

## Considerations from Families Living in Rural Counties



# A Letter of Thanks

Thank you for reading this collection of stories from individuals with intellectual and developmental disabilities and their families living in rural counties in Tennessee. Their stories highlight the barriers they face when trying to find services they need close to home.

The stories in this booklet are extractions from interviews conducted by students from Vanderbilt University and through the Vanderbilt Kennedy Center's Kindred Stories of Disability project. As part of a course assignment, the students interview individuals with disabilities and families to learn more about their encounters with education, health care, housing, employment, and disability services in Tennessee. The assignment gives future educators, advocates, and researchers an opportunity to learn firsthand from families. It gives individuals with disabilities and families an opportunity to educate their elected officials and to make issues concrete and personal, and it gives legislators and policymakers an opportunity to hear from their constituents with disabilities and to learn about the issues that are important to them.

We would like to thank the individuals with disabilities and families who shared their stories. By reading them, you will receive snapshots in time of a diverse group with a variety of challenges and successes. While we did not set off to find stories that focused on how the system is not working, we did find most of the families we interviewed had significant challenges that made access complicated or even nonexistent.

We would like to acknowledge the longstanding partnership between The Vanderbilt Kennedy Center and The Arc Tennessee on the Kindred Stories of Disability project. It is an example of the commitment to collaboration that Tennessee disability agencies have as they work to improve the lives of Tennesseans with disabilities and their families.

To view past and current story collections from Tennesseans with disabilities, please visit:  
[vkc.vumc.org/kindredstories](http://vkc.vumc.org/kindredstories)



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# Introduction

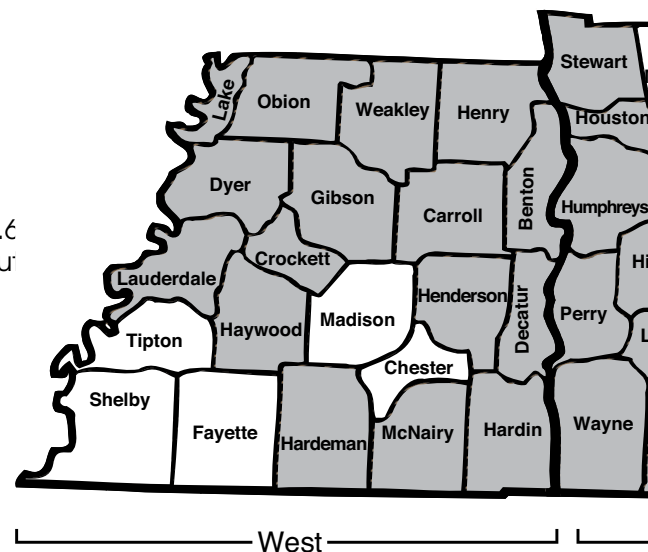
Tennessee is the 17th largest state in the United States. It has 6.6 long (450 miles West ↔ East) and narrow (130 miles North ↓ South) counties and a majority of the counties are rural.

While there are varying definitions of “rural,” we will use the definition of a rural area as one that, compared to a city or even to suburban areas, has few people per mile. We learn how many people are living in areas (population density) each year through the data collection of the United States Census Bureau. Population density data is used to determine things like the distribution of congressional seats to states, planning decisions about community services for areas, and how and where to allocate funds to reach people and communities that need it. Counties that have lower population densities will have fewer services. And that can affect the quality and access to health care, education, neighborhood improvements, transportation, services for the elderly, job training centers, and so much more.

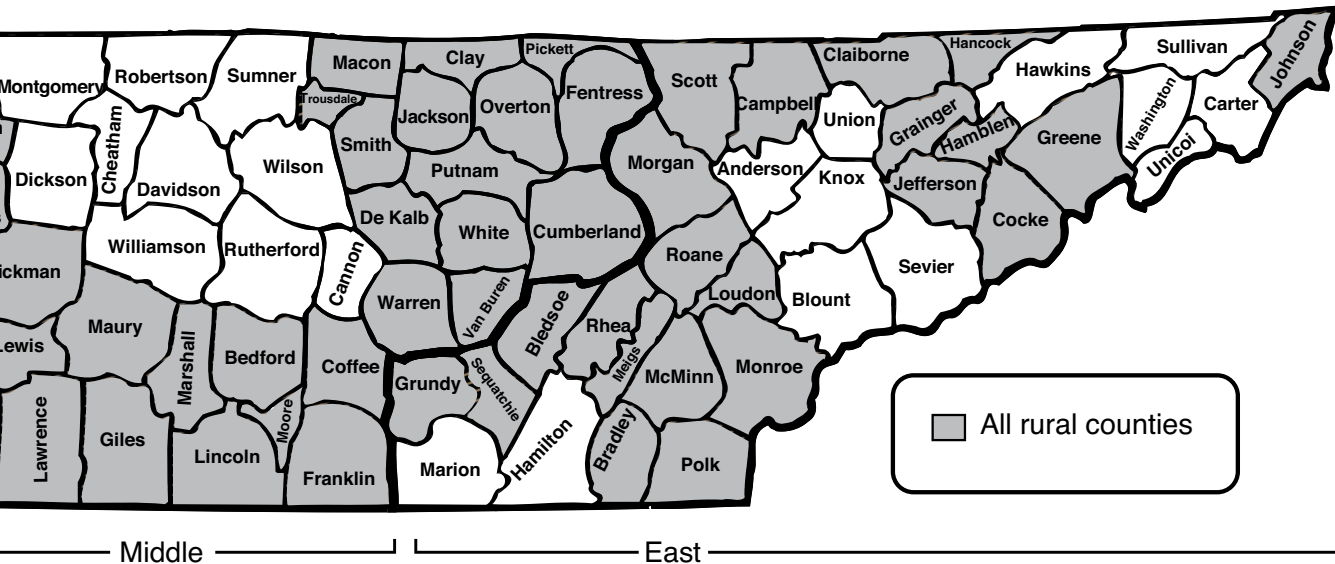
The individuals with disabilities and their families, whose stories are included in this booklet, told us about the challenges they face when attempting to find quality services close to home. Many of the families interviewed travel two to four hours to the nearest cities to see doctors, psychologists, behavior analysts, and occupational therapists. Some families report having to end much needed services because the travel it requires to access them is too burdensome. Other families are unable to access a service they know their family member needs, such as a dentist or a teacher who has received training or who has experience working with people with disabilities. Some parents report having to quit their jobs to stay home and care for their sons and daughters, sacrificing additional income or insurance that are critical components to accessing what they need to thrive.

In addition to sharing their stories, families also completed service-related surveys. These surveys provided insight into which services these families received, how far they had to travel to access particular services, and which services showed the largest gaps between what was needed and what was available in their respective communities. By examining these data, we can provide a bigger picture outlook as to what are the highest areas of need for families in the rural counties of Tennessee. It should also be noted that more people were interviewed than displayed in this booklet, though not every family whose story is shared here participated in the survey component.

From the sample who completed the survey, the most used services, in order, were Dentistry,



## Rural Counties in Tennessee



Speech-Language Therapy, Occupational Therapy, and Specialized Medical Care. Of these, some services required long travel; Specialized Medical Care most often required travel for longer distances, with eight out of nine recipients traveling over 50 miles in order to access the service. Many participants also reported needing to travel over 50 miles to access such services as Speech-Language Pathology, Parenting Skills Training, and Dentistry. When examined by individual, 80% of respondents traveled more than 50 miles for at least one service.

Conversely, families also reported needing many services that they were currently unable to access. Among the most needed services were Respite Care, Parenting Skills Training, Psychological or Mental Health Services, and Behavior Support. For each of these services, a high percentage of the sample was not receiving the service, but over half of that group reported wanting that service. Delving further, many respondents reported that Respite Care Services, Mental Health and Psychological Services, and Parenting Skills Training were simply not available in their areas.

Additionally, individuals with certain diagnoses were also more likely to need services that were not available in their immediate communities. This distinction occurred most often for individuals with autism. Of the six respondents reporting that they needed but were not receiving Psychological or Mental Health Services for their child, all of the individuals with a disability had a diagnosis of autism. Furthermore, four out of the six individuals who reported a need but were not receiving Parenting Skills Training also have children with an autism diagnosis. This finding mirrors prior findings that, even compared to persons with other disability conditions, those with autism often need—but have difficulty accessing—many services.

Combined with the stories shared throughout this booklet, these numbers amply illustrate the needs of individuals with disabilities and their families living in rural areas of Tennessee. ■



## Chaz (age 34)

### Jackson County

let him sit there in his chair and draw, or do whatever he wanted to do. Essentially, he learned nothing. The school system let him down.

There are a lot of services and modifications that would have been good for Chaz that he did not receive in school. He would have benefitted from having a one-on-one support person. That would have made a big difference in his education, but that did not happen. Apparently, the small and rural school systems are strapped for money and cannot afford these things. Not only did the district not have the financial resources, but they were also at a loss as to how to help us decide what Chaz needed. His teachers would tell me they couldn't follow his IEP, because it would not be fair to the other students. Not following it is not fair to Chaz. I looked to the system for advice, but that ended up being a mistake.

Chaz's greatest span of learning has come in the years after school. I see that once he determines that he needs to learn a skill, he works on learning it. He has worked hard on skills like telling time and counting change. His cell phone has been motivation to practice things like reading, writing, and communication.

Chaz has always had difficulties with friendships. He doesn't always know what's appropriate or how to develop relationships. He is naïve, and because of that, people have unfortunately taken terrible advantage of him. Chaz is constantly complaining about being lonely. He wants to communicate and to make connections with others. I wish we had more social activities in our community that would be suitable for Chaz. There is a sports group for people with disabilities, but

We began fostering our son Chaz when he was 14 months old and later adopted him at the age of five. During this time, we were living in Chattanooga, Tennessee, but later we moved to a rural county in Tennessee. The decision to make that move was because of Chaz. We wanted to raise him in a more natural and relaxed environment. Chaz was about 6 years old when we learned that he has autism. He also was diagnosed with attention deficit hyperactivity disorder, obsessive-compulsive disorder, and multiple learning disabilities.

Chaz entered public school in first grade. Unfortunately, formal education for Chaz was a catastrophe. Our community is very isolated and the services are significantly limited. The teachers were caring, but they did not have training in autism. They didn't even understand the basic characteristics of autism, so how could they teach my son? For the most part, they were not successful. They would tell me Chaz just wasn't trying as hard as he should. Chaz was never a troublemaker, so consequently he was one of those students who was just left alone and who fell through the cracks in school. They

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Chaz doesn't like sports much. Because we live in a rural area, there are very few social activities available. We are constantly looking for something for him to do, but we have just not been able to identify any of those opportunities.

Chaz has two jobs. He works for two hours a day at a thrift store chain and for two hours a day at a fast food restaurant. He truly makes a fabulous employee. He has worked for seven years at the thrift store and he has never taken a sick day.

Chaz moved into his own apartment and currently receives daily-living assistance. We were able to get him on a Medicaid waiver through the state. This has just been the best thing that has ever happened for Chaz. He has a personal assistant, Brandon, who works with him 6 days a week for 5-6 hours a day. Brandon has been working with Chaz for 7 years now to help him do things that he has difficulty doing for himself. He supports Chaz in his efforts to learn, helps transport him to work, and takes him grocery shopping. He helps Chaz to be more independent and to feel more confident in his abilities.

Chaz was very fortunate that we had a wonderful advocate who helped him get onto the Medicaid waiver. Not everyone is that lucky. Without the services the waiver provides, without Chaz's support provider, and without health care benefits, we would be in a much more precarious position. Unfortunately, there are a lot of people right now who need these services who aren't getting them. ■

# Brianna & Briella

(age 27) Monroe County

My name is Scotty. I am 63 years old and I live at home with my twin daughters, Brianna and Briella. When the girls were 5 months old, we took them into our home via the foster care system. We were finally able to adopt them when they were 3 years old, and we have had them ever since. It's just the three of us who live here in the house now. I'm a single parent after my wife and I got divorced in 2000. I've had to retire so I could take care of the girls because they need constant supervision.

Brianna has been diagnosed with paranoid schizophrenia with severe delusions. She is also diabetic. Sometimes she has trouble with doing everyday things like going to the toilet or taking a bath. Briella has been diagnosed with several different things, but she was diagnosed with schizophrenia about three months ago.

In a rural area, it is very hard to find medical care that is close. The closest resource for the girls is about an hour and fifteen minutes away. Brianna currently has a psychiatrist who handles her mental health concerns and prescribes her medications. She sees the nurse practitioner at that office every two months. She also has a primary care physician who handles the health problems and her bloodwork. Unless Brianna is in crisis, she is usually seen every two months. She had a crisis recently where she cut her face and she had to go to a hospital in Oak Ridge, Tennessee. We have to travel long distances to get the girls what they need and that can be a challenge.

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Getting services for Brianna and Briella has always been a struggle. Some good news is that we were approved for a state waiver two years ago. We now have 12 people on board to support us, which includes case managers and all kinds of people. We have a meeting about once a month and we discuss the services we are supposed to be getting, but the bad news is we aren't currently getting the services that would be best for our family.

I really need help with the girls at home. I want the girls to stay in their home and an assistant for them would change all of our lives. Right now, I have to take care of the girls all day and night by myself. They just can't seem to find us someone who will travel to us and work for the low amount of pay that is offered for services in rural areas like

ours. Also, the people who you do find don't really seem to understand a lot about mental illness. I think people need more training on mental illness before working with people.

When I do hear of parenting skills trainings or workshop seminars that I think would benefit

the girls, I do try to go. I can't leave them alone so they have to sit out in the car while I'm there. Insurance doesn't pay for stuff like that, so I have to pay out of pocket, which I cannot do all the time. Like I said, I had to retire to take care of the girls, so I have had to sacrifice tremendously. Something has to change for people and families like us out here. ■





## Ben (age 18)

### Obion County

Often, I find that I know more information than the educators do and that makes me angry. For example, my son wants to go to college. Neither his teacher, nor his guidance counselor knew about any college programs for students with disabilities in the state. Even his vocational counselor did not know about any of these programs. I recently found out there are five college programs for kids with intellectual disabilities in Tennessee. Why do the teachers not know that? Isn't it their job? I found out about the programs on my own. My experiences have taught me if I don't find information and advocate for my son, no one will.

My name is Dianah. I live with my eighteen-year-old son, Benjamin, in a small town called, South Fulton in Tennessee. Benjamin has lived in South Fulton for his entire life, so everyone in the community knows him. Benjamin and I do not have any family in town, but the other parents of special needs children feel like family to us.

Benjamin's disability affects absolutely everything in his life. It affects how people treat him, how he learns, and how he takes care of himself. Ben has trouble making friends and is often excluded or treated poorly by his peers. He reads and writes at a third-grade level. He has trouble with daily living tasks and with taking care of himself.

I have found that the biggest challenge we face in our rural community is a lack of access to resources and information. We never receive any information from schools or organizations here. We are never invited to parent meetings. We are never given pamphlets or information that might help us to figure out how to help our sons and daughters. We do not learn about what is out there and it is extremely frustrating.

Ben has faced discrimination as he has tried to find a job. My son wants to work so badly. He has put in job applications, but no one will hire him. Ben could bag groceries, sweep, mop, be the best door greeter that anyone has ever seen, but they always say that there are no openings. Meanwhile, when I go to the store with no openings, I see that they hired new employees that are all high school kids at Ben's school. Ben wants a job. Ben wants to go to college. Ben wants what all 18-year-olds want.

I worry about what will happen to Ben when I am not here to help him. Some of us don't have family to take care of our children after we die. The state takes custody of our children and puts them in group homes or nursing homes. That's why parents want their kids to get more job skills, communication skills, and daily living skills. We are not going to be here to protect our children forever, and we worry about what will happen to them when we are gone. We want our sons and daughters to have the opportunity to live their best life possible. To be independent and happy. ■

# Jensen (age 8 months)

## Greene County

My name is Judy. My husband and I have four wonderful children. My two younger children both have special needs. Jensen is 8-months-old, and he has been diagnosed with Down syndrome, Hirschsprung's Disease, and a submucous cleft palate.

Jensen was in and out of the hospital a lot after he was born, with some visits lasting up to 13 days. He lost so much weight that he almost died, and most of it was due to the fact that we did not have a local physician who was knowledgeable about Hirschsprung's Disease.

We searched long and hard and found a specialist, but the office was located in Columbus, Ohio. Our family resides in Greeneville, Tennessee, and making monthly trips to see the specialist there has been very difficult for our family. Through these monthly trips, Jensen has undergone surgery to try to eliminate the need for ostomy pouches, but it is a process. He has three more surgeries to go to help his gastrointestinal system function like other children his age.

In the meantime, trying to obtain the services that Jensen requires has been very difficult. Jensen's insurance has not been covering his doctor's visits, prescriptions, eye

glasses, ostomy pouches, or his specialty feeders. Due to this problem with insurance, it restricts the number of ostomy pouches that I can receive. The pouches have to be changed daily and sometimes we don't have enough to make it through the entire month. This is very scary for our family because of the increased chance of Jensen getting an infection. Jensen is 8-months-old, and his medical bills are going to collections due to the insurance not paying them. It's very difficult trying to provide the best care for my child, when I can't afford the supplies and services that he requires.



Jensen does have a primary care physician in our hometown that he sees if he is sick. However, he is not familiar with how to provide the proper care for an individual with Down syndrome and Hirschsprung's Disease. Greeneville has a limited number of physicians that have experience with individuals with disabilities. Jensen's specialist appointments are in Nashville, Knoxville, and Johnson City. We also travel to Bristol, Virginia and Columbus, Ohio on a regular basis.

Jensen's stitches around his small intestine and his ileostomy broke twice. One time

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causing the small intestine to prolapse and swell so much that they could not get it back in and he had to be flown to Knoxville to save his life. This occurred when we took Jensen to our local hospital and they had no idea how to provide care for Jensen. Jensen screamed and cried so much in the time that we were waiting to be seen that it caused the swelling to worsen. Jensen's physician out of Ohio had to call our local hospital to tell them how to care for and package Jensen so that he could survive the flight from Greeneville to Knoxville. It was very traumatizing to go in to our local hospital with an emergency they did not know how to treat, and to know that we could have lost our child because of that.

I wish we had more medical providers who are trained to provide care for my child in our area. It's truly a matter of life and death. ■







## Jason (age 5)

### Hardeman County

My name is Denise. I live in Middleton with my husband and our three sons. Each of my sons have a different disability and their own set of medical needs. My oldest, William, is 6 years old. He has ADHD and kidney dysfunction. My youngest son, Andrew, is 2 years old. He is nonverbal and has heart issues. My son, Jason, just turned five and he has multiple disabilities. He has cerebral palsy, muscular dystrophy, and an intellectual disability.

Jason was diagnosed with cerebral palsy at the age of one, and his other diagnoses came soon after. When he was six months old, he received his G-tube due to feeding issues at the time. Currently he eats soft foods (puree) by mouth and takes formula and medicine by his G-tube. He cannot walk, so he currently uses a wheel chair. He can also be in a walker, which he only uses occasionally at school and at therapy. Jason has a hard time communicating verbally. He mainly uses a communication device to talk with us.

Jason needs my help a lot. He can't change his clothes or get himself out of bed. We also have a nurse who comes in to help. Her main role is to go to school with Jason, because before her arrival he wasn't allowed to attend school without a nurse. The school's nurse was afraid of his G-tube and told us she would not touch our son.

The hardest thing for our family to obtain is medical equipment. Between insurance issues and distance from the doctors, it takes

about six months for us to receive equipment and supplies. For the most part, we have some great doctors that my son, Jason, sees in Jackson. It is quite a drive to get to him and our other specialists. At this time, Jason sees a bone specialist, a doctor for his G-tube, a heart doctor, a kidney doctor, a liver doctor, and a genetic counselor. It would be very helpful if every time we needed to see these specialists or ask questions we didn't have to drive three hours from home.

Jason is in his last year of pre-K. It's about ten minutes from our house. His classroom serves about ten other students, with three teachers and a nurse. It is an inclusive classroom, with about 3-6 children with disabilities. At school, Jason receives speech therapy and occupational therapy, but I have yet to meet these teachers. His school will not provide other therapies Jason needs, so on Thursdays I have to pull him out of school for his more specialized therapy at a learning center. As a parent, it is difficult to know what is going on at school. I don't know if he's getting the educational services he needs.

It is difficult to talk about community involvement and Jason, because there is none. Jason does not have any friends, programs, or support. Instead, the parents just look at us like we're weird. Jason's feeding tube especially makes them nervous. It is harsh to watch them stare and whisper.

My concerns for access to services extends beyond my family. Over the years, I have learned to advocate for my family. However, I have a friend who is really struggling to get services. I want to continue my education to help others, but there need to be more people helping families like hers and mine to get access to the services our sons and daughters need to help them succeed. ■



# Kevin (age 18)

## Gibson County

My son Kevin has Down syndrome. Kevin is currently in high school and lives at home with my husband and me in rural West Tennessee. His sister and her husband live three miles down the road from us and she often visits us with her three children.

Kevin has been in an inclusive classroom environment since he was three years old. He is usually only pulled out of his classroom for part of the day for core subjects like reading and math. He takes economics, government, and fashion classes at his school. Kevin is verbal but sometimes people have difficulty understanding him. He also struggles with social skills and we work on them with him on a daily basis. Kevin also has sensory processing disorder so he often takes a few minutes to process something. Sometimes we need to explain changes in his schedule and give him time to process what those changes mean.

I sometimes worry about whether Kevin is getting health care that fits his specific needs. Kevin's compromised immune system is his biggest health concern. We are lucky that we found a good primary care physician he can see when he is sick, but we had to search long and hard for her. When Kevin was born, his doctor at the time told us there was nothing we could do for him. He said that we would just have to wait until Kevin got older to work with him. Of course, that wasn't true

at all. In rural areas, it can be more difficult to find people who are knowledgeable about developmental disabilities like Down syndrome, or who are up on all the latest research.

Outside of our primary care provider and specialists that Kevin sees in Nashville, it is difficult to get high quality medical care. We've had to go to the emergency room four or five times over the course of his life, and it has never been a good experience. Most recently, he had an accident. He was twirling a pole, dropped it on the ground, and it bounced up and cut his eye. I grabbed him and ran to the emergency room. The doctor

came in, he looked at it, put drops in, gave us a prescription for some eye drops and we left. I ran all over town looking for those eye drops and nobody in town had them. My son-in-law is a pharmacy tech in another town and I texted him to ask if he had these drops in his pharmacy. He informed me that their pharmacist was concerned about giving this eye drop to Kevin because there's a very specific warning. It turns out that one drop of that medication can cause seizures in people with Down syndrome,

and they prescribed him three drops. While we are lucky to have a great primary care doctor, any time we have to see another doctor, there are always concerns. ■






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# Addyson

(age 9)

## Grainger County

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My name is Miranda. My wonderful family and I live in Bean Station, Tennessee in Grainger County. Except for a few years after college when I lived in Knoxville, Bean Station is where I was born and raised and has always been the place that my family and I have called home. My husband and I have a beautiful 9-year-old daughter named Addyson who has autism spectrum disorder.

At around 14 months old, I began noticing certain things that let me to believe that Addyson might have autism. Even though I had worked with children with autism in my line of work, I had an extremely hard time getting anyone to listen to and acknowledge my concerns. I initially presented my concerns to her primary care doctor. It took me three to four months to get an appropriate referral from anyone to have her tested. After different referrals and a couple of visits from Tennessee Early Intervention Services, my suspicions were confirmed.

Along with her primary autism diagnosis, Addyson also receives treatment for sensory processing and an attention deficit disorder. Addyson has the ability to say almost

anything, but she struggles in knowing exactly when and how to say it. For example, Addyson does not know how to make requests for things she needs, and often struggles with back and forth conversations. She can easily answer questions if you provide her with choices, but if you were to ask Addyson what her name was, she would most likely not respond.

Addyson's early education was a huge struggle. The school system did not respond well to her and did not understand her needs. When she was in preschool, the school would call me almost every day. They were not supposed to do that. She was often upset and they did not know what she needed, wanted, or what to do in order to help her. They were kind people, but they did not have any training to help Addyson. I was not impressed with the services offered to Addyson in kindergarten either. I did not feel like she was academically progressing in the ways I knew she was capable of, so I began homeschooling. I have continued homeschooling Addyson and she is now in third grade.

Addyson has a tutor who has some special education experience and comes to our house 6 hours a week. We worked with a therapist to decide that Addyson needed another person to teach her other than me some of the time. It is important that Addyson interact with someone else other than me in her educational day. The tutor has done a fabulous job for the time she spends with Addyson. Her services are considered a respite care service, and her time is a benefit we receive from a local organization.

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***Most of her appointments are in Knoxville about 50 miles away.***

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Unfortunately, while I know it is the best decision for my daughter, homeschooling Addyson has most definitely impacted our family financially. I had to stop working for a while, but now, I am able to work part-time to help support our family. Regardless, it has placed a financial strain on our family. In addition to our loss of income, Addyson will also be losing her insurance soon. Currently, Addyson has insurance through TennCare. She receives outpatient care for occupational therapy, speech therapy, feeding therapy, and vision therapy weekly. This would add up to about \$500 a week without insurance, and unfortunately, we cannot afford that out of pocket. Finances are the main obstacle that will stop us from getting Addyson the services she needs.

With regards to medical care, Addyson has had a number of experiences with a wide range of doctors. She has a primary care doctor in Talbott, and that is who she sees when she is sick. Her primary care doctor is great with colds and other basic physical illnesses. However, beyond those physical illnesses, her primary care doctor is unable to help us with much. Because of her current insurance coverage through TennCare, we

have not had any pressing issues seeing a wide range of specialists, from a neurologist to a GI doctor, and even an ear, nose, and throat doctor. Most of her appointments are in Knoxville about 50 miles away.

I wish we could bring the services that people with autism have access to in the metropolitan areas to Grainger County. I would love to know more about Applied Behavior Analysis (ABA) services to see if they would help Addyson. She is a great kid and I want everyone to know it. I want her to have the best possible outcomes, as any parent would. The reality is that the only daily support Addyson has is Jeremy and me. We are the team. We are the advocates. We are it. ■

# Gabriel (age 6)

## Obion County

I grew up on a farm in the country and my husband, Steven, grew up in a small town nearby. When we decided to settle down and start a family we knew the countryside of Obion County would be a good fit for us. Steven and I tried for many years to have a child. When we found out that it was not an option for us, we turned to adoption. We were able to adopt our son, Gabriel, from birth. Gabriel is now six years old and is in the first grade.

Gabriel currently has a diagnosis of Autism Spectrum Disorder and ADHD. His biggest challenge is overcoming anxieties of the unknown or agoraphobia. It is incredibly difficult for him to play in a large group of children and I can barely get him through the door at community events, such as fall festivals at his school. Even going to church each week is a struggle and it will often take more than ten minutes to calm Gabriel down enough to get him into the sanctuary or children's Sunday School. We tried to get Gabriel to participate on a t-ball team over the summer, but this was too overwhelming for him and he would often run away.

One of the most frustrating things about Gabriel's situation is the lack of services that have been provided to him because of our location in the state and because people are not trained in working with people with autism. I have tried for so many years to get Gabriel the help he so desperately needs to feel comfortable in his environment and to overcome the anxieties, but it has been a battle all along the way. We have seen numerous doctors, neurologists, and developmental pediatricians. It took more than two years to get the first diagnosis, and that came after many, many trips to Memphis to see specialists.

There is not only a problem with the lack of services for children and their families in rural areas, but also a total lack of training for teachers and providers on how to work with children with special needs. Gabriel's teachers have not been trained to work with children with autism. There is only one person in the school with special education training who will pull Gabriel out of class for extra help. She is also called into the classroom when his behaviors get too out of control for the teachers. One person in the school with this expertise is not enough. The teachers need more opportunities for these specialized trainings.

In addition to the lack of training for teachers and professionals, more opportunities for parent and caregiver education and training needs to be a priority. I have attended several workshops for parents in Nashville, but it is a long drive and requires a lot of effort to get there. While I have found the workshops to be helpful, I feel like they are aimed at younger children. I wish I had known about them when Gabriel was much younger. Getting information to parents and caretakers early is so important and can help prevent future issues.

I feel like so much more can be done in our county to help not only Gabriel, but all of the other children who do not have the supports they need. It is hard as a mother. I am trying my absolute best to fight for him, to be his advocate and to make his life easier. It is difficult when the necessary services are not readily available. I am trying to be his voice, but I need help. ■



# Bailey (age 18)

## Lawrence County

Bailey is a sociable, sweet teenager from Lawrenceburg. Bailey was born with Down syndrome and two heart defects, which required her to have heart surgery when she was two months old. She did not require any further heart treatments until this past year when she received a pulmonary valve replacement. Bailey also has severe dysphasia and tracheobronchial malacia, which causes her to aspirate on all liquids.

Bailey is an active member in our community. She participates in Special Olympics in events like bowling, basketball, bocce, and track and field. She is the girls' basketball and volleyball manager for her high school, and is very involved with activities at our church. Bailey loves to get on social media, text her friends, hang out, and eat Mexican food. She currently attends high school and is projected to receive an occupational diploma.

Bailey's disability and other diagnoses impact her day-to-day life. Her conditions impede her ability to swallow. This has led to several hospital stays. Because Bailey cannot take any liquids by mouth, her doctors put a G-tube in prior to her heart surgery when she was 16 years old. The doctors were hoping the G-Tube would only be a temporary fix, but shortly afterwards, we realized the G-Tube is now something she will have her entire life...and she hates it.

Up until last year, Bailey received intensive swallowing therapy to strengthen the muscles in her throat and to help to alleviate some of her invasive aspirations. Our private insurance

company recently decided they were no longer going to pay for the therapy. Living in a small rural town, some services can be harder to come by. The swallowing therapy is critical for Bailey, and since she stopped receiving it, she has been in and out of hospitals. Even though she can feed herself, Bailey has to go to the school nurse twice a day to eat. She has to eat with the nurse in case something happens.

Bailey was seeing a local dentist who was three blocks away from us. However, because of her aspiration diagnosis, the dentist dropped her as a patient. They were nervous about providing service to her, and didn't want to be the reason she gets pneumonia or be liable for any issues. So now, we have to drive to a dentist's office two hours away.



Bailey also had a pediatrician 30 minutes from home. However, the providers were unable to manage Bailey's health. Subsequently, Bailey's primary health care provider and specialists are now in Nashville. We also have to travel an hour and a half to see: a pulmonary specialist every three to six months, an endocrinologist every six months, and a cardiologist once a year.

Overall, Bailey receives the services she needs, but it is a difficult and long road to get there. I am the mom who will fight for what my daughter needs, but I think a lot of families in rural communities end up accepting what is given to them and not fighting for services. It's often because they don't know they can. ■



My name is Jennifer. My husband Rusty and I are both longtime residents of Paris, Tennessee. Paris is a rural town, largely a retirement community, which lies on Kentucky Lake. We have our first son, Justin, who is 16, and we have Tyler, who is 5. Tyler was born with Down syndrome.

Tyler has a lot of friends and he gets along with everybody. He likes to listen to music and dance, play basketball, watch movies, and play outside. He's your average stubborn, silly, and determined little boy. In addition to having Down syndrome, Tyler also has sleep apnea, atrial septal defect (a hole in his heart), has glasses, and hypothyroidism. Tyler sees the following specialty doctors for these issues: an ENT, an endocrinologist, and a cardiologist.

We are a determined family and enrolled Tyler in therapeutic services six weeks after he was born. I even stepped down from my full-time nursing job to dedicate time to ensuring that Tyler met his developmental milestones to the best of his ability. I stayed home with Tyler and took graduate courses to earn a master's degree. I read about every book imaginable on Down syndrome. I took Tyler to outpatient speech and physical therapies on a weekly basis. These services were located both in an outpatient clinic in

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## Tyler (age 5)

### Henry County

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Paris and at a children's hospital in Nashville, which is 120 miles from our house.

At one point, we decided it would be in Tyler's best interest to find a daycare program. There are many private options for daycare services in Paris, but none of them would accept Tyler. They said they did not know how to care for him.

Eventually, we found a Head Start program for Tyler where he could go for five days each week. We also enrolled him in Tennessee Early Intervention Services (TEIS). TEIS would come to his daycare to provide intervention services. This was perfect and worked out really well for Tyler and our whole family. Tyler also received physical, occupational, and speech-language therapies through the Head Start program. These services helped with Tyler's development, and we saw great improvements. At the same time, the dependability of the daycare staff was poor and inconsistent, and that had some negative effects on Tyler's experience there.

Tyler and I would travel to Nashville for a clinic for children with Down syndrome as frequently as we could. We also traveled to Jackson, Tennessee for music therapy. Although these services were helpful, they are not close to where we live. We were traveling such a great amount that it became too time consuming and too much for our family.

Currently, Tyler is in a pre-kindergarten classroom at a local elementary school in Buchanan, Tennessee. My biggest concern with Tyler's education is the lack of occupational therapy (OT). Tyler's first evaluation for his IEP indicated that he only needed OT services three to five times

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***Because we live in a rural area, we don't have access to certain therapies and opportunities. Sometimes we don't have access to things most people might not think about, like a playground. Paris does not have an accessible playground.***

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throughout the entire school year. I appealed that decision, bringing in a professional second opinion suggesting that Tyler would benefit from OT at least once a week. The final decision was that Tyler would receive OT nine to ten times within the school year. However, the OT doesn't communicate with us about Tyler's progress, so we are unsure if he is even seen by her at all. I am frustrated that Tyler still cannot hold a pencil. The amount and quality of OT he is receiving is not enough to help him progress. The OT services in our small school district are simply insufficient.

Because we live in a rural area, we don't have access to certain therapies and opportunities. Sometimes we don't have access to things most people might not think about, like a playground. Paris does not have an accessible playground. Although our family tries our hardest for Tyler to have the very best life, we still encounter challenges with lack of resources and education about disability around us. ■



# Resources

Tennessee Disability Pathfinder  
[TNPathfinder.org](http://TNPathfinder.org), (800) 640-4636

Provides free information, resources, support, and referrals to persons with disabilities, their families, friends, and professionals. Through individualized assistance, community engagement activities and trainings, and a community support program, they provide information and resources to individuals of all ages, all types of disabilities, and any language spoken.

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities  
[vkc.vumc.org](http://vkc.vumc.org), (615) 322-8240 or toll free (866) 936-8852

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.

The Arc Tennessee  
[thearc.tn.org](http://thearc.tn.org), (615) 248-5878 or toll free (800) 835-7077

The Arc Tennessee is a statewide advocacy organization that empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime.

Tennessee Kindred Stories of Disability  
[vkc.vumc.org/kindredstories](http://vkc.vumc.org/kindredstories)