

Tennessee Kindred Stories of Disability

Special Edition:

Families From Diverse Cultural Backgrounds



Introduction

The stories in this collection were compiled by undergraduate 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. As part of the course, students interview individuals with disabilities and family members and learn firsthand about encounters with education, health care, housing, employment, and disability services in Tennessee. This particular edition of *Kindred Stories* focuses on the unique experiences and challenges of families from diverse cultural backgrounds now living in the United States.

Families were recruited through the Tennessee Multicultural Alliance on Disability and through the Multicultural Outreach Program of the Vanderbilt Kennedy Center. Only first names are used in this compilation of stories. Student interviewers worked with interpreters when language barriers were present.

Tennessee *Kindred Stories of Disability* is a Website, a series of print booklets for legislators, and a service-learning project for students at Vanderbilt and Belmont Universities. The Vanderbilt Kennedy Center partners with The Arc Tennessee to distribute the stories to legislators during Tennessee Disability Day on the Hill and at the Federal Disability Policy Seminar.

The Vanderbilt Kennedy Center and the Tennessee Multicultural Alliance on Disability 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, ethnicity, 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.

To view additional stories from Tennesseans with disabilities, please visit the Tennessee *Kindred Stories of Disability* website at: kc.vanderbilt.edu/kindredstories.

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Sarah (age 4)

Sarah is a four-year-old girl with an intellectual disability. Sarah's parents were informed of her disability at the hospital where she was born, in Burma. Sarah has had frequent seizures, impairing areas of the brain controlling muscle movement, and leaving the left side of her body weak and difficult for her to move. Sarah's family has been in the United States for over three years. Their decision to move to Nashville in particular, was influenced by United Nations (UN) immigration officials at a refugee camp in Burma. Sarah's mother recounted of their coming to the U.S., "When we came, we faced a lot of challenges."

Most notably, Sarah's parents faced a language barrier that made it very difficult to obtain information and to find the services they needed for their daughter. While Sarah's mother is now learning to speak English, she and her husband spoke no English upon their arrival in the United States. To make matters more difficult, Sarah was very sick during the UN immigration orientation, so neither parent was able to attend. Without this training, they reported feeling nervous and unprepared upon their arrival.

Finding services for Sarah in Nashville has been very difficult. Services supplied by the UN, such as a caseworker and a doctor assigned to the family, offered helpful service, but did not last long. After a year of being in the U.S., they no longer had a caseworker. Even general welfare services such as food stamps have been hard to come by. Last year, Sarah's father worked overtime and, as a result, his salary came in about \$1,000 over the qualifying line for food stamps, so they no longer receive them.

Receiving health care, Sarah's father says, "is really quite difficult for us." After they lost public health care and were switched to a new provider, they found that their new health care provider does not work with the medical supplies company, so they are left to cover expenses on their own. Sarah's diapers, for example, which she wears every day, have been difficult to get. The diapers are very expensive. Sarah's mom recalls calling the supply company every day for them, and when they finally came, they were not the right size.

Finding doctors for Sarah has also been a challenge. Because of the language barrier, Sarah's parents need an interpreter every time they speak with their doctor. Oftentimes, the interpreter must assist over the phone. When this happens, it is difficult for them to understand anything. They also have had extreme difficulties in reaching a doctor to evaluate and update Sarah's medications and dosages. The dosages have not been changed since she was two-years-old. She has gained a significant amount of weight, yet her prescriptions have not changed in the last two years.

Sarah's mother "spends all day with Sarah." Their day begins at 5 am when she wakes Sarah up to go to school. Helping Sarah shower and get dressed is a challenge because her body is stiff as a result of lack of muscle control. School is difficult for Sarah. She does not like to sit for a long time, and she also is frequently ill. Sarah's father works all day. It is hard for her mother to work

because Sarah is sick so often. Sarah's mom takes English classes twice a week, but the class is moving its location, which will make it difficult to attend.

Sarah's parents worry about the services she will need as she gets older. "We have no hope for the future," said her father. "We don't know what we are supposed to do, because we don't know what in America they do for adults with disabilities."

Sarah is getting heavier, and will soon be too heavy for her mother to carry. At that point, she will need a new wheel chair and will certainly need additional services. With the lack of support that the family is currently receiving, her parents will not receive the support they need to ensure Sarah the quality of life that she deserves.

David (age 7)

David was only a year old when his doctor noticed that something was wrong. While most children were close to saying or were already saying their first words, David was not making a sound. At two-years-old, he was diagnosed with autism.

When he was younger, David would bang his head against walls and objects around the house and at school. When he was angry or needed attention, he hit himself. Though hurting himself is no longer a significant issue, he still has problems controlling his behavior. When he is upset or angry, David pulls his parents' and siblings' hair, pushes them, or hits them. His mother Maria insists that he does not generally behave this way. Overall, David has good relationships with his peers, only "acting up" when he is upset or wants attention from people he does not know. Maria says that David can be very helpful, and when she asks for help he helps her. She often does not even have to ask. If David sees Maria cleaning around the house, he grabs a sponge or broom and follows her lead.

David attends a local school, where he spends half of the day in a general education classroom with an aid and half of the day in a special education classroom. Because David's speech is limited and Spanish is spoken primarily in his home, communicating with teachers is often difficult. Fortunately, David's special education teacher speaks Spanish. Although she speaks to all of her students in English and tries to encourage David to do so, she will respond to him if he speaks in Spanish. She makes an exception for David because she wants to encourage any communication.

While David divides his time at school between two classrooms, his day is also divided between school and therapy. Maria picks David up during school and has a long commute to his therapy appointments five times a week. The long commute, combined with the amount of therapy David requires, takes up a great deal of Maria's time and energy.

Maria does not understand a lot about the types of therapies David receives. Because she speaks very little English, she doesn't ask a lot of questions. This is a common problem for her. All of David's classes and services are conducted solely in English, and it is nearly impossible for her to communicate with David's teachers and therapists. David's Spanish-speaking teacher often acts as an "in-between" for Maria and the faculty at David's school. Maria also enlists the help of an English-speaking friend to communicate with David's school and therapists. Sometimes even her seven-year-old son helps with communication as he speaks some English.

Despite the challenges, Maria is pleased with the services David receives. She can see the changes in David and the improvements he has made. David's teachers and therapists have helped David make great progress, but Maria is especially grateful for his teachers. They let her know what they work on with David at school so she can continue to help David at home.

It was about eleven years ago that Maria and her husband left Mexico to work and save money in the hopes of doing better for their family and saving up enough to buy a home. As they planned on only staying in the U.S. for two years, they left their four daughters with family in Mexico. However, after David was born and diagnosed, they made the difficult decision to stay in the United States. Though Maria and her husband wanted to return to Mexico and have their family all together, they knew they had to stay for David. Disabilities are stigmatized in Mexico, and Maria did not want David to face criticism from people as a result. Furthermore, “The closest school and services in Mexico are a day’s drive from where we lived. We would not be able to get the services for David” and all services would have to be paid for out-of-pocket. This predicament would add to the complicated nature of their situation, as it is difficult to find work in the area of Mexico where they are from.

There is so much poverty in Maria’s small, countryside hometown that life as an undocumented immigrant in the U.S. seems more bearable. Back home in Mexico, there are no cars, electricity, or places to work. Despite doing better in the U.S., Maria’s separation from her daughters takes its toll. Her daughters often tell her that they want to be with her, but Maria cannot leave the U.S. to even visit them because she does not have the appropriate documents to return.

Maria and her husband left Mexico when their youngest daughter was only two-years-old. The last time Maria spoke to her, her youngest daughter said, “Mommy, I want to meet you in person. I don’t remember you.” Maria often feels stuck and unsure of what to do. She receives no emotional support from her family or friends back home. Her sister blames her for leaving, and people often ask her, “Why aren’t you here? You don’t even work. You should go back to Mexico and be with your kids.” They do not understand why she stays here. They do not understand David’s condition. Maria says, “Yes, I am guilty for having left my kids. But children with disabilities in Mexico are called crazy, bullied, and laughed at. They are left to fend for themselves. I don’t want that for David. I stay here so David can have a better chance at a better future.”

Although their situation in the U.S. is better, Maria and her husband face many obstacles, often as the result of not having the appropriate documentation. Previously, her husband had a job as a truck driver and traveled for work. Recently, her husband became ill and had to have surgery, leaving him unable to work or help around the house. His inability to work has caused great financial stress. Maria is so busy with David that she does not have the time to find a job. The only socializing opportunity Maria currently gets is going to a parent support group for parents of children with disabilities.

Because of the lack of documentation, Maria lives in constant fear when transporting David to and from services. She fears being stopped by the police, as she has no legal documentation, no permit or license, and no alternative form of transportation. Her biggest fear is that one day she will be stopped, receive an expensive ticket or even be taken to jail. Maria is afraid of what would happen if she were taken away from her children.

Although she is happy with the services David receives, Maria wishes one thing would change. She would love for David’s therapists to come to their home. David has to miss many therapy sessions because Maria’s car is unreliable and there is currently no money for gas, as Maria’s

husband has been sick and is unable to work. In addition to being more convenient for Maria, having the therapists come to their home would be beneficial for David and their family. Maria says, "I would love for the therapists to come to our house so they can see what David does at home. That way they can know what our needs are and help us."

Above all, Maria wishes she could change the situation with her daughters in Mexico.

"Sometimes I wish I had wings so I could fly between here and Mexico and be with everyone in my family when they need me," she says. She dreams of getting a permit that would allow her to travel between Mexico and the U.S. or a permit that would allow her children to travel from Mexico and live with their family in the U.S. Although Maria struggles with the distance and her family's situation in the U.S., she never forgets why she is here: "There are many days when I feel like 'closing up shop' and going back to Mexico because my children need me there. It feels like I'm wasting my time here, but I know I'm not. I'm here for David."

Chioma (age 10)

My name is Onyeka, and I am a mother of a child with autism. My daughter, Chioma, is in the fourth grade and loves to bake, draw, and sing. Despite her disability, she is a very smart young girl who excels in math. Although my four children were born in the United States, I was born in Africa and moved to America when I was four-years-old. My family and I have lived in Nashville for many years; we consider ourselves American. My experiences as a parent of a child with a disability and an advocate have helped me understand how difficult it is to have a child with disability. Yes, Chioma is a typical kid in many ways, but her needs are different. She does not communicate orally; it is hard and sometimes impossible for others, and even myself, to figure out her wants and needs. Few people understand the challenges we have to face on a daily basis.

What makes the role of parent and advocate even more problematic is when you do not fit the mold of an “American.” Since Chioma entered school, I have had so many problems with getting the services that she is entitled to in order to succeed at school. I think that one of the sources of this difficulty is my accent, my name, and the way that I look. A few years ago, one teacher tried to tell me that she was doing me a favor by letting Chioma come to school. I had to tell the woman, “You assume that because I have an accent that I don’t know what my rights are. I do know what my rights are. You’re not doing her a favor because you’re taking every other child who has a disability. So why is it different for Chioma? Because her name is African, you assume she’s from outside? She’s a citizen! She was born here, so she has just as much right to be on that bus as every other child. For me, you can tell me you won’t give me anything. That’s fine. But for your information, I’m also a citizen of this country.” I have an accent because of the people I grew up with, but that does not make me any less of citizen than anyone else. Other people hear our names and our accents and believe that we are not entitled to receive any assistance. America is all I have ever known! How can people assume that I do not know what I’m talking about just because of the way that I talk? My accent should not matter when it comes to getting services for my daughter. There are laws about education, and schools need to fulfill the legal obligations. By the time Chioma comes out of school, she should be able to read and write. She should be able to get on the bus without me having to stand there and guide her onto the bus. I shouldn’t have to go into school and fight for everything. I shouldn’t have to fight for her to be in a general education classroom or to get speech and language therapy or to have textbooks at school. But I do have to fight because of who I am and because Chioma has a disability.

When I first started having to attend IEP meetings and interact with Chioma’s teachers, I did not know that I could challenge what the teachers were telling me. I didn’t know that I could have a translator if I wanted one. I consider myself lucky that I was able to learn English at an early age because I would not be able to advocate for my daughter without knowing English. A couple of years ago, I had been thinking, “How can parents of children with disabilities be effective advocates for their children if they do not understand what teachers are talking about?” My concern for other immigrant families is that they don’t have support emotionally, in the

classroom, or with physical needs like childcare. I tried to start a support group for African families with children with disabilities. I wanted to try to help families know about resources that are available to them and provide training to the families so that they could be better equipped to support their children.

Unfortunately, the support group didn't work out. The main challenge is the stigma; nobody wants to be identified as having a child with a disability. Even though we're in a free country, we still have to interact with people from our own communities where the stigma still exists. Immigrant families face an additional challenge because when we come to the United States, we don't really have any support system because our families are so far away. So we have to work and some of us have to go to school, which leaves little or no time for things like support groups. When I organized the meetings for my group, most of the time, nobody showed up. After a while, I became frustrated because I was putting forth so much effort into this group and even taking my four kids to the meetings because my husband works out of state. My kids were frustrated, too, because they were being dragged to a meeting, and no one was even coming! After trying a few more times, I decided to stop and take a break from the support group. I want to try another time, but for now, the African community is not ready for that.

Even though the support group did not work out, I try to help immigrant families in other ways, like being an advocate for immigrant families of children with disabilities. I want to try to help other families who are adjusting to life in the United States while having to cope with the struggles that entail having a child with a disability. I hope that someday the support group can start again and make a difference in the lives of immigrant families.

Marina (age 11)

Marina is eleven-years-old and has an intellectual disability. Her family is from Egypt, and Marina's mother Samia discussed the struggles and hardships she faced while trying to care for Marina there. Marina was born blind, non-verbal, and with extremely limited physical capabilities. While living in Egypt, Samia used to carry her for miles to find a doctor who would care for her. In hopes of receiving better and more accessible healthcare, Samia and her husband decided to move their family to the United States.

Marina is a student at a local school that caters to students with disabilities. A bus takes her to and from school. School is one of the only places Marina spends time outside of her home. Her family does not have an accessible vehicle, so Marina's time at school is crucial to her socially.

Due to the intense care that Marina has always required, a nurse comes to help the family for about six hours a day. However, Samia reports that the hospital is trying to decrease this amount of time. Samia experiences physical challenges that are due, in part, to her caring for her daughter. She used to be able to work cleaning homes, but the severity of her back pain now makes this impossible. As a result, her husband is now cleaning homes in order to provide for their family. Samia is currently taking English classes with the hopes of becoming a nurse so the family's quality of life and care for Marina can be improved.

Jose (age 16)

My name is Natalie. I'm almost 18-years-old. My brother's name is Jose. He is 16-years-old and he has autism. It's different now that I'm in high school, because everybody knows I have a brother with autism. It's also my first year having other people around with brothers and sisters who have disabilities so that's pretty cool. Here in the United States it's different, because they say in Mexico kids don't get the same treatment or education that others do. They just stay home and not do anything and here he actually has time to be involved and do things that regular kids can do. He has anger problems so it's like when he doesn't want to do something it's just like, he gets mad about it. Like this weekend, he had a soccer tournament and all week he made a fuss about it that he didn't want to do it. Then on Sunday he was just like, they won second place! It was just a really good game. He made three or four goals and it was just all exciting. I don't know if he is wearing his medal right now, but he's been wearing it all day since yesterday. It's pretty cool to see him be happy.

Some people do tell my mom 'Oh well he's not going to break. You don't have to treat him like that.' They say it because my mom treats him more like a baby than she does me. So, he does get more attention, but it doesn't bug me as much because I know he's special. When I talk to his teachers or people who can kind of relate they'll be like, 'well she has to treat him a little bit more normal because if not, he's not going to get better.'

My brother went to another school for elementary and middle school, and three years ago, his freshmen year, he started high school with me. At first he didn't like it. He still doesn't. When we're at school, people hug me and tell him 'Oh your sister is my sister.' He gets mad about it, but also he likes it. He likes me going to see him and likes me asking him how he is doing. But he doesn't want me to tell his teachers what we do at home. He doesn't want me to tell them. And what we do in school, he doesn't want me to tell my parents, you know, so it's like I don't know.

He doesn't like being with us if we're at home. It's just him by himself in his room. Sometimes I hang out with our parents in the living room, or sometimes my parents are in the living room and I am in my room. You know but, I have a boyfriend and sometimes he'll invite me to the movie theater and I'll invite my brother sometimes.

Sometimes I do get mad at him because he frustrates me. Like on Monday when I was asking his teacher what time the game was, I hugged my brother and he just yelled at me. I got mad because he has done it before, like he yells at me. I told him he shouldn't do that and we got in the car and he sat beside me and I told him "Get away, get away from me I don't want to talk to you. You yelled at me, you did this to me, no get away.'" So he told my mom that he wanted to say sorry and stuff. So it's just like, for me he's my normal brother. Sometimes I don't even see him as having autism you know? But then it comes again, and I know he does.

Daniel (age 20)

Daniel is 20-years-old and has Asperger's syndrome. He and his family moved from Mexico to the United States in 1996. He lives with his mother Guillermina, and his brother Cesar (age 24).

The family decided to leave Mexico as a result of limited work opportunities, but faced difficulties finding a place to live in the U.S. Additional challenges surfaced during Daniel's Kindergarten year when the family discovered he has Asperger's syndrome. Daniel had difficulty interacting in large groups with other children, and as a result, was placed in a smaller setting consisting of two to three other children. After that year, Daniel was placed in classes and classrooms with other children with disabilities; this continued through the remainder of his schooling (up until high school graduation).

After graduating high school in 2011, Daniel and his family spent a year waiting on evaluation of Daniel's disability, so that he could qualify to attend a local postsecondary education program for students with intellectual disabilities. When Daniel was in high school, Guillermina began looking for programs that would help Daniel become more independent in society. Daniel was admitted into the program in 2012. Attendance has enabled him to "open up" and to be more confident in initiating and maintaining conversations with others.

According to both Guillermina and Cesar, Daniel is "very organized and always takes time to do chores and homework." Additionally, Daniel is fond of music (specifically rock music) and enjoys life at college. Cesar mentioned that Daniel has "limited social openness... and difficulty explaining himself and his needs, even within the family." However, the postsecondary program has helped him to develop more self-confidence and independence. Daniel now aspires to enroll in a general college program after his remaining year in the postsecondary program for students with intellectual disabilities. Daniel's mother says "Daniel understands that he will be the 'man of the house' one day with responsibilities and so he would like to continue his education." Her desire is for Daniel to be able to continue to gain independence and knowledge, and to eventually be able to start and provide for his own family without her help.

Despite their goals of continued higher education for Daniel, the family faces the challenge of financial assistance for university tuition. Cesar mentioned that he currently does not receive federal monetary aid because he is an undocumented citizen. He is able to attend a private university that has its own rules regarding tuition, but says that public universities require undocumented citizens to pay out-of-state tuition. The family will need to consider their financial ability to pay for Daniel to attend a university, but are hopeful and thankful for the progress they've seen in Daniel.

Gale (age 39)

Gale is a 39-year-old woman diagnosed with cerebellar ataxia. Cerebellar ataxia is a type of cerebral palsy, caused by damage to the cerebellum. Since the cerebellum controls muscle movement and balance, ataxia causes problems in these parts of the nervous system. Gale uses a wheelchair at all times, which limits her mobility. While she can prepare small meals, go to the restroom, and take a shower using a shower chair, she has minimal muscle strength, which limits the number of things she can do on her own. These difficulties have not only affected her life, but also her family's life.

Gale grew up in St. Kitts and spent most of her life there. As a young adult, she moved to New York to live with her sister, Carol. She was attending college in New York City and held a job at a deli. Seven years ago when Carol moved to Nashville to live near her brother, Gale stayed in New York and lived with a friend. When signs of cerebellar ataxia started appearing, Gale had a challenging time walking up and down stairs and using the New York City public transportation system. While her roommate was very helpful and supportive, her family was concerned for her well-being and safety.

Gale moved to Nashville so her family could assist her. Carol babysits children in her home on weekdays, so Gale lives with her brother during the week and Carol on the weekends. However, Gale's brother works and she spends a lot of time home alone.

Gale's brother and sister have had to adjust their lifestyles in order to accommodate Gale's needs. Gale's brother wakes up early each day to prepare food for Gale before he leaves for work. He also leaves in the middle of his workday to check on her. When finding a new place to live in Nashville, Carol had to request an apartment on the first floor because her apartment building doesn't have elevators.

There are a number of challenges that Gale has had to face as a result of having cerebral ataxia. She often becomes frustrated while communicating because she stutters, which makes it difficult for others to understand what she is saying. When the family occasionally travels back to New York, airports pose some problems for Gale. When she travels alone, it is hard to maneuver her wheelchair through the airport bathrooms. It is also hard for her to get situated on the plane without assistance. Gale is very passionate about technology, and enjoys using her computer. However, as her arm strength weakens, she is unable to spend long periods of time on the computer, which is very exasperating for her.

One of the biggest challenges that the family has faced is finding services to help Gale with daily activities. The family has been trying to get Gale an aide for some time, but the process has been long. While anticipating a long-awaited evaluation, Carol says, "The biggest challenge is waiting. Her disability is just a process." By having an aide, Gale would be able to participate in more activities during the day. Instead, she spends her time sleeping and watching television.

In addition, transportation has posed many difficulties for the family. Gale has many doctor appointments, and it is extremely difficult for the family to always be available to drive her. The family recognizes that an aide would be helpful in this respect to ensure that Gale would make it to all her appointments. To improve Gale's muscle strength, the family is requesting to receive government funding for physical therapy. However, without eligibility for an aide, the problem of getting Gale to her appointments persists.

Despite these difficulties, Gale and her family have maintained a positive outlook on life. Her family has learned how to work well together to accommodate Gale's lifestyle, and they have grown closer. While the family has uncertainties about the future when Gale can no longer wheel herself around, they hope that they will no longer be helplessly waiting for services.

About Us

The **Tennessee Multicultural Alliance on Disability** allows for a dialogue between community service agencies that serve individuals and families with disabilities as well as agencies that serve immigrants and refugees. The Alliance aims to collaborate on outreach efforts to enhance access to disability services for underserved populations through education, training, service navigation, advocacy and empowerment.

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The **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities** promotes the independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities. The Center provides training opportunities for families, students, and professionals; conducts research on typical and atypical development; provides outreach through clinics and service programs; and develops and shares practical information and educational materials to improve the lives of people with disabilities and their families.

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