

Family Stories

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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 families. They learn firsthand from them about encounters with education, health care, housing, employment, and disability services in Tennessee.


The Vanderbilt Kennedy Center and The Arc of Tennessee thank all the families who participated in this program and gave permission to share their stories. They 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.



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Kora

“The public school system is preoccupied with passing the problem down...when it comes to dealing with the educational system, parents must be courageous and willing to battle.”

The Family

Stevie and Devin are a young and free-spirited couple with a four-year-old daughter named Kora. Kora has been diagnosed with CHARGE syndrome. CHARGE syndrome includes a pattern of recognizable birth defects including: a cleft in the opening in the eyeball; a problem adjusting to bright light and significant or total vision loss; heart anomalies; a blockage of nasal passages; retarded growth and development; underdevelopment of the genitals; and unusually shaped ears and hearing loss.

Despite the complications associated with her diagnosis, Kora is an energetic and happy child. Her parents describe her as being very caring, affectionate, and intuitive. Kora has difficulty standing, walking, communicating, and sleeping. When it comes to responding to other children, oftentimes Kora exhibits aggression or indifference. She also has problems recognizing boundaries, especially with strangers.

Education

The greatest challenges currently facing the family are educational issues. Kora is not enrolled in the type of program her parents would like, and her Individualized Education Plan (IEP) is not being honored. Although placement in a total communication classroom* was one of Kora’s educational goals, she spent the entirety of last fall in a Life Skills classroom**. At the beginning of this year, the school district unexpectedly announced that Kora would not meet her IEP goals, and due to routing would need to be moved to another school.

Transportation to school has been a very difficult issue for the family. Kora is scheduled to eat breakfast at school each morning. However, the bus arrives too late for her to make it to school in time for breakfast and often in time for class.

Overall, the family’s experiences have led them to believe that the public school system is preoccupied with “passing the problem down” and that when it comes to dealing with the educational system, one must be “courageous and willing to battle.”

The Future

Stevie and Devin hope to have Kora in an inclusive, total communication class next year. They are thinking about the future only in terms of wondering what Kora will be like when she is a teenager.

*Total Communication Classroom: A classroom equipped with the ability to use oral and manual communication systems.

**Life Skills Classroom: A classroom that includes components/curriculum necessary to aid students in developing the functional skills needed to manage their lives independently.

Jake

“I just want my son to have the opportunity to decide among any options that anyone else would have—sports, college, girlfriend, friends, and the list goes on.”

The Family

Scott and Elisabeth brought Jake home from the hospital in May 2006. In August 2007, when Jake was 15-months-old, he accidentally pulled a television off of its stand and onto himself. This caused a Traumatic Brain Injury to his frontal lobe.

The journey with Jake has been emotional and hectic, yet the family reports having had a relatively hopeful and positive experience through it all. They claim their positive experience is due to a variety of factors, including financial prosperity, flexible occupations and employers, familiarity and connection with the medical world, and supportive family and friends.

Support

Elisabeth was working as a nurse practitioner, but after Jake’s accident she stopped working to devote her time to his therapies. Scott’s employer granted him permission to take three months away from work with pay, so that he and Elisabeth could take Jake to an early intervention in-patient treatment center in Atlanta, Georgia.

Because Elisabeth was a nurse practitioner, she was connected to a network of people and knew how to pull strings to get Jake through the waiting lists as quickly as possible. Scott is senior director of an insurance company. Between the two of them, they knew what words to use and who to call in order to get the best assistance from the medical system and the insurance companies.

Elisabeth mentions that the family will meet the limit on their insurance coverage very soon and will begin paying for Jake’s services out-of-pocket. She recognizes and made sure to emphasize that they are extremely fortunate to be in good financial shape. Scott and Elisabeth’s families have been incredibly helpful and supportive to them throughout.

The Future

At this point, Jake is making advancements with his therapies and is making noticeable improvements. However, there seem to be endless questions arising that can only be answered with time. There is no way to know what kind of long-term effects the injury will have on Jake. There is no standard of expectation for brain injuries. Elisabeth says: “I just want Jake to have the opportunity to decide among any options that anyone else would have—sports, college, girlfriend, friends, and the list goes on.”

Brian

“If there won’t be an accurate score, then why should he take an IQ test? We didn’t want a number on the front of his Individualized Education Program (IEP) plan. We want someone to flip the page and read all about him and not just assume what their expectations should be based on that number.”*

The Family

Kelly and Kevin have three children. Brian is 11-years-old, is the eldest sibling, and was born with Down syndrome. Kelly and Kevin work outside the home. Brian currently is in the 4th grade. Brian was 4-months-old when he first underwent heart surgery. The surgery was somewhat expected, because heart conditions are common among children with Down syndrome. The costs incurred for this surgery totaled over \$200,000. Fortunately, their insurance company covered the costs.

When Brian was almost 5-years-old, he received a diagnosis of Celiac Disease. Celiac Disease is an autoimmune disorder that affects the small bowel. It is caused by inflammation due to the inability to process a protein known as gluten, which causes the malabsorption of nutrients.

Religious and Social Concerns

Brian’s diagnosis of Celiac Disease has raised many issues that affect his ability to fully participate in communities. For example, the family is Catholic and Brian, who is willing to take communion this year, must consume a wheat host. Catholic doctrine requires the presence of wheat in the host for communion. His body will not process the gluten. After a fairly lengthy search, Kelly found a low-gluten host made by nuns and is hoping to practice with Brian before his First Communion.

The family also faces behavioral and social challenges with Brian. He has additional diagnoses of Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder and Oppositional Defiant Disorder, which can make his behavior a bit challenging at times. He often throws tantrums and finds ways to try to manipulate his younger brother and sister. Brian is working with an experienced behavioral consultant on these issues.

Brian also has poor language and articulation skills that limit communication. His speech is indiscernible most of the time and as a result, Kelly has to ask him to repeat himself quite often. She, of course, can pick up on certain words because she is around him much of the time. This can be frustrating to Brian in certain settings.

Education

A major hurdle that the family has faced revolves around the school system and federal regulations regarding education and children with disabilities. Last year, representatives from the Metro Nashville Public School System filed due process against the family. The school filed against them because the family would not consent to an IQ test for Brian. Kelly explained that she and her husband believe that because IQ tests are so verbally based, children with articulation problems will have less than accurate scores. Kelly reasons, “If there won’t be an accurate score, then why should he take the test? We didn’t want a number on front of his IEP. We want someone to flip the page and read all about him and not just assume what their expectations should be based on that number.” Kelly notes that she has a “very jaded view of the school system

and what their intentions are for all children with special needs, especially kids with Down syndrome.”

The Future

Kelly and Kevin’s vision of Brian’s future is vague, and they find it difficult to think about. Considering his strict dietary restrictions, Kelly feels uneasy about him moving away from home. She says the ideal situation would be for the family to purchase a new home with a separate in-law suite or an attached apartment for Brian that he could call his own. That way, he could be in control of his own schedule, yet she could still cook for him and still look out the window or down the hall to be sure he was safe.

As far as Brian’s future employment plans are concerned, the family is busy paying attention to and noting the things that interest their son. They have noticed that Brian enjoys being around babies and holding them. He enjoys helping them. With the hope of success from the array of therapies Brian is receiving, Kelly thinks it would be nice for Brian to work at the Susan Gray School, an inclusive preschool, where the environment embraces inclusion.

*Individualized Education Program (IEP) plan: A requirement of the Individuals with Disabilities Education Act (IDEA) that guarantees a specifically tailored program will be developed to meet the individualized needs of each student with disabilities. A written plan is developed in a meeting attended by a qualified representative of the local education agency, generally, the child’s proposed special education teacher, the child’s current teacher, the parents of the child, and the child.

Evan

"There is a huge need for teacher training in educating children with autism, and this training is needed both for special education teachers and especially for general education teachers. Also, the State of Tennessee must start helping serve the needs of individuals on the autism spectrum. It is shameful how little our State does to help people on the spectrum to live as full participants in their own communities."

The Family

Evan is a 13-year-old boy with autism who has a twin brother, Brendan, who does not have autism. Evan and Brenden also have a 20-year-old typically developing sister named Emma. The parents, John and Janet, and the twins live at home year-round. Emma is enrolled at a university and lives on campus during the school year.

Janet tells us that Evan is much like a typical boy. He likes watching movies and animated television programs. He also likes to use the computer, to go swimming, and to ride his special three-wheeled bicycle. He also enjoys reading. His mother is not sure how well he reads, but says that it is well enough that he can search for things on the computer. Evan has good receptive language and good problem-solving skills. He is a talented speller and his parents believe that he may have a photographic memory. Evan also is agreeable in transitioning (some individuals with autism have difficulty transitioning) and is fairly easy going.

Religious and Social Concerns

The family has faced some challenges at church, but church leaders and members have worked with the family to try to address some of those challenges. Janet believes that may be because the people at church are only around him for a couple of hours a week. During the service, the family sits in the back so that they do not distract others. Evan usually has a toy, such as putty, to keep him occupied. No one has said anything to them about not bringing Evan to church, and for this Janet expresses gratitude. She tells us she has had friends who have children with autism who were asked not to come back to their churches.

Education

Evan's progress in school has been hampered by teachers, aides, and even principals who do not understand autism. Children with autism often need specialized instruction, differentiated curriculum and behavior intervention, but the majority of school personnel have not been properly trained in these areas. However, Evan is fortunate to live in a school district that believes in inclusive practices, and he has benefited greatly from being with typical peers. Evan's communication skills are still very limited, and because IQ tests are so language-based, Janet and John do not feel an accurate score is feasible for Evan and refuse to have him tested. They do not want to lower the school's expectations of their son. However, Evan's IEP team has decided he is not able to take the state-mandated tests, and since he will not take Gateway/End of Course tests, he will receive a special education certificate instead of a diploma. This means that he may not be able to attend postsecondary schooling.

Evan's parents think that he needs more speech therapy. He used to attend sessions regularly, but the payments became too expensive and the insurance company would not help. In 2006, a bill was passed in Tennessee that provides assistance to families in this situation but Evan was too old to be eligible. There also is a need for summer instruction. Originally, the school offered a four-week summer program, yet the summer is anywhere from eleven to thirteen weeks. Janet and

John eventually negotiated for the school system to provide six weeks of instruction, but she thinks that this still is not an adequate service being offered.

The Future

The family is concerned about future health care concerns for Evan. They feel there are not adequate medical services for children with autism in Tennessee, although this is slowly improving. Because of this, for several years, Evan was treated by a doctor in Florida who never physically saw Evan, but merely phoned in tests and treatment recommendations.

The Tennessee level of services is based on IQ scores. If an individual has an IQ of 70 or below, the state has a Medicaid Waiver program available, albeit with a waiting list of 6,000 people. If the individual's IQ is above 70, no services exist. The family does not know Evan's IQ. So whether he will be eligible for services in Tennessee is unclear right now. Janet hopes that eventually Evan will be able to find employment. He likely will need supportive employment*. If Evan were to move out of the home, he would need a supported living arrangement.** He most likely will continue to live with his parents.

*Supportive Employment: A service to help people find and keep a job. Supported employment provides ongoing job coaching/supports so that the individual is able to maintain employment.

**Supported Living: Supported living is provided to adults with disabilities in a home that the individual owns, rents or leases. The person lives there and has control of the home. No more than three people may live together in supported living. Staff help with things people need to do every day including bathing, dressing, paying bills and going to the grocery store. Supports also include making it possible for people to participate in community activities to the fullest extent possible.

Rachel

“I wish there was more research on what happens to individuals with a disability once they become adults. It is not very clear what is to be expected after their twenties, and this lack of clarity leaves many families in the dark and scared for their child’s future.”

The Family

Karen and Marshall have a 17-year-old daughter, Rachel, who has Down syndrome. Rachel is the youngest of four girls. Rachel’s mother describes her like this: “If I had to pick one word to describe Rachel, it would be: ‘teenager.’” Rachel is “boy crazy, loves to listen to music, and to sing and dance. She thinks Orlando Bloom is a real hottie.” Karen describes Rachel as a people person who is very friendly and who has a good sense of humor. Rachel’s attributes include her dogged determination and a true dedication to her work.

Rachel’s intellectual disability introduces many struggles into her life. For example, often times it is hard for people to understand her because she has a difficult time enunciating. However, according to her mother, Rachel has learned a number of tools to overcome this challenge. For example, she is able to read a person’s verbal and nonverbal behaviors, and in doing so, is able to recognize when someone might not understand her. She then is able to redirect the conversation and speak more clearly.

Health Care

Specific challenges related to Rachel’s disability include her ongoing health care needs, transportation issues, educational needs, and financial issues. Karen explains that people with Down syndrome have ongoing health care issues such as heart defects, but that the main challenge is finding properly trained doctors. Most pediatricians know how to handle patients with Down syndrome correctly, but, as Rachel grows up, it becomes increasingly difficult to find internists or gynecologists who have experience working with women with Down syndrome. Not only is it a challenge to find appropriate medical treatment, but transportation to the doctor’s office and other places in the community also is a critical issue. Rachel will never be able to drive a car. Karen explains that she would feel better if the public transportation system in Tennessee were safer.

Health care is a huge financial concern. Karen explains: “When raising a child with a disability, there are a lot of out-of-pocket expenses that insurance doesn’t cover.”

Education

In addition to these challenges, Karen explains that the most difficult challenges to overcome are those related to the educational system in Tennessee. Her opinion is that the public school system is very under-funded for all that they need to accomplish in the area of special education. Because the funding needed for students in special education is so high, the potential exists to set up an antagonistic relationship between the school system and parents.

Research

Although Karen and her family face many obstacles because of Rachel’s disability, they are grateful for the loving relationships that the family shares. Rachel’s disability has opened their eyes to many important issues that need to be addressed, especially the lack of information that is available on transitioning from high school to adulthood. Karen tells us: “I wish there was more research on what happens to individuals with a disability once they become adults. It is not very

clear what is it to be expected after their twenties, and this lack of clarity leaves many families in the dark and scared for their child's future.”

Employment

Although Rachel has many strengths and abilities, and although she has learned many valuable methods to overcome her weaknesses, she will never be able to live independently. Her mother explains to us that they have done a lot of family planning for the future. Currently, Rachel and her family are looking into postsecondary education opportunities. This search has introduced new obstacles, because postsecondary education is so novel in the field of special education. They also are looking around the country for a job suitable for Rachel. Rachel has a passion for cooking and also loves interacting with children, so they are searching in the fields of kitchen services and child care.

The Future

Rachel's parents worry about long-term care for Rachel. Specifically, the family has spent a lot of time discussing the issue of Rachel's finances required for long-term care. Karen expresses to us that one of her biggest fears is that she or her husband may pass away and leave Rachel in the care of their daughters. Although Rachel's siblings all have agreed to become Rachel's guardian if needed, Karen worries that her daughters' lives might be put on hold if anything were to happen in the near future. Karen explains that it has taken years of planning and talking to different lawyers and other professionals to organize an appropriate plan for Rachel, and because their individual situations keep changing, it seems as though it is a never-ending process.

Morgan

"Morgan and Allison each have something unique to offer the world. As parents, we want to do everything we can to help them reach their potential. Our goals for our daughters may be different, but the dream is the same. We want them both to lead happy and fulfilled lives."

The Family

Tammy has a 14-year-old daughter, Morgan, who has mild to moderate autism. She also has a 20-year-old typically developing daughter, Allison, who is a sophomore in college. Tammy feels that the sisters' age difference has allowed them to develop a strong relationship as siblings, because Allison was able to comprehend the issues and the struggles of her family when Morgan was born. Tammy says she feels blessed to have Morgan in her life and would not want to have it any other way.

Morgan also has PANDAS (Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections), anxiety, Obsessive-Compulsive Disorder, and osteopenesis. Despite all of this, she has remained a happy, fun-loving child. She likes expressing herself with loud noises, which is unusual for a child with autism. In fact, Morgan has been unable to remain in inclusion classes because of her noisy nature. She is described as being a humorous, funny girl with a dramatic side. She loves computers and playing basketball, and she and her mother bond when playing music together.

Education

In the past, Morgan has tested at typical nonverbal IQ levels, but due to her lack of communication abilities, she struggles in classroom settings. Almost a year ago, Tammy began investigating methods and ways in which to move forward from the Picture Exchange Communication System (PECS) in the hope that Morgan could develop more communication skills. Recently, Morgan acquired a Dynavox, which is an alternative augmentative communication device that uses picture symbols on a mini-computer.

It took a lot of effort on Tammy's behalf and several tries with the insurance company to get them to approve the device. Morgan, her family, and her teachers are in the process of learning how to use it with the help of a specialist. Tammy is excited to see how the Dynavox will open doors for her daughter. She hopes that with this new form of communication, Morgan will learn to take initiative for herself and her needs as well as move up a few grade levels academically.

In terms of education, Morgan has experienced some good years and some bad years. Tammy says the school system is supportive to an extent, but they often struggle with providing necessary supplemental aids due to budget issues. She has experienced a lot of disappointments and broken promises, but they are hoping that with the addition of the Dynavox as a new way to communicate, Morgan will make great strides.

The Future

As for Morgan's future, her mother intends to have her live at home as long as she can take care of her. It is not likely that Morgan will be independent in the future. Morgan's sister, Allison, has spoken with her mother about the likelihood of taking care of Morgan in the future and has accepted it. She realizes the family responsibility and is aware that her mother will not be around forever.

Stephanie and Jessica

“In just six years, the girls had eight different special education teachers. By the time they got used to one teacher, they would get new one.”

The Family

Stephanie is 28 and her sister, Jessica, is 26. Both girls have intellectual disabilities, have epilepsy, and have various difficulties in communicating that limit their abilities to ever live independently. They are like any set of sisters who love each other, and also are like night and day. Stephanie is shy around strangers, loves doing crafts and going bowling. Jessica is sociable, extroverted, and very interested in boys.

Stephanie and Jessica’s parents say the family is in a stable financial situation. They realize this has positively affected their experiences as a family of children with disabilities. They are very open and friendly parents who share the responsibility of caring for their girls. They are both very active advocates in the disability community.

Education

The family faces challenges on a daily basis, most of which are related to education. Before Stephanie and Jessica enrolled in their current day school, they attended a public high school. Their parents say that, although they were accommodated very well, Stephanie and Jessica experienced an extremely high special education teacher turnover. In just six years, the girls had eight different special education teachers. There also were problems with homework modifications, and the parents indicate that their daughters experienced a few problems with peers.

The family states that they are very “fortunate” to receive bus transportation to and from the girls’ current school, because the bus has a limited route. Many of the girls’ classmates cannot take advantage of this service.

Services

The family expresses frustration with their experiences with the legal system. In addition to limited funding, the girls’ mother states that accessing services is “just a bunch of games.” She says the Self-Directed Waiver Program is not self-directed at all. She says it will pay for some educational programs, but only those pre-approved by the State. The girls’ school is not included on that list, but the family believes it has the best program.

The parents tell us that every family and situation is different, and so policies cannot possibly function in a one-size-fits-all manner. For example, the law requires that there must be a different person caring for each person with a disability. It is set up so that one caregiver is not watching five or six people in need and administering medications incorrectly. While this law has good intentions, it prevents the family from using their waiver for both girls. Neither one of them can be watching both of the girls at the same time. Should they want to go out, they would need to hire two people to watch the girls and to administer their medications.

The Future

The family states that they are “trying not to think about the future.” The parents have set up a Special Needs Trust for the girls which will provide funding when they pass away. They hope that Stephanie and Jessica will be allowed to stay enrolled in their school.

Michael

“My basic hope and prayer is that I outlive my son.”

The Family

Brenda is a real estate agent and has a 43-year-old son named Michael. Michael is both deaf and blind, has diabetes, has some developmental disabilities, and exhibits autistic and compulsive traits. He is an only child, lives at home, and is no longer eligible for the vocational rehabilitation and schooling options that the State of Tennessee has to offer.

Brenda is eager to speak with us about the challenges of having a child with disabilities in Tennessee. From housing to services and health care, according to Brenda, Tennessee has a long way to go.

Housing

Brenda would like to see Michael living in a group home, but she has not come across one that meets with her standards of quality care. She says that if she did find one, the transition would be difficult for Michael, because he is not comfortable with change.

Services and Employment

In terms of services offered by the State of Tennessee, Brenda is frustrated that the State continually cuts funding. She understands that the State needs help to put services in order, but finds it troubling that people with disabilities are just sitting around. Brenda feels that the State should find some way to balance the needs of people with disabilities with the high quality of life that every human being deserves.

Education

In terms of educational services, which Michael has completed, Brenda says the State also is lacking. Michael attended a special education school, and Brenda remembers there were a lot of students all in the same place with not enough specialized care and education. While she does feel it was better than nothing, she does not feel that it was a setting conducive to learning. After that school, Michael attended a school that caters to the education of students with vision impairments. He later attended a school that specializes in the education of people who are deaf or hard of hearing.

In Brenda’s opinion, Michael’s progress at the latter was the best of any school. On the topic of education, Brenda says “parents, most of the time, know children better than educators do, but they don’t want to take your word for it.”

The Future

Michael is an only child, so the prospect of having a sibling take care of him is not an option. Brenda does have a lot of family, but does not think it is appropriate or fair for them to “give up their lives and careers” to take care of Michael. “My basic hope and prayer is that I outlive my son,” Brenda tells us.

Jeff

“If my son had been in a regular school system... he might be able to do some things he can’t do now.”

The Family

Jeff is 47-years-old and was born with cerebral palsy. Jeff’s mother died two years ago, and Jeff currently lives with his dad. Jeff has limited use of his legs and uses a walker. He also uses a motorized wheelchair when he has farther to go or feels tired. Jeff requires constant care and will never live by himself.

Jeff has two siblings, and his father reports that the family has strong bonds and remembers they really “pulled together to get through the surgeries” and other challenges when Jeff was born.

Jeff is a very personable and social person and loves to joke around. According to his dad, he can read at a high-school level but does not comprehend what he reads. He loves sports and always knows when a game is on television. He can tell you about all the games, what happened, and who won. He has a great memory for remembering names and dates. He attends programming at an adult activity center everyday, where he and other individuals with cerebral palsy go bowling, see movies, and go out for meals. Jeff also has participated in Special Olympics, engaging in events such as softball throwing and wheelchair races. He also paints and has entered some of his paintings in local art shows. He loves to go on walks around the neighborhood, and the community openly welcomes Jeff and accepts him for who he is.

Education

Jeff began attending a center that specializes in working with individuals with cerebral palsy at age five. He travelled by bus 78 miles each day. For four or five years, he attended classes through a church. When Jeff’s school system tested him, they suggested that the family enroll him in an institution. The family was told that Jeff would never be able to attend a school or learn. The family did not agree and eventually he attended an elementary school in Franklin. When asked about the effectiveness of Jeff’s schooling, Jeff’s father replies that “it has been very effective for him,” but believes that “if he had been in a regular school system... he might be able to do some things he can’t do now.”

Health Care

Jeff receives money from government Medicare and Medicaid programs. He did not begin to receive Medicare until he was 20-years-old, because his parents did not realize he could receive it earlier. In the past few years, Jeff began the Medicaid waiver program, part of which allows for a trained person to come for two hours a week to stay at home with Jeff while his dad goes to Wednesday night activities at church.

It is a priority to keep Jeff walking as long as possible, because he knows Jeff enjoys it so much. The doctors told the family that Jeff would be bedridden by age 18, but he is still walking with his walker at age 47. Also, money is a concern, since funding for the Medicare and Medicaid programs are constantly endangered.

The Future

Jeff’s father feels it is unfair to ask Jeff’s brother to take care of Jeff in the future. It is a huge responsibility and he is concerned about the changes it would inevitably have on their family’s life. However, his son insists that he and his wife will take Jeff.