

Special Edition: Aging



**VANDERBILT
KENNEDY CENTER**
for Excellence in Developmental Disabilities



The Arc
Tennessee

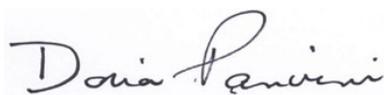
A Letter of Thanks

The stories in this booklet were collected by students enrolled in a Vanderbilt University course that 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 conduct interviews and learn firsthand about encounters with education, health care, housing, employment, and disability services in Tennessee.

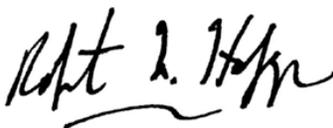
This particular edition focuses on the topic of aging. The stories illustrate both the challenges and joys that individuals with intellectual and developmental disabilities experience as they age. They also highlight the uncertainties, fears, and challenges of their aging caregivers. From health concerns to worrying about what will happen to their sons and daughters when they are no longer able to care for them, 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 can have on family life.

The Vanderbilt Kennedy Center and The Arc Tennessee thank all the families who shared their stories in this edition. By reading them, you will receive snapshots in time of a diverse group of individuals with disabilities, across a spectrum of disability, geographic location, socio-economic status, and race. By sharing these stories, the students and families hope to demonstrate the great importance of not overlooking the unique needs and concerns of aging caregivers and their aging sons and daughters with intellectual and developmental disabilities.

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



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Prologue

“Most people with intellectual and developmental disabilities will need varying levels of support throughout their lives. Medical advances have improved the life expectancy for people with disabilities to the point that it is nearly the same as for people without disabilities. While this accomplishment must be celebrated, it also comes with significant challenges, especially for family members of people with disabilities who are most often their primary support.

Nationally, more than 75% of people with intellectual and developmental disabilities live with their families and more than 25% of family members providing support are over the age of 60 (Braddock, Hemp, & Rizzolo, 2008). In Tennessee, the percentage is even higher. Of the more than 6,800 people on the waiting list for Medicaid waiver services, at least 400 are supported by family members age 75 and older. This number does not take into account the thousands of Tennesseans with intellectual and developmental disabilities who are not represented by waiting list numbers.

An urgent need exists to understand the unique challenges faced by aging Tennesseans with intellectual and developmental disabilities and their aging family members.”

*~Carrie Guiden
Executive Director, The Arc Tennessee*

Braddock, D., Hemp, R., & Rizzolo, M.C. (2008). The state of the states in developmental disabilities: 2008. Boulder, CO: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.

Angela (age 72)

Angela was born in 1942, and spent her childhood and adolescence living with her family in East Tennessee. Angela has an intellectual disability, as well as difficulty seeing, speaking, and hearing. She never received a formal education.

“There wasn’t the kind of help then that is available now, or none that we knew of,” said Angela’s sister Fodell. “When Angela was 22, our mother made the difficult decision to move her to a state institution. I imagine she must have had concerns about who would take care of Angela if something should happen to her. Our parents were divorced, and so it fell to our mother to decide how to provide for Angela in the long term. It was really hard on the whole family for her to leave. It was a very sad time for us. In retrospect, I wish I had spoken more with my mother about it.”

After leaving home, Angela was moved into a state-run institution called Clover Bottom in Nashville. The family lived nearly four hours away at the time, in Kingsport, Tennessee. Fodell does not know why her mother chose Clover Bottom, but only a year later, Angela was transferred to Greene Valley

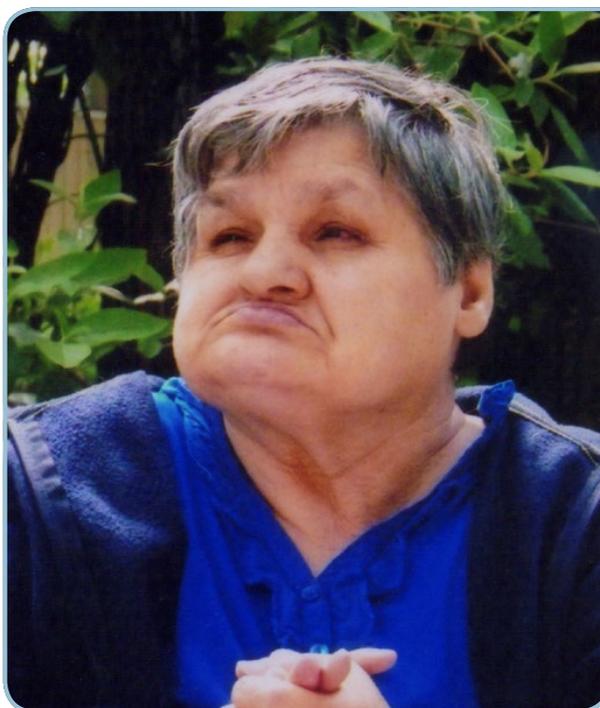
Developmental Center. Moving Angela to Greene Valley meant that she was closer to the family. This would be her home for nearly fifty years.

Fodell is careful to emphasize that by and large the staff of Greene Valley were a group of compassionate and professional individuals. She says they took excellent

care of her sister. Still, she recognizes that the institution’s high occupancy and its sprawling bureaucracy made it difficult for the staff to meet all of the residents’ needs, or to give them the kind of individualized attention that they may have required.

About 30 years ago, Angela and Fodell’s mother passed away unexpectedly at the age of 58. Although their mother left no instructions regarding conservatorship,

Fodell immediately assumed the role. She did this in part because she was Angela’s closest remaining relative, as their brother had also died at an early age. As conservator, Fodell kept a close eye on Angela’s care at Greene Valley. She also was vigilant about keeping up with the changing trends of services and supports for people with disabilities.



“She worries about the people who, like her sister, require around-the-clock care, but unlike her sister, lack family to advocate for them and to help them transition from institutional facilities.”

In an effort to end segregated institutions, many families began transitioning their loved ones into supported living situations in the community. Hearing rumors that Greene Valley was to close, Fodell feared that Angela might be moved to another institution, making it hard to visit her. It was at this point that she signed papers to move Angela out of Greene Valley.

“Angela is so happy in her home now, said Fodell. “She and her three roommates are constantly supported by a team of staff members, including a dietician and a nurse who help her to manage her diabetes. She goes into the community now. She and her roommates go to the park often. Angela loves to go grocery shopping and to visit the local hairdresser. She loves going to church, swimming, and volunteering for Meals on Wheels. Last year, they all took a vacation in Gatlinburg together and have even started a small vegetable garden in their backyard. She is living in a home now, not a facility or an institution.”

Fodell says that Angela has come out of her shell since moving into the community. She loves to help in the kitchen and to do laundry. She likes stacking her dishes and

being able to adjust the temperature the way she likes it in her own bedroom. Angela loves to spend evenings sitting outside in her rocking chair. While at Greene Valley, the residents were inside nearly all of their day. Now, Angela can go outside and explore whenever she wants.

Though Angela is happy, Fodell still has concerns about her sister’s future. She knows that the future is vulnerable to the changing political and economic tides, and she worries. She worries about the people who, like her sister, require around-the-clock care, but unlike her sister, lack family to advocate for them and to help them transition from institutional facilities.

“I want my sister to have a good life in a comfortable home, as I do,” said Fodell. “She has trouble voicing her opinions on her living situation, but I feel sure she wants to feel comfortable and safe, especially as she ages. We all deserve that, at least. We are all God’s children.” ■

ANGELA RESIDES IN EAST TENNESSEE.



Shaun (age 48)

Shaun is a vibrant, warm, and loving man with a supportive and energetic family. He has had many amazing opportunities in his life that many people may never experience. He has clogged at the White House and travelled the world. He has won a gold medal for swimming. He has a great job and he loves to be around people. Shaun also has an intellectual disability and relies on his family for support.

Shaun's mother, Antoinette, is his biggest advocate. Her goal has always been to ensure that Shaun experiences inclusion and socialization in his life. When the family moved to Tennessee, Shaun's options for success became more limited. Access to services that might allow him to gain more independence were restricted. These restrictions give Shaun's mother concerns about the future. What will happen to Shaun once she is no longer able to care for him?

"Shaun's father recently had a stroke," said Antoinette. "He's doing well, but that really brings the future closer. So far, I'm

very healthy, but I know in a minute that could change. The older you get the more you recognize that. I just want Shaun to be happy. He's lucky that he has a brother and a sister to lean on, but you never know what their health is going to be as they age. I need Shaun to end up somewhere where he is content and happy. I know that doesn't always happen for our sons and daughters with disabilities, and I worry about the time when I won't be here to make sure he is okay."

Shaun is on the waiting list for the Home and Community-based Waiver, but Antoinette holds little hope that he will receive services in time for an appropriate and smooth transition into a new living arrangement.

"The situation in Tennessee is upsetting," said Antoinette. "Shaun is on a waiting list for services with more than 7,000 other people who also need help. We moved here to be near our other children. Unfortunately, we did not have any idea about

the waiting list situation in Tennessee. We assumed there would be help for Shaun here, because every state we have lived in had immediate testing and immediate help. Even the foreign country we lived in

for two years had accessible assistance for people with intellectual and developmental disabilities. I worry sometimes about where the compassion is in Tennessee. Where is the understanding for our children?" ■

SHAUN RESIDES IN EAST TENNESSEE.

"Shaun is on a waiting list for services with more than 6,500 other people who also need help."

Jo Ann (age 49)

Jo Ann, a 49-year-old woman with an intellectual disability, is the only child of 84-year-old Bettye Jo. Jo Ann currently resides with her mother in their home in Dickson, Tennessee. When Jo Ann was six weeks old, her pediatrician noticed that her hip joint was misaligned. It was not until age 3, when Jo Ann presented with delayed speech development, that her physicians surmised her issues might be significant and pervasive. It was later suggested that Jo Ann's intellectual disability resulted from insufficient oxygenation during birth.

Besides a period between ages 5 and 10, during which she was enrolled in a residential school, Jo Ann has always lived with her parents.

"When Jo Ann was a very young child, they told us she had a disability," said Bettye Jo. "My husband and I wanted to get her help. We investigated various residential programs. Her daddy looked at Springfield, and what he saw there was horrific. Abuse, really. Needless to say, we did not choose that place. We finally found a private residential school in West Tennessee. They had really good food and it was always clean. However, she only came home once a month. It was the hardest five years of my life."

During the time she attended the school, Jo Ann did learn and practice essential life skills. She learned to bathe, dress, and feed herself. At age 10, Jo Ann's teachers determined that she had reached her maximum potential at the school, and so she returned home. Bettye Jo could not find any suitable public schools that served children with severe disabilities. She eventually was enrolled in a private school.

Because the tuition costs of the school were expensive, the family struggled financially.

Now, Jo Ann is enrolled in the Home and Community-Based Waiver. Her adult services are administered by the Developmental Services of Dickson County, an affiliated chapter of The Arc. A service provider comes to their home 7 days per week to assist Jo Ann. Bettye Jo is grateful for the services Jo Ann receives.

"I wish everyone who needed it could get it," said Bettye Jo. "It has been a life-saver for us. I am getting older too, you know? I use a wheelchair to get around now and I can no longer drive a car. I rely on Jo Ann's service provider to get her to the doctor and into the community to do things she enjoys."

Eight or nine years ago, Bettye Jo underwent vascular bypass surgery on her legs, which required her to rehabilitate in a nursing home for several months. During that time, Jo Ann lived in a group home setting, which, according to Bettye Jo, was a very negative experience. Jo Ann had to return to the same group home while Bettye Jo recovered from another surgery, and had a more positive experience during her second stay. However, Jo Ann has expressed strong resistance to the notion of living in a group home again, even after her mother is no longer alive.

Bettye Jo is worried about the future when she is no longer around to take care of Jo Ann. She worries about the quality of services her daughter will receive. Bettye Jo has made arrangements for Jo Ann to remain permanently in the family's home, and to have a live-in residential service

“I asked her if she wanted to live at the group home when I’m gone,” said Bettye Jo. “She said she wants to live at home. So, she’s going to live in this house. This is her home.”

provider assist with daily living tasks. In addition, Bettye Jo’s niece and nephew, who live nearby, will be available to monitor Jo Ann’s overall welfare and to provide financial support if needed.

“I asked her if she wanted to live at the group home when I’m gone,” said Bettye Jo. “She said she wants to live at home. So, she’s going to live in this house. This is her home. She will have an employee working here the whole time. My greatest worry is about who the people will be. I want to know Jo Ann is surrounded by good people. She is my precious love. She is my only child.” ■

JO ANN RESIDES IN MIDDLE TENNESSEE.

Sissy (age 47)

Sissy's mother, Harriet, remembers Sissy's development progressing typically for the first few years of life. She then began to notice that her daughter developed fewer words than her son by the time she was 2 years of age. When she asked her pediatrician, he recommended an evaluation. By age 4, Sissy had lost all of her language abilities as well as her social skills. Doctors did not understand why and did not have an explanation for this sudden change in Harriet's daughter. Harriet would not have a name for her daughter's condition until Sissy turned 16, when she was diagnosed with Rett syndrome.

Harriet began participating in intervention services early with Sissy, including parent training programs, and a few hours per day of special education in a class run by a nun and a graduate student in a Catholic school. Sissy then attended a private, self-contained school in Tennessee for a couple of years. When Sissy was 7, a federal law (Public Law 94-142) passed that entitled her to a free and appropriate public education. Sissy began attending public schools in the Metropolitan Nashville Public School system, where there was no real curriculum for her and no opportunities for inclusion. Harriet fought for her daughter to receive an education and advocated for her well-being, though, joining the PTA and any other parent groups she could in order to give Sissy a chance for equal opportunity.

When Sissy turned 22, Harriet, like many other parents of children with disabilities, began to ask what would happen to her child after she left school. Harriet reports thinking, "I mean, Sissy's going to go to a workshop and sort nuts and bolts, which she can't do, to do what with if she could?"

"I mean, life skills, please!" Harriet and her husband moved to Dickson County the summer before Sissy turned 22 after hearing about an adult program that existed there.

Developmental Services of Dickson County began providing individualized services for Sissy on her 22nd birthday. According to Harriet, the services have been excellent. Sissy has had a personal care assistant each day since she has been in the program. In the last 2 years, the personal care assistant's role has become more focused around a community-based program. Sissy's assistant takes her into the community every day, but since Sissy has gotten older, she is not able to get out as much as she used to. Sissy has had the same caregiver, Joyce, for the past 14 years. Harriet speaks proudly and highly of the work Joyce does with her daughter. She describes in detail the way Joyce does even the simplest of tasks for Sissy with care and thoughtfulness. Harriet described how she brushes her hair and dresses her "like a princess," and cares for her "just the same way that I would" on a daily basis. Sissy gets tired more easily now, so she is slowing down and can't get out as much as she used to.

As the family has aged, more health concerns and conditions have become a part of the family's life. Sissy has scoliosis and uses a wheelchair as a result. The scoliosis has also given rise to numerous other health conditions that require ongoing medical attention. Additionally, Harriet's husband, Sissy's father, has a heart condition that affects the family as well. After having a heart attack at age 35, Harriet's husband has had numerous other medical concerns related to it and has been unable to work for many years. When asked about these

“As the family has aged, more health concerns and conditions have become a part of the family’s life.”

factors, Harriet expressed, “I’m really worn out, but it’s my mission.”

When discussing the future, Harriet has few concerns about prospective outcomes for Sissy. Harriet plans for Sissy to reside in a residential home environment with up to two other people, while still receiving her daily personal assistance. However, Harriet’s preference is for Sissy to live at home with a family member. ■

SISSY RESIDES IN MIDDLE TENNESSEE.



Brian (age 38)

would be able to live outside of our home, but that just never seemed to happen.

We've never had financial support for any kind of services. I'm trying to get on the waiting list for the Home and Community-Based Services waiver. Of course, with so many people waiting, my husband and I would have to suddenly die in a car accident for him to be enrolled. We are having trouble getting him on the waiting list because we don't have proof that his intellectual disability occurred before the age of 18. He was never labeled as having an intellectual disability, and I did not want him to be labeled back then. We're suffering from not having that label now.

I just had his IQ tested recently. It is low enough that he qualifies for the waiver, but that doesn't help because it's got to be below 70 before the age of 18. They say that saying he has Williams syndrome isn't enough. He does have social security disability, but we had to go before a judge to even get that. That document does say that he is eligible for disability, and he obviously can't maintain a full-time job without lots of support. However, that was all done at 22, not before the age of 18. He doesn't have SSI because he had a job for a few years. Even if we get on the waiver, there is such a long waiting list of people who don't have families that can take care of them, or they have parents in their 80s, not 60s, like us.

Our current situation is heartbreaking to me. I know Brian is not happy. He can't do some of the things he could do before. He used to love reading, but he doesn't read much anymore. He can't seem to keep his concentration on any one thing anymore.

My son, Brian, has Williams syndrome. Williams syndrome is a genetic, intellectual disability. Brian spent much of his early school years in general education classrooms with a lot of resource help. He eventually received a special education diploma. The school held his diploma while he went to vocational rehabilitation and sought employment. I think that is where things started to fall through. They pushed Brian out of school early, because he had a job. We accepted the decision. We weren't as informed as we needed to be. Nobody really guided us to look at the next 20 years. We did not realize what the future was going to be for him. I always thought he was going to get out on his own and have a job. I was wrong. I totally was not prepared for what adulthood was going to look like.

The anxiety that comes with Williams syndrome has gotten much worse. Brian's functional levels continue to deteriorate. Brian has always been anxious about noise, and you can't tell him about a doctor's appointment too soon. When he got out of high school, I started to notice many more severe symptoms. He developed hypochondria. We thought he was having asthma attacks. Pseudoseizures started at about age 21. I always thought that he



I'm not sure if it's the medication he's on or if it's part of his anxiety. He also used to sing all the time. I almost never hear him sing anymore. He's kind of lost his voice a little bit, too. He will still play his keyboard, but not for a very long period of time. He also used to be on the phone all of the time calling friends, but he doesn't do that anymore. He is really isolated.

We can't leave him now for more than a couple of hours by himself because of his severe anxiety. Grooming has become more difficult for him, too. He's not walking like he used to, and he has gained a tremendous amount of weight. The antipsychotics they use for his anxiety have had a huge effect on his weight. Anxiety and depression are hard to treat anyway and when you add an intellectual disability to that, I don't know. That stress on our mental health has been really hard. In a sense, my husband and I are not typical retirees, because going out for golf seems so frivolous. We are currently healthy, but you

“It’s almost like I want to be on the fringes of his life, so that I could die tomorrow and his life wouldn’t be turned upside down.”

never know. I'm worried about 10 years from now.

When I think about the future, I have big concerns. I worry about Brian's health. He has high blood pressure and he needs to exercise, but isn't motivated to do so. He worries so much. He's worried that something is going to happen to his father and me, and he is just worried about almost

everything. I think he would do better if we were not so closely involved. If he had more friends and social opportunities, if he were able to be more independent, I think his well-being would be improved. He needs supports to help keep his day busy, and I've run out of ideas. It's almost like I want

to be on the fringes of his life, so that I could die tomorrow and his life wouldn't be turned upside down. I mean, that's the fear of every parent of a child with special needs; what will happen to him or her when I'm not here. ■

BRIAN RESIDES IN EAST TENNESSEE.

Mark (age 41)

In 2005, after waiting for ten years, Mark received tremendous news—he had finally been enrolled in the Home and Community-Based Services (HCBS) waiver, which serves Tennessee citizens with intellectual disabilities. The waiver provides supports to Mark so that he can live independently.

Mark’s mother, Anne, recognizes that Mark is very fortunate to be enrolled in the HCBS waiver—“We now have the supports Mark needs to have some peace of mind as we age. We are very thankful and feel great responsibility. We do not want to be wasteful with the support, because there are so many people in our state who have no support at all. We need to serve more people in our state. Currently, there are more than 6,500 people on the waiting list for the waiver services that Mark receives who need assistance just as we did. We are very fortunate.”

Mark is now 41 years old. He owns his own home in Memphis, Tennessee and lives with two housemates. For many years Mark battled severe mental health issues that began after he graduated from school. Eventually he was no longer safe at home or in the community. His mother credits the stability that Mark’s supports provide, a confidence that has come from more independence, and the accessible social life that he now has living with two friends as key factors in improving her son’s mental health. He no longer needs a behavior support specialist, and psychotropic medications have been greatly reduced.

Mark leads an active life and it would be very difficult for his parents who are both over 70 to keep up with him. He has two jobs, he has been a board member with The Arc Tennessee, takes a computer course at the University of Memphis,

and wants to be his own advocate. These opportunities to grow and serve are central to Mark’s well-being, and as Anne asserts, “It’s never too late for any of us to learn—ever, and Mark continues to benefit from having many different experiences.” Anne continues to seek out community events and social opportunities for Mark. Socializing is very important to him and to his health.

While Mark currently leads a happy and satisfying life, Anne does worry about his future. Both she and her husband are in good health, but she is concerned that their gradual aging will negatively impact Mark’s quality of life—“How will Mark stay involved in the community when I’m not around or no longer able to help the staff know about resources? His participation in community activities has been essential to his well-being. Who will continue to seek opportunities for him? We have no family closer than 7 hours away and Mark’s only brother lives permanently in another country. I don’t know who will be there for holidays with him. Mark needs help with decision-making, and it is devastating to know that I don’t know who will be there for that.” ■

MARK RESIDES IN WEST TENNESSEE.

“How will Mark stay involved in the community when I’m not around or no longer able to help the staff know about resources? His participation in community activities has been essential to his well-being. Who will continue to seek opportunities for him?”



Charles (age 51)

Charles is 51 years old, has an active social life, attends church and Sunday school, is employed, and has Down syndrome. When Charles was born in 1963, the doctor advised that he be placed in an institution and “forgotten.” His parents refused and chose to have him live at home. At that time, there were few community resources available. Charles’s mother developed early interventions on her own for Charles. He learned to read by watching television shows. Now, he reads the newspaper and has a remarkable vocabulary.

Charles lives by himself in an apartment in Franklin, Tennessee, thirty miles from his older sister, Susan. Charles works at a supermarket as a bagger, and has had a job for the majority of his adult life. He participates in volunteer activities in the community.

Susan and Charles have a close relationship and talk on the phone every day. They spend Sunday afternoons together, which often includes working out at the gym to provide Charles with healthy physical activity. Charles goes on trips with his sister to visit relatives and to maintain relationships and social interactions with his extended family. He also has a busy social life through the non-profit agency responsible for his supervision. Charles votes in every election he can, depending upon transportation.

Planning for Charles’ future concerns Susan because she has found it difficult to find resources for older adult sibling caregivers. She has attended workshops but they mainly focused on helping parents learn how to provide for their children with disabilities. Siblings need to know how to plan in case they predecease their sibling with a disability, and it is very difficult to find that kind of information. At a recent workshop, the presenters did not know what to recommend for a sibling after their death, except to establish a trust. This can be expensive and not affordable for most families. Susan feels that this is an area that the disability community needs to address.

Charles has been relatively healthy but with Down syndrome, he has an increased risk of developing dementia as he ages. This is a concern because of the rising incidence of dementia in the general population. Charles’ sister is also concerned that the health care industry will not be prepared to help individuals with Down syndrome who develop dementia.

Because Charles is on the leading edge of the Baby Boomer generation, he has had to face situations where there was little or no experience in providing appropriate services. It is hoped that because of individuals like Charles with the support of appropriate legislation and financing, future individuals with intellectual disabilities will have an easier time negotiating the maze of community services available for this population as they age and a greater voice in articulating the services they need. As productive citizens who give back to their communities, they deserve no less. ■

CHARLES RESIDES IN MIDDLE TENNESSEE.

Brian

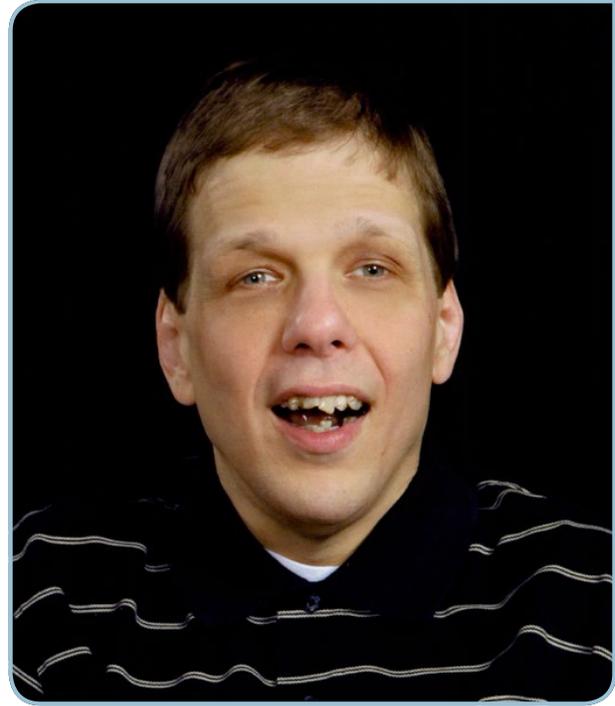
(age 50)

Our son loves to swim! He loves to sit and listen to adults talk. He enjoys just riding in a car around the neighborhood. His favorite band is The Eagles, and he is excellent with anything electronic, especially with the television remote. My son, Brian, is a happy and energetic man who has cerebral palsy and an intellectual disability.

When Brian was fourteen months old, he still had not pulled up on his own. That worried us. Our doctor sent us to a medical center about six hours from our house for some tests. We knew nothing about the process and showed up completely unprepared. Unbeknownst to us, their plan was to keep Brian for three days for extensive testing. We had brought nothing with us, so there we were: young, inexperienced, and completely scared to death. Some of the "tests" consisted of the doctors coming into the room, staring at our baby boy in a crib, and talking amongst themselves. Nobody said a word to us. Nobody gave us any information. Finally, after all of the testing, the doctors told us Brian had cerebral palsy.

We packed up and traveled to Nashville to get more tests at the Vanderbilt Medical Center. A new city, another diagnosis – this time, the doctors added the diagnosis of intellectual disability. Fortunately, the doctors were extremely helpful, and we decided that because of the lack of services in our small town in Alabama, we would relocate our family to Nashville.

Brian eventually attended a preschool for children with special needs. We were terrified that he might never get appropriate services at school, because at that time the law did not mandate education for kids like our son. Fortunately, the bill that



would mandate special education came to debate around that time. My wife and I literally "carried the placards" pushing for the Individuals with Disabilities Education Act (IDEA) to be passed.

Throughout his school life, Brian had the ability to walk but also had a wheelchair. He began standing at age 2 and running around like any young boy. At age 16, the only time Brian absolutely needed to be in his chair was on the bus, but his teachers started to place him in his chair solely to keep him in his seat. While this situation is not what we wanted for Brian, we did not get too upset about it – we needed to choose our battles. Unfortunately, the more time Brian spent in the chair, the more time he needed to be in the chair. Brian's muscles work best if they keep moving. Now, Brian cannot walk but is very capable with his wheelchair. He cuts corners and zips around his home effectively and efficiently.

The year that Brian was to graduate from school, we visited a few day programs for Brian. We chose one particular program because of its small size and its community

“Now, all we can do is enjoy our time with our son and hope that the system continues to work for him.”

feeling. Soon after, we set him up in an apartment with a caretaker. This situation worked for many years, but nine years ago, we decided it was time for Brian to have a more permanent place to call his own. We worked with a local agency to purchase a home that would be suitable for him. Brian loves his home! He especially loves that his name is on the mortgage. I backed the mortgage, but legally, the home belongs to Brian.

Fortunately, Brian is able to pay for most of his bills. His social security and Medicaid cover his living expenses. He tried to work when he was younger. He was a greeter at a toy store once and had a job coach. Brian was supposed to hand out flyers to customers and just say hi, but he is such a sweet, friendly guy; he wanted to give everybody hugs.

As his practical parents, we wish there were more reliable transportation options for Brian. The bus just does not provide the consistency needed to keep up with our busy schedules. When Brian was younger, he would ride the bus back and forth to school. While we loved the bus driver, we never knew if he would show up at noon or

at three. Now, transportation would help Brian get out into the community more and make it easier for him to go to doctors' appointments.

Brian's days consist of routines and activities. He enjoys spending time with his current caregivers, and they are wonderful to him. They have become his family. We see Brian once a week and spend holidays with him, but they are with him day in and day out. We are grateful to have these wonderful people to help us take care of Brian, but worry about what will happen once we are gone. We hope these services will continue and have been fortunate that we have been able to set aside appropriate funds for Brian's future. Now, all we can do is enjoy our time with our son and hope that the system continues to work for him. ■

BRIAN RESIDES IN MIDDLE TENNESSEE.

Barbara (age 47)

When my daughter, Barbara, was in the third grade, we found out that she has an intellectual disability and developmental delays. I was shocked at first because she seemed to be doing fine at school and had been able to keep up with grade material until that point. When she was younger she began walking and talking around the same time most children would. She did have some difficulties with speech, but I simply thought she had a stutter or was tonguetied at times. I never thought it could be something more until the school brought up that they had some concerns.

Currently, Barbara uses limited speech. Once you know her well it is easier to understand and communicate with her. If she is able to write, spell, or say your name, then you know she likes you.

I wish all the resources and services in schools now had been available when Barbara was in school. They just kept moving her forward from one grade to the next, even though the material was not appropriate for her and she was not receiving adequate attention. She attended high school for a short time before she stopped school at age 16. In high school, she was placed in a “low education” class where the students and teachers simply worked with her on her language skills. Of all the things I wish Barbara could’ve had, it would have been a better education.

After Barbara was out of school, and once her brothers began to move out, she expressed an interest in moving out as well. She moved into a group home when she was 19, but she was with about 10 other girls and disliked it very much. We had help in placing her in other group homes, but she did not stay in any of them for long.

She now lives with a woman named Teresa in a single home and we can tell this is a good fit for her long-term. She has only lived there for about a month, but she and Teresa both enjoy many of the same activities. Barbara stays busy helping Teresa run errands. And although she is not able to do things like balance a checkbook or pay bills, she can clean up after herself, and help with the laundry and cooking.

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Barbara also has been able to find employment. My daughter works at two different drugstores for about three hours a day. I am happy that she has been able to find a job and she is very proud to work. However, I do wish she were paid at least minimum wage like everyone else. As of

now, she is paid based on what she does while there. For example, if she takes down 20 boxes in one hour then she receives payment based on those 20 boxes. Because of this, when she gets paid every two weeks, the amount can vary greatly and it is hard for someone to manage their money and plan ahead in life when each pay check

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When thinking about the future, there are always challenges and things I worry about. Many times, I have thought of moving her back in with me. However, I worry that if anything were to happen to me, the transition back into another home would be very difficult for her. Could we find another home in which she felt comfortable, safe, and joyful? It’s something that stays with me.

If something were to happen to me, I at least have the reassurance that Barbara will be okay financially. She does receive money through her SSI and a little from her job. At least I know she will have enough money to pay for things like housing and medical bills. As the years progress, I want to continue to have the peace of mind that she is secure and happy. ■

BARBARA RESIDES IN EAST TENNESSEE.

“I can’t tell you how many times I’ve heard from heartbroken parents that they hope their son or daughter dies before they do. They don’t want to think about what’s going to happen to them after they pass away.”

~Melissa Wilson

Program Manager, Developmental Services of Dickson County

Vanderbilt Kennedy Center for
Excellence in Developmental Disabilities
vkc.mc.vanderbilt.edu

The Arc Tennessee
www.thearctn.org

Tennessee Kindred Stories of Disability
kc.vanderbilt.edu/kindredstories/