TENNESSEE KINDRED STORIES OF DISABILITY

2024

Mental Health and Youth with Disabilities

AbleVoices

VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

The Arc™
Tennessee

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Letter of Thanks

Thank you for reading this collection of stories that highlight the experiences of youth with intellectual and developmental disabilities who have co-occurring mental health concerns.

The stories were collected through interviews with parents and conducted by Vanderbilt University (VU) students as part of the 2023-24 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.

We would like to thank the parents who shared their stories this year. We are appreciative that they wanted to share and educate legislators about what could be helpful from a policy perspective. While this booklet does not include every story we heard, all were equally compelling and shared similar themes about mental health experiences.

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.

An additional heartfelt thanks to VU graduate students Carly Knauss and Leah Sulmonetti, who coordinated and contributed many hours to the project this year. And thank you to all the students, who conducted the interviews that contributed to the content of this booklet.

Finally, we are grateful to each member of the Vanderbilt Kennedy Center Public Policy Team and The Arc Tennessee. From selecting impactful interview topics to disseminating booklets during legislative visits and events, we could not do this work without our amazing policy collaborators.

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

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Introduction

Across the country, profound struggles accessing mental health services for children with disabilities exist. From state to state, a lack of treatment options, difficulty understanding patients' diverse communication modalities, and a small number of professionals willing to treat clients with disabilities continue to pose as barriers. Despite this, children with disabilities need access to mental health services.

By reading the stories in this booklet, you will hear from parents in Tennessee who have sons and daughters with co-occurring disabilities and mental health concerns, and who first-handedly combat difficulties locating affordable, quality healthcare. Some of the stories highlight inadequate and scare service provisions, financial burden, social exclusion, and dismissive attitudes from school and healthcare personnel. Some parents share that their child had to be removed from their home, just to access the services they need. Finally, professionals share how their colleagues hold stigmas about their therapeutic approach and need more group-based continuity in care.

The parents we interviewed want what is best for their child, and they crave for professionals to do the same. To all of the parents, we encourage you to lead with the wise words of one of our parents, which is to keep breathing and find your voice. Your child needs you, and no one fights quite as fiercely as a parent.

To the legislators and policymakers, one of our interviewees shared that she couldn't imagine a world where enough people care about individuals with disabilities. We challenge you to imagine that world. What does it look like? How does your legislation impact it? After all, it takes a village. These youth and families need your support.

We encourage you to share a glimpse into the lives of these individuals. They offer the world many gifts, but they need access to services to ensure that they can share them with us all.

This booklet aims to educate readers about the challenges and experiences of Tennesseans in hopes to bring more awareness and understanding to the impact mental health concerns have on individuals with disabilities.

Devan

My name is Devan Gann, and I am a single mom to my son Ty. Ty is a kind, playful, creative, and smart boy. He is 8 years old and is diagnosed with autism (ASD), attention deficit hyperactivity disorder (ADHD), and disruptive mood dysregulation disorder (DMDD). He sees five therapists over nine sessions weekly and recently got out of a hospitalization. I homeschool him because, with his treatment schedule, a school cannot accommodate his needs.

His education has been a big struggle for our family. It felt like schools and teachers wouldn't work with me. They would tell me about Ty's behavioral issues, but when I finally got an IEP meeting, the teacher claimed there were no behavioral issues. This was frustrating, because I was getting daily reports of challenging behavior, even videos that I did not consent to have taken... I felt so alone.

I was having difficulties with healthcare providers, too. I would go to providers seeking help and instead leave with the blame… that my parenting was causing Ty's issues. I'd keep getting referred without being able to get any actual help. It felt like providers were just referring me so they wouldn't have to help. Navigating the system feels like screaming into the void. When providers hear you, it's a sense of shock.

Ty's disability affects every part of our lives. I am afraid of him having a meltdown in a public place and the response it would cause. I feel lonely. He feels lonely. He can present as violent or aggressive because of DMDD, and I'm afraid that, as a Black child, this perception of him as a "bad boy" will change to "dangerous." I tried to manage Ty's behaviors on my own, but he got too big and wouldn't calm down. I had to call a crisis line and tell them my son thinks about harming others, only for them to tell me to "hide the knives." It's like calling the fire department while in a burning building and they tell you to turn on the water. We needed saving, we needed help. Instead, we were essentially told to make our situation work.

I am struggling to find the support my son needs. Tennessee is ranked as the worst state for family caregivers, and it is a fight to even find the appropriate services. When I've communicated concerns or asked for help, providers regurgitated encouraging yet invalidating comments that do nothing to help. Parents are told they're doing a great job, asked if they've tried another new strategy, and are pressed to build a support system. This simply adds to the list of tasks and internalized guilt many parents deal with while offering no tangible support from the organizations that exist to help them. When I have time that does not revolve around caring for my son, I'm learning everything I can to try and support his growth. That's what I have to do to give my son a "normal" life. My son has a lifelong disability, but I must jump through hoops to prove it, ultimately to be told there's little to nothing that can be done to support him. Children like him deserve better and are capable of great things but can't in the current systems. ■

Amber

My son Kevin and his twin sister experienced a very traumatic beginning, first *in utero* and then out. Unable to be raised by their first parents, their exceptional needs were noticeable but unpredictable at birth, making them hard to place and moving them through eight different homes and families before being adopted by us at 12 months old.

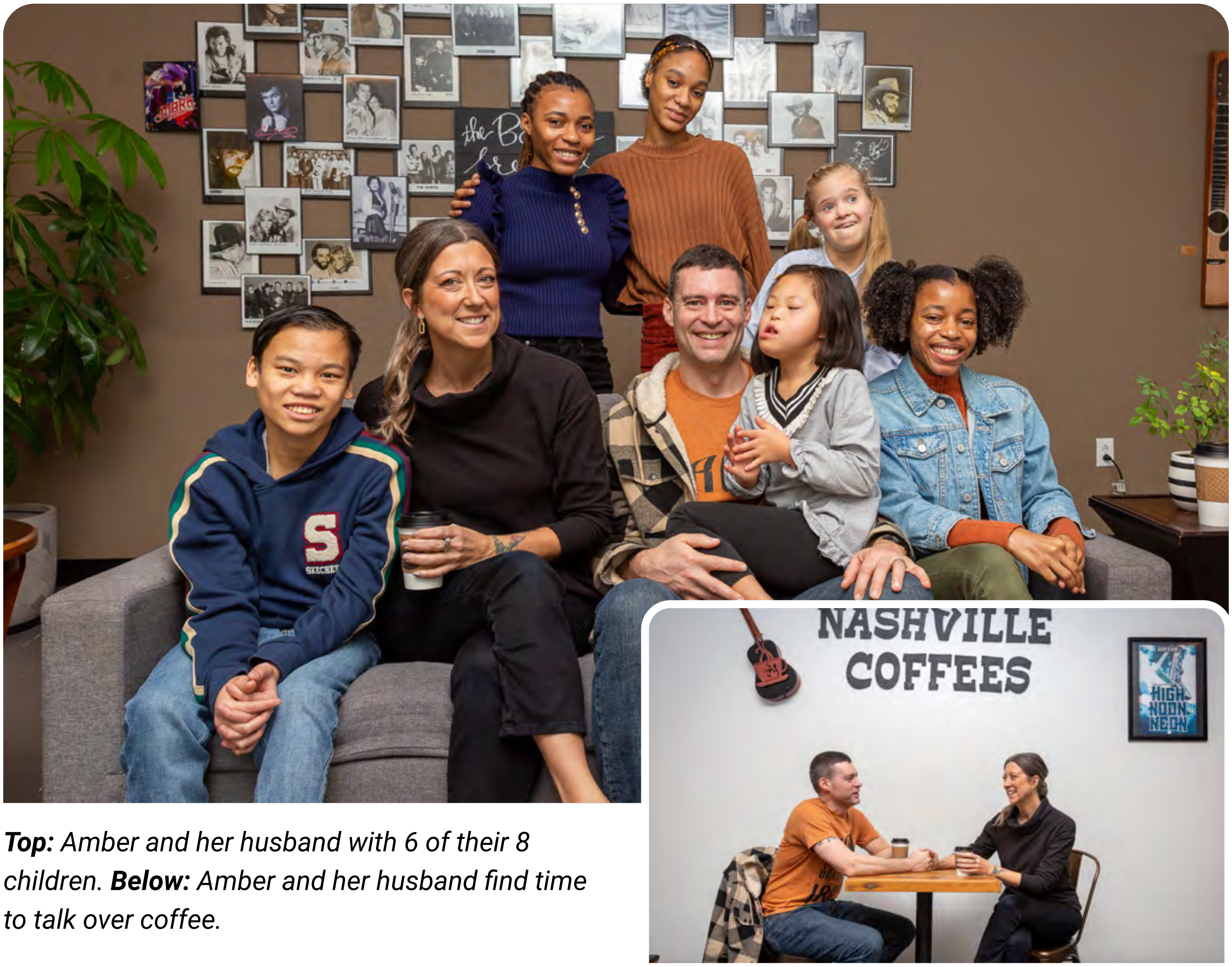
> ***Children and families shouldn't have to be separated to get the services they need.***

By age 3, Kevin was formally diagnosed with autism spectrum disorder (ASD), along with lingering effects of prenatal exposure. The frequent disruption and unimaginable traumas endured in his early life caused Kevin's brain to constantly rewire itself for survival. Despite his many strengths, Kevin struggles with processing difficult emotions and insufficient trust in the world around him. When Kevin even perceives something as potentially threatening – which can include unexpected changes, lack of control, or unmet expectations – he communicates in loud ways, including volatile physical aggression. Kevin doesn't go "from zero to 60" because he lives at 40, just in case he needs to protect himself from further trauma. Despite 15 years of a loving home, he says he "has to keep his head on a swivel." For Kevin, nurturing is the enemy and cannot be trusted. He's lost it too many times over. Now age 16, his diagnoses also include severe Reactive Attachment Disorder (RAD) and Disruptive Mood Dysregulation Disorder (DMDD).

Our home consists of my husband, myself, and our eight children – all of whom have moderate to high support needs. We are multicultural, multiracial, international, and large! We're different from most families in a lot of ways, but one of those is ample amounts of support and love that won't fail. No matter what.

Kevin has had 27 emergency room visits for psychiatric evaluations, 14 acute psychiatric stays, five long-term residential stays varying in length from six months to 10, and four different charges for domestic assault. We have utilized 11 different types of therapies, 10 different school settings, and every medication on the market. We have tried naturopaths, a biocellular practitioner, dietary changes, sensory diets, intercession, mentorship programs, athletics, and even taking turns "living" in a hotel with him on numerous occasions in order to make his world smaller and more predictable, but also keep our other children safe.

Advocating for my son has been my full-time job. Despite our best efforts, we not only failed to see any sustainable difference, but we were also often failed by the systems in place that were supposed to help. So many times we screamed into a void and were mocked, dismissed, or even blamed by doctors or therapists for his extreme behaviors, despite seven other healthy, happy children at home.



Top: *Amber and her husband with 6 of their 8 children.* ***Below:*** *Amber and her husband find time to talk over coffee.*

Kevin recently entered the state's custody on a voluntary placement. We would do absolutely anything for him, except sacrifice nine other people. This is not at all what we wanted, and the process has been nothing short of devastating, but our remaining options were extremely limited due to his age, size, and the acuity of his aggression. Even with both private insurance and TennCare, there were many disqualifiers to accessible services. Most of the "good" practitioners don't accept insurance at all. It often seems you must be a millionaire to receive quality care. It has been a maddening experience. Children and families shouldn't have to be separated to get the services they need.

Kevin's history and medical records aren't who he is. They aren't who he was created to be. He is a beautiful child whose intense needs for peace and stability have only increased through incessant changes and lack of whole-child care by systems that check a box and treat only what's seen on the surface, perpetuating the cycle and causing more harm – both to child and family.

We are so grateful to have a personal community that empowers and supports, helping us find our voice and amplify Kevin's on what is otherwise an extremely isolating road. It truly takes a village to raise any child, but for children like Kevin, it takes access, opportunities, awareness, education, and policy change. We are the village. ■

Pat

My name is Pat. I immigrated from Europe to Tennessee in 2003. I work full-time in a hybrid office environment and am a single parent. In 2004, my son Max was born; he is now 19. He has autism and other medical diagnoses. He is currently in a transition school program. Max is musically gifted, as he loves music and enjoys singing. He is very happy and adores going to new places. Max has taught me to parent better and be a better human in general. I learned more patience because I see what it is like for him to live in this world not designed for his neurological differences.

Max's main struggles are mood dysregulation, challenging behavior, being active, and staying engaged. I have good ways to engage and get him active, but it is hard when caregivers do not initiate the same. If he sits and gets bored, behaviors occur, and he gets negative attention.

His disability has impacted our family in many ways. I am a single parent and sole provider who works full-time. I do not have an extended family or support of that nature, so everything falls on me. He cannot be left alone. Initially, when his father and I divorced, we planned on caring for Max 50/50, but it ended up being every other weekend with Dad's arrangement. Sometimes, all the planning, effort, and arrangements to make it all work feel like a house of cards – one thing moves, and everything falls apart. It can be pretty difficult. Sometimes, caregivers must take time off, and that leaves me without help, feeling like a rug being pulled from underneath me at times.

Employment and Community First Choices resources are helpful, but they only provide 50 hours of support per month, which is insufficient. I feel judged by others; they say, "You make good money, you should be able to do this or that, you must be terrible at managing your finances," but nobody knows I have paid almost $50,000 in caregiving in the past year and a half. People assume we won't be able to make it to events or that my son will be stressed out and ruin the party, so we get excluded a lot, and people have stopped inviting us places.

Around the age of 7, Max started to display different mental health symptoms. It comes in waves. He experiences depression, outbursts, rage episodes, and disordered eating. He sometimes can be overly rigid and displays obsessive-compulsive disorder traits. Sometimes, it's hard to say what is mental health, what is autism, and what is typical teenage behavior.

Due to Max's behavior issues, he has been excluded from some of his school experiences. The school did not handle it well last year. Sometimes, I feel the school chooses the path of least resistance. Last year, his school day was shortened significantly at the emergency IEP meeting without much notice. I knew his behavior escalated, but that came as a shock because his school day, instead of ending at 3 p.m., would end at 10:30 a.m., and no resources were offered to fill the gap. Thankfully, the team worked very hard, and his behaviors have improved, as well as some of his health issues

Usually, the more difficult the situation is (i.e., behavior/health issues are worse), the less support you get. It should be the opposite.

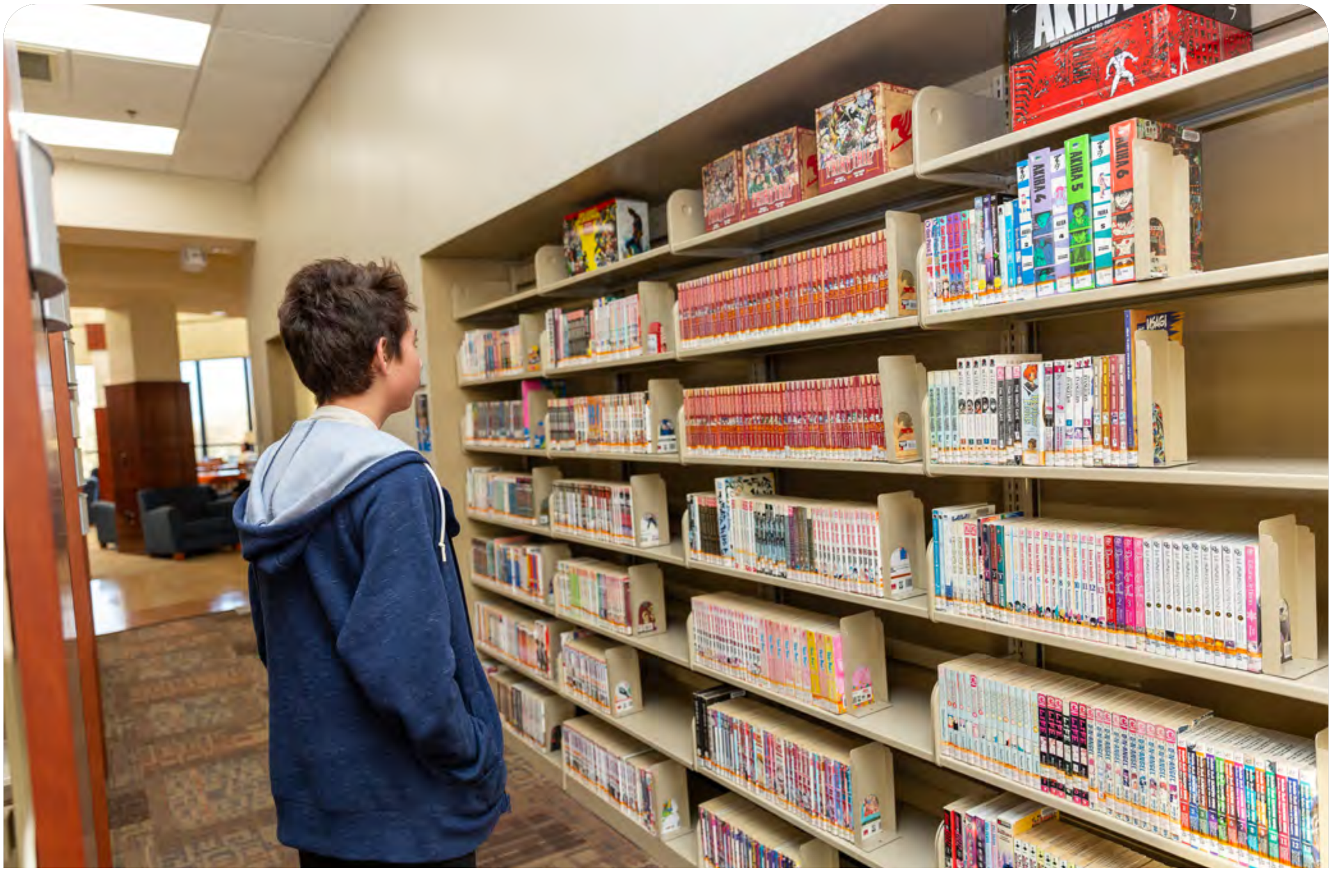
that contributed to his behavior, and he has been having a much better time this year!

The main thing that worries me is Max's persistent level of anxiety that prevents him from experiencing things. I gently and frequently push him out of his comfort zone. We are also somewhat isolated from the community. When Max was little, he had some friends, but as he grew older, they faded out. I have tried to meet up with other families with teens on the spectrum, but it did not work out. Sometimes, I feel like I am not doing enough for him because I should have done this or that. I wish he would socialize more; I feel like it would help with his anxiety.

I wish that policymakers knew the needs of children with disabilities and how behind the state of Tennessee is in meeting them. There needs to be more options for children when they reach adulthood. I looked into a career training program for adults with autism, but it costs $500 per week. Who can afford that? School resources are also lacking. School personnel need proper interventions, more training, and more accountability.

If you are a parent seeking services for your child, start early. Systems have been both an ally and a barrier, depending on the situation. Usually, the more difficult the situation is (i.e., behavior/health issues are worse), the less support you get. It should be the opposite. ■

Ramona



Jude views the anime video collection at the library.

My name is Ramona, and we have a creative, sensitive 13-year-old son with attention-deficit hyperactivity disorder (ADHD), disruptive mood dysregulation disorder (DMDD), and dyspraxia. He has executive functioning problems, sensory processing issues, and a delayed frontal lobe. When he was 8 years old, he was diagnosed with generalized anxiety disorder, and at age 11, he was diagnosed with post-traumatic stress disorder (PTSD). I started noticing concerns from a young age. He has chronic sleep problems, sensory processing issues, and problems with impulse control.

Receiving diagnoses and treatment for Jude was extremely difficult. It was like going down a rabbit hole. The practitioner who diagnosed my son with DMDD had a complete lack of understanding of the disorder itself. She was able to diagnose him but couldn't treat him.

The problem is, no one wants to work with our kids. There appears to be no referral process, and even when you do find a provider, you're paying out-of-pocket and you more than likely know more about the disability than they do. So you try to get what you can get, and you claw for it. We once waited on a waitlist for three years to see an autism specialist before giving up. I wasn't able to find the kind of disability- or mental health-related resources I needed for my son. So, I turned to social media.

I've been lucky that I stumbled upon certain people, not even in the state of Tennessee, who helped me find information about one of his diagnoses. I met them completely by accident. Like a set of dominoes on social media, they started a chain reaction. They told me what they know, and then they put me in touch with another group. I went from there, but that took a lot of digging. And that's taken years. But locally, I have found no resources to help with his treatment. Absolutely none.

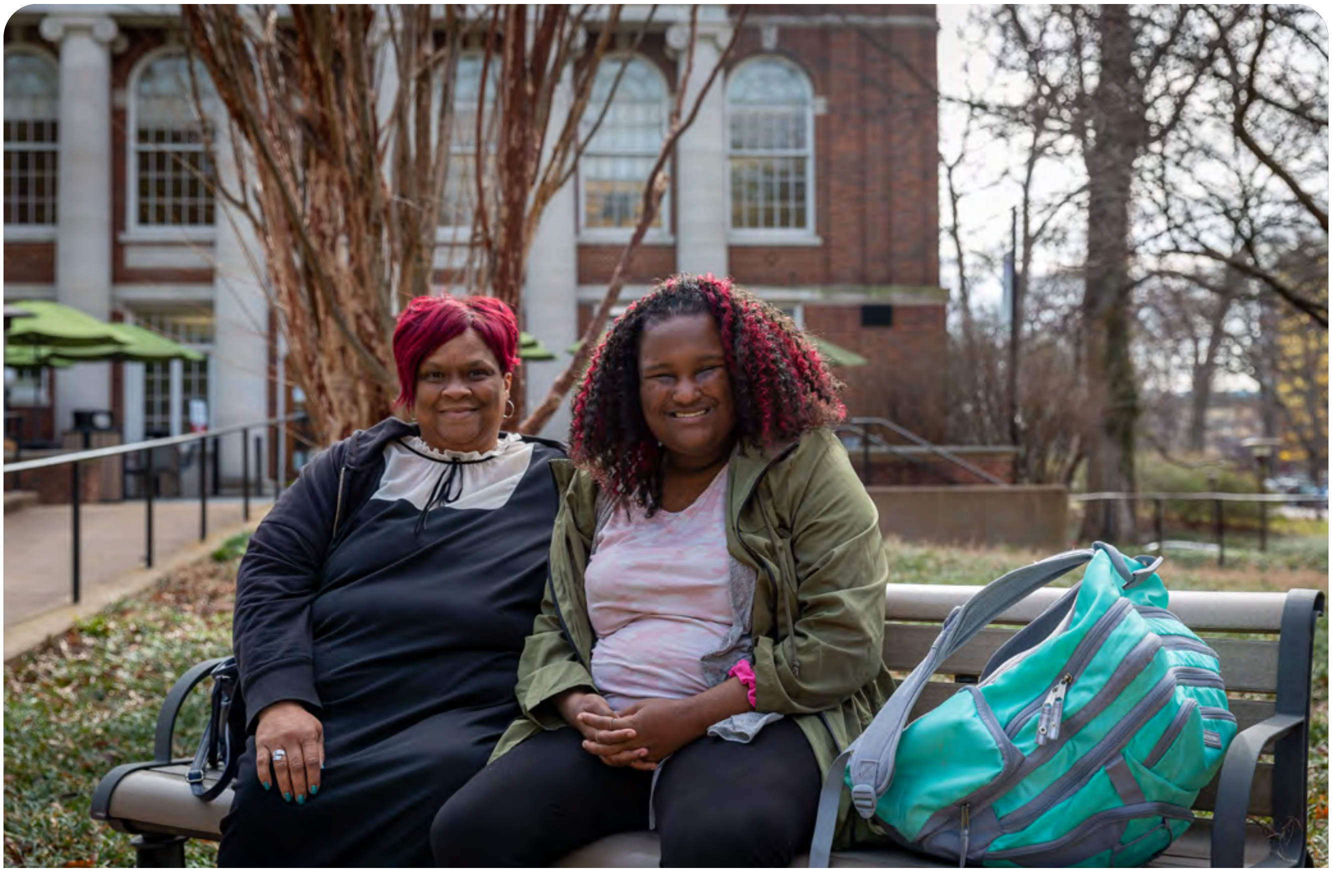
Jude has faced major trauma and discrimination in school due to his disability and mental health issues. Ever since second grade Jude has had trouble in school. Teachers and principals that never seemed to be able to help him or know anything about his disability and mental health diagnoses. I had to tell them what DMDD stood for. They didn't know. He has been restrained, isolated, and pinned to the ground by people who didn't understand him and his disability.

On the day before sixth grade, we already had his clothes laid out for school when I got a call that said he wasn't allowed to come to school the next day. My 11-year-old son was heartbroken. Ever since then, he has been attending private or virtual school. It feels as if there has been a complete abandonment of kids like mine. By the community, by schools, by educators, and by service providers. He's not choosing to have a disability. He's not choosing to have difficult behaviors.

My husband and I work full-time and homeschool our child. We are currently in our second due process case against the school district. We have depleted our life savings to get our son back in school. Everything falls on the parents, and we are exhausted. We feel like we are on an island. And we are just one family of many. One story of so many people who have been left behind because their child is "too difficult" or can't be helped. I hope that someday the needle moves just a little bit. And I'm not going to quit fighting. I'm going to keep trying. ■

It feels as if there has been a complete abandonment of kids like mine.

Tonya



Jasmyn talks with her mom, Tonya, on a bench on campus between classes.

My name is Tonya, and I am a single mother of three kids. My youngest child, Jacob, is a 14-year-old with autism. My middle child, Jeffrey, is 20 years old. Lastly, my oldest, Jasmyn, is 23 years old. She has autism, an intellectual disability, and is hard of hearing. All three of my children have grown up in Tennessee.

My daughter Jasmyn is currently enrolled in the Next Steps program at Vanderbilt University. As her first semester is wrapping up, she has made new friends, found her groove at an institution of higher education, and is getting comfortable in her new routine. Jasmyn thrives working with other people. She loves introducing herself to new people and asking them questions to get to know them better. When I reflect on her life thus far, I am reminded of her resiliency. From being born at only 24 weeks old to taking a leap of faith to attend college, there has always been a fire in her eyes. Every challenge she faces, she comes out on the other side more determined to stay.

Along with her diagnosis of autism, intellectual disability, and being hard of hearing, Jasmyn also has anxiety, obsessive-compulsive disorder, and poor impulse control. The implications of her diagnosis have their fair share of challenges for our family. Her brothers, while supportive and loving, still need a safe place for themselves. It is important to me that I am still able to support her brothers and allow them to take care of their mental health as well.

We are heavily reliant on routines, visual supports, and repetition. Our schedule oftentimes revolves around various therapy appointments or other considerations due to Jasmyn's multiple diagnoses. When her anxiety escalates, it can be very hard for her and our family. She will have meltdowns where she becomes verbally and physically upset. During these times, she mostly just wants to know she is understood and still loved, but these moments can often be misinterpreted by others who do not know her as well. She has worked hard to better understand and process her emotions. I must add that we don't do this journey alone. None of this without the consistent, unwavering support of our "village" – they have stood in the gap through thick and thin.

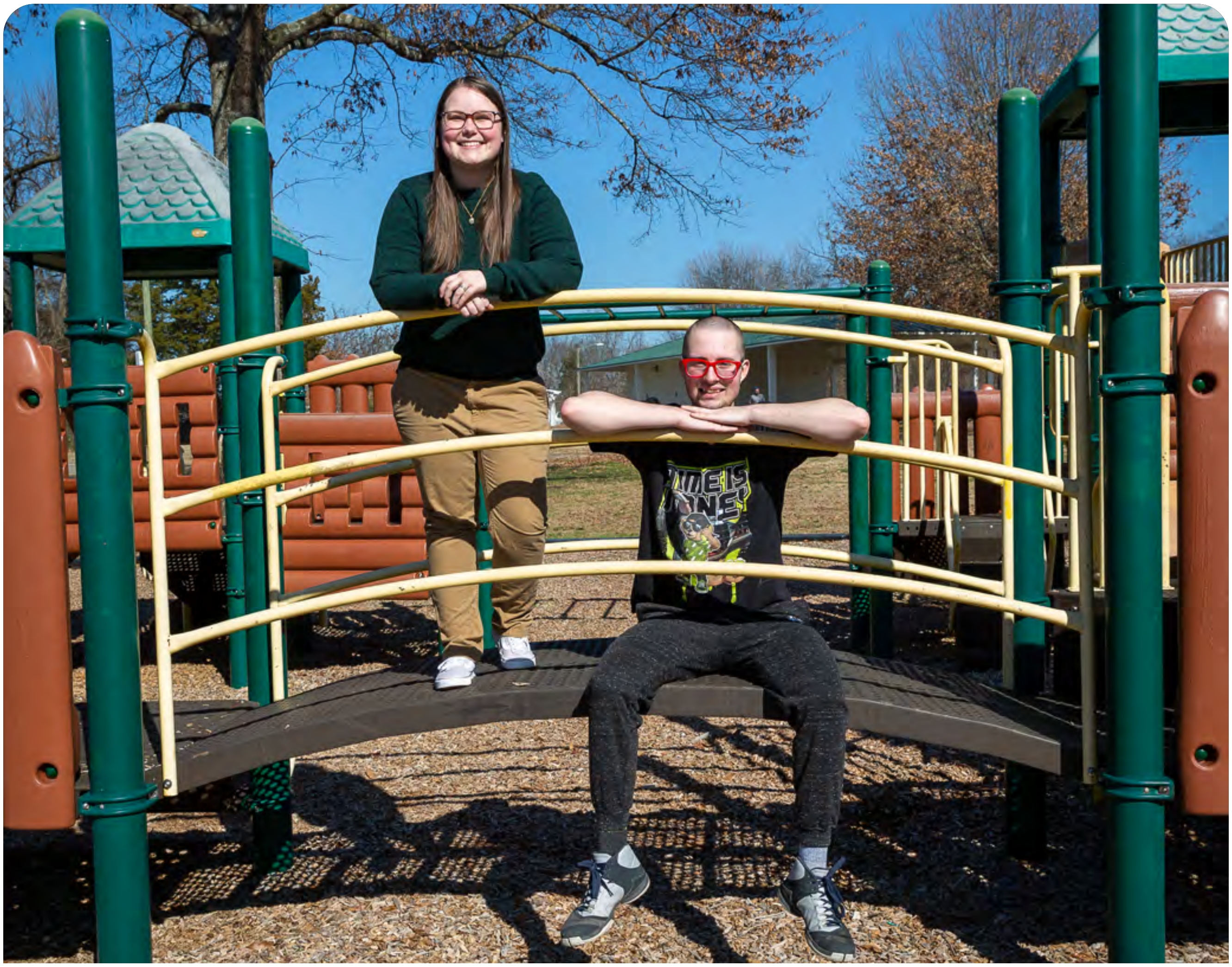
That being said, the biggest challenge we face is barriers to receiving services. I feel stuck in this gray area where services are so hard to come by. Jasmyn and our family need more support. She deserves access to a reliable therapist and medical team, but because she does not reach the threshold of severity, she is unable to receive adequate support. We have hit barrier after barrier because she hasn't been hospitalized for mental health concerns. It shouldn't be that someone needs to be in danger to receive support. The support should be available before there are life-threatening concerns, so it never has to get to that point.

Considering Jasmyn has multiple disabilities and mental health diagnoses, it is very hard to find counselors, case managers, medical professionals, and other professionals who truly understand the implications of her disabilities and mental health concerns. We need more mental health professionals who understand autism and intellectual disability. Jasmyn doesn't process in the same ways we do, and it might take her longer to get to a point of understanding. There needs to be mental health professionals who understand this and have the knowledge and tools to appropriately support her.

> ***We need more mental health professionals who understand autism and intellectual disability.***

Without understanding autism, intellectual disability, and Deaf/Hard of Hearing culture, you can't really know Jasmyn and her experiences. I am often left to fill in the gaps and help figure out what she is truly experiencing, feeling, or thinking. Without me, a lot can be lost within the session or meeting, and then it is not as productive or effective as it needs to be. At the end of the day, I hope that Jasmyn can access higher-quality support where she is truly understood. This will give her the freedom and space to just be Jasmyn. ■

Ashlie



Zach and Ashlie enjoy spending time together exploring local parks.

My name is Ashlie. I am a social worker in Tennessee. I became a therapeutic foster parent for Zach when he was 15. Eventually, I became his conservator. We met because I was his social worker. We had a unique family start, and our love has only grown for each other.

Zach entered the foster care system around the age of 6 because of drug exposure and neglect. Then we later learned that he had severe sexual abuse trauma. Once he entered the foster care system, he was diagnosed with moderate intellectual disability, ADHD, severe childhood sexual trauma, and anxiety. Since leaving foster care and turning 18, he now has a diagnosis of bipolar disorder as well.

Once he got out of foster care, we were able to get him into therapy, in the public school system, and involved with Special Olympics. He was doing great. It was amazing to watch him begin to live. His life really began when he saw the world outside of foster care and institutions. We saw a lot of improvement in his behaviors and watched his personality blossom.

When Zach turned 18, he decided he wanted to live independently. Since he was doing so well, we thought it would be a good idea. However, we did not know that he would not receive any services once he turned 18. Once he turned 18, his clock started over. So, any sort of charges he got as a minor, behaviors he struggled with, or past history no longer applied. Previously, he operated within a very strict routine. He had run a very tight ship based on his therapeutic recommendations. But then once he turned 18 and chose to live on his own, all of that was out the window.

> ***They have to harm themselves or someone else just to get access to services.***

Since then, it has been a struggle to find beneficial adult services for him – in particular, adult therapy that caters towards his intellectual disability and his sexual abuse trauma. He started with one therapy program that was virtual, not even in-person. It was not engaging at all, and he was just bored out of his mind. You know, he doesn't trust people very often. It takes a long time to build up trust, and they just jumped straight into his trauma which he did not like. He did not want to go back.

So, it has been an uphill battle, fighting the adult system for services. There are not enough providers. If a service provider is willing to take him on, they are only willing to care for him for a short amount of time and require a fade-out plan. But the truth is, he is not going to "grow out" of an intellectual disability or sexual abuse trauma. I see that he needs continual, consistent care, but nobody is willing to give it to him.

I wish policymakers knew that, for people with sexually reactive behaviors, or intellectual disability, or on adult waiver programs, they have to do something significant in order to get support. For example, they have to harm themselves or someone else just to get access to services. Can you imagine a kid who struggles with sexual behaviors getting tossed out into the world, but would not get any support until he does something potentially harmful? In that case, no support would be offered, only jail time by then. I wish policymakers were aware that this was a thing, and it just is not fair.

I want him to have as much independence as he can, but the system is making it really hard to get the support he needs to be independent. If it were up to Zach, he would be married, drive a cool car, and work as a fashion designer. In order to even get a job, he needs to have a job coach with him 100 percent of the time. If we can find one, they would have to "fade out" which would not benefit him in the end. None of his dreams are possible until my son gets the developmentally appropriate services that he needs.

I want all families and their children to feel supported as they transition into adulthood. I want them to grow and flourish, and become the people that they want to be, just like I want for Zach. ■

Katie

I wish people did not fear my son. I wish people would see James as an individual, as a unique 16-year-old boy who just wants a car for his birthday. You can see people put up the wall when we say that he has behavior issues, but they do not get to see what a funny kid he is at home; they only see the behavior label. What they do not see is that James loves to golf, fish, ride his bike, and do anything outdoors. However, because he is labeled as a behavior problem, people categorize him and, therefore, fear him.

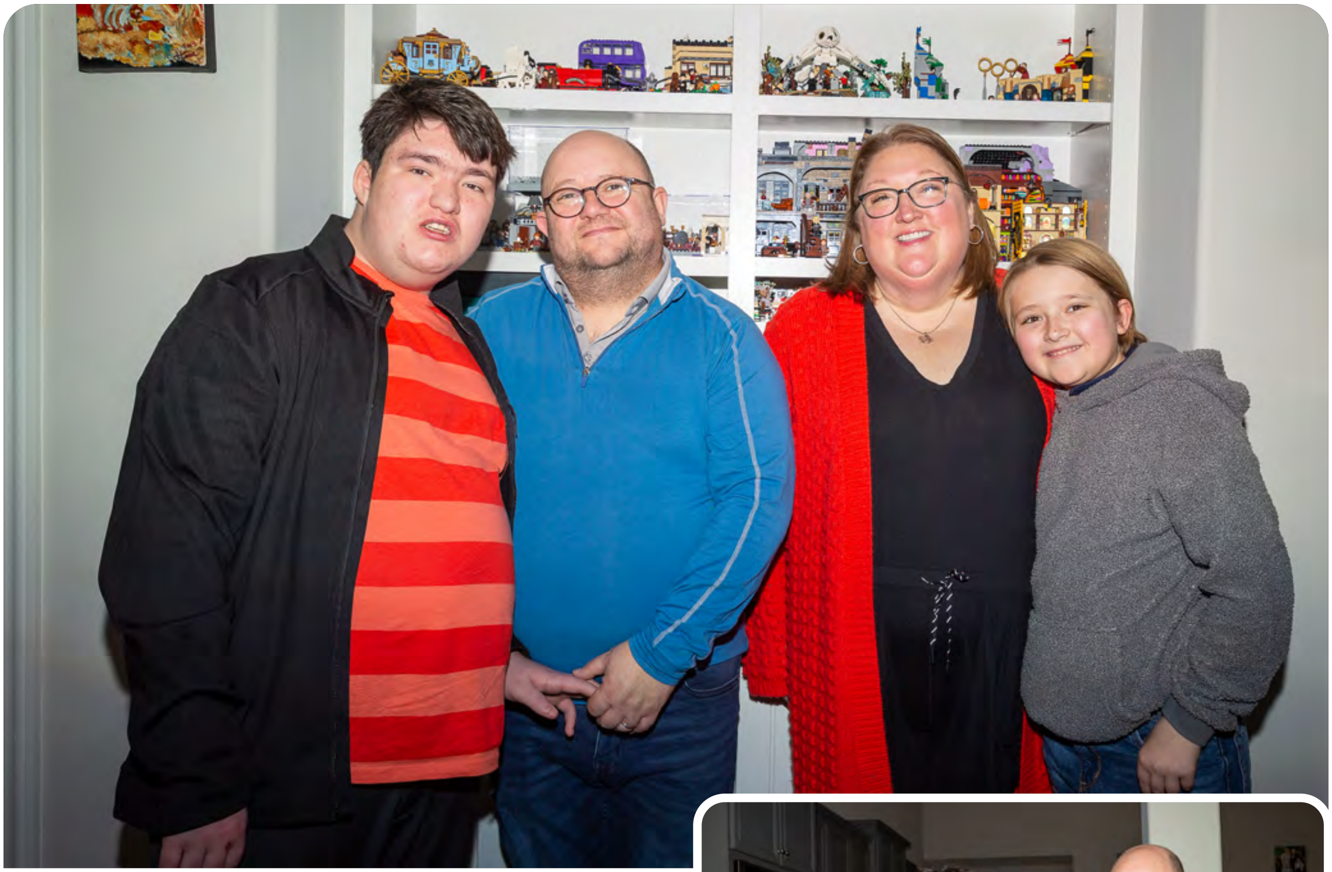
We adopted James when he was 3.5 years old. He had a very rough start to life before we adopted him. We always say when we take him to the doctor that the laundry list of diagnoses grows. James has been diagnosed with DiGeorge Syndrome, oppositional defiance disorder, anxiety, depression, attention-deficit hyperactivity disorder (ADHD), and intellectual disability. He also is being monitored for bipolar disorder and schizophrenia.

Tennessee needs to do better for their kids and families.

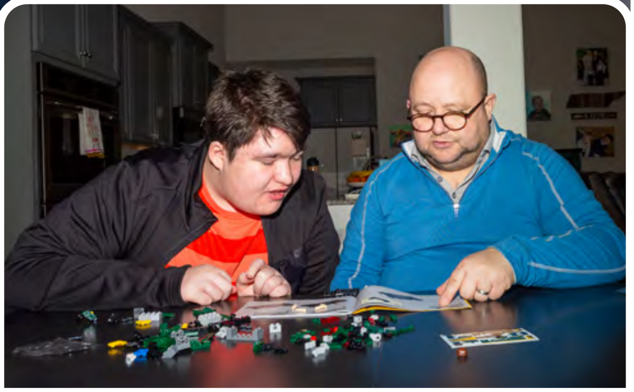
Our whole life revolves around what he can or cannot do on any given day. Sometimes he is capable of doing a little more and other days not. We cannot do anything without careful planning. We cannot always guarantee that he will be able to make it through a full trip to the grocery store, so we have to have a backup plan if he has an explosive behavior. He can go from being stable to his noncompliance stage then to verbally and physically aggressive very quickly. He can turn on that aggression like the flip of a switch and end up hurting himself or others around him. That is why it is imperative that we are prepared at every moment of the day to keep him safe.

In terms of his mental health, there is nothing available for anyone his age with an intellectual disability and mental health struggles in the state of Tennessee. We have been on the waiting list for Tennessee Start for over a year now, and there is no telling if or when we will be accepted. It's a waiting game. However, when you are dealing with mental health struggles, time is not a luxury that we have. He is a boy that desperately craves independence. What teenage boy wants to be followed around by his parents all day? It's incredibly isolating for him. He has no one his age to talk to on a friendship level, and there is nothing professionally available for him either.

Everyone we have talked to – doctors, social workers, ABA therapists, child psychologists – says that we seem to be doing everything they would have suggested to help with his behavior. In James' previous school, we felt we had to hide his disability. His IEP meeting consisted of 13 people sitting in this tiny room telling us that he is a Level 4 threat to them, even though we were apparently already doing everything possible to combat that. He was then sent to a school that specializes in challenging behaviors



Top: The Cundy family; James, Steve, Katie and Henry in their home. *Below:* James and his dad, Steve, putting together a lego car set. Legos are an activity that James and his family enjoy doing together.



and we knew nothing about it. James' new teachers do seem to understand him. We do feel seen and supported there. They see and understand that he is truly a really funny kid, not the "behavior" kid.

Right now, he may be a boy, but soon enough he will be an adult man, and we will have to figure out a whole new route of finding him any kind of mental health services. However, add in his behaviors and there are no supports that work together to treat both. You can't understand the lack of support you feel as soon as you mention that your child is a behavior child; you see the walls go up and the rejection come onto their faces. Even for him to go to a summer camp for a few hours a day, there are multiple people that have to come out to the house to interview him first before they accept him. All the while, he is just like any other boy who craves social connection. Tennessee needs to do better for their kids and families. ■

Rachel

My name is Rachel. I am from England and my husband is from New Zealand. We have two sons. Ken is our 17-year-old biological son and James is our 8-year-old adopted son. James came into our family as a foster child at 2 months old when we lived in New York. James' birth mother was incarcerated when he was born, and he was born with methadone in his system. He has been diagnosed with developmental delay, anxiety, and post-traumatic stress disorder (PTSD). His psychiatrist thinks that he might also have attention-deficit hyperactivity disorder (ADHD), but I also wonder if those symptoms are tied to his PTSD. We are waiting to get an appointment with a neuropsychologist to try and better understand what is occurring in his brain.

When James was 3.5 years old, his birth father wanted to come back into his life. This was unfortunately also when my family was moving from New York to Tennessee. We had already sold our house and were forced to leave James behind. For 9 months, James lived with another foster family. This experience was traumatic for all of us, as he returned to us with burn marks and a scar on his face. We were able to Zoom a few times, but it was really hard to see him struggling and not being properly cared for. James was finally able to rejoin our family in Tennessee, and he was formally adopted in 2019.

James has made a lot of growth over our journey together, but we've had our challenges. James has demonstrated challenging behaviors such as property destruction, physical aggression, elopement, and head banging. With his anxiety, he struggles with constantly biting his nails and has only recently slept through the night independently. Once he has calmed down after being activated, James has shown memory loss by not remembering going into certain rooms or what he had done.

In school, James is in a general education classroom. James takes a long time to process things, but we have found some success in having a one-on-one paraeducator with him throughout the school day. However, the school system has been our biggest challenge. I've taken courses and taught courses about trauma and working with people with trauma. I really wish I could teach one of those courses to school staff. James, and other people with PTSD or complex trauma, need to feel safe.

Through Parent-Child Interaction Therapy (PCIT) and my trauma course, we have made great strides in supporting his physical, mental, and emotional safety at home. So many of his behaviors are solely happening at school. He is working on advocating for himself by requesting a break when he needs it, but he has faced pushback from school staff about receiving that support.

We've had an advocate join his IEP team which has made a great difference in how we, as parents, are treated. I used to pull up to school each day, anxious about whether I would be asked to come inside to discuss an outburst

I wish policymakers knew how hard it is to get any help.

from that day. There have been multiple times where James has gone into crisis in school for four or more hours and my husband and I weren't contacted at all. With the support of our advocate, we now have it written into his IEP that if his behaviors last more than an hour, they must notify us so that we can get involved if needed or at least be made aware of the situation. We've also gotten it written into his IEP that some days James may have a "tricky day," and on those days he needs to be given the breaks that he requests without any work on tolerance-building. James has gotten quite good at requesting breaks when he needs them, and he's trying so hard to regulate his body and emotions. We need to do what we can, as adults in his life, to support him in that process.

On top of the challenges with school, treatments and medications are expensive. We're lucky to have access to insurance that will cover some parts of what James and Ken need, and my family is quite lucky to be able to afford some of it, but it's hard. I would love to have enough money to send him to a small school where everyone understood his trauma. I shouldn't need an advocate in an IEP meeting. I should be able to say, "I know this is best for my son because I'm his parent," but I don't have official letters after my name to make anyone listen.

I wish policymakers knew how hard it is to get any help. If you've got a broken leg, you'd be straight in a wheelchair and a cast, all covered by insurance. But because you can't see it, you don't have access to any of that. I just wish the support that James needs to be successful were more accessible. ■

Scott

My name is Scott. My wife and I fostered and eventually adopted our two boys through the Florida foster care system. We have five kids, two adult daughters who are out of the home, and three little kids: Jackson and Zoey, who are 11 years old, and Ridley, who will turn 10 in February. We lived in Florida until about eight years ago, when we moved to Lebanon to be closer to our family.

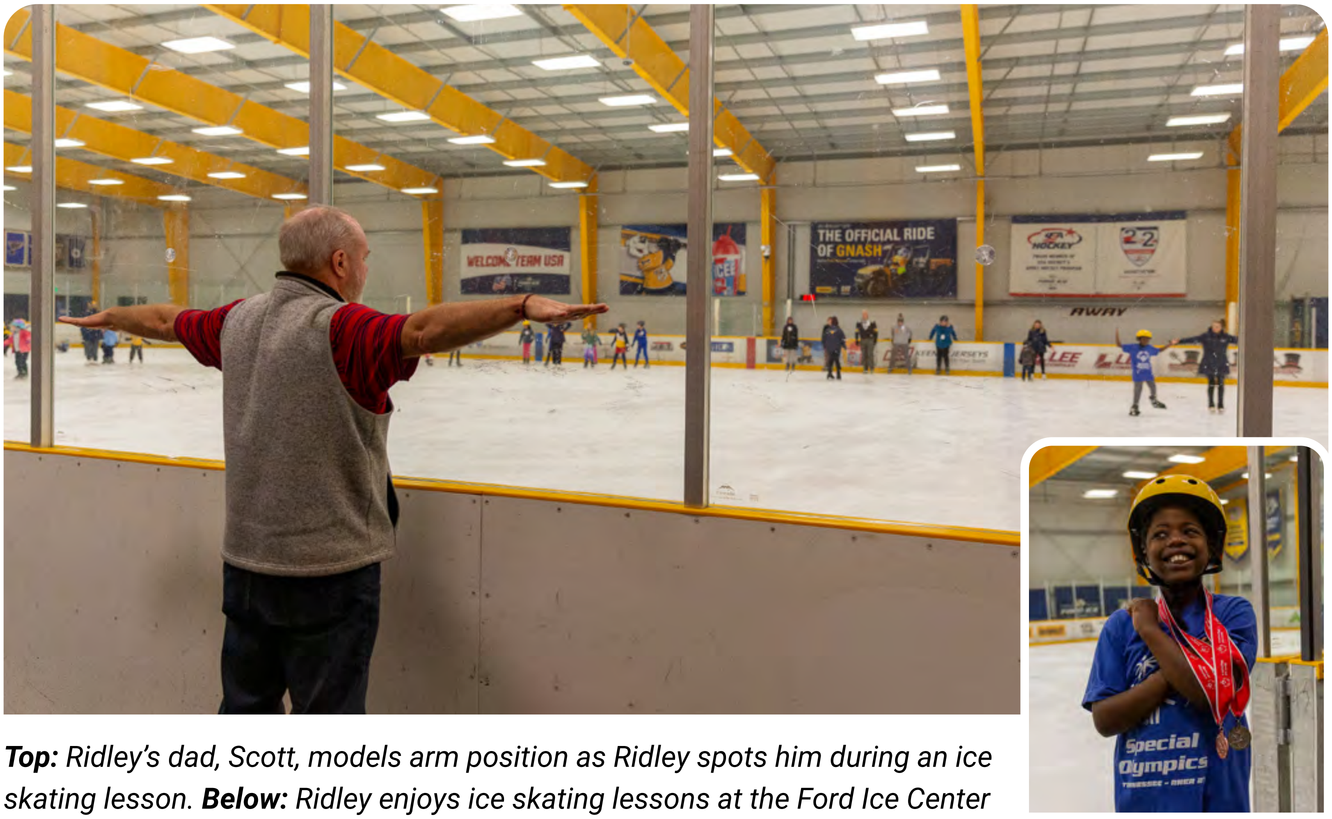
My youngest son, Ridley, has an intellectual disability. He is autistic and has ADHD, so he takes medication, and we do a lot of different therapies. Ridley is street smart beyond his years. He loves all things racing and monster trucks! He always has a big smile on his face and takes good care of his brother and sister and sticks up for them. What continues to motivate me as his father is to see the love that he has for people, the joy that he has for life.

Ridley started kindergarten when he was 6 years old, but we later decided to homeschool him. We found that the school system was a little bit complicated when you get into special education. Sometimes challenges for children like Ridley are more behavioral. As a parent, I'm more focused on behaviors and independent living rather than ABCs or 1-2-3s.

However, our family is in crisis mode right now, as my son is currently not in our home. Ridley is in an inpatient facility in Georgia because his behaviors got so aggressive that we had to go to the ER and eventually into the inpatient facility. It's probably one of the hardest things I ever had to do. A dad never wants to do that with a child. You sort of admit defeat at some level, but it's the only path that we had left. Ultimately, it shows the challenges that we face with not fully understanding or having the ability to manage those behaviors. We've had situations like breaking windows in the house, breaking garage doors, hitting, and punching. Each one of those wears you out and, over the course of time, repeated exposure to that type of trauma just wears you down.

And so right now, my wife, my kids, and myself are getting the help that we need to rebuild. And when Ridley comes home, we have pretty high expectations for being able to move forward with some new skills with some new help, and some new options to make all our lives a little bit better. Ridley is getting some of the best behavioral therapy and medication management in the country. He has done peer group with people his age, and he's surrounded by dozens of other kids in his same age group and level. There's some peer modeling there. You've got a team of doctors and a team approach, which we as parents love, because every so many weeks, they bring Ridley into a conference room, talk to him about his case, and ask him questions. There are psychiatrists, behavior experts, and other people in there observing him and talking with him. There are times where we make some big progress, but it's mostly just slow and steady.

As an advocate and as a parent, I would tell anybody that, in terms of behavioral health, there just needs to be a little bit of consistency, and maybe some quality checks. I'd like to know



Top: *Ridley's dad, Scott, models arm position as Ridley spots him during an ice skating lesson.* ***Below:*** *Ridley enjoys ice skating lessons at the Ford Ice Center in Antioch. Ridley recently won two metals at the Tennessee State Special Olympics Games for speed skating.*

that professionals know what they're doing. I'd also like to know if the business is functioning and operating properly and they're going to be around for the next couple of years. You don't buy a new roof and get a 10-year warranty from a company that's going to be gone in three years. That'd would be a bad business decision for anybody. What a lot of people don't realize is that services in general for special needs families in Middle Tennessee are very challenging, specifically for behavioral health. The top providers, the best, the most experienced, the most skilled, the most specialized, are hard to get to, and most of them aren't going to take a waiver because it doesn't pay enough.

I'm very grateful for the advocates who came before me. I tell people that being a parent of a child with a disability is like having a part-time job. Me and my wife spend about 20 hours a week managing all this stuff. There's paperwork, surveys and evaluations, phone calls and trainings, and appointments, and that's just what I do. My wife and I handle different responsibilities. We are tired. I was recently at a retreat with dads of children with disabilities, and for us men to be able to take a few days to rebuild and get respite is encouraging, and it's something that we need more of.

But right now, having my son out of my home this long is ripping me apart. Every single day that he's not here, I am struggling internally with it. But I do trust where he is. And I do think that there's a gain in this and it's worth the investment. As a parent, to make that type of decision, it's hard. I'm not going to pretend that it's not. But at the same time, I think I would advise another parent to do the same thing. I am also going to continue to advocate in the community to make it a little bit easier for the next parent. ■

Professional Experiences

- My name is **Elisabeth Dykens**. I am a clinical psychologist and senior researcher at Vanderbilt University. I hold academic appointments in the fields of psychology, psychiatry, and pediatrics. It has been my life's work to serve individuals who have developmental disabilities and co-occurring psychiatric, behavior, or emotional disorders.

  Many clinicians are hesitant to work with individuals who have intellectual and developmental disabilities (IDD), for they feel they have been inadequately trained. However, I believe this situation needs to be reframed: a clinician should see an individual with IDD as an opportunity to sharpen their own clinical skills. There are all kinds of literature concerned with how therapists can alter their approach to meet the needs of clients with intellectual disabilities in terms of goal setting, number of sessions, language use, and the modality that they use. There have been studies, mostly conducted abroad, that suggest people with intellectual disabilities can benefit from supportive counseling group therapy, cognitive behavioral therapy, and mindfulness interventions. I really think that if clinicians would get over their stigmas and stereotypes, working with individuals who have IDD could be a really rich experience that advances their own training.

- My name is **Rachel**. I am a licensed marriage and family therapist in Tennessee. I am currently an inpatient clinical social worker at a short-term crisis facility in a psychiatric hospital. As a social worker, I assess patients as they come in, coordinate with families, and create patient safety plans. My facility has patients with and without disabilities and has people with a full range of mental health diagnoses (e.g., depression, psychosis, and/or severe self-harm).

  One of the most profound barriers that I find within the system is parents and caregivers have significant difficulty navigating the available mental healthcare services, and those who successfully find services for their children encounter months-long waiting lists. Additionally, parents struggle to ensure that their child has a true continuation of mental health support throughout their educational career. I find that the main reason for a disruption of services changing for the worse is due to the resources being so strained and limited between school sites. I find that many of my clients do not receive the same degree of mental health support as they transition to different schools, even within the same district.

Resources

988 Suicide & Crisis Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources, and best practices for professionals. Call, text, or chat 988 to be connected to trained counselors. 988lifeline.org

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." TNPathfinder.org, 800-640-4636

The **Tennessee Department of Mental Health and Substance Abuse Services** and a professional network of community service providers and sister agencies provide an array of mental health-related services for young people ranging in age from infant to young adult. www.tn.gov/behavioral-health/children-youth-young-adults-families.html, 800-560-5767

TN Voices' mission is to be a collaborative leader guiding mental health transformation in Tennessee. It is a statewide and national source of referral, support, and advocacy for families and the systems that serve them. tnvoices.org, 800-670-9882

The **National Alliance on Mental Illness** is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness. nami.org

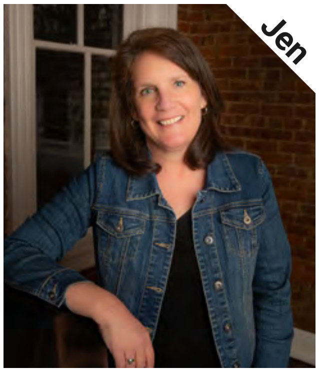
About Us

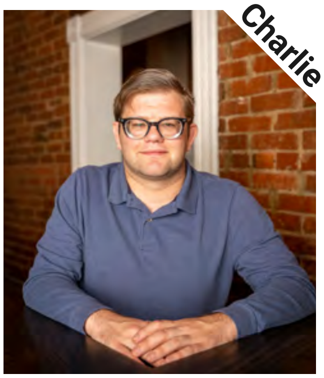
The **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities** provides innovative leadership in education, research, and services to people with disabilities, the community, and families. All activities promote the independence, self-determination, productivity, integration, and inclusion 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. thearctn.org, (615) 248-5878.

About the Photographer

Jen Vogus is a photographer, educator, and parent advocate. She is also the founder of AbleVoices (ablevoices.org), 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 board member of The Arc Tennessee. Vogus was assisted during the photo shoots by AbleVoices Photography Club members Charlie Burrows and Nicholas Coakley.





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