

Tennessee Kindred Stories of Disability



2012

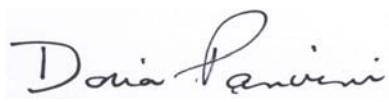
A Letter of Thanks

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. 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 that they will be contributing to improving life in Tennessee for all persons with disabilities and their families.

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

Vanderbilt Kennedy Center
vkc.vumc.org

The Arc of Tennessee
www.thearctn.org

Table of Contents

Charlotte (age 2).....	page 3
<i>"Everybody needs to feel a part of something."</i>	
Deshaun (age 5).....	page 4
<i>"I don't think we should just settle for our kids learning how to clean their clothes and cook. I want my son to learn what it is to earn a paycheck, to drive, all that stuff."</i>	
Emily (age 11).....	page 5
<i>"Lisa and Jeff teach Emily about her diagnoses and medications so that she can be a strong advocate for herself when they are not around."</i>	
Kevin (age 12).....	page 6
<i>"Kevin is looking forward to working just like anyone else."</i>	
Preston (age 13).....	page 7
<i>"During elementary school, Preston had to switch schools a number of times in a search for appropriate services."</i>	
Adelai (age 15)	page 8
<i>"In terms of educational instruction, Adelai's IEP was generally ignored."</i>	
Ginger (age 24).....	page 9
<i>"Lots and lots of parents in the rural areas get lost and overwhelmed by the laws and what the rights are."</i>	
Sharmane (age 38).....	page 10
<i>"Sharmane's IQ cannot predict how much she has been able to achieve and learn."</i>	

Charlotte (age 2)

“Everybody needs to feel a part of something. My daughter is no different.”

John and Emily's two-year-old daughter, Charlotte, has a unique chromosomal anomaly. She has an unbalanced translocation involving the first two chromosomes. During the pregnancy, Emily experienced some complications, including gestational diabetes. Doctors ran a number of tests before Charlotte was born, but the results were never clear. Charlotte was born four weeks early.

While she has significant motor and speech delays, Charlotte has her own way of communicating. Her parents say she has a happy nature and a strong-willed personality that fuel her motivation to learn. Her biggest challenges are a lack of mobility and an inability to form words.

Education

Charlotte is a part of Tennessee Early Intervention Services (TEIS). She also is fortunate to attend a fully inclusive preschool, which means she has toddler classmates who have disabilities and other classmates who do not. While she is still too young to receive formal education in the public schools, both John and Emily feel that she will benefit from being a part of the Williamson County Public School system, which they believe places a greater emphasis on inclusion.

Health Care

TEIS has been extremely beneficial for the family. The programs and service navigation expertise are invaluable. TEIS is able to provide supplemental financial assistance for therapies. However, Charlotte requires many supports and accommodations that TEIS does not cover. She has assistance from many physicians and therapists, and while Emily and John are mostly satisfied with the medical and therapeutic professionals who have worked with Charlotte, they also feel that it is challenging to navigate the medical and health care systems.

Respite

Because of Charlotte's requirements for supports, John and Emily do not often have an opportunity to spend time on individual interests, for example, or to go on a date. However, it is very beneficial that Emily's parents are nearby. They are always eager to look after their granddaughter.

Future Concerns

Charlotte's parents hope that she will grow up in communities that will encourage her to share her gifts and talents and that will recognize the importance of her contributions. Emily says, “Everybody needs to feel a part of something. My daughter is no different.” Because Charlotte is so young, it is difficult for her parents to make any prediction of what her future holds. Their greatest hope is for their daughter is one of inclusion and community. Charlotte's parents do express a concern about the lack of ample, adequate adult disability services. Emily says, “The way I see it, she's two now. We have 19 years until she needs those types of services. However, we can't take 19 years to fix it. There are many adults with disabilities who are 21 and currently

on a list a mile long waiting to receive services. These folks do not have 19 years to wait. They need something to change now.”

Deshaun (age 5)

“I don’t think we should just settle for our kids learning how to clean their clothes and cook. I want my son to learn what it is to earn a paycheck, to drive, all that stuff.”

Since he was born, Deshaun has been a happy child. He hugs everyone. No one is a stranger. He was diagnosed with autism in 2009. The diagnosis was a confirmation of what his mother, Deanna, suspected. Deanna has high expectations for Deshaun and says that he is like every other kid, but just needs a little more help. Deanna is a single mother and has gone above and beyond to provide for Deshaun. The two of them recently relocated to Brentwood, where Deanna took a new job. Having a young child with autism can require a great deal of flexibility, so employer flexibility dictates where Deanna can take a position.

Education

Deshaun is in an inclusive setting in school. He also has an aid in the classroom to support him at all times to be sure he is able to stay on task and understand instructions. His strengths are his memory and determination; he keeps trying something until he can do it, or until he understands it. He doesn’t always excel in application, but he is improving. Deanna has had trouble with his Individualized Education Program (IEP). She says his teachers do not always honor the items in his IEP. When she discovers this, Deanna must go to the school and talk with the teachers. Generally, she finds that after she meets with the teachers they do honor the IEP commitments.

Social and Community Supports

One of the social structures that Deanna thought would be good was a playgroup of children who all had autism. Deanna explains, “All of our kids have autism, but there is such a divide in the autism community...oh you aren’t really that bad off you’re kid only has this or that, whatever.” This take on the autism community really turned her off to the playgroup because children and parents would divide themselves up into particular groups because of what the kids do have problems with or don’t.

Deanna would like to attend church more often, but she is upset with the way Deshaun has been treated. Although he is five, he is placed in Sunday school classrooms with younger children. This is off putting for her, because he is able to comprehend and interact with children his own age. The church is a place that Deanna would like to be able to go and feel comfortable, but she does not feel supported and finds that not going is sometimes a better option.

Deshaun receives Applied Behavioral Analysis (ABA). This service helps Deshaun improve his social skills. It also provides Deanna with some practical individualized methods to address some of Deshaun’s challenging behaviors. Deshaun also is in Occupational Therapy (OT) to help him with everyday activities like grooming and is enrolled in a gymnastics class that helps with his movement and that also has a small social aspect to it.

Future Concerns

Deanna thinks that Deshaun is doing well for his age. She hopes that in the future, people will take the time to understand Deshaun and accept him for who he is. She wants him to be fully included in school, begin to have friends, and simply participate in life just like other five and six year olds. “I don’t think we should just settle for our kids learning how to clean their clothes and cook. I want my son to learn what it is to earn a paycheck, to drive, all that stuff,” says Deanna.

Emily (age 11)

“Lisa and Jeff teach Emily about her diagnoses and medications so that she can be a strong advocate for herself when they are not around.”

Emily is a kind-hearted and determined 11-year-old girl, who loves to help others. With a large circle of family and friends from her community, Emily both gives and receives love and support in everything she does. Emily is an expert speller, does well in school, and enjoys riding her bike and riding horses. Emily’s parents, Lisa and Jeff, are very proud of her.

When Emily was born, she was diagnosed with spina bifida and hydrocephalus. While Lisa and Jeff learned of Emily’s diagnoses several weeks before her birth and were able to do research and make plans, they recall a strong sense of fear and uncertainty. “It was scary to bring home a baby with so many medical issues,” said Lisa.

Education

Emily attends a private school in her area, and over the past three years, she has made some amazing strides. After a major medical crisis in the 2nd grade, Lisa began attending school with Emily as her aid, helping her as needed in the classroom. Emily is now in the 4th grade and only needs aid from her mother two days a week and at home as necessary. Lisa attributes Emily’s academic successes to her school. “So many private schools are not willing and/or able to admit kids with disabilities,” said Lisa. “We are so blessed. What they have accomplished with her is nothing short of amazing.”

Employment and Housing

Lisa and Jeff also have strong hopes for Emily’s future employment opportunities. Emily participates in horseback riding therapy as often as she can and tells her parents that someday she would like to be a hippotherapist. Hippotherapy is a form of physical, occupational, and speech therapy in which a therapist uses the characteristic movements of a horse to provide carefully graded motor and sensory input. To gain this type of employment, Emily would need a postsecondary degree.

Over the past several years, Lisa and Jeff have put a considerable amount of time and money (provided through a small pocket of funding from the state) into making their house more accessible for Emily. For example, they undercut their kitchen cabinetry so that Emily can reach the kitchen counters in her wheelchair. They hope to leave Emily with the house upon their passing.

Social and Community Supports

She and her family are involved with a faith community that focuses on the inclusion of people with disabilities. They encounter many families and children with special needs and are devoted to helping these children and families. Emily's faith community has been a huge support system, and Lisa and Jeff foresee Emily staying involved with a church for the rest of her life.

In the larger community, physical accessibility is always an issue for Emily. Lisa has some frustrations with what is considered ADA accessible versus what is functionally accessible. "Just because a bathroom has a rail doesn't mean we can get a wheel chair inside." Additionally, Lisa feels that community organizations—schools, churches, and more—should consider taking a more family-centered approach to serving children with disabilities. Lisa and Jeff teach Emily about her diagnoses and medications so that she can be a strong advocate for herself.

Kevin (age 12)

"Kevin is looking forward to working just like anyone else."

Kevin is 12-years-old and has Down syndrome. His true strengths are that he loves to learn, loves people, and loves to please others. He is currently working on manners and learning how to introduce himself. He loves to meet new people and literally drags his parents over to meet new people as well. Kevin learns best by routine, so his family ensures that he keeps the same daily routine. When his routine is disrupted it can cause behavioral issues and stress – i.e., he started a new school last year with new teachers and had a hard time adjusting to the "newness" of it. His behavior greatly improved once teachers and parents worked together to develop a curriculum for him.

Education

Kevin started school fully included from day one. Half of his classmates are typically developing children and half of the children have some type of disability. The class is structured so that the typically developing kids serve as "peer buddies." This is beneficial for both parties. The schools general and special education teachers and parents work closely to ensure that the best curricula and routines possible are developed for Kevin.

Employment and Housing

Kevin is not working at age 12, but he says wants to work at a restaurant when he grows up. He is looking forward to working just like anyone else. Debbie, Kevin's mother, works with several organizations that focus on adults with disabilities and she also is highly involved in the community. Since there are not many opportunities for adults with disabilities once they leave school, Debbie thought it important to be involved with adult service agencies and get a jump start on navigating and advocating for Kevin. His parents want him to do whatever he wants to do. This is very important to them. They want him to have choices and to be independent.

Social and Community Supports

Debbie and her husband were very involved in church before Kevin was born. However, when Kevin was around age 3 they stopped attending. They found it difficult to manage Kevin's behaviors in a way that was suitable for the community's expectations. About two years ago, they found a new church that Kevin loves. He is involved in their youth group and is included in everything just like any other kid.

Respite

Debbie and her husband are fortunate because they have a large community of willing people who will "babysit" Kevin. This enables them to have time alone, but she says they probably don't take as much time for themselves as they should because everything revolves around Kevin. Debbie also said, "Things are not nearly as much fun without Kevin there." They simply do not like leaving him because he is such a joy to their family.

Future Concerns

Debbie believes that her whole role as a parent is to prepare Kevin for adult life and to make him as independent as possible just as any parent would want for their child. However, her concern was evident when she said, "We don't have a lot of family that would take care of Kevin if we were both gone." Their stepson lives far away and even though their daughter is married and lives down the road, they don't want her to feel like she would have to be responsible for Kevin if something happened to them.

Preston (age 13)

"During elementary school, Preston had to switch schools a number of times in a search for appropriate services."

Preston is 13-years-old and received a diagnosis of Asperger syndrome at age three. Preston lives with his mother, father, and his younger brother. He is highly interested in computers, great with numbers, and has an unbelievable memory. His classmates even refer to him as "the human calculator." Reading comprehension, however, is challenging for him. This summer, his reading and language abilities were evaluated and it was determined that he stands at a fourth or fifth grade level. He has challenges making friends and Latresa, his mother, tries to get him more involved with people. Still, Preston laughs, cracks jokes, wrestles, plays video games, uses Facebook, and talks to his girlfriend on the phone. He is also very musical.

Education

Preston started school at a Montessori preschool and it was at that time that he received a diagnosis of Asperger syndrome. He had difficulty understanding the abstract teaching methods of a Montessori school, so Latresa removed him from the school. During elementary school, Preston had to switch schools a number of times in a search for appropriate services. During his second grade year, Preston was placed in a special education program. He did not perform well in this setting, so at the encouragement of his mother, he was placed into a mainstream

classroom. The teachers in these classrooms were not trained to work with students who have autism. He did not receive adequate instruction.

He also was a victim of bullying. As a result, Preston was extremely frustrated in school from first through fourth grade. In fifth grade, Preston became involved with a program that integrated him into the school community, which was helpful in stopping the bullying. Bullying is no longer a major problem. Preston chose to join the wrestling team at his middle school this year. This is a significant change. According to Latresa, “He’s not been one in the past to want to do anything besides go to school and come back home.” It is currently unknown where Preston will attend high school. Latresa would like him to attend a private school.

Social and Community Supports

Latresa feels very welcome in her faith community. Latresa has educated her church about disabilities. She has, in turn, been provided with constant support. Preston is involved in a teen church program, where he is making more friends and learning to interact well with others. This program is slowly helping to bring Preston out of his shell.

This year, Preston’s family worked on his transition plan. Latresa said that once Preston turns 15, he will be involved in an employment program for people with disabilities. He has expressed an interest in working with computers, and he wants to earn money. He’s even told his family that he wants to be completely independent. Latresa is trying to teach him how to manage money, which will especially important when he starts working.

Despite challenges, Preston is moving forward. He has overcome many challenges already, and he is discovering his strengths. His loving family is very proud of him and is learning how best to support him each day. They love Preston for who he is and want him to attain his goals and a fulfilling life. They have faith that this is possible for him. They have worked together tirelessly to make Preston’s dreams a reality. According to Latresa, all of their striving for Preston’s success “has been worth it to see him do so well.” And it will continue to be worth it.

Adelai (age 15)

“In terms of educational instruction, Adelai’s IEP was ignored.”

Adelai is 15-years-old and has global developmental delays, an intellectual disability, and epilepsy. She has daily seizures even though she is currently on medication. Joe, her father, admits that there are stronger medications available that will bring her seizures under control, but usually at the cost of Adelai losing all function. She also has a vagus nerve stimulator to help control her bigger seizures. The stimulator comprises of a wire that is wrapped around her vagus nerve. The wire is controlled by a device that sends a jolt of electricity to her brain when turned on and off and offsets her more severe seizures. Despite having so many seizures, Adelai is still able to function after one and can sometimes continue communicating with her parents while she has one. Another challenge Adelai faces is that she cannot feed herself and must receive

nutrients through a feeding tube connected to her stomach. Her parents prepare liquefied meals and directly inject this into her digestive system.

Another challenge is Adelai's limited ability to express herself verbally. She has trouble talking, but her family has come to understand her through an elaborate breathing and sniffing system that Adelai developed. To respond to "yes" or "no" questions, Adelai will change the cadence and pattern of her breathing to convey her response, usually three short sniffs for "yes" and one long breath through her nose for "no." Adelai has recently started working with a 16-button talker through which she is able to answer basic questions.

Education

Adelai has gone to both "good" and "bad" schools. When she was still young, Tennessee Early Intervention Services directed Adelai and her family to an inclusive preschool. Adelai saw a lot of growth and development during her time there, and Christy, Adelai's mother, considers her teachers as "the best teachers we ever had." After preschool, Adelai attended a public elementary school where she continued to thrive. Adelai was enrolled next at a school that specializes in special education, but she encountered many problems. For example, according to Christy, Adelai was neglected and had a lot of accidents. When Christy confronted the school about these accidents, the school placed the blame on Adelai. In terms of educational instruction, Adelai's IEP was generally ignored. After her struggles there, Christy and Joe transferred her to a school where she received one-on-one instruction. This helped with her development and she began talking more and could walk without a wheelchair. Adelai is now in the 9th grade at a public high school. She is learning how to read and can even pick out words. In the afternoon, Adelai participates in different activities that help her build life skills. She delivers mail at the school. Every Wednesday, she helps stuff boxes of school supplies for the non-profit LP PENCIL Box, and every other Friday, she goes on shopping trips. Christy and Joe are very satisfied with the current education Adelai is receiving and hope to have her stay until she is 22.

Future Concerns

In terms of long-range plans for Adelai, Christy and Joe are taking a day-to-day approach. Her school wrote a transition plan for Adelai, but failed to include Christy and Joe in the process, so they are uncertain about what it entails. Despite this, they do have some ideas about how they want Adelai to progress after she finishes school. They would like her to be as independent as possible. They also feel that their role is to encourage what Adelai wants and find the resources to support her no matter what she chooses.

Ginger (age 24)

"Lots of parents in the rural areas get lost and overwhelmed by the laws and what the rights are."

Ginger is a 24-year-old woman with cerebral palsy. She lives with her parents. Her father, Ricky, explained to us that while Ginger is embraced by the community, he has experienced many sleepless nights worrying about her future. After Ricky and his wife are unable to take care of Ginger, what will she do? Who will take care of her? Where will services come from? Ginger

has an older brother named Charlie. Ginger and Charlie have a strong relationship and he has expressed interest in taking care of Ginger when their parents can no longer do so. Ginger's parents care for her deeply, and Ricky affectionately refers to her as a "social butterfly." Together, Ginger and her family show sheep across the United States. Of his daughter, Ricky says, "She can't do lots of things, but she can show sheep to anyone in the country."

Education

Ginger graduated when she was twenty-two. She was mainstreamed in high school and often used a soundboard while attending classes like science, where the instructor differentiated instruction to Ginger's abilities. Ginger generally required the assistance of an aid in her mainstream classes, but her intelligence shined through in her schooling. "She's a lot smarter than her IQ. A lot of her teachers have told us that." Ricky generally was positive about Ginger's experience in school, but he did acknowledge that he had called the state in the past to report instances where basic services were not being provided. He was also quick to point out how lucky Ginger had been in her situation. Being very much involved with the local chapter of 4H, a youth outreach program, many of her town's school-aged residents were familiar with Ginger and her family even before she entered high school. Many of these personal connections formed during her school years have continued into her adult life.

Social and Community Supports

While the people in their hometown are very friendly and generally accept Ginger, Ricky expressed many concerns about life in a rural town and the ability to provide proper outlets for adults with disabilities. The town used to have an employment program where adults with special needs would work to separate agricultural equipment, but that is no longer available. Ricky said that after graduation "you get kicked out of the boat and it's either sink or swim." In rural communities there is also a general lack of knowledge about services. "Lots and lots of parents in the rural areas get lost and overwhelmed by the laws and what the rights are. Some of them don't know what they are." While Ginger has been fortunate enough to be raised in a family fully aware of their entitlements in regards to services, many other families are not as fortunate.

Future Concerns

Ricky's biggest concern about Ginger's future has to do with money. Supplemental Security Income (SSI) will not provide Ginger with enough to pay her living expenses when her parents are gone. There is a great concern in Ginger's family about this and about who will care for Ginger. Ricky acknowledged that this general worry over the future is not unique to his family.

Sharmane (age 38)

"Sharmane's IQ cannot predict how much she has been able to achieve and learn."

Joe and Vivian are the stepfather and biological mother to the charming Sharmane, a 38-year-old woman with Down syndrome. The three of them live together in a small town outside of Nashville. In 1973, when Sharmane was born, Vivian remembers researching the available

services for people with Down syndrome only to find, “There was nothing.” Vivian became fearless and persistent in her efforts to provide Sharmane with the highest possible quality of life. Regarding this experience, Vivian noted that it, “...forced me to become more of an advocate. Before having Sharmane, I was shy and unassertive.”

Sharmane’s biggest strengths include her outgoing and gregarious nature, fearlessness and openness to experience, senses of responsibility and appreciation, and a strong desire to work. With such traits, the family sets high expectations for Sharmane, and she maintains equally high standards for herself. Sharmane has developed a skill set that includes powerlifting, basketball, swimming, bowling, horseback riding, cooking, cleaning, and reading, to name a few. She speaks for herself and has proved to be capable in almost any setting.

Education

Sharmane graduated from high school in 1994, where she mainly was in self-contained classes, but was put into mainstream classes for physical education, art, and music. The school also had a peer-tutoring program that has created lasting friendships. Vivian says Sharmane had amazing teachers that taught not only academics, but also skills like cooking and cleaning. In addition to these classes, Sharmane spent time with a job coach, who helped her to transition from high school to a job in the workforce.

One educational challenge the family brings up is about IQ testing. The schools are constantly giving people with intellectual disabilities IQ tests in order to set standards for special education services. However, Vivian believes these scores cannot predict much and that they only set limits on the capabilities and abilities of students. IQs become a barrier that must be overcome. Vivian states, “Sharmane’s IQ cannot predict how much she has been able to achieve and learn, so in order to push your child to achieve and meet their full academic and learning potential, you need to expect more than you ever thought possible and motivate them to do more.”

The family also believes that mandating IQ testing and setting restrictions on services is where the government agencies fail. Vivian hopes that in the future something can be changed to make it easier for government agencies to provide services because people who currently need services are being left in the dark or put on years of wait lists.

Employment

Sharmane worked at a chain restaurant for more than a decade in both Kentucky and Nashville. Sharmane quickly became one of the establishment’s best employees, but had to quit after a break-in at her home. Currently, Sharmane has an internship at a foundation that focuses on accessible sports.

Social and Community Supports

Sharmane currently lives with her parents. Sharmane’s parents say that their lives have been shaped by Sharmane. Two very large focuses in the family’s life are the Down Syndrome Association and Special Olympics. She also is involved with the Vanderbilt chapter of Best Buddies.

Health Care

Sharmane has not had the health challenges that so many individuals with Down syndrome have. However, she does have to monitor her cholesterol, blood sugar, and sugar intake due to hypothyroidism and hypoglycemia. Hypothyroidism is an under-functioning thyroid gland, which slows down her metabolism and makes it difficult for her to lose weight. She takes medication for this. Hypoglycemia is low blood sugar. She cannot consume processed sugar, and only limited amounts of artificial sweeteners. She also has high cholesterol, and she takes medication for that. Sharmane is a very avid participant in controlling her sugar intake and can touch a food to her mouth and immediately know if the object has too much sugar for her. In addition, Sharmane is a very fit individual. She participates in power lifting competitions and plays basketball with the local Special Olympics team. She maintains a very active and healthy lifestyle that will hopefully keep her fit for years to come.

Future Concerns

When we asked Sharmane what she wanted for herself in the future, she said, “I am happy, if I could change a thing, I wouldn’t.” She does add that she hopes to find a more permanent job and be more self-sufficient. Vivian considers, “that a growing number of companies are hiring people with disabilities because they understand that people with special needs can be dedicated employees.”

Her parents’ main concern is that they will both die before Sharmane. If this were to happen, who would take care of Sharmane? Because Joe is 16 years younger than Vivian, he will likely live longer. He is more than willing to take on the responsibility of care taking and helping Sharmane.

Vivian and Joe recently went to court to declare themselves co-conservators of Sharmane. As a co-conservator, Joe and Vivian have the legal right to make medical decisions on Sharmane’s behalf. Also, because Joe is not Sharmane’s biological father, there are more issues to sort out in regards to the will. They want to ensure that when they die, especially if their deaths were to occur simultaneously, all of their possessions would go to Sharmane. However, because she gets SSI, they have to put their estates into a trust that will help support her. If she received their estates directly, she would lose her SSI benefits the way the laws are written now.