Tennessee Kindred Stories of Disability

Special Edition: Waiting list for home and community-based waiver services

The Arc Tennessee

VANDERBILT KENNEDY CENTER for Excellence in Developmental Disabilities

A Letter of Thanks

The stories in this collection were compiled by students enrolled in a Vanderbilt University course on families. This course provides an introduction to the field of family studies, with special attention paid to families that include children and adults with disabilities.

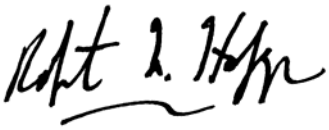
The course offers future educators, advocates, and researchers an opportunity to learn what it's like for a family to include a member with a disability. As part of the course, students interview individuals with disabilities and family members. They learn firsthand from them about encounters with education, health care, housing, employment, and disability services in Tennessee. This particular edition focuses on families who are currently on the waiting list for home and community-based waiver services. Only first names are used in this compilation of stories.

The Vanderbilt Kennedy Center and The Arc Tennessee thank all the families who participated in this program and gave permission to share their stories. By reading their stories, you will receive snapshots in time of a diverse group of individuals with disabilities, across a spectrum of age, disability, geographic location, socio-economic status, and race. These stories demonstrate the limits as well as the lack of supports and services in Tennessee for individuals with developmental disabilities and the impact this has on family life. By sharing these stories, the students and families hope to increase the likelihood that new funding will be allocated to the waiting list, and that they will be contributing to improving life in Tennessee for all persons with disabilities and their families.

In addition to the stories, this edition includes waiting list information broken down by county.

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

Doria Panvini
Chair
Community Advisory Council
Vanderbilt Kennedy Center



Robert Hodapp, PhD
Professor of Special Education
Director of Research
Vanderbilt Kennedy Center

Carrie Hobbs Guiden
Executive Director
The Arc Tennessee

The Arc of Tennessee
www.thearctn.org

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities
kc.vanderbilt.edu

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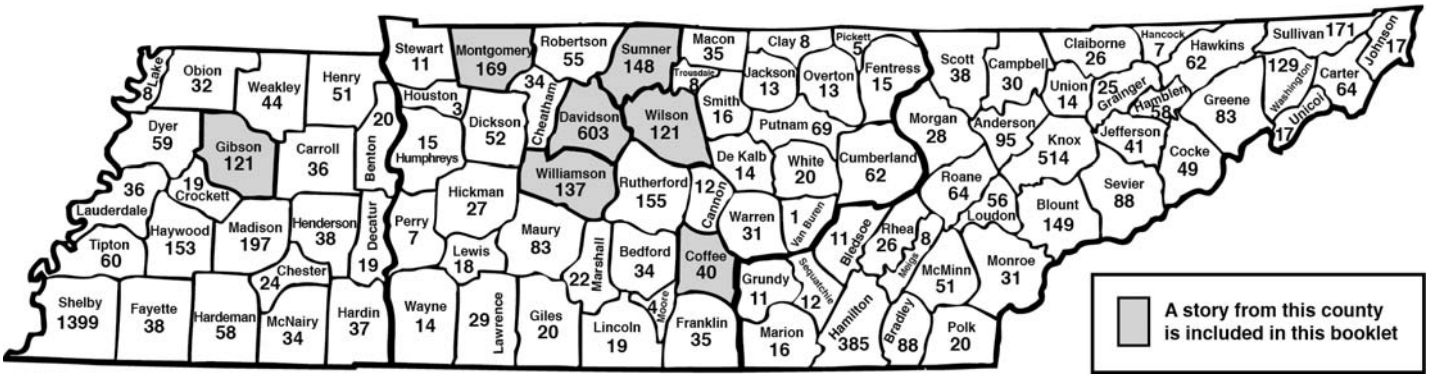
Tennessee County Waiting List Numbers (June 2012)



People on the DIDD* Waiting List

	June 2011	June 2012
By level of need		
Crisis: homeless, no caregiver, imminent danger to self or others, needs services immediately	92	**79**
Urgent: significant risk of abuse/neglect, caregiver aging or in ill health, needs services soon	795	**796**
Active: requested services but does not meet Crisis/Urgent criteria	4,658	4,808
Deferred: requesting services more than 12 months in the future	1,351	1,496
Total	6,896	**7,179**
By Category		
School Age (0-21, excluding DCS)	2,739	**2,614**
Dept. of Children's Services (0-21)	91	**92**
Nursing Homes	129	**112**
Regional Mental Health Institutes	22	**11**
Adults – no services	3,915	**4,350**
Total	**6,896**	**7,179**

*Department of Intellectual and Developmental Disabilities Data Management Reports July 2011, July 2012

Family Quotes

The quotes included in this section were collected at meetings held by The Arc Tennessee as a part of their "It's Not Too Late to End the Wait" campaign.

Rutherford County

"I recently had a stroke and I have problems, physically. My daughter has cerebral palsy and uses a wheelchair. I can't lift her anymore. If we could get waiver services, we could afford to buy a lift for our van and a special bed for her."

Shelby County

"My biggest fear is my daughter ending up in a nursing home. She cannot talk or walk and is totally dependent. She has behavior problems and it will take a lot of love and compassion to care for her. I am scared she will be abused."

"I had to quit my job in 2009 because of my own medical issues. My husband has health problems too, and we have a son with seizure disorder and behavior issues. He doesn't fight, but he is getting more aggressive. My fear is that someday my son will wake up and there will be no one alive to care for him. He really depends on us for everyday living. We can't afford to pay for services for him. If we had money, I could get him dental care."

Sullivan County

"I do everything humanly possible as a single mom to do all I can to care for four kids with disabilities. What happens when I can't take care of them?"

Wilson County

"My husband and I have to work different shifts so we can take care of our son. Our other son has had to sacrifice a lot to help take care of his brother. If we were no longer on this earth, there is nothing for him."

Darren (age 40)

Although Darren was born in Pennsylvania, we have lived in Clarksville, Tennessee since he was very young. Our family is just the two of us, and Darren has a rare chromosomal disorder that affects all aspects of his daily life. He has vision and hearing impairments, and although he has corrective lenses for both eyes he has total hearing loss and does not have a formal method of communication. He doesn't sign or read lips, but he has his own way of getting over to you and letting you know what he wants. Darren also has seizures, but they are currently controlled by his medication. Darren loves to do puzzles and watch television, especially programs with motion. His favorite things are motorcycles, horses, and football.

Darren is now 40-years-old. He went to elementary, middle, and high school in Clarksville. While he was in school, I was able to have a part-time job because Darren was supervised during the school day. Once he graduated from high school, I had to quit my job in order to support Darren's needs. Since then we have been living off of Darren's SSI because I have no program or supervision for him during the day, and it is challenging. Two people trying to live off of that check is very challenging. Once I pay for our basic needs with that money, there is nothing left. My grandmother and uncle used to be able to take Darren for a couple of hours occasionally when I had essential outings such as a doctor appointment. Now, Darren is older and my uncle recently passed away and our options are limited.

Although Darren's challenges appear to limit his daily life, he does pick up things by association. For example, he helps me with putting laundry away after it's folded and he knows where everything goes in our house. He knows how to ride a bike (but not how to apply the brakes!) and will occasionally go to the grocery store with me as long as he walks with me and helps me push the cart. While he is dependent on me for help tying his shoes and toileting routines, he is moderately independent with feeding himself and getting dressed, and he does not display any problem or aggressive behaviors.

I can't even remember how long we have been on the waiting list. During that time life has just been so hard. I worry all the time. I worry about Darren's health and his well-being. I worry about money. We don't have enough and I don't feel I have options. It is really hard for me to take him out to different places by myself, so we just don't go out much. He probably gets tired of being in the house, but I have no other help besides my grandmother occasionally. My biggest fear is the possibility that I could have to go to the hospital, which would leave Darren with no supervision. When he was younger I used to be able to take him with me because he was smaller, but now that he's older it would be very stressful if I got sick and had to spend a couple of days in the hospital. We are lucky in many respects though. While Darren was in school and I was able to work, I bought a house, so we don't have a house payment. But we have property taxes and insurance and I don't always know how we are going to make it. Life is very stressful. We used to get money that helped us to pay for things like getting Darren's wisdom teeth taken out or clothes for him. We got it for about 2-3 years, but that stopped and it is really hard.

I got approved for the CHOICES Waiver through TennCare on October 31. We got that waiver because Darren has a physical disability. I am now getting help at home three days a week, for about six hours each day. In addition to this assistance with his bathing routines and light

housekeeping, CHOICES supplies his Depends and my home help is able to go with Darren and me to run errands, or they can stay at home with him while I run errands and go to things like doctor appointments.

While we are adjusting to getting services through CHOICES, my biggest fear has not changed much. Though the services have helped give me a little break, they don't address Darren's need to access community activities. Services are still limited. They're not enough if something happens to me and I need to be away from Darren. I have family in Pennsylvania that would care for him once I am no longer able to, but I have no plan for the future. Even so, "you take it one day at a time."

Mark (age 42)

Mark was born in 1970. By the time he was 2 or 3-years-old, we knew something was different about him, but we didn't know exactly what it was. I just knew he didn't play like other little boys played and he wasn't interested in being with the other kids in the apartment building where we lived. He preferred to play alone.

When he was 5-years-old, he entered the public school system. I didn't expect things to go perfectly, but we needed some help in finding out what was wrong. We felt this was the place to start for some professional help. He was evaluated by the school psychologist and was given a label of classic autism. Mark went through the Nashville public school system in special education until he was 22-years-old.

After graduation, he entered a sheltered workshop where he stayed for 5 years. The workshop wasn't enough for him. He wanted a "real" job and through their supported employment program, he was able to do just that. With the help of a job coach, he was able to obtain his first "real" job as a bus boy at Shoney's where he worked for 2 years. He decided he wanted to find a different job and he chose Kroger for his next employer.

He went to work at Kroger and is still there today. He is in his 12th year as a courtesy clerk and we hope he can stay there until he retires. Mark had always wanted to live independent of us when he grew up and we felt this was something he would be able to achieve with the right help.

While Mark was at the sheltered workshop we placed him on the waiting list for residential services. Since he was young at that time, we weren't ready for him to live anywhere else but at home. So, he was placed in the deferred category. That was approximately 15 years ago. Within the last 5 years we were able to get him moved from the deferred category to the active category because of our age and health. His father is in his mid 70's with many health problems, and I am in my late 60's with health issues as well. We have no one else who can care for Mark should something happen to us. We feel very isolated a lot of the time.

We always thought there would be a place for Mark when the time was right and when we needed residential placement. We had no idea what we would be facing today. We have just about given up on ever getting residential placement. I have no idea what will happen to Mark when we are no longer able to care for him. It would be best for him if we could find a way to ease into a residential placement. It's often hard for people with autism to transition into new settings. I would feel more at peace and he would feel more at peace if we could help him transition to a new home while we are still here. During the past several years, we have had a number of case workers assigned to us but it is meaningless to us now. Nobody can help us. Year after year, all we ever hear is there is no funding. Will there ever be funding? It is so unfair to us and to him. We need residential services now. I feel like if we got waiver services today it would be like being let out of prison.

Louie (age 13)

Louie is 13-years-old and has Angelman syndrome. He can't talk and he has to have someone with him 24/7. Most kids with Angelman syndrome don't sleep and some of them don't sleep at all, like 2 hours a night. We are pretty lucky. Louie can sleep well but he sleeps in a special bed that is enclosed. He can be left in the bed, but we still have to have a monitor on all the time in case something happens to him. My husband and I both work, so we use babysitters. We have a big house and empty bedrooms because our older kids have moved out, so we trade free room and board for childcare. Right now we have one person living with us and she works about 20 hours a week watching Louie.

Louie is great. He is very affectionate and sweet to people. He is getting calmer all the time and for that I feel really lucky. He uses about 20 signs and he will initiate communication. I think he is doing fabulous. He hasn't had a seizure since 2004. He has been on only one medication, and we are really lucky because most people with Angelman have severe uncontrollable seizures.

He can walk really well. His motor skills compared to other children with Angelman are good. He can go up and down stairs. He can feed himself. He eats everything and he has no feeding issues. He does have some challenging behaviors. He pinches. He will just pinch you really hard. It is better now but he used to really hurt people. He kicks sometimes too. He kicks waiters in restaurants. He kicks teachers at school who he doesn't like. He kicks students who bully him. He also kicks people who are really nice to him. If my husband is trying to take him to the bathroom and he wants me to take him to the bathroom he will kick my husband. We are trying to replace that with kicking a soccer ball.

The toilet also has been a challenge. He does have a sign for bathroom and he does use it appropriately, but he will also use it to get out of anything he doesn't feel like doing. There are times where he doesn't sign. He doesn't wear a pull up anymore but he still has accidents sometimes. They are few and far between. He is basically toilet trained but that was a huge challenge.

Louie is really attached to his sisters. The oldest one he never lived with because she was in college when he was born. They are not as close. The second one just graduated college. She really adores him, but she is also very strict with him so they fight. The twins are like a pile of puppies with him. When they come home after they have been gone for a while he doesn't speak to them for a couple of minutes because he is mad since they have been gone. Then he laughs and hugs them and he won't let them go.

Louie is on the waiting list. I got him on the waiting list when we moved here seven years ago. Since we make good money, he is not ever going to move up the waiting list. Maybe when he turns 18 and they review his own personal income he might get bumped up a little. That is why they tell people to sign up for the waiting list no matter what because if something happened to me and my husband, at least he will have moved up. Or if he turns 18 he will have already been on the waiting list, so he might have a higher chance of actually getting off the waiting list and getting services.

In California you are entitled due to your diagnosis. It is not a need-based thing. Back in California we had respite according to the level of disability and the amount of care we had to provide. In California we were getting 8 hours of respite when we left, but we would be eligible for at least 20 hours a week by now. Now I'm paying for all of that and those hours. If I didn't have the money to pay for that I wouldn't be in school and I wouldn't have a job. It would be impossible. In California Louie had a lot of special equipment and that was all paid for by the state. In Tennessee it has to be covered under our own insurance. Insurance doesn't necessarily pay or you have a big deductible. For him, therapy is supposed to be done at school and in California there were therapies that could be done through the program. But here it has to be either at school or through your personal insurance. I knew right before we moved here that living as a family with a kid with a disability was going to be a lot harder in Tennessee.

We have services now but we pay for everything. I wouldn't be as worried about bills if Louie got services. It doesn't matter how much money you have you still worry about bills. We don't get financial aid for any of our kids. We are broke at the end of every month just like everyone else. And what would happen if one of us lost our job? We definitely wouldn't have enough money and we wouldn't have any help. If we were to come off the waiting list we would probably get Louie more therapy.

My biggest fear for the future is what will happen to Louie when I die. Well that is the other thing about coming off the waiting list. What I would hope is that we can find some kind of a program for him that wouldn't be a warehouse but that had ongoing therapies and activities that would keep him awake and alert. There is a program I know about in Kentucky that seems promising. To be eligible, you have to function as a 5-year-old. So, we are doing all we can to get him functioning on that level. What is nice about that place or a place like it is that they have school and structured activities forever. I'm aiming towards that. I think it is a farfetched goal and I think it is not likely that he will function at a 5-year-old level, but we are working at that regardless.

His sisters used to say when they were younger that they couldn't believe we would consider putting him in the Kentucky program, but now that they are older I think they get it. If he didn't have a place to live and thrive and if something were to happen to my husband and me, it would mean living with them. They love him, but living with Louie and taking care of him is very challenging. My husband and I take care of him. I am the main one who takes care of him. His sisters haven't felt it as a huge burden. We have talked about this place in Kentucky and they are coming around. They want to go with me and look at it and think about it. I have told them that if I'm dead and he is there, that means they need to go and be there for holidays and take him home. It doesn't mean they don't see him. It means they are active in his life. They all say they really want that at this point. All of these people who love him so much are just kind of busy and I'm not sure about the future. I'm sure they would rise to the occasion if something happened, but I'm not sure they have really contemplated what it means. I really try to not worry about this on a daily basis, but it never really leaves my mind.

Whitney (age 22)

Whitney is 22-years-old and has a diagnosis of developmental delay. She loves listening to music and playing on her iPad. Although she can be quiet, Whitney is friendly and outgoing, especially when she recognizes somebody in her community. According to her mother, Debi, some of Whitney's biggest challenges are in the areas of communication and mobility. Whitney currently lives at home with her mother and stepfather.

When Whitney was 13-years-old, the director of special education in their hometown suggested that Debi put Whitney's name on the wait list to receive waiver services. While the family is on the wait list, they are currently doing all they can to ensure that Whitney is happy and healthy. Debi currently works in order to pay for daily expenses. However, she had to reduce her work hours recently and take a cut in pay to have more time to take care of Whitney. Debi says the family "is just making it one day at a time."

Currently, Whitney does receive some money that helps the family pay for her expenses. All of her monthly Supplemental Security Income (SSI) currently goes toward paying for her day center costs. If Whitney was able to receive services from the state, there would be money to access services and supports to improve Whitney's life. The family could also use the money to pursue activities that interest Whitney and that would help her in the future. The money might also go toward hiring someone to care for Whitney so that Debi could work additional hours. The money might also go towards paying for housing expenses so Whitney could begin to transition to another residential placement and live more independently.

Debi says she is scared about what is going to happen when she is not around to care for Whitney. Specifically, Debi is worried about who Whitney would live with. Another concern that Debi has relates to residential placements. Debi mentioned "the longer she lives at home, the harder it will be to transition later on." This is a valid concern because Debi wants the best for Whitney and wants to make life as easy and convenient for her as possible, like any mother would. If Whitney were to begin receiving services, many of the fears and concerns that Debi has for the future could be put to rest. Debi would be able to pay for dependable caregiving for Whitney and also would be able to pay for a future residential placement for her that would continue to last even if Whitney's family were no longer able.

Dylan (age 19)

As a young mother of 19, I soon realized something wasn't right with my son. It wasn't long before I suspected autism at about 6 months. After literally fighting doctors, who continually tried to tell me that I was just, "a young, inexperienced, over protective and over reaching mother who really didn't know what I was talking about," I finally got someone to listen…a year and a half later! There was no handbook, no instruction manual…nothing!!! The doctors didn't have a clue of what to do or what to tell me and I was at a loss for the next step. Needless to say our journey began.

I remember feeling helpless and hopeless. I was only 19. What did I know? I was a baby myself. It seemed as though the doctors agreed with my thoughts, so I began to teach myself. I read everything I could find concerning autism. I was like sponge trying to soak up all the information I could. We finally got a diagnosis at the age of 2 of P.D.D (Pervasive Development Disorder), which is under the autism umbrella. I was totally beside myself and scared to death of what to do next. Every parent expects to have a perfect healthy baby. When you find out that's not the case you become overwhelmed with several different emotions - anger, hurt, feelings of it being your fault and then mourning of what you won't have.

We went through so much with doctors and teachers. The doctors wanted to institutionalize him while the teachers just wanted to babysit him. I was told by the doctors that he would never give or receive affection, never talk, and never be social in society. When Dylan was 5-years-old they told me he would have to be institutionalized by the age of 7. The teachers told me there was no reason to teach him because he'd never be able to learn. The actions by others only fueled my fire to fight harder and learn more. I read every book, looked up everything I could on the internet, I even went to several workshops. I figured if they weren't going to fight for his rights I sure was. It was amazing, somehow - someway God gave me the direction I needed and put the right people in my life to help further my fight for my sons' educational rights. Don't get me wrong it wasn't easy and it was most definitely a long hard road. One that I can look back at now and say we fought the good fight and my son surpassed everything the doctors ever said he would never do. Dylan is now 19. He has autism, an intellectual disability, and an IQ of 47. Although, I still mourn the things he will never do, I celebrate the things he has accomplished far beyond what anyone ever thought he would do. He is an awesome, fun loving, caring and thoughtful young man. I am so blessed to have him as my son.

Now comes the hard part. Dylan is nearing age 22. We've been on the waiting list for about 10 years with no help in sight. I'm scared that there will be no help after high school. I've seen some workshops first hand and he will never go to one to work as a slave laborer. I want my son to be productive in his community. He may not be able to "work" for a paid living but he can volunteer and give back. The system drops our kids at 22 and leaves the parents to wonder and worry all over again about what comes next. As if we haven't already gone through years of it already… The first 12 years of his education I had to fight and fight for his right to be educated. Now, it looks like I will once again have to fight for his right to be a part of his own community.

Seth (age 23)

I have two children. My youngest is 21 and typically developing. Seth is almost 23 and has autism. When Seth was a baby, he never really slept. He was awake all the time. I remember timing him and in a 36 hour period, he only slept 6 hours. Although he had all the classic signs of autism he was misdiagnosed throughout early childhood until a re-evaluation when he was 10-years-old. We were living in New York at the time.

When we finally had the diagnosis, things began to look up a bit in terms of his education. He began to attend a school that catered to kids with autism. His teachers seemed to know what they were doing and he was maintaining a passing average. In 9th grade he began a transition program. He was in a classroom with one teacher, 8 kids, and one assistant. Seth also had his own private aid that sat with him to keep him on task. He could walk the halls and there were kids there he knew from the neighborhood. And then I was offered a job in Tennessee. Everyone I called, including people in the school system, assured me that the programs in Williamson County in Tennessee were comparable to those in New York. Not so.

They only put him in the two classes he needed to pass the T-Cap; math and English. After class he would sit with a tutor to go over the material, but the rest of the day he spent watching movies. I was called constantly with them telling me he was being disruptive. Once, an assistant principal called and told me they could not handle him that day and asked if I would pick him up. I told him absolutely not. I told him to call his autism specialist or whatever he had to do, because it was his job to educate him. I was livid that they would tell me they couldn't handle him when they refused to give him the services he needed to succeed. They had no right to deny him an education. It was a tough road but Seth graduated. He has a regular high school diploma, but they basically just gave it to him.

There was a summer program that Seth was able to go to at TRC in Williamson County for one summer. The problem was the counselors weren't equipped to deal with somebody with autism especially in a new environment the first few days. When you put these kids in a new environment, they melt down. They don't understand what is expected of them. There's no structure, no routine, no schedule. He couldn't adapt quickly enough for them and so they wanted him out of the program. A new psychologist on staff was really tuned in to kids with autism and he created social stories for Seth that helped him know exactly what to expect throughout his day. It worked beautifully. We had ups and downs in the program, but in the end it just wasn't a good fit.

My boss gave Seth a job in the mailroom. He got a wonderful job coach through Vocational Rehabilitation, but he was only approved for 20 hours of coaching. Seth needed months of support from a job coach. When they took the job coach away it didn't work out. Seth went from working 12 hours a week down to 4 hours a week. He had this great job opportunity, but they pulled the job coach too soon. So now essentially, my boss's company is letting Seth come in one day a week just so he has something to do.

While we are waiting for the waiver, I hate to say it but he is just home alone all day. He can't go anywhere. He's trapped in the house. He can't manage on his own. He can't commute. He can't drive. He can't manage money. He fights us constantly. His mood is terrible. His behavior is becoming harder for us to manage.

He does leave the house twice a week. He goes to work one day and he takes piano. He just practices and practices. It gives him something to do. He plays piano really well. If a kid is bright enough to learn piano, he is bright enough to have a job. It's just his learning curve is so long and so slow. You look at him and you just want him to be an adult and he's not. He can't do it. It's hard. I have to make sure our neighbors know he's alone just in case. We don't have any family here so it's tough. There is really no support for him. He has no friends. It is hard on our family. There's no respite. We really can't do anything. My husband and I can't go on a vacation. We can't take him places. You can't change his routine. We just basically stay home and do nothing.

My younger son knows, in the back of his mind, that one day we're not going to be here. He's going to have to take the responsibility and it's not something he wants. We've tried to make accommodations. We have an insurance policy that when we both die there will be a trust that is funded. He'll have some money, but it's not going to be enough. We just don't have that kind of money to fund it enough to maintain him. My younger son will have to support him. It's scary. I don't know what will happen. When we're gone he'll be eligible for the waiver because he'll be homeless. But then again, what does a state run group home look like? I have no idea, because I don't want to face that reality. We have no choice.

If Seth had waiver services, everything would change. He would have something to look forward to and something to do. All of us would be happier because of it. When he has something to do, he's not as disruptive. We know he'll never live alone, but he would have something to look forward to everyday and he wouldn't be miserable all the time. He's got to be depressed. He's got to be. You can't live and watch TV all day. I'm trying to get him into an adult day program, but it is $9000+ a year without transportation. He's on SSI but that won't cover it. He's eligible for the Medicaid waiver, but we don't have the waiver. He's on the waitlist and we're trying to get him into a group home, but there are 10,000 people on the list.

It's really hard for families who have kids with disabilities. When our kids are younger there are a lot more services. It may not be perfect, but services exist. My husband and I both have to work all day. That's just the reality. School services ended and now Seth stays home by himself. Talking to other parents has been the best resource, but the story is unanimously the same, there is nothing out there.

Lillian (age 25)

Anthony is a single father of three grown children. Two of his children are married with families living out of state. That leaves Anthony to solely care for his 25-year-old daughter, Lillian, who also happens to have Down syndrome. The transition to single parenthood has been a challenging venture for Anthony; he was not expecting to take on singular responsibility of his daughter at such an early paternal age.

Anthony and his wife moved to Nashville approximately six years ago for Anthony's job transfer. Anthony was traveling a lot for work, and his wife was planted in Nashville working as a nurse at Vanderbilt University Hospital. Due to Anthony's time spent away from home, his wife took on the duty of advocating for Lillian and figuring out their daughter's postsecondary goals. Lillian's mom was very involved in getting Lillian connected to community activities and resources. However, due to the wife's unfortunate and untimely death, Anthony found himself in a position he could not have imagined for himself.

Forced to face a long and mournful grieving process with the passing of his wife, the immediacy of single parenthood with a daughter with special needs was almost unbearable for Anthony. Nevertheless, Anthony was obligated to rise to the occasion in order to secure a future for Lillian; she depended upon the efforts he made in advocating for her. Anthony slowly and surely began to take over his wife's role in Lillian's life, and through trial and error, began learning how to connect Lillian with the resources she would need in order to be successful. Anthony spoke about the frustration he faced time and time again in trying to find support for Lillian, both emotionally and financially. The agony he faced in spending time on dead-end phone calls, all the while having a heart that was trying to mend, became a source of defeat.

Additionally, Anthony was recently laid off and is in a tough financial bind. Thus, the assistance that he requires for Lillian is more needed than ever. Anthony also is concerned about what will happen to Lillian once he passes away. He does not want to burden Lillian's older brothers and their families and he does not have a solution.

Lillian has been on the waiting list for services for years. Filled with emotion, Anthony speaks about the frustration due to the lack of government support and the immediacy of his need. Every father deserves to know what will become of his child once he is no longer able to provide for their needs anymore. Unfortunately, Anthony does not have that luxury. He has to live in uncertainty as each day passes, unsure of where and how he will be able to meet Lillian's future and pressing needs.