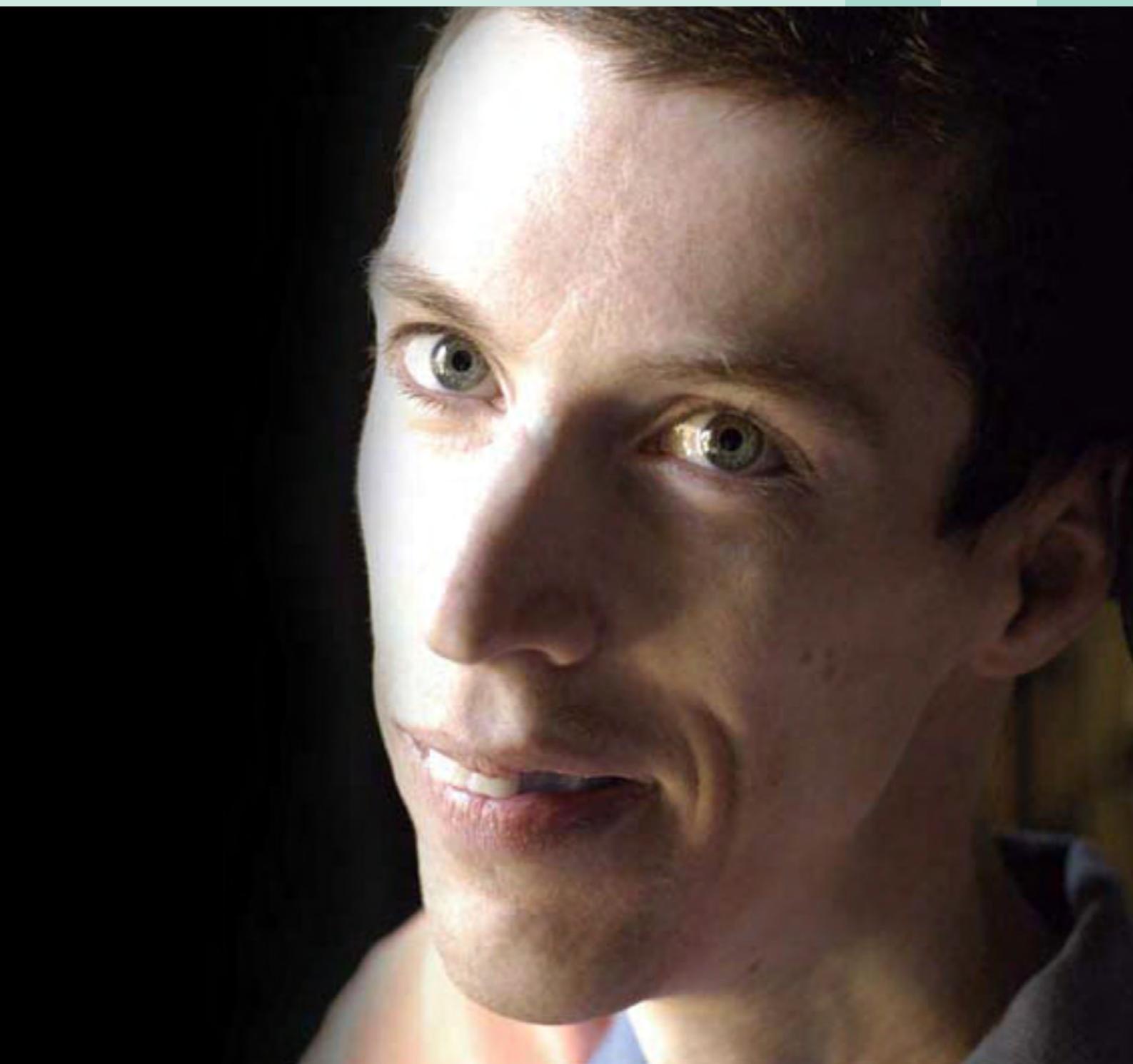


The Right to Communicate



A Letter of Thanks

Thank you for reading this collection of stories from Tennesseans with complex communication needs and their families. As you read, you will learn that their experiences highlight the importance of having access to augmentative and alternative communication (AAC) devices. Having a voice to communicate needs and wants and to engage with the world is a crucial component of leading a healthy and fulfilling life.

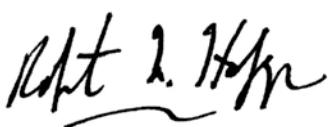
The stories in this booklet are extractions from interviews conducted by students from Vanderbilt University and through the Vanderbilt Kennedy Center's Kindred Stories of Disability project. As part of a course assignment, the students interviewed individuals with communication challenges and their families to learn more about their encounters with education, health care, housing, employment, and disability services in Tennessee. The assignment gives future educators, advocates, and researchers an opportunity to learn firsthand from families. It gives individuals with disabilities and families an opportunity to educate their elected officials, and it gives legislators and policymakers an opportunity to understand the impact their decisions might have on their constituents' lives.

We would like to thank the individuals with disabilities and families who shared their stories. By reading them, you will receive snapshots in time of a diverse group with a variety of challenges and successes. We also would like to acknowledge the longstanding partnership between The Vanderbilt Kennedy Center and The Arc Tennessee on the Kindred Stories of Disability project. It is a fine example of the deep commitment to collaboration that Tennessee disability agencies and organizations have as they work to improve the lives of Tennesseans with disabilities and their families.

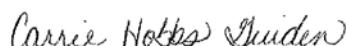
To view past and current story collections from Tennesseans with disabilities, please visit vkc.vumc.org/kindred.



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“Living without being able to communicate is like being behind four glass walls. You are able to see others and they can see you; but you are ignored, or worse, talked down to until you stop remembering who you are and why you are important.”

-Rick Creech, Augmentative and Alternative Communication user, US Senate testimony

Introduction

A recent survey of over 5,000 individuals with disabilities, conducted by Temple University, concluded that 70 percent of individuals who could not effectively communicate with his/her voice did not have access to a communication system.¹ Access to communication is foundational for any individual's ability to be independent and to live a good, fulfilling, and healthy life.

In an effort to support work being done at the national level for a proposed National Technical Assistance Center on Augmentative and Alternative Communication, we wanted to learn more about some of the challenges, barriers, and experiences of individuals living with complex communication needs. We talked with families living in Tennessee. The individuals we spoke with have conditions like cerebral palsy, intellectual disabilities, autism, Rett syndrome, ALS, TBI, and aphasia. The experiences they share about communication highlight a critical need for access to augmentative and alternative communication (AAC).

An individual's inability to communicate can cause poor school and post-school outcomes. It increases risk of abuse and neglect, and can cause challenging behaviors. Individuals who cannot

communicate their wants and needs effectively are more likely to have health concerns and will likely have trouble getting and keeping a job. They will have decreased independence and fewer connections with communities.

In this collection, you will meet Emily (age 5), who loves being around people and playing. Communication is critical to her happiness and to her ability to interact with her peers. In another story, Jim (age 45) shares about being a beta tester on an AAC device he still uses today and that helped him to complete graduate school and gain independence. You'll also read about Joshua (age 17), whose father says that more than 50 percent of his frequent aggressive and self-injurious behavior is caused by communication issues.

Individuals and families share frankly about how they best communicate and how they came to access or have been unable to access AAC. The stories certainly point out the benefits of undergoing communication assessments to individualize what type of AAC works most effectively, and ultimately these stories drive home the point that everyone deserves to have a voice and a right to communicate. ■

¹ Feinstein, Celia, (2017) AAC research unpublished ppt, Temple University, PA

Emily (age 5)

My name is Kim and I live with my husband Roger, my 7-year-old son William, and my 5-year-old daughter Emily in Nashville, Tennessee. I am going to tell you about Emily. Emily was born prematurely when I was only 29 weeks pregnant. I just stopped feeling her move and so I went to the emergency room. A few hours later she was born via emergency C-section. She was in distress... she was dying. Emily was born with multiple injuries to her brain including her cerebellum and Periventricular Leukomalacia (PVL). A few years ago, Emily was diagnosed with apraxia of speech and ataxic cerebral palsy. Currently, she has some trouble with her balance, but I would say her major challenge is speech. She is currently non-verbal.



Emily loves being around people and playing. As a result, communication is critical to her happiness and her ability to interact with her peers. Emily is an opinionated girl who knows what she wants and becomes extremely frustrated if she can't get her point across. It's easy for us, for now, to understand her needs. We are familiar with the tones of her voice, her gestures, and her modified sign language. It is much more difficult for non-family members to understand her.

Emily is enthusiastic and curious, and she wants to connect with others. Her ability to communicate with people around her is important. Unrecognized or misinterpreted communication attempts often result in frustration. Sometimes Emily is casted as the "bad behavior kid" by those who don't know or understand her. She gets so frustrated when she's unable to be understood. Try to imagine what it would be like for you if you had a lot on your mind but were unable to communicate it to anyone. For example, Emily might have a meltdown at the grocery store because there is something she wants to communicate, and I don't understand, and I'll have someone telling me, "She's so tired. She needs a nap." They have no idea.

Emily's challenges with communication led us to an augmentative and alternative communication (AAC) expert in order to try out various AAC devices. At first, Emily experimented with both low-technology

Emily's device has changed the way she can communicate with the people around her. It allows her to be heard.

and high-technology AAC devices for about a year, to see what worked best for her. It has benefitted Emily to have introduced the device early, but we had to wait until she was developmentally ready.

Emily now has a Tobii-Dynavox speech-output device, which we were able to purchase through insurance. Because the device is still new to her, we are working on redirecting her to prioritize AAC to communicate. Emily's speech therapist taught me how to model using the device with Emily to reinforce its use. We're all working on it. Emily's device is now a part of her. She won't go anywhere without it. It's her voice. She needs to use her voice.

We need help from others on this, too. My husband and I cannot be the only ones redirecting Emily to use her device and modeling its use. We need Emily's teachers at school to also make the device available to her and to model it as well. Emily's current teacher is fantastic and is very determined to help Emily communicate effectively. However, her teacher has limited experience with AAC devices. There was definitely a regression in Emily's AAC use when she started in her new school this year. Due to the broad lack of teacher exposure to AAC, I fear that every time Emily starts in a new classroom, her communication will have a setback. I have to work hard to be

sure that her teachers have the resources they need to use the device effectively.

Emily's device has changed the way she can communicate with the people around her. It allows her to be heard.

What frustrates me the most is that I think every child who has a communication challenge should be able to access what it is that helps him or her to communicate. Emily has significant resources because my husband and I are educated. I have a flexible schedule and we have a decent income. My family was able to find appropriate resources for Emily, when others cannot. Thankfully, we can afford specialists and the tuition for her to attend specialized programs. But I often think about other families who may not have the same resources that we do. What about the parents who don't have flexibility at work and can't take their children to appointments every week? There are people who don't have the money, or the transportation, or even know where to go. It is beyond unfair knowing that so many children have a barrier to communicate, and it might be because of their parents' financial or work situation. Everyone deserves to have their voice heard. ■

Savannah (age 16)

My name is Elizabeth. I live with my son, daughter, and two dogs. Both of my children have special needs. My daughter is nonverbal and my son has autism. My daughter's name is Savannah. She is 16 years old and she loves fashion, getting dressed up, and getting her hair done. She likes to go shopping and loves her family and friends. She is very opinionated and she will let you know if she does not like the way your hair looks or what you are wearing. She loves to travel and go to school at her local high school in Johnson City, Tennessee.

My daughter has a caring personality but she also can be self-abusive and aggressive towards people. The aggression is now under control with her medication,

but before she was on her medication she would put her head through walls or sometimes would kick through them. After a while, I decided we needed to have her room padded at my house. We were on the waiting list for six years before we got the pads. We now have 2 ½-inch-thick pads against all the walls. I chose pink because I wanted them to be a little feminine for her and I know she loves pink. Aside from the walls, we got a 3-inch-thick pad for her bedroom floor in case she throws herself down on the floor when experiencing a psychiatric episode. She has the pads so she cannot damage the walls or herself.

Savannah's diagnosis was a long and ever-changing journey. She has a global developmental delay with regressive and autistic traits. She began losing skills at a very young age, and one of those skills was language and her ability to communicate. She was diagnosed with autism, but later that diagnosis was taken away. We saw a self-injury specialist in Minnesota who discovered Savannah's hyperekplexia, which is a genetic disorder. She has the rare form, and it exhibits in panic attacks.

Savannah is nonverbal and uses an iPad to communicate. She has her iPad with Proloquo2Go on it. It is a great fit for her. It is a Picture Exchange Communication System (PECS)-based program. You can put in anything you want and add in your own pictures. Savannah can also organize it anyway she wants. The first thing she said



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She takes her iPad with her everywhere she goes. However, she does not always want to use it and she is not always encouraged or forced to use it. In general, she will only use her iPad for something she really wants. I have asked her teachers to use it more. She needs to strengthen both her oral language and her iPad skills. They don’t use it as much as they should in school. She won’t use it with people if they will let her get out of it. Her aid at school can usually understand what she wants without it, so Savannah thinks that she does not need to use it.

I want her to be able to communicate with people because I am not going to be here forever. She is going to have to be able to communicate to be independent in the world. It will be less frustrating for her if she can communicate effectively with the people around her throughout her life.

When AAC became a serious possibility, no one performed an assessment for an AAC device for Savannah. When I asked the schools for help on this, I was told that Savannah was not capable of using AAC. The first time she had it in her hand she used it to say, “I want a hug.” Therefore, she is very capable.

I am a single mom and my daughter’s combination of disabilities keeps me from having a job. I cannot work because I never know when she will need me. I cannot get food stamps because those opportunities are only for those looking for employment. What am I going to do? There is no one to take care of her, and I do not have any family here. A special needs nanny is too expensive for us and most of them don’t have psychiatric training anyway. They are also not allowed to give medication. When Savannah has an episode, I have emergency medication that has to be given to her and they would not be allowed to do that. Therefore, I cannot leave her with them and I have not worked in 11 years. At some point I would like to be stable and on my own, but at this point I am tied down. ■

Jim (age 47)

My name is Jim Shannon, and I am 47 years old. I live in Hendersonville, Tennessee, in a wing off my parents' house. I currently work for TennCare and I love my job. When I was very young I was diagnosed with cerebral palsy (CP). I could read, add, and subtract by the time I was 3, but when I was about 6 years old, I lost the ability to talk. My family helped me find other ways to communicate with them. I click my tongue for "yes" and I stick my tongue out for "no." I use a wheelchair to move around, and my physical movements are very limited. The only part of my body I have total control over is my chin. Other than that, my childhood was similar to any other child.



I attended kindergarten and elementary school and was always in advanced classes. Until the age of 12, I used a basic Prentke Romich Company (PRC) device with ticker tape to complete my homework and to communicate with my teachers. It was time-consuming and very frustrating to use.

It was my mom's idea for me to have an assessment done at the Technology Access Center (TAC) in Nashville to figure out if there was a better way for me to communicate with people. When I was 12, I went to TAC and they suggested I try using EZ Keys with a voice synthesizer to communicate. EZ Keys is a type of alternative and augmentative communication (AAC). It is a computer program that allows me to type using small movements of my chin. Letters on the EZ Keys are organized by how often the letters are used, and it also has word prediction to speed up typing. I was a beta tester for EZ Keys. They trained me on how to use it and gave me information about how to integrate it into my life. It was much easier than the ticker tape. I have been using this system ever since. I was lucky that my school had the funding to pay for my device.

My parents, teachers, and friends were trained to use EZ Keys too. It made good communication between all of us so much easier. It changed everything for me. For the first time, I could engage in conversation because I was able to type

My parents, teachers, and friends were trained to use EZ Keys too. It made good communication between all of us so much easier. It changed everything for me. For the first time, I could engage in conversation because I was able to type fast enough, and add my own thoughts and ask questions.

fast enough, and add my own thoughts and ask questions. It made interacting and participating in school so much better and more interesting.

My improved communication helped through high school. After high school, I decided to attend Volunteer State Community College. I graduated four years later, magna cum laude, with an Associate's Degree of Business Administration. Throughout my time at Volunteer State, my parents and I kept looking for a university that could and would accommodate my physical challenges on campus. Middle Tennessee State University seemed to be the best fit for me.

I was accepted and it meant that I would be living an hour away from home, which required careful planning. I was excited to finally be on my own and to have some independence. After a few weeks, I had acclimated to the campus well. I was living in my own apartment with a care person, who assisted me 24 hours a day. Fast forward, and I ended up earning both my bachelor's and master's in Computer Information Systems. None of the above would have been possible without AAC.

I was hired by TennCare in 2000 as their website maintainer. I have shifted positions slightly since then and am currently monitoring patient admission evaluations. I am able to work from home, which I am very grateful for. Outside of work, I have served on the Board of Directors for Technology Access Center. I am passionate about sharing my story and helping others to gain access to technology so they can reach their fullest potential.

Legislators need to be aware of the importance of properly funding places that provide AAC services, such as the Technology Access Center. Having the adequate resources available to provide communication and technology to more individuals with various needs is important so they can have the same opportunities as anyone else. ■

Joshua (age 17)

My name is Vance. My wife is Kristy. Our son Joshua is 17 years old. We also have four younger children.

Joshua is actually Kristy's nephew. We adopted him. He was a victim of shaken baby syndrome. He has cerebral palsy, autism, a mood disorder, severe aggression, and self-injurious behaviors.

Joshua underwent a number of different surgeries in the month after the incident had occurred when he was a baby. The doctor told us that Joshua would never be able to walk, talk, see, or hear. He pulled through though, and we made it.



Joshua is very prone to seizures. From 3 to 9 months old, he was having 30 to 50 seizures a day. When he was 5 years old, he fell off a playground slide, and the fall triggered a severe seizure that caused him to regress. He became completely non-verbal, lost most of the words he could say. We constantly live with the reminder from the neurologist that he could have a seizure at any moment. We've had that hanging over our head from day one.

As he grew older, we sent him to Signal Centers where he started therapy and intervention and he began to learn to communicate. They used the Picture Exchange Communication System (PECS) and they also taught him some sign language. Because of his cerebral palsy, sign language was challenging. He could not control the left side of his body, but we came to understand what he signed. When he entered the public school system in early intervention when he was 3, the school had a device for him where the teachers would put in questions and choices for him. He could select from what they programmed in there and communicate with the teacher.

In the last five years, his aggression has increased and we had to take him out of school. None of the communication devices really work well for him anymore. He throws away pictures from the PECS. When you try to work with him on the communication app on the iPad, all he wants to do is to get on to YouTube and listen to music. If you try to stop him, he will throw the tablet away.

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We don't know for sure what triggers his aggression, but I would say that more than 50% of the time it is a communication issue. One time he was pointing to himself repeatedly, and we did not know he was trying to tell us his ear was hurting. Days later we saw drainage from his ears. He was in so much pain, but he couldn't tell us. He couldn't make us understand what he was feeling.

Joshua is a great kid, but once aggression takes over, he is no longer the same person. We have had a number of intense incidents. Last year, I received a black eye and over 50 bite marks on my body. Another time, our youngest daughter had to hide in her room away from Joshua because he was targeting her. The past five years have been so incredibly stressful for our family. He has had unhelpful experiences in some treatment centers and has been denied admission by others. All the while, his aggression has increased.

Joshua was admitted to a center in South Carolina this year. They are still trying to stabilize him before they can start working with him on his communication. We go visit him at least once a month, yet the stress to our family is never gone. We still have

nightmares and wake up in the middle of the night worrying about him. When we get phone calls from the center about him breaking another tooth or hitting somebody, those are hard calls. It's hard not to be there to fix things, not that we could fix anything, but he's our son and we are hours away from him.

The journey never ends. Kristy and I try to share about our experiences and help people feel less alone about certain things. We set up a Facebook page called "A Voice for Joshua" and a Facebook support group for parents who are in similar situations. We will keep advocating for the rights of our children and telling our stories to help others. ■

McKenzie (age 15)

McKenzie is 15 years old and has Rett syndrome (RTT). She lives in Nashville. Her mother and father describe her as brave, compassionate, and a fierce advocate for herself and others with disabilities. McKenzie was in kindergarten when she was officially diagnosed with RTT. Her doctors told her parents that she may lose the ability to walk and that her speech would be limited due to apraxia. McKenzie and her family had a different idea. They began searching for therapies and interventions, and found speech therapy services.

"We decided we were not going to let Rett syndrome define us but that we were going to define it," said McKenzie's mother.



When she first started attending speech therapy, McKenzie and her family learned about the possibilities of augmentative and alternative communication (AAC) through their speech language pathologist. McKenzie's mother explained that she "started from the bottom" with a simple picture communication book so she could learn to communicate with pictures. McKenzie's mother says that her challenging behavior immediately started to decrease because McKenzie was learning to communicate her needs with others.

Through many more years of speech therapy, McKenzie moved from simple picture communication books to an iPad with a communication app, and all the way to high-tech dedicated communication device. Somewhere along the way, McKenzie and her family discovered Nashville's Technology Access Center (TAC), a non-profit organization that aims to provide services for Tennesseans with disabilities. Through TAC, McKenzie has been able to try out different forms of AAC and find what really works for her. Though McKenzie's communication continued to flourish with the right tools, her mother describes that it's been a constant battle to ensure McKenzie gets the tools and supports she needs.

One of the hurdles McKenzie's mother described is getting others to understand that these devices and picture communication books are McKenzie's

McKenzie's family noted the importance of advocating for her and working to constantly adapt her communication toolkit as crucial to her success. As McKenzie's mother said, "Everyone deserves to have a voice."

voice. She describes an incident on the school bus where McKenzie tried to communicate that she was thirsty and no one would listen. As McKenzie arrived at school very upset, she used her communication device to tell her teachers that she was angry because she wanted to tell someone on the bus that she was thirsty and no one would listen. This incident inspired McKenzie's mother to educate the bus drivers and monitors and to write a letter to Congress detailing the importance and significance of AAC in McKenzie's life.

AAC has helped McKenzie become a key figure in her high school. She is a cheerleader, sophomore SGA Vice President, honor student, and a role model to all. McKenzie's family noted the importance of advocating for her and working to constantly adapt her communication toolkit as crucial to her success. As McKenzie's mother said, "Everyone deserves to have a voice." ■

Lou (age 19)

My name is Terry Jo, and I want to tell you about my son, Lou. Lou is 19 years old. He has four sisters who are between the ages of 26 and 37, but they all live in different areas. Lou lives with us in Nashville. Lou is in his junior year of high school right now and will stay in school for two more years before exiting. He has Angelman syndrome. Because of this, Lou has an intellectual disability, some motor difficulties, and had some seizures early on in his life. Thankfully, however, the last time Lou had a seizure was when he was 4 years old, so we consider him lucky.

The number one symptom of Angelman syndrome is difficulty with communication. That's where Lou's iPad comes into play.



He sometimes uses the Proloquo2Go app to communicate. If asked, Lou would be able to tell you that he loves listening to music and watching movies, as well as watching YouTube videos of concerts on his iPad. He would say that he considers himself a food connoisseur, specifically of macaroni & cheese and chocolate. He is funny, friendly, and is affectionate towards all of us in the family. Lou is also involved in Young Life Capernaum once a week. It is a great social outlet for him. In all, Lou is a very likeable and social person. He cares about people and doesn't shy away from being social and communicating with others.

Early on, especially when we were still living in California, our relationship with the school was discouraging and often a battle when advocating for Lou and his communication needs. There were even instances when we walked out of IEP meetings without signing the IEP because of disagreements with the school over his having an iPad to communicate. One of the things that was most disappointing about our early experiences with Lou's schools is that his school in California did not seem to understand that because of Lou's diagnosis, he has different communication needs than a child with autism for example. They only focused on his intellectual disability and didn't work to personalize that support.

Lou first began using augmentative and alternative communication (AAC) as a baby. He first used Picture Exchange

Lou understands a lot more than we realize, and he and others would greatly benefit from research that helps us to develop interventions and communication devices that help people use their voices.

Communication System (PECS) symbols, then in early elementary school he used a Dynavox device. It was between fourth and sixth grade that he began using the iPad. The assessments Lou did early on to determine his AAC use did not show how capable and smart he is. Even though he can operate an AAC device like an iPad, he could not do certain prerequisite steps that they initially said he needed to do to get an AAC device.

The hard thing now is that the school district pays for one of Lou's iPad's that he uses with Proloquo2Go at school, but we had to pay for the other one. Through my husband Dave's insurance, Lou receives speech therapy once a week with an SLP that helps teach Lou how to use his iPad and Proloquo2Go and coordinates with the school personnel. TennCare pays for four hours of employment and community exploration per week, and we pay for an additional 14 hours of this service, so I can work. It is hard because if we used this money for another iPad, we wouldn't get the other services funded.

It took a while for us to figure out the iPad and Proloquo2Go as being the right AAC for Lou because his initial testing did not reflect his abilities. We also pay for a sign language

tutor to work with Lou once a week at school and occasionally with the family and caregivers. We are also fortunate to have insurance that covers part of Lou's supports, but there is still a lot that we have to pay out of pocket.

I wish there was a way for people to understand how Lou uniquely communicates. I really wish that his communication between school, Capernaum, and us at home were more coordinated and connected. Sometimes it seems like Lou has to create a separate language for every different group of people he wants to communicate with.

What concerns us the most is thinking about what will happen with Lou after he turns 22. We want him to have a productive life after school. We also want him to be more independent and hopefully have a job, with the help of an aide. All of this means he will continue to need communication therapy. We also advocate for more research funding on AAC. Lou understands a lot more than we realize, and he and others would greatly benefit from research that helps us to develop interventions and communication devices that help people use their voices. ■

Joey (age 41)

My name is Frank, and I live in Bartlett, Tennessee, with my wife, Diana. Our son, Joey, has autism. Let me tell you about Joey. He just turned 41 years old. He is 6'2" and weighs 330 lbs. He was living at home with us until three years ago, when his behavior got to be more than we alone could handle. Joey is on the Medicaid waiver and is supported through West Tennessee Family Solutions.

I am 69 and my wife is 67. I am retired now, but I worked for many years in sales and marketing and convention planning. I also served on Governor Lamar Alexander's Developmental Disabilities Council. I went to Nashville twice a year for meetings. I felt that was the best way to learn about resources available for Joey, and I was glad to be there.

Joey crawled, walked, and developed some speech along typical timeframes, putting short sentences together. When he was a little older, we began to have questions about some of his behaviors and loss of speech. We asked his pediatrician about it, and he told us all kids develop at their own speed. We ultimately changed

Joey has always loved game shows. If we phrase questions like they do on the game shows, then he will answer.

pediatricians because he would not help us identify Joey's disability.

Joey's communication style is unique. Basically, it includes humming, flapping his hands, and other self-stimulatory behavior. I don't know how it evolved, but he will answer a question that can be answered with yes or no. He does not answer who, what, when, or where questions like "What did you do today?" or "What would you like to do?" I don't know why, but he can't or won't do that.

However, Joey has always loved game shows. If we phrase questions like they do on the game shows, then he will answer. If you ask him, "Name something you did today," he might say, "I want to say, bowling," which means he went bowling that day. If I say, "Name something you want for supper," he might reply with, "I want to say, McDonalds." That's still how we communicate. If we ask him "Did you have a good time," he will say, "Ding!" (the sound of a bell), which means he had a good time. If he did not have a good time, he will say, "Eeh" (the sound of a buzzer).

And he writes! He has the most beautiful printing in the world and he can write cursive. He forms each letter carefully. When we visit him at his house, he always gives us a grocery list that is carefully printed. When a new staff person saw his writing for the first time, she said, "Wow, his printing is amazing! I wish I could print that clearly!" We have a printed list on the refrigerator now with everything he wants for Christmas. ■

Resources

American Speech-Language-Hearing Association (ASHA)

www.asha.org/public/speech/disorders/aac/

Learn more about Augmentative and Alternative Communication (AAC) and different types of AAC

The Arc Tennessee

[www.thearcn.org](http://www.thearctn.org), 615-248-5878

The Arc Tennessee empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime.

Association of University Centers on Disability (AUCD)

www.aucd.org, 301-588-8252

AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. AUCD provides leadership on major social problems, advocacy with Congress and executive branch agencies, and technical assistance. AUCD currently is working with national groups to propose a National Technical Assistance Center on Augmentative and Alternative Communication.

Communication Bill of Rights

www.asha.org/uploadedfiles/njc-communication-bill-rights.pdf

Read the "Communication Bill of Rights," drafted by the National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC)

Technology Access Center

tacnashville.org, 615-248-6733

The mission of TAC is to promote the independence and participation of individuals of all ages with disabilities in school, work, play and everyday activities through their use of assistive technology.

Tennessee Disability Pathfinder

familypathfinder.org

615-322-8529 or toll-free 800-640-4636

Tennessee Disability Pathfinder is a free statewide phone, web, and print referral service in English and Spanish. It connects the Tennessee disability community with service providers and resources. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC, TN Council on Developmental Disabilities, TN Department of Health, and the TN Department of Intellectual and Developmental Disabilities.

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

vkc.vumc.org/ucedd

615-322-8240 or toll free 866-936-8852

Provides innovative leadership in education, research, and services to people with disabilities, the community, and families. All activities promote the independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities and provide supports for families.

A recent survey of over 5,000 individuals with disabilities, conducted by Temple University, concluded that 70 percent of individuals who could not effectively communicate with his/her voice did not have access to a communication system. Access to communication is foundational for any individual's ability to be independent and to live a good, fulfilling, and healthy life.



Tennessee Kindred Stories of Disability
vkc.vumc.org/kindred