

Family Stories:

How Disability Affects Tennessee Families



VANDERBILT
KENNEDY CENTER
for Excellence in Developmental Disabilities

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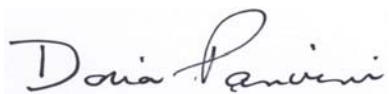
A Letter of Thanks

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.

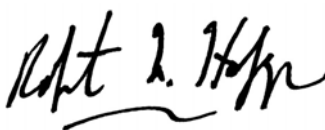
The course offers future educators, advocates, and researchers an opportunity to learn what it's like for a family to include a member with a disability. As part of the course, students interview families. They learn firsthand from them about encounters with education, health care, housing, employment, 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. 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 previous editions of Family Stories, please visit: <http://kc.vanderbilt.edu/publicpolicy/>



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Dylan

“There is a deficiency of well-trained special education teachers and general education teachers should be more knowledgeable about disabilities as well.”

Dylan is 3 years old and has Down syndrome. He likes to do everything himself. He is outgoing and affectionate with strangers, which, according to his mother Lisa, “can be a little bit of a concern.” One of Dylan’s strengths is that he knows his routine. For instance, “He knows when it’s time to take a bath and go upstairs and brush his teeth.” Lisa uses a picture schedule with him, so that he can follow the daily regimen of activities.

Lisa and Dylan’s father, John, did not know that Dylan had Down syndrome prior to his birth. They found out about 8 hours after his birth. When they were told, Lisa’s mind started racing. As a former special education teacher, she had studied Down syndrome extensively. She was anxious about the heart defect issues and about his life expectancy. Her husband dealt with the disappointment of “not having the child who would go to Harvard.”

Education

Dylan currently is enrolled in preschool. Lisa is already “getting the sense that the teachers and administrators don’t put the children with developmental delays into the least restrictive environment that they can.” She knows that Dylan may not be in a general education class for academics, but she would like him to socialize with his peers and to be included with all of the other children when they go to lunch, recess, and the specialized subjects. However, Lisa has not observed this socialization and inclusion in their current school system. She has also recognized that the teachers and administrators do not work to assist parents and guardians of children with disabilities. She said, “They’re not going to outright lie to you, but they might not work with you because they think that you don’t know what your rights are.” Moreover, most teachers, including Dylan’s current teacher, are not trained extensively in special education. Lisa emphasized the point that there is a deficiency of well-trained special education teachers and that general education teachers should be more knowledgeable about disabilities as well.

Healthcare and Services

Dylan has congenital glaucoma, in addition to Down syndrome. He also has a gluten allergy. The doctor advised the parents to remove gluten from his diet, and he has not had it in over 2 years. However, he needs to be tested for Celiac disease, an autoimmune disorder of the small intestine, which is prevalent in people with Down syndrome. He must have gluten in his diet for 3 months prior to being biopsied for Celiac disease. As such, the family must find an allergist who can reintroduce gluten into his diet in order that he can be tested. Dylan had tubes put in his ears in September 2009, which has helped his speech significantly. Overall, being close to Vanderbilt has made a significant difference in the healthcare availability for the family.

The family started TEIS (Tennessee's Early Intervention System) when Dylan was 3 weeks old. This program assisted the family in understanding the resources and services available to them currently, as well as those that may be useful in the future.

Employment and Housing

Lisa said that every parent has his dream of what his or her child will be. Her hope is that Dylan “is married, has an apartment, and is independent.” Lisa would like Dylan, when an adult, to

have a steady job and live in a supervised apartment. At the same time, Lisa hopes that the apartment is close to their home in order that she can supervise him.

Social and Faith Community

Lisa would like Dylan to socialize with “a wide-array of people.” They are integrated in their church community. Other children, who are of similar age to Dylan and have Down syndrome, attend the same church. Dylan also socializes with typically developing children in his Sunday school class. The parishioners of the church have openly accepted the family. The church membership is broadminded and willing to help their family, whether it means adjusting the curriculum or the staffing in Sunday school classrooms and in other church programs.

Respite

When Lisa and John require respite, they look to Lisa’s parents for support. Lisa’s parents relocated to the area a few years ago. However, the family does not spend much time apart. Dylan goes wherever the family goes, especially on vacation. Lisa said, “We don’t go on vacation without him. He goes with us!”

Future Concerns

Lisa is concerned that Dylan will develop Alzheimer’s disease when he gets older. She is especially concerned because she and her husband will have most likely passed away by the time it develops. Therefore, their daughter Kayla must care for her brother. She is also concerned about possible significant weight gain, thyroid troubles, and dementia, as these are all medical issues common in older people with Down syndrome.

Brooke

“Early assessment and intervention combined with a holistic approach to treatment are the things that have made the greatest difference in Brooke’s life.”

Brooke is a cheerful young girl who loves to sing everywhere she goes and to anyone who will listen. This delightful young performer is in many ways like any other 7-year-old girl. However, this was not always the case. At the age of 4 months, Brooke was diagnosed with epilepsy, and by 13 months, she began receiving occupational, speech, and physical therapy from Tennessee Early Intervention Service (TEIS). She also has received feeding therapy and deals with sensory issues as well. Until the age of 3, Brooke’s primary means of communication was through the use of sign language. Interacting with others and with her environment has not come easily, but early intervention has made a huge difference in Brooke’s development.

Brooke’s mother, Lynise, recognized early that Brooke was not developing as a typical child would. Brooke did not smile until she was 5 months old. She had very low muscle tone, making her body very limp. Since she could not support herself, Lynise held her almost constantly. A special bond was forged between the two as a result.

Gastrointestinal issues have plagued Brooke’s life. It seems she has an incredibly high threshold for pain, since she experienced it constantly until about 4 months ago. Until that point, she would wake up as many as eight times a night. Also, she could not gain weight. Her mother describes Brooke’s stomach as growing over the course of a day and becoming distended. Recently, Lynise discovered that Brooke is lactose intolerant and has started her on a gluten-free diet. Removing dairy and gluten from Brooke’s diet has relieved many of her gastrointestinal issues and has allowed her to gain weight.

Education and Advocacy

Entering kindergarten, Brooke had difficulty identifying shapes and even writing letters. She received assistance from an occupational therapist, and by the end of the year she was ready to move on to first grade. This year, she is able to write all of her letters as well as her name, and she completes about fifty to sixty percent of the foundational material presented to her. She experiences some frustration and is likely to repeat first grade so that she will be sure to have a firm grasp of the basics. However, she is progressing socially and continues to make great strides.

During the school day, Brooke receives services and accommodations. When her Individualized Education Plan (IEP) was created at the beginning of the year, Lynise was adamant that Brooke receive the same information, tests, and learning expectations as her typically developing peers. As the year has progressed and goals have been assessed and re-evaluated, some of the expectations have been altered to be more manageable for Brooke. For example, she may be presented with eight weekly spelling words instead of the full complement of ten. Nevertheless, Lynise is very clear that her goal for Brooke is to be in a general education classroom without accommodations within the next 3 years.

Lynise became trained in special education advocacy through participation in the Volunteer Advocacy Project. “I wanted to become more educated about the laws surrounding special education and the rights Brooke has to services,” said Lynise. Armed with education and information, she successfully advocated for an extension of services for Brooke at her preschool when, at age 3, responsibility for her services transferred from TEIS to the public school system.

Lynise was told that it would not be possible for Brooke to remain at her preschool, but Lynise found “the decision was unacceptable because Brooke was not going to fit in any other program they offered.” With persistence, Lynise was successful and is very grateful that she stuck with it. She strongly believes that Brooke would be a very different child today, had she not received the day-to-day therapies and small teacher-student ratios that Brooke’s preschool offers.

Early assessment and intervention combined with a holistic approach to treatment are the things that have made the greatest difference in Brooke’s life. TEIS was able to provide home visits and made an effort to provide treatment wherever was the most convenient for her family.

Overall, Brooke has been a very lucky little girl. Her mother had the time and resources to become knowledgeable regarding her daughter’s rights and has pushed for her to receive the best of all possible treatments. Sadly, many children with disabilities do not receive the early intervention that would help them so greatly nor have family members who know what they can push for from state and educational systems.

Meghan

“I think there are a large number of parents out there with kids with disabilities who are unaware of the services out there.”

Meghan is 10 years old and has Down syndrome. When Jen and Craig found out that they were having a baby with Down syndrome, they decided to plan their lives month to month. In the first months after her birth, they spent much of their time educating themselves about what to expect from a child with Down syndrome and how they could best accommodate their daughter while also building their family. Meghan, along with her four siblings, all live at home with their parents and get along as any typical siblings do. Alexis is 15, Ryan is 7, and Owen and Colin are twins and they are 4.

Jen described her daughter as friendly, social, caring, empathetic, and even a little bit stubborn. In many ways Meghan is like a typical girl who has bad hair days and needs to see Miley Cyrus in concert.

Education

As Meghan approaches her eleventh birthday, so does the process of creating a new IEP (Individual Education Plan) for the upcoming year. Some of the aspects that usually need to be taken into consideration for her IEP include a modified work schedule, a personal aide in the classroom, the continuation of the Wilson Reading Program, and her challenges with communication.

Overall, Jen is extremely pleased with Meghan’s education and her school. As a fourth grader, Meghan feels good about the work she produces and “she is challenged and supported appropriately.” Communication among the classroom teacher, Meghan’s personal aide, and Jen is essential to Meghan’s educational success. The classroom teacher sends Meghan’s upcoming work home for Jen to review a week ahead of time. For example, Meghan has a social studies test coming up on the Constitution. Jen, as well as the teacher, looked through the study guide and chose which questions would be appropriate and still thought-provoking for Meghan. The teacher then finds a few minutes to orally administer the test for Meghan based on Jen’s recommendations and her teacher’s ideas of what Meghan should know and can do. This process ensures Meghan is advancing with her peers.

Jen understands they are lucky to have such a dedicated teacher who works with Meghan so well. She says attributes of a good teacher are good communication with the parents and a willingness to make thoughtful accommodations for all students. While Meghan does have a good teacher, Jen mentions the difficulties they face navigating through a school system with a child with a disability. “I think there are a large number of parents out there with kids with disabilities who are unaware of the services out there.”

Generally, Meghan seems to feel happy and included in school. In her school “she’s really well known and very well liked.” Yet, Jen has realized Meghan’s “own level of awareness of the things she cannot do.” Some days she does not want help with her school work, or she does not want to have an aide with her at school because she does not want to seem “different and not exactly like everyone else.” Perhaps, as a result, outside of school Meghan has moved away from her typical friends and has strengthened her relationship with her best friend, a fifth-grade girl who was also born with Down syndrome and her cousins who are the same age.

Employment and Transportation

When thinking about Meghan's immediate future, Jen worries about the transition from the familiar elementary school into the very unfamiliar middle school. Luckily, Meghan's elementary school goes through sixth grade and they will have some time to figure out what is best for Meghan's educational future. After that, Jen is just speculating about what is to come in Meghan's future. Her hopes and goals for Meghan are the same as for all of her children. She expects Meghan to graduate, get a job, and fully contribute to her financial needs. Jen imagines that Meghan would make an excellent restaurant hostess because of her outgoing and bubbly personality. Meghan has also expressed a desire to work in the food industry. When discussing transportation options in Meghan's future Jen stated, "I think we will always provide her transportation. I have a hard time imagining her taking the bus but she would be perfectly capable. I might follow the bus three cars back for a year, but we would work with her if she wanted to do it."

Housing

In the future, Jen and Craig expect to be on their front porch rocking in their chairs with Meghan rocking alongside them, but she realizes that this may not be what Megan wants. As for Meghan living on her own, Jen says, "I do push her and challenge her, but the thought of that right now is just a little bit overwhelming." Meghan's older sister, Alexis, has always said she cannot imagine Meghan living with her brothers when they are older, so she will be living with Alexis. That is comforting for Jen, because a major concern is what will happen to Meghan if something were to happen to Jen and her husband, just as that is a concern for every parent. Jen mentions that there are many backup plans. However, knowing they have such close family and friends who care about Meghan puts Jen and her husband at ease.

Joey

“When Joey was first diagnosed with autism, I came across an article that said children with autism oftentimes grow up with very few friends. That hurt. I look to his school as a place where he can be with others. When he is out of school, I hope we will find new places where he can be with his peers.”

Joey is 13 years old and has been diagnosed with an autism spectrum disorder. According to his father, Wade, Joey’s best qualities are his good personality and his great sense of humor. People tend to enjoy interacting with Joey and he has many fulfilling relationships. In particular, Joey loves his niece Hannah and feels very protective of her. He and his sisters usually get along, displaying pretty typical sibling interactions.

In his spare time, Joey enjoys watching movies, playing videogames, and any activity that involves trains. He also likes to read and is very strong academically in math. Joey’s temperament is usually cooperative, yet he can be “a lot bit stubborn” and according to his father, sometimes does things only “if he wants to... If he wants to is a big thing with him.”

Joey’s stubbornness can be problematic, especially when he insists that he does not want to take his medication or when he gets upset when things don’t go his way. Joey received a diagnosis of autism at 2 years of age. Since Joey’s original diagnosis, he also has been deemed by professionals to have Obsessive Compulsive Disorder (OCD), Oppositional Defiant Disorder (ODD), an intellectual disability, bipolar disorder, and possibly a seizure disorder.

Education

Wade talked about the various aspects of Joey’s life that are successful as well as those in which they have particular challenges or needs. Joey’s education, which started at the age of 3 in Japan through the military school system and has included some summers, has enabled Joey to make tremendous progress. Currently, Joey is in a special education classroom for the majority of the day, but he does take part in general education courses as well. Wade feels that Joey gets along with the teachers, aides, and the other students in his school environment. However, the family has struggled with attendance issues lately as Joey sometimes refuses to go to school.

For Joey’s future education, Wade feels that Joey will need more daily living skills education because “Joey’s disabilities will probably prohibit him from living on his own.” Wade also would like for Joey to have an aide with him more frequently, but understands this to be impossible as his public school does not have the staff for that kind of assistance.

Wade finds it extremely important that Joey be offered social interaction at school. “What I look for from Joey’s education is mostly the social interaction,” he said. “It may sound strange, but I don’t care if he ever learns geometry or algebra or any of that. I don’t care particularly that he ever writes a term paper, but I want him to be able to interact with people. When Joey was first diagnosed with autism, I came across an article that said children with autism oftentimes grow up with very few friends. That hurt. I look to his school as a place where he can be with others. When he is out of school, I hope we will find new places where he can be with his peers.”

Health Care

The family has been fortunate to receive high-quality health care due to Wade’s retired military benefits. Wade stated that the insurance pays a lot toward Joey’s medications, which otherwise would be very expensive for the family. However, the one thing that Wade’s insurance does not cover is in-home behavioral therapy. The family would like in-home behavioral or occupational

therapy to improve some of Joey's day-to-day functioning and help the family work with him. There are some issues that Joey faces for which this type of specialist could be helpful. The family is unable to provide that assistance.

Employment and Housing

If Joey were employed in the future, he would require a supported environment for individuals with disabilities. However, Wade did state that "You can't really limit him either, because you never know." Along the same lines, in terms of housing, Joey will need to reside with his parents or in a supportive living situation for the rest of his life. Currently, Joey lives on a dead-end street with his family, which has been very helpful because there is not a lot of traffic. Their house has a fenced yard, and Wade feels lucky that the family is very familiar with the area and has a strong network of neighbors and relatives in their immediate environment who are very supportive. These factors are especially helpful if Joey wanders off of their property.

Wade is unsure where Joey will live as he and Ashley continue to age, stating that "I don't want him to be lost. I want him to be taken care of and to continue his life as seamlessly as possible. I don't want to send my child away to a group home, but as he becomes an adult that may become the best long-term decision." Although Joey's parents will have options, it seems this will be a difficult situation for them to come to terms with in the future.

Community and Current Challenges

Wade feels that his family has had mixed experiences in the community, depending on others' knowledge and understanding of disabilities. Thus, how welcoming others are towards their family and son is largely situational. Wade, Ashley, and the rest of the family take Joey to parks, grocery stores, and the movies. However, movies can be difficult due to loud volume and the amount of people. Usually, their concern is about how comfortable Joey will be rather than how welcome they are in these places.

In the school environment, Joey is largely met with a welcoming attitude by peers. Wade stated that he feels "they like him for who he is."

A major challenge for this family is that Joey requires someone to be with him at all times. This can be exceptionally difficult because both Wade and Ashley work, and thus the family has had to rely on babysitters or his sisters to help care for him at times. This also leads to financial difficulties. These difficulties are further exacerbated by Joey's restricted diet, as trips to the supermarket can become quite expensive. Overall, Wade and Ashley seem to be coping with these challenges in a way that enables them to provide the best possible environment for the growth and success of all three of their children.

Another challenge is that people do not always recognize that Joey has a disability and so they are very judgmental when he has behavior issues in public. "Sometimes when people see Joey or look at him they think he should be a normal teenager," said Wade. "If he's having an episode and if he's crying or screaming a bystander may not know what's going on and may make assumptions that they shouldn't make." This can be difficult for Joey and the family when they are out together in the community.

Future Concerns

As parents, Wade and Ashley plan to stay active in Joey's life, even if he does move to a group home. As they age, they will continue to take care of him to the best of their abilities. In regards to Joey's long-range future, Wade feels he will not go any further with his education after

secondary school. They do not have any particular plans for him after he is unable to go to school. While they do not want to limit him, they are trying to remain realistic about his options.

Knowledge and Awareness: Areas of Improvement

In general, Wade feels that people need more education about autism. He doesn't think people understand that autism looks different in each individual. "I think a lot of it is that we are ignorant about things," he said. "I didn't know what autism was until my son's diagnosis. And I think that most people don't, unless they are affected by it or it's part of their career path. Just like it's the same with any other disease or disability—if it doesn't affect you, you have enough things to worry about. And I think that, I think that there's a lot left to be done."

J.T.

“What is helpful to one person with autism is not necessarily workable for another. Therefore, any policy or view that attempts to compartmentalize people with autism may be ineffective.”

J.T. is a fun-loving, energetic, and happy 18-year-old boy living as an only child with his mother and father near Clarksville, TN. His mother, Margaret, playfully calls him “Little Mr. Social Butterfly” because of all the friends he has made in the community. J.T. has many interests in life, especially practical jokes, movies (he can recite his favorites from start to finish, in character voice), and travel. Of all of his interests, his biggest passion is the ocean and aquatic life. He hopes someday to work in a field where he can help save endangered animals.

J.T.'s life is not free of challenges. On his second birthday, J.T. was diagnosed with autism. While J.T. has since shown a remarkable ability to exceed expectations, he still struggles with many of the traits that are common to the disorder. For example, J.T. contends with a speech impediment that dampens his ability to communicate in English (though, amazingly, he is very adept at communicating and generalizing in both Spanish and French). He also tends to become overwhelmed by changes to his regular schedule and must make frequent use of a well-planned calendar to help him function comfortably.

J.T. cannot tolerate some of the sounds present in everyday life, such as white noise and very high and very low pitches. He requires the use of specially crafted headphones to attend social and public events. If J.T. becomes overwhelmed in these situations, he does have the ability to mask traits often associated with autism (e.g., rocking, folding hands, and hitting his head) until he is safe at home. His mother sees it this way: “I think it is self-preservation. He just wants to be like everybody else...because he is so aware how it affects him and how other people look at him.”

Education

When it comes to J.T.'s education, Margaret states that she does not wear “rose-colored glasses.” Nonetheless, it is highly likely that by the time he ages out of the education system at 22 years old, J.T. will graduate with a regular education diploma. Currently, J.T. is a senior in high school and attends general education classes with his peers for all subjects except English. English is the main area in which he struggles and the only area in which he has not yet passed the “gateway” test required for graduation. With the help of additional English classes and a tutor to aid him in reading and comprehension skills, Margaret has high hopes that he will graduate with the rest of his classmates on time. Postsecondary education is not part of his plans.

While some aspects of J.T.'s education have been positive (e.g., socialization), others have been less than ideal. Margaret's main frustration with the school system is the need for better education for the teachers. She has firsthand experience with this topic, since she went back to school after J.T.'s diagnosis to become a special education teacher. She contends that many special education and general education teachers lack the knowledge and training to modify instruction to the individual needs of not only students with autism, but students with other disabilities as well. Moreover, school administrators frequently do not allow teachers to “work outside the box” to the extent needed to reach every individual child. To her, education for students with disabilities must go beyond their IEPs and embrace a variety of methods and ideas.

Employment

Like any parent, Margaret wants J.T. to be happy and successful in the career path of his choice. Yet because J.T.'s dream is to save endangered polar bears and whales in Antarctica, she

approaches his vision with some apprehension. To help their son achieve his dreams, Margaret and her husband have constructed a very specific employment plan that will work with J.T.'s strengths and weaknesses. He will first work at a local veterinarian's office in Clarksville, TN. The plan would then culminate with a position at Sea World. Margaret is hoping that this will be enough to satisfy J.T.'s ambitions without requiring a move to Antarctica.

J.T.'s future is bright, but not without challenges. For one, he cannot and will not be able to drive. This makes transportation to and from job sites a situation that will require some considerable planning. Currently, J.T. must rely on his parents, friends, and family for conveyance; however, these supports may not be available as his future employment plans take him farther and farther from home. Secondly, J.T. will require a lifetime job coach for interpreting and safety. This is not a huge problem until J.T. must cross state lines. At that point, the family will likely face problems with Medicaid and state waivers for these services. While Margaret and her husband are able and willing to pay for services out of pocket for J.T., Margaret is quick to point out that they are fortunate to be able to do that for him. Not all families are so lucky.

Housing

Currently, J.T. is living comfortably in his parent's home. As he gets older, there will come a day when he will need to move forward. His first step, when he is ready, will be a transitory move to an apartment that is located in the basement of the family house. Since J.T. cannot do some basic things on his own (e.g., cooking), he will never be able to live completely alone. Though none of this poses an immediate problem, Margaret does sometimes worry about the very serious obstacles J.T. would face if she and her husband were for some reason unable to care for him.

Social and Faith Community

J.T. and his family are incredibly fortunate to have a very welcoming and fulfilling community life. J.T. seems to make friends everywhere. He has friends at school, in church, and even at the grocery store and bank. He has an especially close relationship with his pastor and his worship leader, whom he calls "Perfect Mustache." J.T. also makes friends through a variety of organizations. His dad is a member of a civic group called "Bikers Who Care," which raises money for children's charities. J.T. loves it when the group gets together so he can spend time with the guys. He is also very active in an athletic league called "Buddy Ball."

Future Concerns

Margaret's vision for the future is no different from that of any other parent. She wants her son to be happy and she will always be there to support him in that endeavor. She points out that her family faces the same life issues as anyone else; it is just that they sometimes have to go about getting to the end result differently.

It has been a long journey for J.T. and his family, but it will never be over. Through the course of 16 years, they have weeded through a mass of often contradictory information to ultimately find out what works for them. These experiences have shown Margaret that autism affects everyone differently. "People with autism and their families cannot be grouped together in one big mass," said Margaret. "What is helpful for one person with autism is not necessarily workable for another. Therefore, any policy or view that attempts to compartmentalize people with autism may be ineffective."

Tripp

“From this point on, I want you to remember that it’s your job to prepare Tripp for the path, because you cannot prepare the path for Tripp.”

When Tripp was 4 years old, he received a diagnosis of mental retardation, which is now referred to as intellectual disability. Tripp’s mother, Pam, remembers this day as being filled with confusion and uncertainty. “We didn’t know what to do,” said Pam. “I asked the doctor ‘What’s the next step?’” She said the doctor told her something she will never forget. He said, “From this point on, I want you to remember that it’s your job to prepare Tripp for the path, because you cannot prepare the path for Tripp.” Pam says that insight has stayed with her throughout Tripp’s life.

Tripp loves sports. Football and golf have played significant roles in his life as they have offered meaningful opportunities for bonding with others. Tripp has had several opportunities to lead prayers before games for the University of Tennessee at Chattanooga’s football team and has become a source of inspiration for the players. He also is an avid—and adept—golfer, which is an activity that gives Tripp and his father great bonding time together.

Tripp’s father, Joey, believes that his wife, Pam, can take most of the credit for Tripp’s success with friends, school, neighbors, and a new job in Rand Hall at Vanderbilt University. The family made a decision that Pam would stay at home, rather than return to work, and this increased attention was extremely valuable in Tripp’s development.

Sibling Support

Tripp’s sister, Taylor, also has played a large role in his life. Taylor recalls how she made lists for her parents of teachers who would be able to support Tripp and how she advocated with schoolmates when high school students were mean to kids with disabilities. “If my friends couldn’t accept Tripp and treat him with respect, they weren’t part of my life,” said Taylor. “Everyone loves Tripp though. He is so loveable and likable. I am known as ‘Tripp’s sister’ rather than ‘Taylor’ in some circles.”

Taylor has thought about the future and knows her life includes Tripp. “Wherever I go, Tripp will be a part of my life,” said Taylor. “I wouldn’t even mind if Tripp and I live together. Maybe even with a dog.” Taylor didn’t always feel that way. “My childhood stopped when Tripp came along,” she said. “I felt a lot of responsibility for Tripp, mostly what I put on myself.”

Health Care

Tripp’s family shares that this “trip” with Tripp has not been without worry and struggle, particularly with regards to long-term care and health care. Pam and Joey, who believe they have been “blessed” with the financial means of caring for Tripp, wish for reform in healthcare. Tripp has a full-time job at Vanderbilt University, but due to this he might lose his TennCare health care. Pam and Joey’s greatest concern is what would happen if Tripp lost his job at Vanderbilt and he had to re-qualify for TennCare.

“I wish policymakers would provide, somehow, for people like Tripp who might need TennCare coverage again,” said Pam. “Should we really have to go through all those hoops again? It needs to change. We have always been able to take him to the doctors and specialists he’s needed... what happens when we’re not around to do that?”

Transportation

In the time since the family was interviewed for this story, they made the decision to discontinue Tripp's work at Vanderbilt due to travel difficulties. How to handle transportation and getting Tripp everywhere he needs to go is a huge concern. The family seeks to meet Tripp's needs and provide him with the best opportunities, but sometimes circumstances make fully achieving this complicated.

Education

Another difficulty the family faced occurred when Tripp entered school. In elementary school, Tripp had an excellent teacher, and both he and his family were very pleased. However, this seemed to change in later years. School support dwindled. The family wanted increased inclusion for Tripp and a more straightforward approach to an educational plan. After research, Pam and Joey found just what they were looking for at Nashville Christian School. Despite their satisfaction with Tripp's high school experience, the family was displeased with the dissemination of information for options after graduation. It was only through a stroke of luck that Pam found out about Project Opportunity, which provides individualized work experiences at Vanderbilt University Medical Center for young adults with disabilities.

Community and Quality of Life

The most defining aspect of Tripp's life, in his opinion, is his faith. When he introduces himself, Tripp solidly gives credit to his faith, "Well, I am a Christian boy," said Tripp. "I preach, worship, and praise God...God always has a plan." Pam and Joey add, "We don't take credit for that spirit." While they are not "Sunday regulars" at church, this family has a strong bond through their faith. Tripp likes to pray, and has a special relationship with his Uncle Bill, a retired preacher, with whom he prays and talks on the phone about sermons.

Tripp also has carried on a family tradition and plays Santa Claus at Christmas. When he first asked for a thirty-dollar Santa suit, Pam said, "I am not spending that money on a Santa suit!" Joey beams at his son, adding, "He loves it. He never asks for anything..." Seamlessly, Pam picks up, "So I headed back to the store to buy the suit, and he wears it every year. He works to buy coloring books and crayons for the neighborhood kids." Tripp knows how to get the job done or "knock it out," whether it's at work, with friends, or as a volunteer.

Pam boasts, "We are blessed. Tripp has changed my thinking about who I thought I was and he's helped me not worry about the next step. He always says, 'Mom, Why do you worry, don't you know, God has a plan...you know, it really has been a trip with Tripp, and we wouldn't have it any other way.'"

Kimberly

“It’s just like the state says, ‘OK, you’re 21, school is over, we forgot about you.’”

Kimberly has cerebral palsy. She uses a wheelchair, is non-verbal, and has seizures. She has no motor control and cannot feed herself. She is 24 years old and has aged out of the public school system and aged into – nothing. Her parents, Carol and Clarence, are frustrated and concerned about her future.

Education and Adult Services

There is no daytime continuing education, socialization, physical therapy, support, or out-of-home respite care provided for adults with disabilities where the family lives in Mount Juliet, Tennessee. “It’s just like the state says, ‘OK, you’re 21, school is over, we forgot about you,’” Carol said. “Kimberly needs something to do. Everybody needs something to do on a daily basis to occupy their time. Kimberly needs something also. Along with that, she needs transportation to get to the place where she can do that something, which is not provided.”

“When Kimberly was born she had so many wires and hoses attached to her—it was overwhelming,” said Clarence. “Since premature veins are only so big, she has scarring all over her neck, because they ran out of places on her arms to do blood tests and blood transfusions. However, if you were to go to a NICU unit today, they have laser sensors that attach to their fingers that read blood oxygen levels, replacing previous test methods. Technology has progressed rapidly since Kimberly was born. What if, next year or in a couple years from now, research progresses and they are able to help people like Kimberly? What if they came up with something that could improve her physically or mentally? That’s why we believe people like Kimberly need to maintain a good quality of life.”

Clarence and Carol worry that, without mental and physical stimulation, their daughter’s abilities are actually declining. They remember, with sorrow, what it was like to realize that they were completely on their own during the transition process out of school. The schools had no knowledge of what was available for their daughter in the community, what the possibilities for her were. “Anything that we found out, we found out on our own,” Carol said. As it turned out, there was not much to be knowledgeable about.”

The family moved to Tennessee from upstate New York. There, respite care and therapies were provided by the state. So, when Clarence was offered a better job here in Nashville, they asked about support for Kimberly and the rest of the family. They were given an inch-thick listing of various support organizations and services for children with disabilities and their families in Middle Tennessee. They thought they were covered. When they arrived, they found that nearly all of these organizations were nothing more than a name, the therapies provided by the state were minimal, and respite care was nonexistent.

When they sent Kimberly to school, they were constantly disappointed by her lack of support. “For example,” Clarence said, “in Rochester, Kimberly used a Dyna-Vox (an electronic device that allowed her to communicate). We came here; the teachers didn’t even know what it was. It just sat there in the classroom for all the years she was in school here. They never used it.” Kimberly’s school in New York provided hands-on daily therapeutic services. All services in New York were paid in full.

Clarence and Carol have certainly been frustrated, disappointed, even angry, but they have never been bitter that Kimberly is in their lives. “Like anyone, Kimberly has strengths,” Carol said. “She is intelligent, very aware, and has a great sense of humor. She has a natural ability to draw people to her that came out when she was in school. She has friends who have gone away to college and have come back on their breaks to visit with her.”

Kimberly has challenges, as well. Right now, she is experiencing a lot of seizures, which are difficult to handle. Additionally, the fact that she has practically no physical ability is becoming very difficult, as she is getting older and heavier. “Lifting her ten to twelve times a day is getting very difficult,” Carol said.

Health Care

Just as they have had to fight for support in the education system, they are continually frustrated with health care, as well. Even though Clarence’s employer provides insurance for Kimberly, and even though she also qualifies for TennCare, they still pay large sums out of pocket because there is so much that is not covered.

Employment and Community

Employment and independent living are not possible for Kimberly, and the lack of adult services, respite, and transportation assistance place a heavy burden on the family, especially on Carol, who stays home with Kimberly. Her only social outlet is her faith community. The church has been very supportive for the family.

Future Concerns

Clarence and Carol are worried about what might happen to Kimberly when they are no longer able to take care of her, given the lack of support for adults with disabilities in this state. They have no plans for her future at the moment, and although their other two children (a son, 26, and a daughter, 20) have said they will always take care of Kimberly, Clarence and Carol still worry.

However, these fears and frustrations have not been debilitating. Clarence and Carol are committed to struggle for the rights of people with disabilities. Clarence is a frequent attendee at Board of Commissioners meetings in their home district of Mount Juliet, where he raises issues about accessibility at businesses, restaurants, and government offices. He spoke to the Mount Juliet Chamber of Commerce, to make businesses aware of issues with ADA compliance. He assisted the City of Mount Juliet with meeting Code of Federal Regulation requirements on posting notifications on the local public access television station #3 in regards to ADA laws. He started a support group with some friends, and he sees his advocacy role continuing and growing in the future.

In the end, Kimberly is their daughter and they love her dearly. They see themselves growing as advocates, drawing purpose and strength from their own frustrations as they work to bring care and justice to their own daughter and to all those with disabilities.

Kelly

“I wish Kelly had been able to stay in school beyond the age of 22, because there was so little available for her once she got out.”

Kelly is 36 years old and has cerebral palsy. She lives with her parents, Bill and Linda, in Mt. Juliet, Tennessee. Bill and Linda are retired. Kelly also has a brother, Brian, who is 31 years old.

Although Kelly has a positive outlook on life, she does face many challenges. She finds communicating difficult. At times, it is even a challenge for her parents to understand her. Furthermore, she does not like to attempt to communicate with people with whom she is unfamiliar. Mobility is another challenge that has come as Kelly has aged. She must now use a walker or a wheelchair. Kelly only has use of one of her hands and many daily self-care functions are a challenge for her. She has become more and more frustrated with her inability to complete tasks that she once was able to complete.

Caring for Kelly has become more difficult for her parents as well. The family is grateful that they have been able to have an assistant for her for the past 2 years. Though frustrated, Kelly is extremely determined in everything she does. As a child, she was always happy and had the drive and motivation to push through difficult tasks.

Education and Employment

“I wish Kelly had been able to stay in school beyond the age of 22, because there was so little available for her once she got out,” said Linda. “Also, I wish she had been taught more independent life skills. She has always been determined to be self-sufficient, but she really needed to have more instruction along the way that she just did not receive.”

In terms of employment, Kelly has found it difficult to find a job. There are a few local businesses that have a history of hiring people with disabilities, but Kelly’s parents have personally witnessed them being treated disrespectfully. Because they do not want Kelly working where there is noted discrimination, job opportunities for Kelly are few and far between.

Health Care and Housing

In terms of health care, the family finds that “it is very difficult to find the right doctor. Many doctors either do not have experience or feel comfortable working with children and adults with disabilities,” said Linda. Kelly does have a terrific relationship with a dentist. The downside is that his services are very expensive.

When Bill and Linda get older they will have to face the option of putting Kelly in a group home. They would like to avoid this for as long as possible, and with the assistant coming now it makes it easier on them because they have help. They know of some group homes that are particularly nice, where 3 people live together and share. This is a goal for the future, and they believe it would be nice for Kelly.

Adult Services, Transportation, and Respite

Kelly is involved with an agency in Lebanon, Tennessee, called Prospect, Inc. Prospect provides services and employment to people who have disabilities. The Prospect van provides transportation for Kelly back and forth, and the personal assistant may take her places now, which is a big help to Bill and Linda. Kelly’s parents also drive her when needed and have driven her for most of her life, so transportation has never been much of a problem for Kelly. In terms

of respite, the adult day services that occupy Kelly during the day, as well as the personal assistant, provide Kelly's parents with breaks from being sole caregivers. This is more necessary as they get older.

Future Concerns

The family believes that research on disabilities needs to be continued. They also hope for improved education options in the future for people with disabilities. "They need more than just a certificate when they graduate. They need more training," said Linda. She also wishes that typically developing children would be taught more about disabilities, because so many people just do not understand.

The family would like to see accessibility improved for people with disabilities in the community. They find that many places are not easily accessible for people who use wheelchairs. People who do not need accessible parking spaces often take them, and the ramps to enter businesses often are too far away from the accessible parking spots. Additionally, public bathrooms are not always made to comfortably accommodate wheelchairs.

Although caring for Kelly gets more difficult every day, both of her parents want to keep Kelly with them for as long as they can and provide her with as many opportunities as possible. "It's been a hard road, but Kelly really brings so much joy to my heart," said Linda. "Kelly has always been a very sweet person who is able to brighten everyone's mood in an instant." When Linda went through breast cancer, both Brian and Kelly were so supportive, and Kelly was always offering help and hugs. They have met many challenges throughout the years, but have always tried to focus on the positives. Both Bill and Linda say that they could not imagine life without Kelly.

Jonah

“If more people were able to get to know somebody with a disability, it’d be a big giant step. It changes your life. It’s real easy to look away and feel sad and not do anything, but it’s another thing to get involved—and be real sad—and then do something. Then that sadness goes away because you started doing something.”

Jonah was born in June of 1973. He was born with cerebral palsy and an encephalocele, a sac-like protrusion located at the base of his brain near the occipital lobe. Jonah’s mother, Merrill, wasn’t allowed to see or hold Jonah upon his birth. Instead, the doctor handed him to the nurses and walked out the door. Merrill was never able to see or speak to the doctor. It wasn’t until the next morning when Jonah’s pediatrician arrived that Jonah was cleaned and surgery was ordered to repair the encephalocele.

Jonah’s parents describe him as a strong individual, with a determined mind, a sense of humor, and a definite stubborn streak. “His strengths,” Merrill said, “were all these things you couldn’t test. Jonah couldn’t do math, but he had a will. There was a presence to him. You could see it in his eyes. There are a lot of people you can look at...and they’re not present, even though they walk among us.”

Jonah had “high standards for people.” He hated to be patronized and took advantage of anyone who had the misfortune to underestimate him (for example, fooling a teacher at Tennessee School for the Blind into thinking he couldn’t get out of his wheelchair). Jonah “knew his mind and exactly what he wanted, how he wanted it, and when—and those wants covered everything from good food, good clothes, and room service to roller coasters, the ocean, his church, and his all-time favorite musician, Cher. But it was sometimes a challenge for Jonah to find people, outside his family, who would respect him as an individual, who would allow him to make his own choices and decisions. For those who did, though, Jonah gave them respect back tenfold.

Advocates

“Jonah’s doctors cared a lot about him,” said Merrill, “Anybody who got to know him did.” The last several years of his life, Jonah spent an inordinate amount of time at Summit Hospital in Hermitage, but the doctors and nurses on staff in the intensive care unit—where Jonah was most often—“were wonderful.” They saw what a fighter he was and understood his spirit and his will to live. Throughout Jonah’s life, when issues would arise—whether they would be in finding an appropriate school environment or, later on, residential housing as an adult—they were usually linked to people or organizations forgetting—or even refusing—to recognize that Jonah was a person with a unique personality and outlook, and not a disability.

Jonah had many advocates, and first among them was The Arc of Tennessee. “The Arc was upfront,” said Merrill. “They were always there. Always. From the beginning they were there. They went to battle for us the most.” If Jonah hadn’t had the many social workers and advocates that he did throughout his life, Merrill says she can’t imagine what she would have done. “You couldn’t do it without them,” she says. “I don’t know how anybody could do it without help. Just as a parent, you know how to parent and you learn the medical part and the social part and the educational part and all that stuff, but it takes other people to help you learn.”

Housing

For the family, one of the people there to help was Linda, a special education teacher. On several occasions, she had provided weekend respite care for Jonah when he was younger. In 1982, the family was experiencing some difficulties, and Jonah went to live with Linda permanently.

Jonah stayed with Linda until he was 21, at which point it was decided that he needed to transition to living in a residential facility. The change was hard on Jonah, and he became depressed. The organization in charge of the home had assured the family and Linda that there would be aides there to assist Jonah 24 hours a day. Whether it was taking him to the movies or helping him outside so he could sit and listen to music—as he loved to do—Jonah’s life would be as active, productive, and meaningful as it had been prior to the transition. The change was hard on Jonah, though, and in an example of gross neglect, he was left to sit in his room, his family having no idea he had quit eating until the Sunday when Linda came to visit and found him on his bedroom floor with barely a pulse. Rushed to the hospital, Jonah survived, but afterwards he would require the use of a wheelchair and a feeding tube for the rest of his life. The family chose not to prosecute, but the state closed down the organization. Jonah’s family was able to find a new residential situation for him, one that allowed him to be as active and a part of the community as possible.

Health Care

Jonah’s health was greatly compromised after the incident at the residential facility. He hated the feeding tube. “He would mess with it,” explained Merrill. “He really didn’t like it. He would pull it out and he knew he wasn’t supposed to do that. He’d pull it out and maybe throw it across the room. He let you know he hated it.”

Jonah’s spirit was strong, but his health wasn’t. His bones were fragile, and the week he was scheduled to be in his sister Hannah’s wedding, he fractured his shoulder. Taken to the hospital, he was hospitalized for several days. “We thought things were OK and he was going to be all right,” said Merrill. “Then this doctor calls me one day and just says on the phone, out of the blue, ‘Had I thought about just letting Jonah die?’ He said that Jonah had pulled his feeding tube out, and he took that to mean that Jonah didn’t want to live anymore. He wanted us to put Jonah in a place where they just wouldn’t feed him for so long and he wouldn’t be in any pain. He said it would be pleasant and that Jonah wouldn’t feel anything. He wouldn’t know what was happening and then he would just die. He thought Jonah was telling us that he didn’t want to live anymore.”

Merrill asked the doctor where Jonah’s feeding tube was, and he told her it was lying on his stomach. Merrill knew this meant the tube must have fallen out on its own, as sometimes happened. “If Jonah had taken it out himself it wouldn’t be laying on his stomach,” explained Merrill, “It would be across the room somewhere because he’d thrown it.” Even if Jonah had pulled the tube out, “that’s not a sign he wanted to die,” said Merrill. “I’ve got to have some more proof before I believe that. That doctor didn’t even know Jonah.”

Merrill and the doctor argued back and forth over the issue. “We got in a fight,” said Merrill. “I told him I really disagreed, and they told me they weren’t going to put it back in... They said they couldn’t.” It wouldn’t be until the next day that Jonah’s feeding tube would be re-inserted, and then it was only because the on-call resident was unfamiliar with the disagreement between the family and the doctors at the hospital. Jonah never returned to that particular hospital and Merrill was banned from it.

Jonah would live 3 more years. “That’s the thing about Jonah,” Merrill explains. “We always felt like, when Jonah was ready to go it was between him and God. We weren’t going to be the ones to do that. And that’s how it happened.”

In December of 2007, Jonah died in his sleep. His family is grateful for the many people who supported and loved him throughout his life.

“The average person out there has no idea what it’s like to even touch somebody with a disability,” said Merrill. “They can look at them. They can see them out there, but as far as touching, shaking their hands, being there with them and talking to them or doing something, they don’t have that chance. If more people were able to get to know somebody with a disability, it’d be a big giant step. It changes your life. It’s real easy to look away and feel sad and not do anything, but it’s another thing to get involved—and be real sad—and then do something. Then that sadness goes away because you started doing something.”