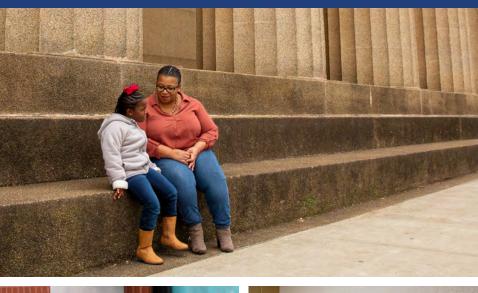
TENNESSEE KINDRED STORIES OF DISABILITY

Behavior Supports and Practices in Tennessee Schools













VANDERBILT KENNEDY CENTER





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Letter of Thanks

Thank you for reading this collection of stories from parents who, alongside their sons and daughters with disabilities, have experience with behavioral supports and practices in Tennessee schools. The parents share candidly about the impact those experiences have had on their student and on their family. This collection also includes perspectives from teachers, who have experienced and addressed challenging behaviors in the classroom.

The stories were collected through interviews conducted by Vanderbilt University (VU) students as part of the 2024-25 Tennessee Kindred Stories of Disability project. This annual project gives students, who plan to be future educators, advocates, and researchers, an opportunity to learn firsthand from individuals with disabilities, families, and disability professionals. The project's culminating booklets are shared with legislators and policymakers each year to educate them about issues that impact their constituents with disabilities and their families.

We would like to thank the parents who shared their stories this year. These are not easy stories to share, and we are grateful they have participated to educate Tennessee legislators and policymakers. We would also like to thank the teachers who shared about their

Courtnestaylor

Courtney Taylor Director of Communications and Dissemination

A. Pablo Juárez Co-Director, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD)

experiences in classrooms. While this booklet does not include every story we heard, all were equally compelling and shared similar themes to those included in the booklet.

The images that accompany the stories were taken by photographer Jen Vogus and members of the AbleVoices Photography Club. We are so grateful for the partnership with AbleVoices, which provides photography programs for individuals with disabilities as a means for self-expression, empowerment, and advocacy. A huge thank you to the Tennessee Arts Commission for funding the photography and printing of the booklet this year.

An additional thanks to VU graduate students Camille Reynolds and Sanskriti Singh, who coordinated and contributed many hours to the project this year. And thank you to all the students, who conducted the interviews, listened deeply, and enabled the sharing of these stories.

We hope these stories bring more awareness to the barriers that students with disabilities and their teachers face as they work to meet the needs of students in Tennessee schools.

To view online collections of *Tennessee Kindred Stories of Disability*, please visit <u>vkc.vumc.org/kindred</u>.

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Julie Lounds Taylor Co-Director, Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD)

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Bob Hodapp Professor of Special Education; Director of Research, VKC UCEDD

Introduction

The stories you will read from parents and teachers in this issue highlight the barriers students with behavior challenges often face as they seek a free and appropriate education in Tennessee classrooms. Shortages of special education teachers and high turnover as well as a lack of training and resources mean that students have difficulty getting proper supports and therapies they need for their complex behavioral needs.

Schools are struggling to efficiently support students with complex behavioral needs, which can greatly impact the course of these students' lives and often leads to poor outcomes (academic, professional, social, or emotional). Many times, challenging or distressing behaviors are a function of a student's disability and can be a method of communicating feelings and thoughts. More education and training is needed for educators and para-professionals working with these students in order to improve their outcomes in school and life.

Additionally, both general education and special education teachers report feeling underprepared to work with this group of students. This has often created a punitive culture within Tennessee schools. Some educators and administrators rely on harsh formal and informal disciplinary measures, such as excessive and inappropriate use of restraint and seclusion, in the place of policies that work with a student and family to address their behavioral patterns and provide them with individualized support. This booklet aims to highlight some of the root causes and the ways behavior support practices play out in Tennessee schools from the perspectives of key players involved. We hope that in reading this collection of stories you will be motivated to find out more about behavior policies in your local schools and speak up on behalf of a more caring approach to supporting students with complex behavioral needs.

This booklet aims to highlight some of the root causes and the ways behavior support practices play out in Tennessee schools from the perspectives of key players involved.

Rebecca

My name is Rebecca. My husband and I are the proud parents of our son, Thomas. Thomas is a 13- year-old boy, who loves sports and taking trips to the local museum in our community. Thomas is extremely kind and curious and loves looking for fossils in the museum. When he was in kindergarten, he was diagnosed with attention-deficit hyperactive disorder (ADHD), sensory processing disorder (SPD), and autism spectrum disorder (ASD). In spite of these diagnoses, not a lot about Thomas' personality changed.

When Thomas was first diagnosed it was a bit of a challenge. My husband and I were navigating three different diagnoses. However, despite already having degrees and established careers, my husband and I stepped up and pursued additional degrees. I received a Master of Arts in Special Education, and my husband received a doctorate in Special Education Administration. Our hope and goal with furthering our educations was to better support our son and create change within the public education system.

The public education system can be incredibly complex and daunting to parents of children with disabilities. Despite our education, it is too complex for even us to navigate. Thomas' school district was not adequately able to provide the support that he needed to succeed in the school setting, thus leading to increased behavior issues. When the school informed us that Thomas was eloping more frequently, my husband and I fundraised to get Thomas a service dog. We hoped that when Thomas received his best friend, Dougie, his running away at school would decrease. And it did.

The school later told us Thomas was doing great and requested they try school days without Dougie. We agreed to leave Dougie at home, but as we expected, Thomas started running away again. One day he ran all the way out to the road and the staff barely got to him in time. We knew that Thomas needed Dougie, but they refused. At an IEP meeting, they told us that because Thomas was not Dougie's official handler, Dougie could not return.

For more specifics on the law regarding service animals in schools see: Taking a Service Animal to School | ADA National Network <u>adata.org/service-animal-</u> <u>resource-hub/school</u> A few months later, I got a call that there was an incident at recess. I soon learned that my son had been thrown to the ground and handcuffed by the school resource officer. All of this because he threw a rock at the fence - not at anyone. After this, the officer walked him around the school in front of all his peers. When I saw Thomas, he had a broken toe, scrapes, bruises, and burns where the handcuffs were on his wrist. So, we got an attorney and reconstructed his Individualized Education Program (IEP) again.

The school provided Thomas with a one-on-one teacher, an aide, and a private classroom. This was supposed to be a solution to his behavior. However, this was a technique for seclusion. Thomas was having a lot more meltdowns at this point because, number one, he didn't have his service dog, and number two, he was traumatized. The staff's response to his behavior was causing him to escalate and naturally, he is going to kick and punch, because he got hurt last time. Last November, I was told to come pick up Thomas because he was being expelled from school.

The school offered us two options: three hours of homebound services a week or a residential treatment facility. The thought of removing him from home was absurd considering he was not demonstrating behavior issues within my home. We attempted the homebound services, but there was no instruction being provided. I quit my job to homeschool Thomas, which reduced our income significantly. We really struggled to make it work on just a teacher's salary. I took it upon myself to have him tested to determine his reading level and math level. I am disappointed with what the public education system has offered him. They have done nothing. Educational malpractice doesn't exist, like there's medical malpractice. The only avenue to



Thomas loves animals and one of his favorite things to do in the community is visit zoos. Thomas excitedly points out that he wants to visit the tigers next.

take legal action would be to claim a violation of his right to a free and appropriate education (FAPE). But we have no interest in putting him back into public education.

My biggest advice to other parents is to keep advocating and keep pushing. You know what your child needs. I have to scream at the top of my lungs, that all behavior is a form of communication. Good behavior is a form of communication as well as bad behavior. Parents and teachers must ask what a child is trying to communicate through the behavior. It is very sad that Thomas can't have an equal opportunity for a full public education like other children. The main message we want to convey is that



Thomas poses for a family portrait with mom, Rebecca, and dad, Les, at the Knoxville Zoo.

it is never acceptable to put manual restraints on children. There are other ways around it. Thomas didn't used to have those behavior episodes like he does now, and he doesn't have them now at home because he feels safe.

If they do this to me and my husband, knowing that we know the law, we know the legalities of FAPE and the Individuals with Disabilities Education Act (IDEA). What are they doing to the students and parents who have no educational knowledge of these laws and systems? When I talk to families, it's staggering the number of kids that are being ejected from the school system. And it's just being allowed because they're offering them three hours of homebound a week. They've got a behavior problem, so rather than fix the problem, we're just dismissing them all. And that is the problem within itself.

As Thomas' parents, all we want is for him to be included – included in the classroom, with his peers, and within his community. I do not know how to fix the public education system and access to proper behavioral supports. However, I do know that as parents and caregivers to children with disabilities, we must continue to advocate for the children we love. We must work together to ensure that all children have access to a free and appropriate education and that, most importantly, no other family goes through what my Thomas had to experience.

Angela

As a mom of two children with autism, I've had lots of experience with practitioners about behavior supports. My son, Vance, is 15 and my daughter, Natalie, is 11 and non-verbal. Because my children are very different, I've had a variety of experiences with their behaviors, especially during growth spurts as those have impacted the most noticeable changes.

Natalie's behaviors tend to be internalized, due to her inability to communicate verbally with us about what she needs and about what she is feeling. My son demonstrates behaviors in the form of physical aggression. As Vance's growth spurts began, we saw an increase in aggression, and he began to appear as though at times he did not care about others. His aggression has led to him spending 13 months in a residential facility.

My children both began their academic journeys in the public schools. Over time, we found that it was a good fit for Natalie but not for Vance. The school had a seclusion room in which to place him when behaviors occurred. However, it did not meet his needs to regulate his aggression and meltdowns. Additionally, his therapists were not allowed to visit him in school to provide him with the support he needed. Due to this, we moved him into a small private school.

The smaller school was a better fit for Vance. However, as his aggression continued to increase and work completion decreased, I had to attend every day to support him. Additionally, he was frequently placed in restraints by staff, therapists and sometimes by me. Despite this, I found this school to be very cooperative due to their willingness to allow ABA (applied behavior analysis) therapists to work with him. This was different from the public school he was in where ABA wasn't offered. While this was a good fit for Vance, his behaviors increased to the extent to which he needed to spend time in a residential facility. While it did help with behaviors, its primary focus was on behavior management strategies rather than academic instruction. This means now that he is out of the facility, we are having to homeschool to catch him up, while ensuring his behaviors decrease to the extent to which he could return to his school without putting himself, his classmates, and his teachers in danger.

My children are in need of many services, such as physical therapy, occupational therapy, feeding therapy, ABA therapy, medical appointments, and therapist appointments. I think what is most needed at this point for Natalie is an ABA therapist. Having one was impactful for her progress. However, her therapist quit, and the school has not rehired someone, which means my daughter is no longer receiving the services that she needs and requires.

One of the long-term impacts of the COVID pandemic, is that I have been unable to get my children back to the therapies that they need. Before the pandemic, my children were able to receive the support, but due to them being at a high risk of getting sick, they temporarily stopped receiving services. When I tried getting them back into it, the demand was so high that I was told I was no longer able to.



Everyone joins in for a family hug on a cold day in Springfield.



One of Natalie's favorite activities is swinging. Vance giving her a push at a local park in Springfield, TN.

I think that more hours should be provided for ABA therapy. ABA providers should be included in all public schools because they work best when they can coordinate the services in school, home, and outside environments. If ABA and other therapies were offered during the school day, it would fill the school hours and give parents a break from having to pull their children from school to attend the therapies.

I love both of my children and want nothing

but the best for them. Others may see them as a burden, but I see them as a joy. I'm thankful my children have insurance and financial support, but I wish parents of students with disabilities could get the help they need without forcing them to the poverty level. Behavior management comes easy to all of us but to some people with disabilities it needs to be explicitly taught, and the right supports have to be in place. It is not their fault that they require these supports; therefore, it should be a right, not a privilege. ■

Shannikka

As a single mother, I, Shannikka, share a special bond with my 8-year-old son, Jayce. Traveling and playing outdoors are our cherished activities. After his public school experience in kindergarten and first grade, I selected a tailored private setting for him this year, focusing on children with disabilities or "unique learners." Jayce's nonverbal communication often leads to behaviors such as eloping (running away) and crying. When he isn't properly supported during times of distress, his behaviors could escalate to self-injurious behaviors.

Jayce has had a difficult time in public school settings, which is why I decided not to enroll him this year. I wanted him to be in an environment that was welcoming, neuro-affirming, and that could meet his needs on all levels without me having to consistently advocate for basic necessities. There were several times Jayce presented behavioral challenges, due to the lack of support or his education plan not being followed with fidelity. Kindergarten was very hard for him because that was his first year in a public school environment. Before that, he was in ABA, which was a very therapeutic setting. They emphasized self-regulation and sensory needs. All his behaviors were at baseline - they were so low, that he practically didn't have any. But when he transitioned into kindergarten, he experienced a major behavior spike and many adjustment issues. Jayce went from having three behavior issues a week to 100 in one day.

There were times Jayce struggled with behavioral issues when he was trying to express himself, his needs were not being met, frequent schedule changes, sickness, lack of support, and adjusting to the different environments. I remember the school calling me more than once to come pick him up because he had been crying for hours. Typically, they would say something like, "Hey, Jayce has been crying for several hours. Could you come get him? He's not having a good day, and we're not sure what's wrong." No detail as to what interventions were utilized. As his mom, it was hard to hear that he was so upset. I knew that if he had been crying for a long period, it was a clear sign that something was wrong. So, I would go pick him up to get him the support he needed.

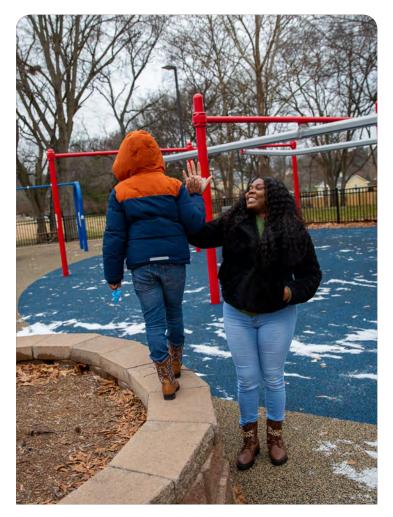
My child's rights are really important to me, but in those specific moments, the mom in me couldn't let him stay at school and continue to be in distress or pain. I honestly have lost count of how many times the school has called me. It was definitely more than five, probably more than ten. I don't recall ever being notified when they had already removed him from the classroom, as communication and transparency were huge issues with public schools. In those moments, I focused on what I thought was best for him, which was helping him regulate.

I often felt in the dark about what was happening during my child's day at school. Some days I picked him up, and he would come home with puffy eyes, bruises, and scrapes, leaving me worried and confused. After a significant amount of time demanding daily communications from the school, I started to receive brief updates regarding his day, but it was never consistent. Some days I still wouldn't receive any updates.

I have gotten notes saying, "We had a good day." "We had high behaviors today." "Didn't eat much lunch today." Things like that. Nothing in much detail. To reiterate, that was after many incidents of the school not keeping me informed about anything. It required me to advocate tirelessly throughout his entire time in public school just to receive those brief updates about his day. It felt like a small victory, but it was progress, nonetheless. It was difficult and not likely for me to receive consistent communication though. Oftentimes during meetings, teachers shared that there are so many kids, and they can't call a parent each time something happens, or if they are short-staffed. But in my eyes, if the behaviors are interfering with the child's learning, I think it's very important to reach out to the parents and navigate ways to de-escalate, redirect, reassure, and offer support to the student. I mean at the very least, try to identify what was triggering in the environment to begin with.

My child has experienced restraint multiple times in a school setting, yet I, as his mother, have only received formal notification once. I'm certain he has. Variations of restraint exist, including holds which some individuals are certified to do. However, I infer from my child's behavior at home that restraints occur more frequently than disclosed. His fear to hug and receive affection due to fear of being squeezed or restricted indicates past restraint experiences. Even when formally notified, I received no detailed explanation of events leading to restraint from the person who called. Notification arrived late, post-school day, and an email follow-up yielded a vague response lacking clear justification for restraint.

My child is traumatized. He has severe school trauma. He is averse to anything school-related at this point, which led me to try something different. He doesn't trust anyone, he doesn't get close to people, he's fearful, and he has socially



Shannika smiles and high fives Jayce as he runs by.

declined. He's very hesitant now. He's different. As his mom, it's painful to watch your child decline due to lack of supports and trauma. It's a horrible feeling. It's very hard. He's not my bubbly, confident, silly boy anymore. School is supposed to be a great experience but for Jayce, it has been a nightmare.

In the past, Jayce communicated his needs and wants fluently with his AAC (augmentative and alternative communication device), but he had some school staff members using his AAC in a negative, forceful manner. This has made matters worse with his communication. His communication has significantly declined due to this method. Visual aids and his AAC were



Jayce enjoys being outdoors at the inclusive playground in Brentwood, TN

his preferred methods of communication for a while. He was being forced to communicate the way the staff wanted him to. As if his words or gestures didn't have value. So now he associates AAC and visuals as negative anytime it is presented. As I said before, he's now averse to a lot of things education, which is not what I had hoped to see. This is all due to the lack of supports and training in schools. Removing him from public school was the best decision. We are working on strategies to help my Jayce regain skills that were lost in hopes of seeing progress and getting him back on the right track.

To better support students with behavioral needs in public schools, a certified behavior

specialist should be planted in every school. Mandated staff training is also crucial, focusing on ongoing education for teachers and administrators to address behavioral needs effectively. These individuals are the first to interact with students yet may not possess the necessary skills for de-escalation or redirection, necessitating continuous specialized training.

If I could give parents advice, I would say don't give up. Keep advocating. Keep showing up. If you need to show up every day, call your IEP meetings, and attend them. Keep advocating. You are your child's best advocate and the expert on your child.

JoAnne

I have four kids with disabilities, two have autism, and two have ADHD. One of my sons, Stephen, has experienced the most behavioral support struggles in the school system out of all of my kids, while my daughter has had more emotional behaviors. Stephen has autism and is 16 years old. He was not formally diagnosed until 2020. I would bring up concerns to my pediatrician, and he said that the school will identify if there are any problems and will send a form home to start the assessment process. Even with ABA services, I have been trying to get them for Stephen for the past three years. The smaller companies are merging with the bigger companies, forcing people on the wait list to have to restart the whole assessment and intake process.

As for school, Stephen is in the 11th grade and is in predominantly general education classes. He used to have someone help him out to do homework and classwork in previous years, but this year the person got promoted and someone new is in the position, which has been hard for Stephen.

Stephen has had a few outbursts and has been suspended from school a few times due to behaviors. But I think this has to do with the school and administration not following his IEP. Stephen is very sensitive to other students, especially male students that he does not consider a friend. Stephen was waiting to be picked up from school one day, and there was a group of boys who were calling Stephen's name in mocking way. Stephen told them to stop, and they didn't, and Stephen got upset. He said to them, "If you say my name again, I'm going to kill you." Because of this incident, Stephen got suspended for two days, and the school changed where we picked him up and dropped him off. Instead of being proactive and working with Stephen's father and myself on ways to support Stephen better, the school dismissed us and his needs and chose to ignore our request to find better ways to help him.

Another incident was where he stood up and yelled in his Algebra class. Algebra is Stephen's least favorite subject and is his last class of the day. The school wanted to give Stephen a two-day in-school suspension. Granted, I did agree that Stephen knows better and should not have done that. However, I told the team that we are not sending the right message to him by suspending him. The school reassured me that he will not be getting an in-school suspension, but he will be attending a different class to catch up on his classwork. I brought this up to the vice principal that we needed a manifestation meeting because it seemed like Stephen's IEP was not working. We just had an IEP meeting, and I expressed that it seemed that more supports were being taken away from Stephen with each IEP meeting. His team told me that it is because they don't feel like Stephen needs the support. However, after these IEP meetings, an incident will occur, proving he does need those supports that are being taken away.

The supports throughout Stephen's academic career have been variable. In elementary school, there was an intervention where Stephen participated in group therapy and could talk to

I think schools and their districts need to educate all teachers, not just special education teachers, on students and children who are neurodivergent.

a school psychologist if he needed to talk to her, but the psychologist did not pull individual students out to do therapy. Once Stephen entered the county school system, he did not have that anymore. Now, in high school, he is in this program called RISE, but they help with more academic supports rather than behavior support. I feel that Stephen could benefit from a contact person to help assist in reminders that are stated in his IEP, such as leaving class five minutes early to get to another class, as well as turning in homework assignments on time. I expressed this to the school and how I feel that this would be a simple solution to making his school days smoother and more successful. But because it didn't "look" like he needed these supports, they refused.

To recall resources in the school system that have helped my children with their behavioral needs, I really don't think there are many that have helped. For another example, my daughter, who also has autism, has suffered from hallucinations. When she had these hallucinations in school, the school would just call me to pick her up. I do think that at the county school board level, there are some amazing resources. However, they do not seem to trickle down to the individual schools themselves.

I think schools and their districts need to educate all teachers, not just special education teachers, on students and children who are neurodivergent. They need to teach them not to look at these children as a burden or a behavior problem but look at them like they are brilliant minds. Once these teachers are educated on all types of students, then they can assist these kids in forming friendships and better peer relationships. I advise educators, parents, and advocates that wherever you live or wherever your school is zoned, your state representatives are there as your voice. So, as you see things that you feel need to be changed, don't rely on your teachers' association or unions. Reach out to your state representative and let them know your personal experiences and that you want to see legislative change.

Alecia

My name is Alecia, and I am a mother of three from the Middle Tennessee area. My middle daughter is 18 years old. She is diagnosed with autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), post-traumatic stress disorder (PTSD), anxiety, and depression. Today, I am here to share my story. However, "story" isn't the right word here. The word "nightmare" is more indicative of my experience. Nightmare, exhaustion, defeat, a never-ending cycle of failure, those are all of the right words. This is my family's experience with behavior support in the Tennessee public schools. This is a story of grief.

People began to see that my daughter was smart- really smart. From a young age, she could communicate in ways that were beyond her years. But, instead of being praised for that, she was punished. While my daughter was and remains bright, she had behavior challenges in school that impeded her ability to learn. What was the school's solution? What did the experts recommend? They gave her things like a piece of paper to remind her to stay calm. They told her, "When you feel frustrated, reach into your pocket and pull this out to remind yourself to be calm." It was like they expected her to magically be able to control herself with a piece of paper. Needless to say, that didn't work. Her behaviors escalated and her classmates started to pick up on them. I remember one day, she came home from school and said, "Everybody thinks I'm a monster, but I'm just a kid." That "monster" was a third-grade little girl. But surely things would get better with time, right?

When she got frustrated, she would leave the classroom and run to the bathroom. They called it "eloping." There was one incident where a classmate was offering to help her with an assignment. My daughter politely refused the help, but the kid wouldn't relent. It was at this point that she stabbed him in the hand with a pencil. The kid had been trying to help her, but it was just another example of people at school being completely unaware of my daughter's needs and trying to force things on her that were unhelpful. Her classmates were scared of her-they didn't know what to do; the teachers weren't any better. They had labeled her as a 'bad kid,' and that was that.

I can also remember an incident with a teacher during her middle school years. In her IEP, there was a behavioral support added that allowed my daughter to carry a book around with her, even during the car rider line. Once, the teacher wouldn't allow her to do it. My daughter, being as smart as she is, knew what her IEP said and what that meant. When her teacher continued to refuse, she stuck her finger in the teacher's face and said, "I'm allowed to have this book, and you can't take it away from me." I guess her finger poked the teacher's cheek, and next thing we knew, the school resource officer was called in. We ended up in Juvenile Court. It felt like they were treating her like a criminal.

One day, she came home and told me that the staff in the room where she was meant to receive behavior support would come in and spray students with a water bottle when they weren't doing what she was supposed to do. Now, it's up to you, Tennessee policymakers. In order to allow our kids to flourish, we must have evidence-based, individualized behavior supports. We need trained personnel. We need expertise.

She said to me, "Mom, that's how we train the dog." She also reported being physically picked up and dragged when she refused to get off the floor. This would leave her with bruises. She still talks about how she was abused that day. It's heartbreaking. After that, I just said, "OK, we're done."

As a mother, I could no longer stomach my child being subjected to this kind of mistreatment. This was supposed to be school. She was supposed to learn. She was supposed to be safe. Instead, she is being treated like a criminal and a dog! I had reached my breaking point. We found a small private school that specialized in kids with unique learning needs. Every child was evaluated individually to figure out what kind of curriculum and teaching style worked best for them. That's where she really thrived. She graduated, something we never thought she would be able to do. Now, she is a freshman at Western Kentucky University studying creative writing and English with a minor in gender studies. She's a great self-advocate and doing so well. It feels like a miracle.

I share my story with you today to bring light on a pressing issue. I don't want any child to struggle in school like my child did. Now, it's up to you, Tennessee policymakers. In order to allow our kids to flourish, we must have evidence-based, individualized behavior supports. We need trained personnel. We need expertise. We don't need spray bottles and SRO officers. You wouldn't expect a child to read without their glasses. Why are you expecting my child to go without the support she needs to access her learning environment? The ball is in your court. What's it going to be? A nightmare or a fairytale?

Yolanda

My name is Yolanda, and for the past five years, my life has revolved around my granddaughter, Riley. When Riley was diagnosed with autism at the age of 3, it felt like the world had changed. My heart ached as I navigated the complex world of medical professionals, schools, and a system that often overlooked the needs of children like Riley, especially in a community where color mattered more than care.

Riley is now 5 years old and attending the Vanderbilt Autism School for Children. It's a place I fought hard for her to attend. I was determined that she would get the education she deserved, but being one of just three Black children in her program, I couldn't help but notice the stark difference in opportunities for children of color. But I knew I had to keep pushing, keep advocating. And thankfully, with the help of the wonderful therapists there, Riley has blossomed. She talks now, her voice bright and full of questions, just like any other child.

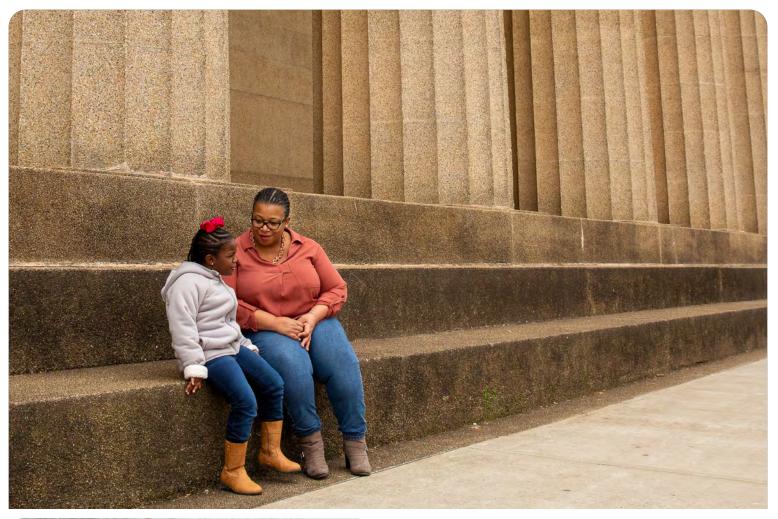
Yet, with every victory, new challenges arose. Riley was struggling to sleep alone at night. Fear had settled into her heart, particularly of the dark, and she often woke up screaming. My heart broke that day, knowing that her anxiety reflected the struggles she faced in school.

Riley often regressed in her behaviors after a long day. She would come home and strip off her pants, her way of saying she needed to be free. The moment she hit the trampoline in our backyard, I could see the tension ease from her body. Jumping was her way of regulating her emotions, and I was grateful for every bounce that brought her joy. But what happened at her previous school weighed heavily on my mind. There were incidents where teachers, despite their degrees, didn't know how to support her. The so-called "Be Well" room meant to help her was, in reality, isolating her even more. They thought they were helping, but how do you create a safe space for a child who can't articulate her needs? Riley was being treated like a behavioral problem rather than the sweet girl she is, and that broke my heart.

Sometimes I wondered if the teachers were even aware of how their actions impacted her. The thought of her being restrained or put in seclusion sent chills down my spine. I often worried that without my constant presence, she wouldn't be protected. This wasn't just Riley's story; it was mine too, and I would do anything to shield her from harm.

But through it all, I learned resilience. I took classes on how to advocate for her and learned about the intricacies of her Individualized Education Plan (IEP). I didn't want to just be a voice for Riley; I wanted to be a beacon for other families like ours. I realized that the world needed to know what children with autism experience in the school system—especially children of color who were often left behind.

At first, my friends and family didn't understand my efforts. The lack of training among school staff, the underfunding of resources, and the systemic issues that faced children like Riley fueled my determination. If I didn't fight for her, who would? I wanted more than anything for





Top: Yolanda sits with her granddaughter at the Parthenon in Nashville and asks her about what part of the park Riley would like to explore next? Left: Riley stops to smile for a portrait before heading over to see the ducks at Centennial Park.

her to have the same opportunities as any other child, to thrive, and to be understood.

As I look back at the struggles, I also see the light that Riley brings into my life. She has taught me patience and love in its purest form. Riley is my whole heart, and I will always fight for her. I want to leave a legacy of change, for Riley and all children like her. I want the system to see them, to understand their needs, and to provide the support they deserve.

Lindsey

My name is Lindsey, and I love being Gavin's mom. Being Gavin's mom means being a fierce advocate. It means refusing to give up and refusing to be silent, even when battling a system that doesn't seem to listen. I am a fighter.

Gavin has a rare genetic condition called 47 XYY and has been diagnosed with autism, ADHD, and asthma as well. These labels do not define him as a person. The challenges that he faces at school, the difficulty following routines and regulating emotions, the hitting -- they do not define my son in the world. When my son has the support that he needs, he is able to learn, grow, and thrive. He has benefited greatly from ABA therapy and finds joy in all sorts of places, including school.

Unfortunately, his challenges do define him at school. Sometimes, it feels like nobody there knows how to meet his needs. They've tried suspension, withholding recess, and directing him to take naps -- these are not solutions. They are punishments. His ABA therapist knows how to meet his needs. I tried explaining this to the school administrators, but they won't listen. I don't feel like I'm being heard. The last time I requested that his ABA therapist be allowed to come to school, I was looked straight in the face and told "Your medical professional opinions aren't worth the piece of paper that they're written on."

Of course, that didn't stop me from trying. I attended over a dozen IEP meetings when Gavin was in kindergarten last year and attended three IEP meetings within his first month of first grade. That's a lot of time and effort, but there was never any hesitation. I will always do what I can to help my son. I wish that his school administrators felt the same way: they didn't want to complete Gavin's IEP because it would be 60 pages long.

My child is worth so much more than 60 pages.

When I asked for him to repeat kindergarten, they said no because of his score on a survey called the Light's Retention Scale that his teacher filled out. He was disqualified by two items: having a disability (he will always have a disability) and emotional disturbance behaviors (he has these due to his disability). At that moment, it felt like my opinion as Gavin's primary caregiver wasn't worth the love, time, and hard work that it was built upon either.

Advocating for Gavin has impacted our entire family. His father and I have had to rearrange our lives to attend meetings, challenge policies, and make sure Gavin gets the care he needs. I left my career to take care of Gavin and advocate for him full-time, and my husband steps in for meetings that I can't attend, such as the mandated truancy court hearing that was triggered by the school marking Gavin absent when he was at medically necessary ABA therapy.

Even Gavin's siblings have been affected, especially his older sister, who goes to the same school. Last year, immediately after we hired a lawyer to ensure that Gavin's legal right to a free and appropriate public education is respected, she was accused of bullying another student. Weeks later, I got a call from the principal, who said they had reviewed the video footage and



Family portrait at The Commons in Collegedale, TN.



Lindsey and Gavin enjoy visiting the Collegedale Public Library to check out books and spend time together in the community.

found my daughter wasn't even near the other student during the incident.

Advocating is incredibly hard, not just because of the time and effort it takes, but because most parents don't even know where to start. I have a background in policies and compliance, which has equipped me with the tools needed to navigate these meetings and hold the school accountable. But many families don't have that knowledge. I've talked to parents who had no idea that they could challenge the school or request extra services. The system often takes advantage of that lack of awareness so they can direct their resources elsewhere. Why do we keep fighting? It's not just about helping Gavin survive at school. It's about preparing him for a future where he can thrive. If we don't address these behaviors now, they'll become much harder to manage and more socially inappropriate as he gets older. My ultimate goal is to help Gavin lead an independent, successful adult life. To do that, we need to recognize and solve these challenges early with proactive strategies and the right support.

I've had moments where I've questioned whether it's worth it, whether I should simply pull him out and find another way. But I remind myself of one simple truth: the minute you stop and pull your child out, nothing will ever change.

Jackie

I'm a mom who just recently moved from Pennsylvania to a five-acre farmstead in Tennessee with my daughter, Jayden. Jayden is 21 and has a Syngap 1 mutation, resulting in an intellectual disability and autism. Jayden and I have enjoyed our new home as we now have two dogs, six bunnies, and nearly forty chickens.

One of the characteristics of Syngap 1 is a significant decrease in Jayden's synaptic (brain) protein. Her brain is constantly trying to regulate itself. She gets overstimulated very easily, whether there's too many people in the room, if there's too much movement, if there's too much noise or sudden noise. This dysregulation usually manifests as challenging behaviors. So, the name of the game is keeping things level. You don't want to get her too excited because it will kick into cortical overactivity in the brain, but you don't want her so bored out of her mind that she gets agitated. With Syngap 1, a snowflake can become an avalanche very quickly.

If I could snap my fingers and make the necessary support for my daughter immediately appear at home, I would simply wish for more options for my daughter. I want her to go places and have different experiences. Though my daughter engages in forms of challenging behaviors, those behaviors are not a result of her core personality. She has no more control in those challenging moments than when she has a seizure.

I'm a 110-pound mom, I don't have a master's degree in applied behavior analysis, I'm not trained as a direct support professional (DSP).

Never, not a single time, have I ever received an injury that requires hospital treatment. Yet, the state wants to view my daughter's behaviors as unsolvable and extreme. Yes, I have been scratched, and she has destroyed property, but scratches will heal, and property can be replaced.

Unfortunately, it seems no amount of money from Employment and Community First CHOICES (ECF) can provide her with 1:1 support. What's even more frustrating is that the state seems to believe that it's impossible to staff DSP jobs. Even if the money was there, there are hardly any workers. My daughter is not unsolvable or a threat. At times, much like everyone else, she simply needs help communicating. At home, for example, if she points to a light switch, I know she wants the light off. It takes time and patience to learn her language. She just needs a professional who is willing to get to know her.

It's unacceptable to me that our disability system in Tennessee does not recognize behavior conditions in the same light as physical conditions. The state rightfully wouldn't deny someone with cerebral palsy a wheelchair. Without a wheelchair, that person wouldn't have access to meaningful daily activities. But my daughter also requires support for her to access the same meaningful daily activities. It would be discriminatory if the state didn't provide that wheelchair, otherwise those individuals would be excluded from their communities. The same is also true for my daughter, except there is no support for her. It's disheartening to me that for



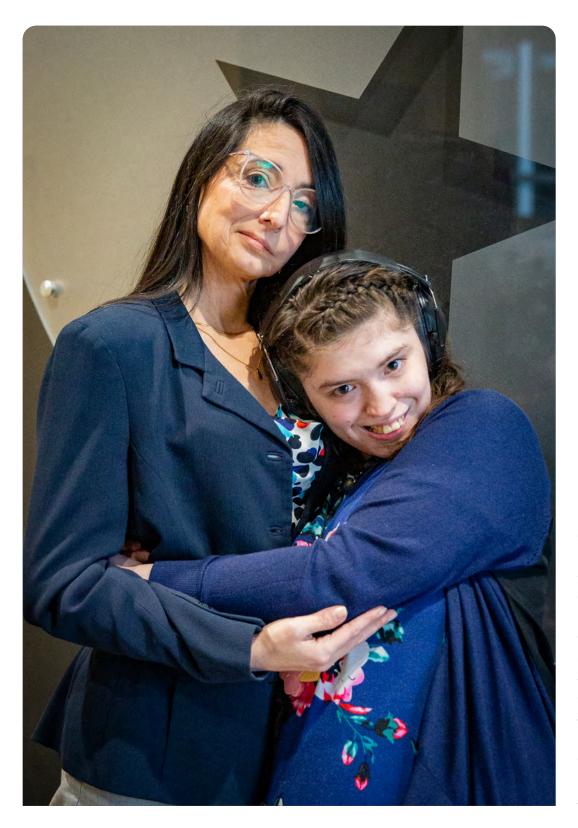
her, and others like her, that we don't see how this is exclusionary and a form of discrimination.

I get called by the school often to come pick up my daughter, which they never call a suspension, but we all know that it is. As annoyed as I am by the call since it is not OK, I want them to call me when they feel that overwhelmed, so that it does not end up in some sort of police interaction or a situation which leaves her harmed in any way. But, when I pick her up and ask what happened, they always begin to tell me what she did and I say, "I didn't ask you what she did, I asked what happened". But they just keep telling me what she did, so I reply, "Look, let's play a game. How about you tell me what went on during the day without using her name and without saying anything about her, and I will guess what she did."

I know she has challenging behaviors, that's why she has a behavior intervention plan (BIP).

It's not that anyone necessarily did anything wrong, it could have been something as simple as somebody accidentally brushing up against her and that itself could trigger her. As her mom, I know these triggers and the nuances of her care, and I don't expect everybody else to have that automatically downloaded, but I can't help people at school modify and prevent this occurring again in the future if they don't tell me what happened before she engaged in challenging behavior.

To the parents with children in school who are going through this journey for the first time and also the professionals supporting those families, I recommend being as collaborative with each other as much as possible. Please keep in mind that there is no reason for defensiveness. There isn't a reason for one group to become set against another, for there to be contention. Both groups are underresourced, under-supported, and stressed. It's



Top Left: Jackie (left) shares the challenges of not having caregiving support for Jayden (right) at a recent SPPC (TN Dept of Disability and Aging Statewide Policy and Planning Council meeting) meeting, where Jackie is a member. Right: Jackie has long been without a caregiver for daughter and as a result, Jayden needs to go where her mom goes at all times.

OK to be flexible and to choose your battles. At times, it makes sense to just pick up your child at the request of the school. Being graceful and forgiving is as important as frequently advocating for others to maintain higher expectations of your child.

Tennessee Educator #1

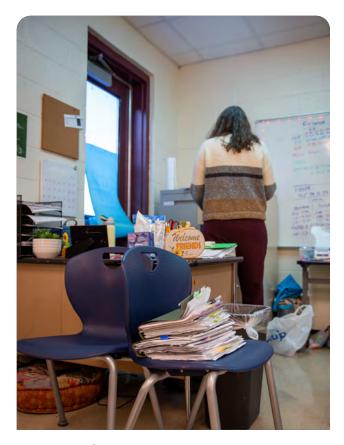
I am a special education teacher that has worked in both rural and urban parts of Tennessee. Throughout my work and personal life, I have had the incredible opportunity to work with a whole host of kids with low incidence disabilities (disabilities that occur in low numbers, or are less common, within the general population) and significant support needs. I genuinely love my job, but that does not mean it comes without its unique difficulties. One such challenge is attempting to teach, support, and advocate for students with challenging behaviors in an educational landscape that is under-resourced and underserved.

At the outset of my teaching career, I worked as a special education teacher in a rural school in Tennessee. I felt more than equipped to handle my first year of teaching after earning both my bachelor's and master's degrees in special education, completing hundreds of hours of classroom practicum experience, and volunteering in my personal life with special needs individuals. However, I soon realized



Educator 1 updates the student artwork on the bulletin board outside of her classroom.

after starting my position that no matter how prepared I felt to teach and manage some behavior, I was not prepared for doing those things while being extremely understaffed and having almost no behavior specialist or BCBA (board-certified behavior analyst) support. I taught a small classroom of only seven kids, one of whom had acutely challenging behaviors, with minimal paraprofessional support. The behavior that this student displayed was unfortunately so harmful towards others that I was frequently having to clear the room of other students, giving the student half of the classroom space so they could be alone, and working diligently to ensure the classroom was as safe an environment as possible for my other students and myself. This took up most of my time and I often felt like I had the training to know what to



Educator 1 files papers in her special education classroom after the school day.

do, but I lacked the staff to help implement it.

Consequentially, due to the lack of staff and support from the district, I quickly burned myself out and felt that the other students in the class were not receiving the best possible education I could provide. I soon left that job and moved on to another school where I felt I could better serve my students in safer environments. There are, of course, barriers for teachers and parents trying to access better resources for children with significant behavioral support needs in urban schools, but rural schools often face the greatest number of barriers. Many time the families I worked with were unaware of how to navigate the IEP process to best advocate for their child's behavior needs, my district maintained that there were not enough funds to hire 1-1 paraprofessional support staff for my classroom, and there simply were not enough qualified professionals willing to work in a rural area. People forget that kids with severe disabilities and significant behavioral support needs exist everywhere, not just in cities!

Teachers need support in order to do the best job we possibly can when educating our children. Working with students who have high behavioral support needs takes a lot of time, experience, and training. It can be draining at times and without adequate support, even traumatic. Many of us care deeply about working with this population and want to make sure these kids also receive the high-quality, appropriate public education they are legally entitled to. However, for us to make that a reality for more kids in Tennessee, districts need to have a better understanding of exactly what challenges teachers are facing in the classroom, focus on broadening training and education about behavior in schools, and hire more staff.

Tennessee Educator #2



Educator 2 walks down an alley in East Tennessee that once was a place that people considered scary, but now covered in street art and draws crowds of tourists. She shares, "This happened because a community saw potential, and came together to create something beautiful, piece by piece along the path. This feels like the perfect metaphor for the work that teachers do in supporting our most vulnerable students. Teachers hold the transformative power to look past students' deficits, and see the beauty of who they could be, if given consistent, meaningful support and quality education."

My career in education spans 10 years, including eight years as a special education teacher and two years in general education before transitioning to higher education. Throughout my time in public schools, I worked with students who had diverse support needs, experiencing firsthand both the rewards and challenges of education.

Students come to school facing profound challenges that impact their learning and behavior, limiting social and academic progress. Teachers are expected to address socialemotional, behavioral, and academic deficits for the students coming to their classroom. In order for educators to meet the persistent needs of their students, they need support. Schools need funding to hire more teachers and support staff, as well as provide high-quality, research-based training to ensure that educators have access to the skills and knowledge needed to navigate the complexity of the modern classroom.

While my teacher training covered behavior management and the importance of building relationships, the realities of managing a classroom proved far more complex. It takes time, experience, and ongoing training to cultivate a meaningful understanding of behavior as a form of communication. The negative circumstances that many students face outside of school, as well as their prior experiences within school directly impact behavior in the classroom.

In order to ensure that students can be successful in school, educators must provide resources and support for issues happening both inside and outside of the classroom. Educators, particularly those working with students who have complex behavioral support needs, should have consistent opportunities to engage in professional development and training to expand their capacity to the meet the unique and urgent needs of their students. Substantive training should include intervention and de-escalation techniques, data collection, and relevant research related to neuroscience, education, psychology, etc. Without proper training and adequate support staff (school counselors, social workers, instructional assistants, etc.), both students and teachers face unnecessary risks. Teachers may face injury during behavioral escalations, while students risk both physical harm and punitive

consequences.

As a special education teacher, I often worked with students who had complex support needs being served under the emotional behavioral disorder (EBD) category. These students are among those most at risk for poor long-term outcomes, often struggling to finish high school, maintain employment, build and maintain successful relationships, etc. Many of the students I taught had experienced significant trauma in their past and/or had mental health conditions that critically impacted their ability to learn and participate in the school community. I saw educators put forth tremendous effort to support many of these students. Despite our best efforts, too often we lacked the resources (human and financial) and sheer capacity to make a significant impact on the outcomes of these students.

It was during this time that I began to grasp the broader limitations of educational, juvenile justice, and mental health systems to meet the needs of our most vulnerable children. These systems tend to see students with behavior issues as a problem to be solved or managed, rather than young person who is need of support and direction. The people working within these systems are often given limited options and asked to make difficult choices that will have an ongoing impact on the lives of the children with whom they work. Affordable mental health care, access to basic resources, and increased funding for early intervention, public schools, and after-school care programs could work to mitigate the risk of poor outcomes for many of these children.

While working in public schools, I saw countless instances of escalated student behavior. I have witnessed students in circumstances that resulted in their detention by police. I have also supported students through situations that resulted in their placement in a mental health facility. In most instances, protocols were followed, but there were times that I saw things take place that did not align with policy and ethical expectations. Ensuring that students' rights are not violated at school should be a top priority. Achieving this objective will require resources for training and expanded staffing, as well as a persistent push to shift the culture of discipline within public schools from a punitive stance to one that has a greater emphasis on research-based, trauma-informed practices with relevant, reinforcing consequences.

Too often lost in these conversations about discipline rubrics and equity, are the real, lived experiences of students. Behavior and discipline data from across the state are a clear indication that students need more support and resources. Proactive measures to meet student needs would likely mitigate many of the challenging behaviors that are currently so pervasive while improving student outcomes.

The growing shortage of special education teachers is an indication that educators also need more support and resources. The scarcity of professionals willing to work in this field is directly linked to salary and workload. Most teachers work long hours, taking on far more responsibilities than are outlined in their job description: sponsoring a club, helping with a fundraiser, offering tutoring, taking time to listen to parents and students share concerns not related to school, etc.

Teaching is a profession that demands a tremendous amount of intellectual and emotional labor. Special education teachers have the added responsibility of ensuring that federal laws and procedures are followed. It seems unreasonable to ask young adults to choose an incredibly difficult career in which their efforts will be astoundingly undervalued by society in exchange for a meager salary and limited professional mobility. The vast needs of students demand bright and engaged teachers. Recruiting these professionals will require a shift in how we pay and retain teachers.

I am deeply honored to have worked as an educator in Tennessee, and to have had the opportunity to be part of my students' lives. I am certain that the impact they had on me far exceeds the impact that I had on them. They taught me so much about resilience, regulation, and empathy. Supporting students, especially those with emotional behavioral disorder, also elucidated opportunities to improve the educational system and proactively address students' needs.

Public schools need increased funding to hire and adequately pay social workers, school counselors, special education teachers, and support staff. More funding for schools would also mean that educators could access training and resources needed to better understand and respond to unexpected student behavior, ultimately reducing the chances that students would be subjected to disciplinary measures. Persistent underfunding and resource scarcity contribute to inadequate behavior supports and negative long-term outcomes. These outcomes ultimately impact the lives of individual students, as well as their families and communities.

Resources

Tennessee Disability Pathfinder helps people with disabilities, family members, educators, and other professionals find and access resources, support, and services through a telephone helpline and an online resource directory. Search "mental health." <u>TNPathfinder.org</u>, 800-640-4636

The **Tennessee Disability Coalition** published the 2024 Special Education White Paper, which examines the state of special education in the state of Tennessee, focusing on issues related to the ability of the state's public schools to support students with disabilities that present behavior needs. tndisability.org/2024-special-education-white-paper

The Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (VKC TRIAD) can serve schools, and/or districts to foster meaningful educational engagement, increase safety, ensure maximal access to the least restrictive environment for students, and build skills for independence. Student outcomes are addressed through individualized and multidisciplinary training, coaching, and consultation that is designed to address student-, classroom-, school-, or school system-level needs. <u>tn-tan.tnedu.gov/support-services/intensive-behavior</u>. VKC TRIAD also offers printable resources on topics such as accommodations and modifications, discipline and FAPE, behavior intervention plans and functional behavior assessments, and more. Access here: <u>triad.vumc.org/ebp-resources</u>.

About Us

The **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities** provides innovative leadership in education, research, and services to people with disabilities, the community, and families. All activities promote the independence, self-determination, productivity, integration, and belonging of individuals with developmental disabilities and provide supports for families. vkc.vumc.org/ucedd, (615) 322-8240 or toll free (866) 936-8852.

The Arc Tennessee empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime. The Arc Tennessee's goal is to provide information and resources during the journey of raising a child with a disability to lead a full, independent, and meaningful life. <u>thearctn.org</u>, (615) 248-5878.

The mission of the **Tennessee Arts Commission** is to cultivate the arts for the benefit of all Tennesseans and their communities. The vision is a Tennessee where the arts inspire, connect and enhance everyday lives. The Tennessee Arts Commission was created in 1967. <u>tnartscommission.org</u>

About the Photographer

Jen Vogus is a photographer, educator, and parent advocate. She is also the founder of AbleVoices (<u>ablevoices.org</u>), a nonprofit organization that teaches photography to individuals with disabilities as a means for self-expression, empowerment, and advocacy. Jen is a graduate of the Tennessee Council on Developmental Disabilities' Partners in Policymaking Leadership Institute and a past board member of The Arc Tennessee. Vogus was assisted during the photo shoots by AbleVoices Photo Academy photographers Nicholas Coakley and Sami Zinni.



To view online collections of Kindred Stories, visit vkc.vumc.org/kindred