

Access to Health Care



**VANDERBILT
KENNEDY CENTER**
for Excellence in Developmental Disabilities



The Arc
Tennessee

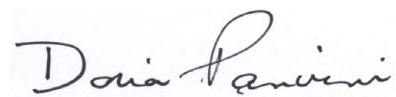
A Letter of Thanks

Thank you for taking the time to read this collection of stories that relays the experiences of Tennesseans with intellectual and developmental disabilities as they seek access to quality health and mental health care. Studies have shown that individuals with disabilities face a variety of health disparities, and it is clear from these stories that they often do not have access to the same quality, patient-centered health and mental health care opportunities as the general population.

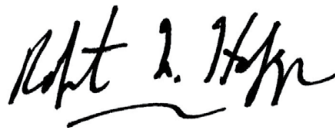
The stories in this booklet were collected by students enrolled in a Vanderbilt University course that provides an introduction to the field of family studies, with special attention paid to families that include children and adults with disabilities. The course offers future educators, advocates, and researchers an opportunity to learn firsthand from families about encounters with education, health care, housing, employment, and disability services in Tennessee.

We would like to thank the individuals with disabilities and families who shared their stories in this edition. By reading them, you will receive snapshots in time of a diverse group, across a spectrum of disability, geographic location, socioeconomic status, and race. We would also like to thank Courtney Taylor for her coordination of the Kindred Stories project. By sharing these stories, we all hope to demonstrate the challenges individuals with disabilities and their families face when seeking out and receiving health and mental health care, and to encourage creative ways of addressing and removing those barriers.

To view additional stories from Tennesseans with disabilities, please visit:
kc.vanderbilt.edu/kindredstories



Doria Panvini
Community Advisory Council
Vanderbilt Kennedy Center



Robert Hodapp, Ph.D.
Professor of Special Education
Director of Research
Vanderbilt Kennedy Center



Carrie Hobbs Guiden
Executive Director
The Arc Tennessee

The Arc Tennessee
www.thearc tn.org

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities
vkc.mc.vanderbilt.edu

Table of Contents

| | |
|--|----|
| Introduction | 4 |
| Lorri (age 50) | 5 |
| Rhonda (age 47) | 6 |
| Samuel (age 30) | 7 |
| Brian (age 39) | 8 |
| Rebecca and Nelda (ages 60 and 58) | 10 |
| Heather (age 40) | 13 |
| Evan (age 21) | 14 |
| Sadie (age 3) | 16 |
| Morgan (age 23) | 18 |

Introduction

Thank you for taking time to read the stories in the booklet, and I add my thanks to the many families who shared their stories and the students who made this booklet possible. We are one of the families that shared our story, and as you read these stories, you will find consistent themes regarding health care. Individuals with disabilities face:

- Difficulties finding health care providers who are knowledgeable, willing and trained to care for people with disabilities.
- Difficulties finding health care providers who accept TennCare.
- Difficulties affording health care, if the individual is not on TennCare.
- Extreme difficulties finding mental health providers willing to provide medication management or trained to offer counseling to people with disabilities.
- Transportation barriers, particularly in rural areas of Tennessee.
- Communication barriers.

We share our stories in hopes that we may also to be part of the solution. The Vanderbilt Kennedy Center recognized the problems surrounding health care for people with disabilities, and the Center has launched efforts to improve care. I work at the Vanderbilt Kennedy Center as the program coordinator for the Developmental Disabilities Health Care Toolkit, which is also known as the IDD Toolkit. While the IDD Toolkit focuses primarily on the health care of adults with intellectual and developmental disabilities, great information and resources are available across lifespan at www.iddtoolkit.org.

We have partnered with a number of organizations and individuals to develop the IDD Toolkit, including the Special Hope Foundation of Palo Alto, California, the Tennessee Department of Intellectual and Developmental Disabilities, TennCare, the Boling Center at the UT Health Science Center in Memphis, The Arc Tennessee, and many health care professions, people with disabilities and their families. We now have:

- The IDD Toolkit website- www.iddtoolkit.org
- On-line training for health care providers and for people with disabilities and their families, which can be accessed from the website
- The ability to provide live videoconferencing telehealth training on key disability-related medical topics for health care providers

But there remains much to do. For additional information or if you have questions, don't hesitate to contact me. I can be reached at janet.shouse@vanderbilt.edu or call me at 615-875-8833.

Thank you again reading!



Janet Shouse



Lorri (age 50)

My name is Lorri. I am a little over fifty years young, and I have many gifts that make me who I am. I am emotionally supportive to others, I take care of a dog, and I work to facilitate research for people with disabilities. I have a lot of talents. Because I work and strive to remain active, there are often places I need to go and people I need to meet with. It is critically important that I remain in good health, and have fair and fast access to the doctors and the services that I need to not miss any of these meetings or appointments. Did I mention that I have cerebral palsy?

I have cerebral palsy. This is also an important part of who I am. I use my wheelchair for mobility, and I use an iPad to communicate. So, as you can imagine, there are frequent challenges that arise when it comes to accessing the healthcare services and supports that I need to keep being me.

I receive TennCare and Medicare. While you might think that access to both of these would be helpful for me it is often difficult to find doctors who will accept these types of waivers and benefits. On the occasion that my caregiver or I have been able

to schedule and secure appointments with clinics that accept TennCare and/or Medicare, other obstacles often arise. I have had trouble entering inaccessible buildings because of my wheelchair, communicating with nurses and doctors in a timely way because of my AAC system, or receiving respect from professionals in clinics.

Just this past April my caregiver scheduled an appointment for me at a women's clinic right here in town. My appointment was scheduled for 7:00 a.m. in the morning. However, when we arrived, the clinic was not prepared for me or my wheelchair. They had no lift. I had to wait until almost noon (FIVE hours!) for them to secure a wheelchair lift so that I could enter the building and then the exam room. After I was inside, nurse practitioners and doctors scurried about the clinic trying to accommodate other patients, and seemed to forget me as I was trying to communicate with them about the purpose of my visit and complete paperwork with my caregiver. Finally, as I entered the exam room, the doctors continued to only communicate with my caregiver, and not with me. I have a voice. I could have answered their questions. But they look at me as a child, and often do not treat me like an adult. This clinic visit is only one example of many.

For me the issue of quality healthcare for people with disabilities in our state only begins with accessing sustainable benefits. I understand that changes in legislation often invite change within the systems that serve us (i.e., healthcare). But the challenge doesn't stop here. Financial access to this type of care doesn't always mean that doctors, therapists, or specialists are logistically prepared to serve me or others like me. It is important that these types of clinics or practices learn about developing physically accessible spaces for individuals who use mobility devices like wheelchairs. It is also important for them to understand that we are not children, and we deserve to be dignified by being treated as adults.

Like I said, I have a lot of gifts and talents and am a busy woman. No one has five hours to spend at the doctor waiting for a wheelchair lift! ■



Rhonda (age 47)

my insurance company said to me, "Do you understand this is a very expensive item?" I said, "Do you understand that I live in this chair? If you don't pay for this, you might as well cut my legs off, or should I cut off yours? Because that is the same difference." They paid for it.

I got my new chair on June 29th of last year and on July 5th, my insurance company stopped paying for my physical therapy. They ruled it no longer medically necessary, but didn't tell me, my doctor, or my physical therapist. I was the one who caught it and had to get documentation. And do you know they still fought me after 81 pages of documentation and pictures? Just because I got a new wheelchair doesn't mean my cerebral palsy went away.

Because of the awesome medical team I have now, I'm very independent. When I went through the fiasco with the insurance company, my physical therapist continued to treat me from October to February without getting paid. That is someone who cares. Also, when I had surgery in 2014, my doctor came and visited me more than the actual surgeon who performed the surgery on me. Although it took many years, I have finally found a solid medical team that I feel cares for me.

Although I've had many issues with insurance and health care, I've realized the importance of self-advocacy. No one knows our bodies better than us, and it is important for us to make sure that our needs are met. No one should be able to tell us who we can and cannot see and what therapies or services we can't have access to. It is important to fight for what we know we need. ■

I was born in 1969 with spastic cerebral palsy. My parents were told I wouldn't live past 48 hours and I'll be 48 years old in July. They were told I would never live independently or do any of that stuff. I have two college degrees. I have a degree in medical billing and coding. I don't like the coding part, but I do like the insurance part because I get to fight for people.

When I first moved to Nashville, one of my goals was to be off of government assistance, including government insurance. Being off of government insurance meant I could go to the doctor I wanted to go to. I don't want to be told how many times I can go to the doctor. I don't want to be told how many prescriptions I can have filled. I just don't want to be told where I can go, whom I can see, and what I can do. My current insurer is kind of getting that way but I've fought them big time. A lot of people don't understand insurance, but I do. That's one of the main reasons I went to medical billing and coding school, because I deal with it on a daily basis. I wanted to educate myself and help other people. Somebody should not be telling us what we can and can't do.

Last year, I got a new wheelchair because my old wheelchair was starting to fall apart. I had to fight for it, though. A representative at

Samuel (age 30)

I am a special education teacher living and working in Maryville, Tennessee. I have three sons and one daughter. My oldest son, Sammy is 30 and has multiple disabilities. He has autism and an intellectual disability. He is blind, hearing impaired, and non-verbal. He also has chronic ear infections and motor impairments. Sammy lives in Knoxville in his own home.

My son Sammy is currently on TennCare. It can be very difficult to find providers and specialists who are comfortable and trained to work with adults with autism and who accept TennCare. High quality neurologists are particularly difficult to find. There are not many neurologists in Tennessee who will accept TennCare. Additionally, we have great difficulty finding primary care physicians who will take his insurance where we live in Knoxville. We are extremely lucky that we have additional resources that allow us to continue to pay out of pocket for private consultations—not everyone is able to do this.

I have traveled a great deal to take my son to the best doctors possible. I realize not every family is able to do this. And, honestly, it is getting more and more difficult for us. Because of his age, present health, and behavior, it is currently not in his best interest to make these long trips. It is a constant battle between traveling and finding the best care.

Our current doctor is nice and I have nothing to complain about him in particular. However, it is extremely hard to switch from a doctor with whom you have a history

and trust. I feel as though there is an overall lack of understanding in the medical field. For example, doctors occasionally want to put an IV in my son, yet they don't realize that you can't do that if he is awake. He will continuously rip it out. Additionally, doctors can seem frustrated when my son is not cooperative or engages in challenging

behavior, but we often have to wait hours before receiving care. So, of course he's engaging in challenging behavior after being in the waiting room for hours.

I also think it is vital that physicians listen to the family, as our son doesn't have a voice. We are his voice—his advocates. For example, my son's appendix ruptured and we were in the emergency room for over eighteen hours. We don't know when exactly it ruptured because he didn't present the typical

signs, there was no fever and he was able to walk when the ambulance picked him up. I just knew something was seriously wrong because I'm his mother and I know him.

It is a major worry to parents and family members. What will happen when you are gone? What would have happened if I was not there? Would my son have even gone to the emergency room? Would he still be here today? I understand that doctors are extremely busy, but you have to get to know the individuals with whom you are providing care. If you don't, how can you know the necessary care to provide? ■



Brian (age 39)

My name is Sue. I have three children, and we are originally from Michigan. When we retired 14 years ago, we moved to Tennessee with my now 39-year-old son Brian. We brought Brian with us because we did not want to leave him up there in Michigan; he was very lonesome after he got out of high school. Brian has something called William's syndrome.

There are some unique health issues associated with William's syndrome. There is a pretty prominent anxiety component. I'm a nurse, so I can advocate pretty well for the medical issues that arise. However, our challenge came when we first moved to Tennessee. Brian developed pseudo seizures. I thought he was having epileptic type seizures, and we have had him tested many times for epilepsy. He continues to have pseudo seizures, and while controllable, they have not completely gone away. They probably have an underlying cause of anxiety. In addition, four years ago, Brian had an acute anxiety break down and he was suicidal. As a result, the challenge became where to take Brian for something like this? Where do I take him for therapy? Although he is pretty high functioning, Brian does have an intellectual disability. Therapy might look different for him.



I've found out that a lot of adults with Williams syndrome have anxiety when they're younger, but it's usually associated with sounds and other various stimuli. As they age, anxiety levels can worsen and many individuals will face big challenges as a result in the adult years. I just couldn't find help for Brian. He was admitted to a psychiatric unit where they put him on drugs, then took him off drugs, and put him back on drugs again. I had him seeing a psychiatrist

and a therapist. The therapist was just wonderful, but she had to totally adapt her techniques to Brian. She had to research Williams syndrome, and we were lucky she committed to that, but he was changing medications so fast that it was a challenging time.

There is another challenge as our sons and daughters with disabilities age. There seem to be a lot more health care professionals available to provide services to children with disabilities. Finding health and mental health providers who fully understand how to work with adults with intellectual disabilities has been a much bigger challenge.

We are lucky that Brian has had access to good therapists. When his last therapist retired, she actually went out to find him a replacement therapist. I thought Brian would

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benefit from long term, in-patient care, so that he could receive the right type of medication and therapy for his anxiety and with observation, but there aren't places that will accept people like Brian.

We really have been through awful times. At one point, Brian was so drugged that people would ask if he was okay. After we visited the Lurie Center in Lexington, Massachusetts, our life changed for the better. Brian is off almost all of his drugs now and is doing well, but his mental health problems are our biggest challenge. Financially, it costs a lot to travel to Boston to see Brian's two doctors once a year. I have received some financial help from the Williams Syndrome Association, but not by any means does that cover all of it.

Brian's challenges have definitely impacted our family. I am not taking the trips in retirement that my peers take. Although Brian is doing well, we don't leave him overnight because he is just not comfortable alone. We do leave him during the day, but not at night, so we are limited in any travel. In addition, I'm going to be 68 and I still feel like I'm parenting a 12-year-old. I worry about his hygiene, and he doesn't have enough social outlets. I'm constantly trying to make plans for him. Transportation is another challenge. We will have to, eventually, move back to Michigan where my other children can help with Brian as our health deteriorates.

Insurance has also been a challenge. Since Brian has an IQ in the 70s, he has never been able to receive benefits through Medicaid waivers. He does receive Medicare insurance because he qualified for social security disability through a job he had in Michigan. He has a part of TennCare, which is just medical benefits. I do feel lucky because under Medicare and the TennCare medical benefit, everything is paid for, except for therapy for behavioral health issues. As a result, I pay for the therapy out of pocket.

We have been lucky in terms of medical needs. You need to find a primary physician that will really take the time, and that isn't always easy. We had to change doctors a couple of years ago, and Brian's current doctor will listen to me and take in the suggestions that I bring back from the conventions and the conferences. The Williams Syndrome Association has also worked hard to identify these health issues.

Brian has faced many social issues as an adult. When he was in school, there was a lot going on and he was being helped and included, but all that stopped when he left the school system. I'm sure his mental health issues have been exacerbated by his lack of social contact. It's not just that we need more connection and resources, but we also need more opportunities for our kids so that they don't need all these physicians and don't have as many health problems. ■

Rebecca and Nelda

(ages 60 and 58)

My younger sister Nelda and I were both born with congenital sensorineural hearing loss. I was diagnosed at age 2 1/2 and my sister's hearing loss was confirmed when she turned five. Once our hearing losses were confirmed, we immediately started intensive speech therapy and auditory stimulation in our hometown of Memphis, Tennessee. I wore one hearing aid in one ear and functioned and identified myself as hard of hearing thanks to good intervention. I lost my residual hearing in the better ear in my forties. I now have a cochlear implant in one ear and hope to have a second cochlear implant in the near future. Nelda has more profound loss. She wore her hearing aid in one ear until her teenage years, but then lost what minimal residual hearing she had. After high school graduation, she became more involved in the Deaf Community and began to embrace sign language to communicate as well as speech reading and talking (Total Communication).

Nelda was always sick as a child. She had strep throat infections, recurrent pneumonia, and kidney failure in her later years of childhood. A few years prior to her kidney transplant at age 15, she was on dialysis. Our mother donated the kidney, and Mom's kidney has lasted 42 years to date! Two years ago, Nelda had a stroke. It may have been largely due to her not being willing to take on a new medication for serious heart

fibrillation. The stroke has left her paralyzed on the left side of her body. She can no longer use her voice to speak, her signing skills have significantly decreased. She has the additional challenge of previously acquired diagnoses including heart fibrillation, end-stage kidney disease, kidney stones, and being prone to skin cancer



from anti-rejection medications for the kidney transplant. Since her stroke, I have taken on power of attorney responsibilities for her health care and finances.

I do believe Nelda has had access to good health care, both in Memphis and in Nashville. The current health system has done an incredible job of providing sign language interpreters

for her various specialty appointments. The interpreters are for Nelda's communication need, not mine. I use speech reading and can speak with Nelda's medical personnel one-on-one. With that being said, we still have our struggles in the health care system. The main issue I have is working full-time during work week and having little time to respond to and navigate the phone calls for Nelda's health care and with her multiple insurance coverages. Due to the added challenge of my own hearing loss, I have asked repeatedly to communicate either by emails or text messages. I can respond to emails and texts during lunch breaks. Many companies have policies against alternative communication and yet the American's

Disability Act (ADA) is supposed to allow for this. At least that is my understanding. I do plan to pursue further inquiries on answers to my rights to alternative communication.

Immediately after her stroke, Nelda was placed in a rehabilitation facility for approximately one month. At the rehabilitation facility, a nurse was asking Nelda about her pain level during an assessment. I was at work at the time and an interpreter was not provided. To gauge her pain, the nurse provided Nelda a sheet with happy faces and sad faces. Nelda pointed to a sad face, and was consequently given pain medication. When I came by to check

on her after work, I could immediately tell there was something wrong. Having learned she was given pain medication, I requested they stop. I did not believe Nelda was in pain, but actually conveying feelings of sadness because of her stroke. She was so out of it, and I knew her transplanted kidney likely wasn't able to process the medication well, so I was very concerned. Communication challenges can be potentially dangerous.

At the nursing home where she now resides, no one knows sign language. Over time, they have gotten to know her, but there is still a huge communication barrier between Nelda and her nurses. I stop by after work most

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days and Nelda will convey her needs and frustrations to me. I will then communicate to the staff. Another example where communication became an issue was of nurses giving laxative doses more than she needed. One reason this had been occurring is because assistants weren't always recording her intake and output levels

accurately or diligently. Nelda wasn't able to communicate her distress and discomfort effectively. I pointed this out repeatedly, and the nurse practitioner finally surmised that the dosage was more than necessary. Again, this is an instance where communication is key to effective health care.

Nelda has Medicare Part A, private health insurance, and also TennCare for long-term nursing home care. I spend hours on the phone going back and forth with insurance companies using captioning or relay service because of my hearing loss. Nelda also qualifies for Medicare—Wellcare Part D for medication coverage because of her low income. At first, Medicare—Wellcare did not want to cover her medications post-stroke because they didn't think they were responsible. In two instances, the nursing home said Nelda's medication coverage had been denied and that I needed to call Wellcare. Hours were spent using a telephone relay service, being on hold for an extended period of time, and being transferred to different divisions trying to resolve coverage. At that time, she was on around 21 medications and supplements that were supposed to be covered. Before her stroke, she was only on three medications.

All of these challenges have taken a toll on me emotionally, physically, and mentally. Being power of attorney for her finances and health care, caregiver, and advocate for her communication barriers, I feel I have no time to spare. I want to find a job that is 4 days a week instead of 5, so I have a solid day to devote to dealing with her case management needs. I was told the nursing home do not have case managers on staff. I visit her every day after work to be sure her health care needs are being met and to provide her with emotional support and company. I can tell she is getting depressed and tired. Her doctors are recommending treatments for her kidney stones that I know she is too exhausted for. She wants to just have a normal routine with no more stress or pain. She has recently entered palliative care because she declined a biopsy and other

treatments for kidney stones. The nursing home nurse practitioner recently met with us, along with an interpreter, and reviewed her medication list. With Nelda's agreement, some medications were stopped due to the goal of palliative care and quality of life. With some medications out of her system, there is now a noticeable improvement in her spirits and she is expressing renewed interests in activities outside the nursing home. She is more alert and seems to have more energy. Her smile is beautiful and she is looking great!

Despite the challenges, I have discovered the joys in providing care to her. The communication challenges for both of us will always be there and self-advocacy remain a necessity. There is still much to juggle. Life is a journey and one we both learn from daily. ■



Heather

(age 40)

Heather, my daughter, has an intellectual disability and bipolar disorder. She lives at home with us and spends time volunteering at the Country Music Hall of Fame. Over the years, we have interacted with a lot of medical and mental health professionals and have faced a lot of challenges. Receiving Heather's bipolar diagnosis was a scary and frustrating time for us. We didn't have answers for a long time. Heather would have mood swings and confusion, and when I would take her to her doctor they would say it was a urinary tract infection. She was hospitalized several times trying to figure out what was going on and even experienced hallucinations. They did a spinal tap on her. They put her on an antipsychotic medication and that was one of the scariest things as a mom that I have ever seen.

We finally found a psychiatrist who diagnosed her with bipolar disorder. At one point she was placed in the psychiatric wing of the hospital and I was unable to contact her while she was receiving treatment.

That was so hard for me because I couldn't go see her and I couldn't give the doctors any information. They had no idea what her baseline was, or who she is, or how she

communicates. It was frustrating not to be there and serve as her advocate. But, Heather did continue to see the psychiatrist and we were beginning to gain some understanding together and then he left the practice. When he left, I cried. I didn't know what we were going to do. Thankfully, he referred us to another psychiatrist and I do think it has been a pretty good fit.

Our family lives in rural Tennessee and there are a lot of barriers to accessing health care that come with where we live. There are not many medical and mental health professionals in our area who have strong knowledge about people with disabilities and about Heather's specific kinds of needs.

Currently, Heather has a very good primary care physician. She and Heather have a good relationship, but I just found out she is leaving. It's very stressful, because finding and building a good relationship with a doctor who works with people with intellectual disabilities is tough. Because Heather also has mental illness, finding doctors who can understand the way that dual diagnosis affects her is next to impossible.

Our family lives in rural Tennessee and there are a lot of barriers to accessing health care that come with where we live.

I wish there were more doctors and mental health professionals with knowledge on how to work with those with needs like Heather's. I wish there were more support groups for families. I wish

Heather had more opportunities to make friends who share common interests. I want Heather to be able to explore new learning opportunities and have community. ■

Evan (age 21)

My name is Janet and my husband of 33 years and I have three wonderful children—two boys and one girl. My sons are twins and one of them, Evan, has been diagnosed with an Autism Spectrum Disorder. Evan is now 21 years old and is currently a student in the transition program in Franklin High School in Franklin, Tennessee.

Finding and obtaining appropriate and affordable healthcare for Evan has been a struggle for our family since we were first attempting to get a diagnosis for our son. At about 18-19 months, Evan lost all of the language that he had developed up to that point. When I initially took him to his pediatrician at 19 months old, I was told to wait until he was 24 months—at his 2-year check-up—to do a developmental screening. When we finally did the screening, the pediatrician agreed that something was going on and recommended early intervention services, however we did not get any kind of diagnosis. At 27 months old, we got a speech evaluation for Evan, and after another 5 months, he was given a psychological evaluation, and we finally got a diagnosis.

After the diagnosis, we went to see a developmental pediatrician in Nashville. On our first visit, she recommended we

bring Evan back in 6 months so we could talk about medications. We were confused because our only issue was that he couldn't talk. I asked her if she had a medication that could make him talk, and since she didn't we decided he did not need to be on these powerful medications. She was recommending atypical antipsychotics—

what you would give to someone with schizophrenia—or antidepressants. For our 4-year-old!

By 16 years of age, Evan began presenting some significant behavior issues, such as putting his head through the drywall in our home, and lashing out hurting other people. At that point, we decided that putting him on medication for behavior management was reasonable, and began giving Evan atypical antipsychotics. Our biggest hardship was finding a doctor to provide mental

health services and related medication management. Evan's pediatrician would not prescribe the medications that he needed—we had to go to a mental health specialist in order to keep Evan on his medication. So many of the psychiatric doctors we found, did not take our insurance (or any insurance), or had no experience whatsoever working with individuals with developmental disabilities.



My wish is for primary care and mental health providers to have a willingness and a working knowledge of how to care for our children and young adults as patients.

Now, at age 21 we are getting into an area of even more difficulty as Evan is having to move from pediatric providers to adult providers. Again, we are having tremendous difficulty locating providers who have any previous experience with adults with developmental disabilities. Some doctors we have been able to see for several visits, then they announce that they are leaving private practice or leaving the area, so we are left scrambling to find someone new. Currently, we think we have found a developmental behavioral pediatrician who has agreed to see him, even though Evan is 21.

In 2015, Evan put his hand through a window intentionally during one of his rages and he lacerated his arm badly enough to require a trip to the ER. He was 19 years old. By this time, he had already had a number of very serious episodes of self-injury and property destruction. This was the first time it was serious enough to warrant emergency intervention. The doctor in the ER thought we needed to hospitalize him in a psychiatric facility to see about changing his medications. My husband and I had never, ever thought about the possibility of Evan needing a psychiatric hospitalization. As we sat in the ER watching our son sedated and having his wounds stitched up, I sent a desperate text to our former psychiatrist to ask him, "What do we do?" Even though it was nearly midnight, he called me back immediately to talk, and said that given what I had told him, he also felt Evan needed to be hospitalized. Evan's current psychiatrist, his previous psychiatrist, and his developmental pediatrician all agreed that he needed to be in there.

It took five long and anxious days with both Evan and our entire family on edge,

to even find a placement and make the arrangements, but they finally got him to a bed in the psychiatric hospital. I kept thinking that we were going to try to get him into the children's psychiatric ward. I just strongly suspected that they were not going to know how to deal with him on the adult side. It became really clear, really quick that they did not know what they were doing. They weren't showering him, or helping at all with his personal hygiene routines. They were allowing him to sleep in his clothes. I had to have a little heart-to-heart talk with the staff to say he needs to stay in a consistent and predictable routine. I had to explain how critically important such a routine is for people with autism. They had put Evan on the detox ward, because they said it was calmer and quieter on the detox ward than it was on the regular psychiatric floor with patients dealing with other mental health issues. The psychiatrist in charge of his case acknowledged right out of the gate to my husband and me that he had very little experience with people with intellectual and developmental disabilities. The staff tried to be accommodating, and there were several individuals there who did care, but they just didn't step up to the plate and do the things that needed to be done. It is likely they just simply didn't know how to properly support someone with his particular needs and limitations. But the reality is they are going to be dealing more and more with people like Evan, who are nonverbal, who may have an intellectual disability and may be diagnosed with an autism spectrum disorder.

My wish is for primary care and mental health providers to have a willingness and a working knowledge of how to care for our children and young adults as patients. The need is so great and growing. ■

Sadie (age 3)

"Sadie was a HUGE and beautiful surprise to us" Kristie says of her 3-year-old daughter, who has Down syndrome. She was born premature and was extremely resilient at birth. She waived some of the concerns about her early birth by being a vigorous feeder and not having any time in the NICU. Sadie was able to go home relatively quickly, but had to return back to the hospital due to a medical situation that could have been avoided.

"Sadie contracted the Respiratory syncytial virus (RSV) soon after her birth," said Kristie. "The horrible experience started with a questionable result on her PKU test with her thyroid. Her pediatrician at that time was insistent about doing an immediate retest through a blood draw. We found out that no one in our town could do the blood draw, so this forced us to drive her over an hour to Knoxville. We sat in an emergency room waiting area full of sick kids, completed our lab work at the hospital, and then drove back home. It was shortly after this visit that Sadie started showing signs of respiratory problems. We found out later that it was the worst RSV season in the history of that particular hospital, and Sadie was in the (took out extra "in") ICU for 17 days as a result of contracting RSV." "Sadie's previous pediatrician should

have known that her immune system was compromised," said Kristie. Why didn't her initial pediatrician consider that going for a blood draw in another city could equal danger for Sadie in the middle of winter and at her age and condition? Why don't our doctors individualize more when treating people with Down syndrome or other disabilities?"



Sadie currently has a wonderful Primary Care team meeting her needs however, Kristie expresses frustration that they have little access to pediatric specialists close to home. The family lives in Crossville and often have to drive to Knoxville or Nashville. Kristie says even seeking out providers for a simple dental cleaning and certain therapies is a major challenge. Kristie says another challenge is the lack of collaboration and communication among Sadie's health care providers. Her specialists do not communicate

with one another, and it falls upon them to keep track of her medical information and to navigate what is important or not important to share and with whom. She says it is a full-time job, given Sadie has seen 13 specialists to date, with keeping track of medical paperwork and to ensure that all of Sadie's health professionals are aware of what the others are doing.

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Kristie also says some doctors are actually hesitant to listen to them. When Sadie was 18 months old, she began exhibiting symptoms of severe gastrointestinal distress. Kristie believed Sadie was infected with C. diff bacteria from antibiotic use. When she brought up this concern to a gastroenterologist, they brushed her off and suggested it was simply a milk allergy. Sadie was actually prescribed an expensive formula that was 52% corn syrup solids. This medical call exacerbated the C diff as it thrives, as do other bacteria, on sugar. Over the next few months Kristie persisted with this argument. Instead of simply testing her for the bacteria, the doctors were hostile towards Kristie. Finally, after about three months, with Kristie's demanding a screen for C Diff they discovered that she did in fact have the infection. Sadie's months of illness could have been avoided had health care providers listened to Kristie from the beginning.

Sadie does not communicate verbally and is not able to express how she is feeling. Kristie must act as her voice. Kristie also notes that some children with Down

syndrome may respond differently to medical treatment than do typically developing children. She wishes that doctors were more accommodating and more willing to think creatively when treating individuals with special needs. ■

Morgan (age 23)

Tammy and her husband have been happily married for 31 years and have two daughters. Their daughter Morgan is 23-years-old and has autism spectrum disorder. The Vice family lives in the Nashville area.

In terms of access to a health care professional, Morgan was fortunate to have a pediatrician with whom she had a great relationship. However, the family faced numerous challenges in the transition from pediatric to adult health care services. To start, neither the family nor the pediatrician could identify a medical professional to whom Morgan might transition.

"It's frustrating that there are not more doctors and specialists who have experience working with adults with autism," said Tammy. "Knowing that our daughter needed treatment and medications, and not being able to find a provider who could meet her needs and who would take our insurance before medications ran out, was very stressful. Parents should not have to worry about that."



Morgan's first experience with adult health care was with a provider and staff who appeared to have no training or experience in treating patients on the autism spectrum. They did not communicate with Morgan directly. They spoke about her and treated her as if she wasn't there. Tammy says their interactions were fraught with stereotyped assumptions about autism, and about Morgan's behaviors and movements. One remark she remembers well was, "They all rock like that."

Disability awareness and training are a must for medical professionals to adequately meet the individual needs of patients.

"Let's just say that we did not go back," said Tammy. "I didn't know how important it was to have a medical professional who saw Morgan as a person with individual needs, a professional who respected our experience and

self-knowledge, until we didn't have that anymore. Disability awareness and training are a must for medical professionals to adequately meet the individual needs of patients. ■



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