiction book or thought-provoking podcast

**What pets do you have/what is your favorite animal and why?** My husband and I adore our two bunnies, "Basil" and "Pocket".

**What's something on your "bucket list" for the next few years?** Finding, buying, and settling into our first house – which sounds both exciting and overwhelming!



# Get to Know: JoEllen Fowler



**OFFICE RESOURCES MANAGER**

**Time with the Council:** Almost 19 years (started October 2003)

**Main areas of responsibility:**

Administrative lead for agency operations, Technology/sensitive asset coordinator, Coordinates council meeting venue logistics, serves as agency records officer and public records request coordinator, and increasing agency efficiency with new and/or changing systems

**What brought you to this work in the disability field?**

Working where I have an opportunity to contribute to positive change for people fuels my fire: From working with domestic violence survivors, to Choctaw children struggling to succeed in “white” schools while also losing their native culture, to the Vanderbilt Kennedy Center, where I discovered the disability field was my home before joining the Council. Also, my favorite cousin has Down syndrome!

**What one word/phrase best describes what you bring to the team?**

Problem Solving!



**What is one accomplishment/contribution from your time at the Council that you’re especially proud of?**

Learning about and implementing our records management program, something we had to do as part of becoming an independent state agency. It is complex but I love getting rid of paper!

**What is something you think makes the Council special?**

Our success with meaningful, positive systems change is directly tied to our Council members. We have a unique role in state government that has allowed us to instill many changes over the years. Sometimes they happen quickly, sometimes it can take a decade, but we have been part of many improvements that impact the lives of people with disabilities and family members.

**When should people contact you directly for help?**

Anytime! If I can’t help directly, I’ll do my best to find someone who can.

**What is your favorite way to spend a day off?**

Riding around in the country with friends.

**What pets do you have/what is your favorite animal and why?**

I don’t have any pets at the moment, but I have had several cats over the years and love them all. I also love dogs, but they can be a little high maintenance for me.

**What’s something on your “bucket list” for the next few years?**

Taking a real beach vacation before the end of the year!



# Get to Know: Jolene Sharp

CHIEF PUBLIC INFORMATION OFFICER



**Time with the Council:** 3 years

**Main areas of responsibility:** Oversee all Council communications

**What brought you to this work in the disability field?** My entire life path! My dad has been blind since I was 18 months old, and I participated for many years in my parents' disabilities ministry work at churches across the Southeast. That introduced me to so many people with all types of disabilities from all kinds of diverse backgrounds. As an adult, I now have two children with



disabilities. I am so grateful to have this chance to bring my professional communications skills to work that is so personally meaningful.

**What one word/phrase best describes what you bring to the team?** Raising the Bar

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?** I think we've made great progress on increasing awareness and understanding of the Council. I am so proud to see more folks knowing about us and reaching out to engage with us, which allows us to keep growing our impact.

**What is something you think makes the Council special?** Our unique role of connecting real-world disability experiences with the whole system of disability

services. Our agency is the only one with a bird's-eye view of the system, and the ability to plug people in so their experiences are informing how services and policies work.

**When should people contact you directly for help?** 1) Any time they have a news item or story idea they think our audiences should hear about 2) Any time they have communications-related ideas or questions

**What is your favorite way to spend a day off?** Traveling to new places, spending time in nature, or curled up with good coffee and a good book

**What pets do you have/what is your favorite animal and why?** Our dog, Reilly, is a shepherd mix our family adopted in 2020. She's goofy and sweet and I adore her.

**What's something on your "bucket list" for the next few years?** After staying home during COVID, I am craving travel! This year, my husband and I are celebrating our 20<sup>th</sup> anniversary with a trip to Scotland. My son is lobbying for a trip to Greece soon, and we really hope to visit friends in Australia before long.



# Get to Know: Lauren Pearcy



**EXECUTIVE DIRECTOR**

**Time with the Council:** 5 years  
*(starting Fall 2016)*

**Main areas of responsibility:** My role is to see the big picture. The Executive Director brings all the pieces of our work together toward a common vision.

**What brought you to this work in the disability field?** I started my career at the National Governors Association, where I was assigned staff to Delaware Governor Jack Markell's initiative, "A Better Bottom Line: Employing People with Disabilities." That initiative was an unexpected, intensive education about disability policy. I was hooked, and I have been committed to the field ever since.

**What one word/phrase best describes what you bring to the team?** Big picture thinker

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?** I am proud, but mostly humbled, by our work expanding access to adult-size changing tables.



This project is led by Council members and has required "all hands on deck" by our staff team, which has made every setback and every accomplishment feel like a truly shared experience across the whole Council.

**What is something you think makes the Council special?** We are a rare organization that is equally connected to the people experiencing disability and government services for disability. I like to say, "We have a foot planted firmly in each camp." It is when those two perspectives come together and truly hear each other that lasting, positive change happens.

**When should people contact you directly for help?** I want to hear from anyone who has interest in the

Council, especially if you are having trouble with (or having trouble finding) services and supports you need. If I can't answer your question, I can get you to someone who can.

**What is your favorite way to spend a day off?** I go to the Ellington Agriculture Center every chance I get. It's endless exploration for my two young kids, and I love to be outdoors.

**What pets do you have/what is your favorite animal and why?** I do not have pets because two toddlers is already a zoo!

**What's something on your "bucket list" for the next few years?** I am from Northern California but have not lived there since 2007. I can't wait to take my kids to experience my favorite places, from Alcatraz to Lake Tahoe.

# Get to Know: Lynette Porter



DEPUTY DIRECTOR

**Time with the Council:** 22 years  
*(Started June 1, 2000)*

**Main areas of responsibility:**  
Agency budget, fiscal, and operations. Federal and state compliance.

**What brought you to this work in the disability field?** My now 29-year-old daughter with a disability.

**What one word/phrase best describes what you bring to the team?** Problem solver

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?** Selection for and participation on the State's inaugural Government Leadership Council, focused on supporting and strengthening leaders in state service.

**What is something you think makes the Council special?** The staff! Everyone has a personal connection to disability or a deep passion for the work that we do. It's an incredible, versatile, committed team.

**When should people contact you directly for help?** If you are interested in serving on the Council, or if you aren't quite sure who else to contact. I'm always here to help.

**What is your favorite way to spend a day off?** Walking on Tennessee trails. We are fortunate to have so many state parks and natural areas, and I'm always looking for new ones to explore.



FINANCE, WAYS & MEANS COMMITTEE

Finance, Ways, and Means Committee- Budget Hearing

**What pets do you have/what is your favorite animal and why?**  
How much room do I have for this section? I have 2 Shetland sheepdogs and 3 cats. They are all rescues. They make our fur-covered house a home.

**What's something on your "bucket list" for the next few years?** I'm not sure if it will happen in the next few years or not, but I've always wanted to go to New Zealand. That's my once-in-a-lifetime big bucket list trip.



# Get to Know: Mildred Sparkman



**ADMINISTRATIVE SECRETARY**

**Time with the Council:** 18 years

**Main areas of responsibility:**

Fiscal Transaction Support, Assisting Directors with special projects, meeting support, Greeting visitors and customers to our agency

**What brought you to this work in the disability field?**

Interested in helping others and working with a positive purpose

**What one word/phrase best describes what you bring to the team?**

positive energy and personal commitment

**What is one accomplishment/contribution from your time at the Council that you're especially proud of?**

Always ready to help where I can with team members and our customers



**What is something you think makes the Council special?**

Passion working with purpose, a positive outcome

**When should people contact you directly for help?**

Contact the office when someone has a question and not sure where to get an answer, or looking for information about disability services.

**What is your favorite way to spend a day off?**

Playing and spending time with my grandchildren

**What pets do you have/what is your favorite animal and why?**

Dogs are my favorite pets because they show unconditional love. Dolphins & whales are my favorite animals – gentle swimmers and I love to swim.

**What's something on your "bucket list" for the next few years?**

Experience sights and sounds of Hawaii, and a return visit to Grand Canyon and Bryce Canyon. It is so beautiful and peaceful there.

# Two Restorations

By Elisa Hertzan, Esq.

## WORDS TO KNOW FOR THIS ARTICLE

**Restoration** – returning something to the way it was before; giving something back to its right owner

**Terminate** – to end

**Conservatorship** - If an adult with a disability cannot make their own decisions, the court can legally assign someone else to make decisions for them. The person the court assigns to make decisions is called a "conservator." <https://www.tndecisionmaking.org/conservatorship-lev4/>

**Circle of support** – trusted friends or family who help someone make decisions

I was hired by Disability Rights Tennessee (DRT) to be their supported decision-making attorney. DRT was awarded a two-year grant from the Council on Developmental Disabilities to grow supported decision-making in Tennessee. The grant would allow me to represent clients who wanted to end their conservatorships.

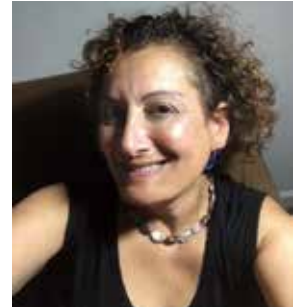
Jen Cook was a 37-year-old woman with a mild intellectual disability. She had been in a conservatorship for as long as she could remember and was ready to make her own decisions. She wanted her independence.

Cindy Gardner, an attorney who was Jen's conservator, called me to talk about terminating Jen's conservatorship. It was clear that Cindy adored Jen. They had spent many afternoons together, cheering on the Lady Vols and eating out at Jen's favorite restaurants. Ms. Gardner had always encouraged Jen to make as many of her own decisions as possible. She favored ending Jen's conservatorship.

Terminating a conservatorship in Tennessee should be easy, but it's not. The first step would be to have Jen examined by a doctor to see if she could make her own decisions. The doctor agreed that Jen was very capable of making her own decisions. The case could proceed.

I filed a motion with the Chancery Court in Hamilton County asking to terminate Jen's conservatorship. The court scheduled a hearing on April 20, 2021. Jen and I worked hard to prepare for the hearing. She would have to convince the judge that she could make her own decisions and could rely on her circle of support for help.

One week before the hearing date, I suffered the loss of a lot of my vision. Vision loss is frightening, and the doctors weren't sure if or when my sight would be restored. I could not represent Jen under these circumstances. She had worked so hard. I thought she would be disappointed. I worked up the courage to call Jen and told her about my vision loss. Jen asked if the case would be postponed. "Yes," I answered, "and I'm so very sorry."



Elisa Hertzan

"Don't apologize," Jen scolded. "I know what it's like to have a disability. I've waited a long time to end my conservatorship. I'll just wait a little longer."

I wanted to hug her. The court was just as kind. They agreed to reschedule the hearing and wished me a speedy recovery. It took six months, but much of my vision returned. My vision loss and restoration helped me appreciate what it would mean for Jen to have her lost rights restored.

On December 22, 2021, the court agreed to end Jen's conservatorship. We won! I worked with Sevita, Jen's service provider, to set up some extra supports. We set up an ABLÉ account to help Jen save money and a healthcare directive to explain what medical decisions she wants in an emergency.

Jen and I are both doing great. We know we were brought together to love and support each other on this journey. We learned that whatever your disability, special people will journey with you. No one is ever alone. Thank you to Disability Rights Tennessee, to Cindy Gardner, and to the Council on Developmental Disabilities for bringing me and Jen together. Finally, I want to give a special shout-out to the Tennessee Center for Decision-Making Supports, which offers help about using supported decision-making: [www.tndecisionmaking.org](http://www.tndecisionmaking.org). ■

*Elisa Hertzan has practiced law for more than 30 years. She joined Disability Rights Tennessee in Oct. 2020 as their Supported Decision-Making Attorney.*

# Families find the help they need with TN's Katie Beckett program

By Cara Kumari, Assistant Commissioner of Communications and External Affairs, TN Department of Intellectual and Developmental Disabilities

The Katie Beckett program started in November 2020 and is now supporting nearly 1,500 kids across Tennessee who have disabilities and complex medical needs. The program serves children under the age of 18, even if their parents make too much money to get Medicaid. Katie Beckett has two parts, A and B. Many families have found the program helps their children to thrive and live their best lives. Families of children enrolled in Part A and Part B are sharing how the program meets their child's individual needs.



*Katie Beckett paid for a Freewheel accessory so Emory can take her wheelchair off-road to join in the fun with family and friends.*

## Emory's Story

Emory is a 5-year-old bundle of light and laughter with a twin sister and three other siblings to keep up with. Needing a wheelchair makes it difficult for Emory to participate in all the fun outdoor activities with her siblings and classmates. Using the funds available for Assistive Technology in Katie Beckett Part A, Emory now has a FreeWheel® for

her wheelchair. This device is a third wheel that clamps to the wheelchair and turns it into an off-road vehicle. Now, Emory is not limited to watching from the sidewalk when others are playing on the field or joining in fun activities. Instead, she can be in the thick of the fun and activity.

## Eli's Story

Eli is 18 years old and relies fully on caregivers and supports to ensure his needs are met. Through the help of the Katie Beckett program, Eli's mom was able to get connected with Eventa for added respiratory (breathing) supports. Eventa has positively affected Eli's quality of life. It makes sure his family has all the right equipment and supplies to care for him at home. It has helped Eli to avoid emergency room visits and unplanned hospitalizations. His mom says she is grateful that she can use consumer-directed services to pay for Eli's caregiver. She was paying for the caregiver without any help before Katie Beckett.

Eli just turned 18. This means he will be the first person in Katie Beckett Part A to transition into the Employment and Community First CHOICES program as he enters adulthood. His nurse care manager is helping Eli and his family with this change between programs.



*Katie Beckett has helped Eli to stay healthier at home. Now, he's 18 and is the first person in Katie Beckett Part A to transition into the Employment and Community First CHOICES program as he enters adulthood.*





*Two-year-old Cosette Smith loves to be on the move. Her walker was purchased with the support of Katie Beckett Part B*

### 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 Katie Beckett Part B. The new walker replaced a pre-used walker that was donated to the family. They appreciated the older equipment, but it wasn't functional for the challenges Cosette was facing with cerebral palsy. Buying a new one would be very expensive. Nicole says she would've had to wait for another donated walker if it wasn't for Katie Beckett funds. That would have delayed some of her daughter's progress towards gaining the independence she wanted. Now her new walker is allowing Cosette to move herself across the playground, interact with other children with and without disabilities at daycare, and join in classroom events that she couldn't join before. "Katie Beckett was a game-changer for us," Nicole added. "With medical costs as high as they are and Cosette's ever-changing 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 get non-traditional therapies recommended by their doctor. Combined with

### What's the difference between Katie Beckett Parts A and B?

**Part A** helps children in Tennessee with the most significant disabilities or complex medical needs. A child must meet "institutional" level of care. That means they would qualify to get care in a medical setting like a hospital or a nursing home but want care at home. Children in Part A receive full Medicaid benefits. They also can get up to \$15,000 in nonmedical services, called home- and community-based services. A child must have private insurance, and a premium may be required based on the family's income.

**Part B** is for children in Tennessee who have disabilities and complex medical needs who do not qualify for care in a medical institution. They meet "at risk" level of care. Children who qualify for Part A can get Part B if there is no slot available in A. Children in Part B do not receive Medicaid. Families get up to \$10,000 a year in services to care for their child. Families can spend the money in Part B in any or all of 5 different ways:

- A card to pay for medical expenses
- Paying for a child's private insurance premium
- Getting paid back for certain services including non-traditional therapies
- Hiring your own staff to provide respite and supportive home care
- Having a community provider for services

services through Tennessee Early Intervention System (TEIS), Nicole believes Cosette has a solid team of support that is improving her quality of life and setting her up for success. ■

### Learn more and apply

Learn about the Katie Beckett program, how to apply, information about intake and enrollment, and program data at <https://www.tn.gov/didd/katie-beckett-waiver.html>.

For help with filling out the application or questions about the program, call your regional Dept. of Intellectual and Developmental Disabilities office:

- West Tennessee Regional Office: (866) 372-5709
- Middle Tennessee Regional Office: (800) 654-4839
- East Tennessee Regional Office: (888) 531-9876

# Dancing our way to health and confidence

By Dave Griffin, 2021 graduate of Partners in Policymaking® Leadership Institute

My name is Dave Griffin. I am on the autistic spectrum. I wanted to write about my experiences with ballroom dancing along with two other men on the autistic spectrum: Benjamin Rubbelke and Orlanden Frazier. I also wanted to introduce you to Ballroom Dance Studios, owned by Brooke Mortimer and Devan McClish. This is where all three of us are students.

## INTERVIEW WITH BROOKE MORTIMER

### What have you learned through teaching dance to students on the autism spectrum?

We truly live by our mission, "Anyone Can Dance." That includes anyone on the autism spectrum. We currently have several students with autism who have excelled in this activity. It just reinforces our mission and shows that anyone can learn how to ballroom dance!

### What have you found most satisfying in your work with students on the spectrum?

We have found that it helps those students' social skills



Brooke Mortimer and Ben Rubbelke perform together.

and motor functions. Not only are they learning a new skill, but they are also learning how to interact with people better!

### What advice do you have for people on the spectrum who are interested in learning ballroom dancing?

Anyone interested in learning ballroom dancing should know there is a community of people on the autism spectrum already within the Tennessee ballroom dance community. They are accepted and welcomed, especially in our studio!

## DANCE STUDENT PERSPECTIVES

### How Did You Get into Ballroom Dancing?

**Benjamin Rubbelke:** I was first introduced through swing dancing and danced swing for 2 years. Then I was introduced to Big Band Dancing in Centennial Park in 2019. Just before COVID hit, I went to check out one club that was open. I enjoyed it so much. COVID happened and the studio reopened and recommended me to Brooke and Devan. They have been my instructors ever since.

**Orlanden Frazier:** My mom introduced me to Brooke and Devan.

**Dave Griffin:** Interestingly, I decided to pursue social relationships with women about one year before I realized I was on the autistic spectrum. I tried dating services, but I felt too much pressure meeting a total stranger and trying to see if there was a romantic connection.

I wanted to do something with ladies that we both enjoy that did not involve the pressures of dating. I tried ballroom dancing. Four showcases and two competitions later, the results in being more comfortable around women have been amazing. I value the emotional fulfillment I get from having so many meaningful connections with so many women. But I am just friends with all of them.

## How has dancing changed you?

**Benjamin Rubbelke:** Ballroom dancing has changed me both physically and mentally. I've improved staying active with moving my body and expressing myself with emotions that are much more physical than verbal. I've been told I'm very visual. This has helped me to watch movements. The movements they teach are so elegant that it provides a wonderful feeling that can stay with me the rest of the day.

**Orlando Frazier** (Orlando's mom, Lee Ann Horton, helped with these questions)

Orlando believes that dancing was a good thing for him to do. He also said, "The worst thing about the show experience was all the people watching me, and the noise." The best thing about the show experience was "just the fun of dancing and showing my friends and family how hard I worked."

Lee Ann feels ballroom dancing offers Orlando a great opportunity to gain confidence both within himself and improve his gross motor skills in a fun way. Lee Ann said, "He also increased his social interaction skills in a safe and loving environment. Brooke is very talented in seeing individuals' strengths and working with them to counterbalance weaknesses."

**Dave Griffin:** Feeling socially insecure around people in general and women in particular is common among men on the autistic spectrum. This has certainly been my experience. I think I can safely say that trust and confidence have replaced my fear and anxiety about being around women. Ballroom dancing has played a major role in this transformation for me. In short, ballroom dancing helps me feel better about me.

## How can others get involved with learning to dance?

**Benjamin Rubbelke:** Ballroom dancing is very intricate. You have to be patient, dedicated, and have a lot of passion. Once you progress down that road, it produces wonderful results. It gives you a way to dance long stressful weeks off. I would advise when you learn dance not to rely on what you see but you feel. If you are interested in ballroom dancing, I would highly recommend reaching out to Ballroom Dance Studios. They are affordable, professional, and most important, they will never, ever pressure you into spending money you don't want to spend or learning something you don't want to learn.



Students Ben Rubbelke (far left) and Dave Griffin (far right) celebrate studio owners Brooke Mortimer and Devan McClish.

**Dave Griffin:** I would recommend Ballroom Dance Studios to anyone interested in ballroom dancing, whether they are on the spectrum or not. For more information on taking ballroom dance lessons, you can email Brooke Mortimer and Devan McNish at [ballroomdancestudios@gmail.com](mailto:ballroomdancestudios@gmail.com) or you can visit their website at [www.ballroomdancestudios.org/booknow](http://www.ballroomdancestudios.org/booknow).

Or, as a self-advocate who has pledged to be available to any self-advocate, my direct cell number is 615-679-6997. You can call me if you need help. I think anyone could benefit physically, emotionally, and spiritually from ballroom dancing. Give it a try!

## Other social opportunities to explore

If you need some social outlets to help you prepare for ballroom dancing, or you just want to try something else, I am part of some programs designed for people on the autistic spectrum. I am the Teen and Adult Program Manager for Autism Tennessee.

- I facilitate a Game Day, which happens the first Saturday of each month at On The Avenue from 2-5 p.m. Game Day is for people of all ages on the autism spectrum and their supporters.
- Thrive, a social skills class for autistic young adults ages 14-22, happens right before Game Day from 12-1:30 p.m.
- On the fourth Thursday of each month, from 6:30-8:30 p.m., Autism Tennessee offers a social skills class, which I lead.

Please contact me at [dave@autismtn.org](mailto:dave@autismtn.org) if you are interested in learning about any of these programs. ■

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