

Mental Health and Disability



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The photography for this booklet is made possible by a generous grant from the Tennessee Arts Commission.

Cover Image: *Teneice and her son, Edward, stand outside the Nashville Parthenon. Teneice is reminded by the Parthenon that Nashville is considered “The Athens of the South” and with this the importance of education and advocating for her two sons.*

Letter of Thanks

Thank you for reading this collection of stories from individuals with intellectual and developmental disabilities, their families, and mental health professionals in Tennessee.

The stories were collected through interviews conducted by Vanderbilt University (VU) students as part of the 2022-23 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 everyone who shared their stories this year. Talking openly about mental health is not always easy, and we are appreciative that they wanted to educate legislators about their experiences to 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.

For those who were willing for their pictures to be shared, 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 Shannon Agnes and Leah Sulmonetti, who coordinated the project this year. And thank you to all the students enrolled in the VU course, *Advanced Issues in Family Intervention*, who conducted the interviews that contributed to the content of this booklet.

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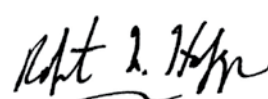
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Introduction

Adults with intellectual and developmental disabilities (IDD) report mental distress almost five times more often than adults without disabilities. Despite the prevalence, little is known about the best approaches for supporting the needs of people with IDD and co-occurring mental health challenges. In the stories shared in this issue of *Kindred Stories of Disability*, we see consistent themes. Tennesseans with co-occurring disabilities and mental health concerns face:

- Increased stigma due to disability and mental health concerns;
- Feelings of isolation;
- Lack of professional support and treatment options;
- Inability to afford ongoing treatment; and
- Lack of knowledge and vocabulary about mental health.

Individuals with IDD can experience any psychiatric disorder in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), including, but not limited to, attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder, behavior disorders, substance abuse disorders, depression, obsessive-compulsive disorder (OCD), anxiety, post-traumatic stress disorder (PTSD), and conduct disorder. However, unlike the general population, psychiatric symptoms in this population are often attributed to their disability rather than mental illness, in a phenomenon known as “diagnostic overshadowing.”

Beyond getting diagnosed correctly, adults with disabilities experience a number of additional barriers to mental health treatment. First and foremost, it is difficult to find therapists who are trained and confident in treating individuals with disabilities. In comparison to the general population, people with disabilities are not a part of research about mental health treatment and are not always considered when designing treatments. Adults with developmental disabilities may not be able to participate in the traditional form of “talk therapy,” especially if they have communication challenges. Additionally, adults with disabilities are more likely to live below the federal poverty level, and mental health care is not always sufficiently covered under insurance, if it is covered at all. These barriers make it extraordinarily difficult to properly address mental health concerns for adults with disabilities.

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.

Sherry

My name is Sherry. In my family, I have two daughters and a husband. My youngest daughter, Kendall, is 20 years old and has autism. In addition, she has a learning disability in math/reading, anxiety, and obsessive-compulsive disorder (OCD).

At 3 years old, I noticed that something was different with Kendall. Initially, she was misdiagnosed with ADHD right before her sixth birthday, but I knew that wasn't right. I would often spend nights studying ways to teach her and homeschooling her during the day. I would spend hours researching possible diagnoses for Kendall and came across autism spectrum disorder. When I learned about it, Kendall checked every box on the list, and I knew that this was the missing puzzle piece that I had been looking for this entire time. However, it was not until Kendall was a few months before her 18th birthday that she was diagnosed with autism. This was due to it taking so long to get through the process, and the system kept failing us in receiving the proper diagnosis. It was so frustrating because I knew all along that my daughter had autism, but it was an uphill battle for her to get those services.

Throughout her life, Kendall has had to face people treating her differently because of her disability. Many people did not include Kendall or my family in activities because of feeling uncomfortable and not understanding her disability. Due to her disability and mental health issues, Kendall has faced bullying by her teacher who would say she was not as smart as the

other students in the early days of school. She stopped communicating with her family and withdrew from everyone, which is why I began to homeschool her. I wanted my daughter back, and it took years for her to openly communicate with me again.

Kendall experiences a lot of struggles. Her anxiety causes her to have a hard time being around people so often she needs to remove herself from social situations. Due to her OCD, she has a pattern that she must complete before she goes to bed that takes three hours and often causes her to go to bed very late. It wears upon you as a parent as it causes her to struggle with making friends.

Kendall began receiving therapy services at 18, which has been helpful in dealing with her anxiety and OCD. When Kendall "slays one of her dragons" with her therapist, she has an outlet aside from us, her parents, to share her accomplishments and be proud of her. In addition, her therapist has encouraged her to come out of her shell through monthly challenges such as writing a book with me. She wrote a book titled with a message about everyone being unique in their own ways. Through therapy, she has become an advocate not only for herself but also for other people with disabilities. I am amazed by her confidence and sense of self that have grown through attending therapy.

One thing I wish that people knew about Kendall's disability is that, to her, this is her normal, and other people's normal is not her



Sherry and her daughter, Kendall, pose outside of the Sheltering Tree Ranch General Store. Sherry and Kendall volunteer in the General Store every week.

normal. She is happy with herself, and she has learned to be accepting of that and tries her best every day. She is a beautiful person who just happens to have autism. Recently, Kendall was interviewed for a paper in which she said, "try to do it even if it's hard," when they asked her to give advice to other working women.

I believe policymakers should know about the challenges in receiving a diagnosis for your child with a disability and mental health issues. I wish it was not as much of a battle to receive a diagnosis, because then that opens the door to receiving the therapy and services that these children need. Kendall has grown so much in the past year since receiving a diagnosis because

she has been able to access life-changing services such as therapy. I have often thought about how much more confidence Kendall would have had if she was able to receive therapy earlier in her life.

I want all families of children with disabilities to have the opportunity to see their child grow and flourish like Kendall has by accessing services. We, as parents, should not have to be a teacher, counselor, and advocate with little to no support, and we should have access to resources that allow us to support our kids as Mom and Dad. ■

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Kendall brushes her favorite horse, Freckles, at the Sheltering Tree Ranch.

Eric

I had an Air Force life. I was a nuclear weapons missile launch officer. It was a lot of stress, watching the missiles. A lot of paranoia. I didn't know back then that I was bipolar. I always experienced the moods. There were the highs where just everything is better. And the lows. The sadness, the melancholy. I don't get the highs as much anymore, but I still get the depression. I started drinking at 25 years old to deal with the stress and the mood swings. I didn't know then that I was turning on the alcoholism gene. I've been an alcoholic ever since. In the Air Force there was this stigma around even just mentioning mental health. You didn't talk about it, so I didn't. I finally got diagnosed with bipolar/ADHD in 2011 through the VA.

I am a 100-percent disabled veteran. That came about a year ago. I have autism, bipolar disorder, and ADHD. If you look at the 21 reasons on my disability, it's all about not fitting in with people in social situations and jobs. I can't be in a large group of people. I can't be next to somebody bipolar on a manic high. If they start going up, I'll start going up with them. I can't go with it. I can't be there. I have to get away from it, and I can't be in large groups of people. I can't deal with it, and I don't. I live an isolated life. I never got involved with women. I didn't know what was wrong, I just knew that something wasn't right. And I wasn't going to screw somebody else up with me.

I see a psychologist and a psychiatrist on a regular basis. I don't know if counseling is doing

it for me, but what I do value tremendously in my isolation is the conversations I do get to have, like during my time volunteering at the Chattanooga Autism Center. I have a terrible problem with meeting people. I can't stay and talk to people because I don't know what to say. So, the conversations with my psychologist and my psychiatrist are valuable to me.

The thing that I'm really always going to wonder all my life is how much I could have controlled my mental health. I know that alcohol was my way of dealing with the moods, but that got me into a lot of trouble. But the Air Force taught me not to mention it, not to talk about it. When I finally got a diagnosis from a doctor, he gave me the pills – and I know that's not the silver bullet – but what do I do? How do I deal with it? He never told me. So, I'm never going to know how much of an effect I could have had on my mental health.

I have a hard time trying to explain my disabilities and mental health to other people. There's almost like this unawareness surrounding mental health in Tennessee. People think, "why do I need to know about that? That's just something I don't deal with, that's something I don't know." Until you've experienced this, you can't truly know what it's like. It's hard to make people care about mental health. They don't want to respond to mental health unless it touches their life in some way. Talking about mental health can feel like cries in the wilderness. ■

Jessica

My name is Jessica. I am a licensed psychologist and researcher in Nashville, Tennessee. My professional career is centered around the intersectionality of disability and the mental health field. Additionally, I am a sibling to a brother with autism and an intellectual disability.

One of the reasons I got into the disability field was because of my family connection. I grew up seeing/experiencing firsthand the challenges both my brother and my family faced just trying to get the adequate services we needed. The school system and our family did their best to support him. However, we were against constant systematic barriers at many levels, such as underfunding and lack of resources.

There are neurodivergent people or people with disabilities everywhere, including mental health facilities. This population is more likely to be at risk for depression, anxiety, and self-injury and to have suicidal ideations. One of my first clinical experiences was working in an inpatient mental health facility. At this placement, I

noticed that my colleagues with expertise in mental health expressed uncertainty and limited training in working with patients with dual diagnoses that included intellectual or developmental disability. This is not anybody's fault. Typically, professionals in the disability and mental health fields are not trained to work with individuals outside their scope of practice. This is how I became interested in working and serving individuals with mental health and disability diagnoses.

I currently work in the Department of Psychiatry and Behavioral Sciences at Vanderbilt University Medical Center (VUMC). I have been at VUMC for the past three and a half years and presently, I am an assistant professor and researcher. My research program focuses on individuals with dual diagnoses of mental health disorders and disabilities. These projects primarily investigate the complexities of depression and suicide among individuals diagnosed with autism spectrum disorder and intellectual disabilities. Additionally, we assess, intervene, train, and support individuals and their caregivers in risk management and cognitive-behavioral approaches.

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The most significant barrier I've seen for individuals with dual diagnoses are accessing services throughout our health care system. In general, they encounter well-intentioned providers who continue to express uncertainty in best practices for this population. By chance, if families connect with providers, there is



generally a lack of appropriate and high-quality services to meet their needs. Many of these concerns stem from the lack of awareness and funding in the area of mental health and disability diagnoses. Furthermore, they have fewer opportunities to access adequate/appropriate housing, quality vocational training, and meaningful employment opportunities.

Specifically, regarding mental health, there is a misunderstanding that people with disabilities can't have co-occurring mental health challenges, which is false. Due to the lack of awareness, many individuals' mental health

needs go undiagnosed. Notably, those in the low-incidence population (i.e. individuals with disabilities that occur in low numbers, or are less common, within the general population) with fewer language abilities and higher support needs often go undiagnosed. A common misconception is that people with disabilities like to be alone or struggle to show empathy, but this isn't always the case. Often mental health characteristics are passed off as part of their disability when, in reality, these are two different things and should be treated as such. In many cases, individuals with these diagnoses are alone, isolated, and with little to no support.



Jessica Swartzman prepares diagnostic materials for a patient visit.

I would want policymakers to know there are steps we can take to better support this population and their access to mental health services. I believe more collaboration across mental health and disability fields would improve the lives of this population. Providers need more readily accessible trainings, workshops, and research to meet the needs of all patients, including those who are neurodivergent. This needs to be a priority for everyone, not just stakeholders within this field. There is an overall lack of awareness considering the number of individuals and families impacted by dual diagnoses. We need different disciplines, jurisdictions, and stakeholders to collaborate

to address how to better help those in our community who are facing these barriers. We cannot move forward without addressing the lack of resources and funding to support these individuals and their families.

Mental health needs to be at the forefront of the disability community. The pandemic was arguably highly challenging for everyone. We all experienced our own version of isolation and separation from our communities. Unfortunately, this is something that individuals with dual diagnoses of mental health disorders and disabilities tend to experience daily; it is time for this to take precedence. ■

Leslie

My name is Leslie, and I am 32 years old. I have lived in Tennessee since I was in my teens, when I was taken away from my parents. My mother and I are still in communication. I do not have a good relationship with my father or brother. I have no family in Tennessee, but I made a family here.

I did not have a good experience in school, as I often practiced self-harm. However, I have not harmed myself since Aug. 2022. My mom taught me right from wrong, and that is what got me through life. I wanted to be a nurse after high school, but I never got around to fulfilling that dream. I also wanted to take care of people with disabilities since I can relate to them, but I also have not got around to doing that.

I have diagnoses of borderline personality disorder, post-traumatic stress disorder, and depression. These diagnoses have smacked me down when I have least expected it. They have prevented me from getting a job and getting stuff I want in life. When I was younger, I didn't know I had disabilities and always thought I was just like everybody else. However, when I got older, I started to wonder why I was so different and didn't have any friends.

When I was 20, I finally got diagnoses from doctors. I can be doing good in life for a year or two, but then something triggers me, and it feels like I'm falling off a cliff. I black out when I'm triggered and can become very aggressive. I don't even know what I'm doing though. This can happen multiple times throughout the year, and I have no control over it. My mental health

problems have affected my life in bad ways, like when I'm aggressive.

When I'm helping people, my triggers are not as strong and I'm happy. I help people learn how to write and spell, or I talk to them when they get upset. To treat my mental health disorders, I get a shot and talk to a psychiatrist every three months. I have been seeing the same psychiatrist for four years, and I like her a lot. I ended up seeking treatment because I was having self-harm issues and depressive episodes.

The people I live with know when I need help because I will shut down and become frustrated. Initially it was very hard to get treatment, because I wouldn't open up to anybody. I was scared. Now, I have staff with me around the clock every day, and I have medication management.

I believe that people treat me differently because of my diagnoses and mental health problems and because I have cuts on my arms. When I walk around without sleeves, people look at me differently. I was bullied when I was younger because of how different I was. I was treated like trash, verbally and physically. I think it only made me stronger though. I am able to talk about my diagnoses and write poetry.

I wish that policymakers would help us to better understand how to not treat anyone differently or misuse people just because of their disabilities. I wanted to share my story with everyone because I thought it might be able to help somebody else to come out of their shell. ■

Alana

My name is Alana, and we have an 18-year-old son who had a stroke in the womb. It basically killed the left side of his brain. He has many diagnoses, but I would say the brain injury is the one that impacts his life the most. He also has autism and intractable seizures. Cameron's disabilities require 24/7 care, and I mean that literally. He can't be left alone for more than 10 minutes, or he is going to start playing with the toaster or pushing buttons on the fridge. He loves getting into things if he knows no one is around.

He has severe behaviors. He has made holes in the walls, busted windows, and even broken furniture. I think a lot of these behaviors are because of his communication challenges. He wants to tell us something, but he can't because he is nonverbal. It also is just stubbornness sometimes. We did all the behavioral therapy when he was younger and that was great, but now that he is older, there just isn't much in terms of services for him. We have been through so many behavioral therapists, but none of them could help release his anger. He can do some things on his own, but he needs a lot of help.

We feel stigmatized out in public because people stare. They just don't understand why he is ripping out the grass or trying to hurt himself. Even medical professionals sometimes don't understand. He can't wait in waiting rooms because he will start destroying the waiting room. We have to try so hard to find people with

a specific skillset or else they will be terrified. There isn't enough education in the medical community or hospitals for him to get the care he needs.

He sees a psychiatrist, but we have tried to find him inpatient treatment because it got so bad that we couldn't take care of him ourselves. We have had to physically restrain him sometimes. We have another son, so we are trying to keep everyone safe. They told us they couldn't meet his needs because he was too "medically complex." He has a feeding tube and, of course, also the seizures. Instead, they told us to get him prescribed stronger medications. I feel like sometimes doctors think we are making it up, the severity of it. They often want to focus on his autism, but they forget he is functioning with a traumatic brain injury. It really takes a toll on us having to make sure we can keep him and everyone in the house safe. We have to switch off taking our other son to his games because we tried to take Cameron a few times, but it was a disaster. It ended with us having to throw him over our shoulder and leave.

He is a part of school programming, but we do have trouble getting him the nursing hours we are qualified for. His school is okay, but he has lost the activities he enjoyed, like swimming, because of COVID. I don't know if those will ever come back. We really need that respite care though. We are supposed to have 28 hours, but we are lucky if we get 10. In two years, I think

There isn't enough education in the medical community or hospitals for him to get the care he needs.

we have gone through seven or eight caregivers because of the turnover. I don't blame them. The pay is low, and it is hard work. It's tough when Cameron gets used to someone and then they leave. The only option is to pay a private company, but that would be all out of pocket for us. We just need more reliable respite care for families.

The hospitals here also have no clue how to handle Cameron. We had a horrible experience with a scheduled surgery, and we had to leave. Even in the emergency room, they have no idea what to do with him if he is out of control. They have said they can't transport him because of all his diagnoses. It leaves us with nothing, having to do our own research and fending for ourselves.

People just don't understand what is happening. A lot of people are scared, and I was, too, when I first saw Cameron have an episode. I mean, it's something you don't see coming, and it is a scary thing. But we need more education and community engagement. These kids are part of the community, too, and they will grow up. They need a place to fit in. I won't be here forever. It is frustrating because I just want people to ask instead of whispering and making faces. Disabilities are not "one size fits all." Seeing this really changes you as a person. I think people need to know that nobody asked for what they were given, and people don't understand that there are families behind these kids, and their lives are significantly impacted. ■

T.A.

My name is T.A., and I currently live in Nashville, Tennessee. I identify as an individual who is multiply neurodivergent, and additionally, as the caregiver for those with disabilities, and as an advocate for those with disabilities. I have multiple disabilities including autoimmune disorders, dyslexia, dyscalculia, dysphasia, Tourette's, and autism.

Growing up, my family was very poor, and we had a lot of instability where we had to move almost every year of my life. I have found that it is difficult to be disabled when you are poor and cannot afford basic necessities. I managed to pursue an academic route to find my way out of poverty and pursue a career in disability research. My son who was diagnosed with autism at 2 years old is currently 27 and unable to afford to live on his own. I currently live with my son who is neurodivergent and lives with mental health disorders, and my father who identifies as autistic and has PTSD. I act as their caretaker and understand the role of parenting a child with disabilities and caring for a parent with disabilities. Additionally, I can speak to the role of disability advocate as I work as a disability researcher in the Department of Neurology at Vanderbilt University Medical Center, studying clinicians' perceptions of treating sleep disorders in autism.

Many individuals with disabilities qualify to receive supplemental security income to assist them in meeting basic needs. However, this amount is below the federal poverty line, meaning many individuals with disabilities live

in poverty. Additionally, when individuals begin to work, money is deducted from their supplemental security income, which disincentivizes work instead of incentivizing it. One policy change I feel strongly about is that individuals who receive supplemental security income should receive all their benefits until they have an income through employment that is greater than the federal poverty line. This policy would incentivize work as well as reduce the stress for individuals with disabilities when doing complex calculations to determine employment and state benefits. These complex calculations and stressors about income and meeting basic needs can lead to stress-induced health disorders.

Accessing affordable housing is very difficult in Nashville and the surrounding areas. Personally, I know of people who are disabled and unable to afford housing and have succumbed to renting plots of land in rural parts of the state where they live in tents or in their cars to avoid the struggles of homelessness and costs of metropolitan life. These rural areas do not provide many employment opportunities or transportation options for getting to work, medical care, or social activities. Many of these people who struggle to find alternatives to unaffordable housing also experience mental health disorders in addition to their disability. Further, the demands and challenges of being unhoused lead to further health complications. Access to mental health services and support is nearly non-existent if you are living in rural parts of the state on undeveloped land. Even as



a homeless individual in a metropolitan area, being unhoused creates a barrier to accessing services.

As an advocate and researcher, part of what I study is sleep disorders in individuals with autism. The National Institutes of Health do not fund any physical health-related research in autistic adults. The lack of funding is a problematic policy as individuals with autism deserve research on their physical health disparities. This means that research is mostly focused on “curing” or preventing autism instead of researching ways to reduce

co-occurring physical health conditions. This further marginalizes an already marginalized population.

As an individual with disabilities, a caretaker of individuals with disabilities, and an advocate and researcher in the field, I feel strongly that individuals with disabilities deserve better than the status quo. Policy changes in practices around SSI, affordable housing, and health research would improve the quality of life for these individuals and improve access and status of available mental health services. ■

Bruce

My name is Bruce, and I am the Deputy Commissioner of Clinical Services for the Department of Intellectual and Developmental Disabilities (DIDD). As the deputy commissioner, I oversee the clinical services that go on throughout the state and have a staff of clinicians who oversee particular areas.

After college, I always thought I was going to be a therapist and work at a mental health center or my own office. However, within a week working as the associate psychologist at a facility for people with intellectual disabilities in Missouri, I was hooked and knew I had found the thing I really wanted to do.

The biggest barrier I see within the health care system is the lack of recognition that individuals with intellectual and/or developmental disabilities have co-occurring mental health disorders. I am president of the National Association of Dual Diagnosis, which makes this barrier all the more surprising to me since we have been working to alleviate this problem for almost 40

People associate everything that happens to that individual back to their intellectual disability, and that is a real travesty.

years now. Although it is not my goal to place more labels on people who already have many, I do want them to have access to the mental health support they need.

I wish more people understood that I work with a very diverse population of individuals. I would ask that people please not paint them with a broad brush and allow the individual's diagnosis to overshadow the entire picture. People associate everything that happens to that individual back to their intellectual disability, and that is a real travesty. This way of thinking limits people and prevents them from accessing the opportunities they want and need.

I would like to share a story of a friend of mine. I started as his therapist, which is when I learned he had an interest in farm animals. Since I work with horses, I invited him to my property to help with farm work. I found this was a great way to talk to him because it took the pressure off sitting in a room and talking. Over the course of time, I taught him how to drive my tractor and complete work on the farm. I have put my trust in him and now pay him to complete work for me independently. The biggest issue I have noticed is that people with disabilities do not feel trusted, however, I demonstrated my trust in him. He was being hospitalized at a minimum of twice a month, however he has become successful with the support of many individuals who gave him confidence in himself. Since then, he was able to move on to be successful in multiple other job positions. This is the kind of story that I hope gets across to people.



Top: Bruce stands outside his office at Tennessee's Department of Developmental and Intellectual Disabilities in Nashville. **Below:** Bruce, the Director of Behavioral and Psychological Services, works at his office desk.

I find the work that I do quite rewarding, but there is a great need to develop more available and appropriate services. Hopefully, we can all work together to continue building the system so that it works well for people with co-occurring disorders across Tennessee. ■



Teneice

My name is Teneice. I am a dual certified teacher in Special Education and General Education and the very proud mother of two wonderful young kings. Justin is 29 and diagnosed with ADHD, functional delay, and psychogenic nonepileptic seizures (PNES) brought on by extreme stress. He owns his own business as a freelance photographer. Edward is 27 and diagnosed with Asperger's, ADHD, and anxiety. He graduated from Tennessee State University two years ago with a bachelor's degree in graphic design, and a minor in interior design.

My boys grew up in Tennessee. I think that, when they were younger, not a lot of people knew how to approach them and/or deal with them. They had teachers who didn't expect them to attend college and friends who made jokes about them going to therapy for their mental health. But one of the things I told them was, "You teach people how to treat you. Remember always that Mom has your back, and I want to see ya'll not just survive but

And just truthfully speaking, in communities of color, therapy is not something that people talk about.

thrive." I know that being that type of parent and advocate for them early in life helped them as they got older.

My boys get anxious and sometimes depressed. They did not look and do the things that their friends did, so they would sometimes get down on themselves. And just truthfully speaking, in communities of color, therapy is not something that people talk about. In the community, you don't go get therapy. But I tell people who have mental health issues that they should go talk to someone. People went to school for this. There's a reason that this industry exists. People should get the help. You wouldn't sit there and literally starve yourself if you know that you can have access to food. So why would you starve yourself mentally? Why would you mess with your emotional and mental health when there's something to feed you?

Everything really does go back to God with us. There's a lady by the name of Miss Jefferson, and she's a therapist at the church that we go to. The first Sunday that we were there, she walked up to my boys and said, "I'm so glad you are here." She knew nothing about them. She was just someone who saw people come in and thought, 'they've never been here before, let's connect with them.' She didn't treat my sons like a package. Because they're two years apart, most people automatically consider them a package deal. This was the first time that someone intentionally separated them and saw them for themselves. They started talking with Miss Jefferson on a regular basis. To this



Teneice and Edward walk and talk along the path in Centennial Park in Nashville.

day, I don't know what they talk about in their sessions. I just give them that space.

Because of their experiences with therapy, now they talk to their friends. Edward had a friend whose parents died. Edward made sure his friend didn't go to a dark place by inviting him to do things with him and just being around him when needed. I asked Edward one time why he did that and he said, "Because somebody did it for me, so why wouldn't I be there for him? He is my friend." I think because of what they've experienced in their life, their humanness and empathy is so amazing. They've had to overcome so much and continue to overcome. I'm honored to be their mom.

I wish that policy makers sat down more often with the people their policies will impact. If you're going to put a policy on the books that's going to create a barrier for someone, you need to go talk to the people who you create the barrier for. Because at the end of the day, whatever you put into law there's somebody that's going to be impacted and affected by that. ■

Jamelle

My name is Jamelle. I am a nurse and a mother to five wonderful adult children. Two of my children have disabilities. Harold, who has autism, also experiences mental health struggles. Harold is my 21-year-old son who plays football at Alabama A&M. Football itself has helped him with stemming, and the hitting has helped with his sensory issues.

Our diagnosis journey has been a challenging one. As a child, Harold was diagnosed with ADHD and oppositional defiant disorder. However, I never felt this diagnosis was a complete “match.” When Harold received a diagnosis of autism, it all made sense. The diagnosis explained his attention and compulsion deficits. It seemed appropriate to me that Harold had the same symptoms before age 1, but they lasted way past the time they should have. His diagnosis explained why he reacted and expressed his feelings through actions and not verbalizations. It explained why he didn’t have emotions when he looked at other people or looked you in the eyes. It also explained why he treated everyone the same as there was no distinction between peers and authority. This has led Harold to get into altercations with the police because he doesn’t understand the difference in approach and the different levels of relationships.

Feeling settled about this diagnosis, I knew I had to advocate for Harold. My advocacy has not always been accepted by healthcare providers. Throughout this journey, we have been told

that Harold was “cured of autism” and that his autism had “cleared up.” Feeling unheard and unhelped, I decided it was time to take matters into my own hands. I decided to hire a private provider to care for Harold.

Autism isn’t the only diagnosis that Harold has. Harold has also struggled with anxiety and depression throughout his life. He has always seemed sad and removed from others. I feel Harold’s depression and anxiety stem from the world wanting him to act his age. This is from Harold getting older and being expected to produce at age-level appropriation. Since Harold’s autism is not apparent to the world, people have higher expectations of him. People seem to want a person with a disability to have that disability visible for all to see otherwise the disability doesn’t exist in their minds. The world expects that a person’s value is from how they can be productive in society. People need to allow a person to be who they are and not have to live up to what the world expects.

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Jamelle reminisces with her son, Harold, on a bench at Cora Howe School in Nashville.

The combination of his autism and his mental health struggles results in Harold having a hard time communicating with anyone. Sometimes this communication barrier makes doctor appointments, evaluations, or services difficult. This results in providers giving up on Harold because they do not understand him. Harold expressed at one of his past PCPs that he was suicidal, and that same practitioner stated “that was not in her scope of practice” and did nothing. I have tried finding providers that understand adults with Autism and how mental symptoms affect them in this stage of life. But it seems that providers are only knowledgeable of children with Autism or strictly mental illnesses. These things are not only difficult for Harold

and me, but it becomes dangerous as he isn’t receiving the care that he needs. Truly, Harold lives in a world that he cannot maneuver. I’ve done my best to help Harold, but at the end of the day, I feel isolated and alone.

I also must watch my son face stigmas and societal rejection. Within the Black community, there are a lot of stigmas surrounding an intellectual disability. I have had to refuse any sort of emotional or intellectual disability diagnosis to protect my son. You see, Black men are expected to be strong, not weak. If Harold can overcome his disability, he will be considered strong. If he does not, he will be labeled as weak. With a lack of support from my



Harold poses in front of Cora Howe School. Jamelle shares that this is the first school that really understood Harold and his educational needs.

community and doctors, I often feel like we have been put in a hole that we can never get out of.

Caring for and advocating for Harold is tiring. It takes a lot of time and effort to make sure he gets what he needs. However, I do it because I love him, and I want him to succeed. I wish that more people knew him and loved him as I do. I wish that people got over his exterior and came to know his interior. I wish that there was more research on medical care for young adults who have a disability and struggle with mental health. I wish that there were improved services for students with disabilities transitioning into college. I also wish people wouldn't take his lack of expression or communication as a sign of

disinterest. I hope that present levels of performance evaluations continue into adulthood to give caregivers a better picture of the person. I wish for a lot of things. At the end of the day though, I simply hope that one day there will be a perfect match of services for Harold. He deserves it. He deserves to be seen. He deserves to be understood. He deserves to be loved. ■

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

Tennessee Department of Mental Health & Substance Abuse Services offers a wide range of supports and services for Tennesseans living with mental health and co-occurring issues ranging from essential mental health services to employment and housing services. tn.gov/behavioral-health

Mental Health America of Middle Tennessee connects the community with specialized mental health and wellness resources. mhamidsouth.org

Mental Health Association of East Tennessee offers free mental health screenings, individual client assistance accessing mental health care or medications, information and referrals, and public education and advocacy. mhaet.com

Tennessee START Assessment & Stabilization Teams are a statewide resources for individuals with IDD, who have complex behavioral or mental health needs. tn.gov/didd/ast

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

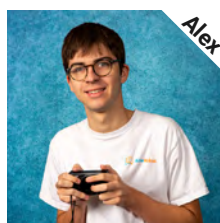
About Us

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. thearc.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 Sami Zinni, Alex Balkon and Brock Bordeaux.



Talking about mental health can feel like cries in the wilderness.

Policy changes in practices around SSI, affordable housing, and health research would improve the quality of life for these individuals and improve access and status of available mental health services.

Tennessee Kindred Stories of Disability
vkc.vumc.org/kindred