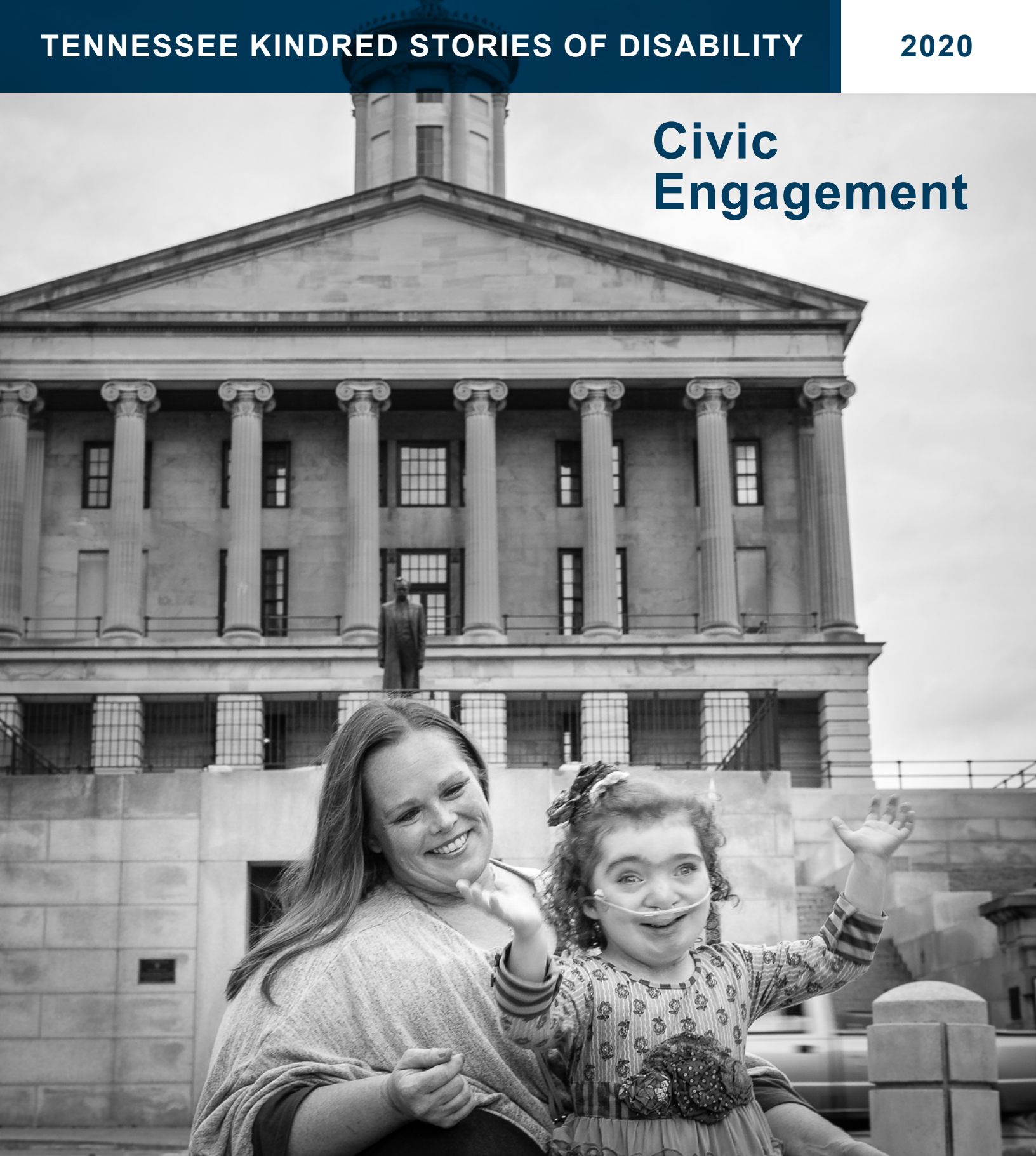


Civic Engagement



A Letter of Thanks

Thank you for reading this collection of stories from Tennesseans with disabilities and their families who are using their voices to vote, to educate legislators and policymakers, and to stand up for their own rights and for the rights of others.

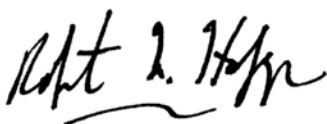
These advocates shared their civic engagement stories with Vanderbilt University graduate students as part of the Tennessee Kindred Stories of Disability project. The project gives future educators, advocates, and researchers an opportunity to learn firsthand from families. It gives individuals with disabilities and families an opportunity to educate future disability leaders and their elected officials, and it gives legislators and policymakers an opportunity to understand the impact their decisions can 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 would also like to thank photographer and parent advocate Jen Vogus, whose powerful images combine with the stories to amplify the voices of the advocates. In addition, we would like to acknowledge the longstanding partnership between The Vanderbilt Kennedy Center and The Arc Tennessee on this 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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Asher

My name is Michelle. I live with my parents and my two daughters, Tatum and Asher, in Jonesborough, Tennessee. Tatum is 20 years old, and Asher is 6.

Asher loves music, bubbles, and swings. Her favorite mode of transportation is bouncing. She is also a huge fan of SpongeBob SquarePants and Sesame Street. She is a happy, strong, and determined little girl.

Asher has faced many medical complications and to date has been under anesthesia 31 times for medically necessary procedures including a tracheostomy, a cleft lip closure, open-heart surgery, and surgery for a feeding tube. Asher has a very rare chromosomal translocation, which affects two different chromosomes. This syndrome with no name requires Asher to have a gastrostomy tube, be oxygen dependent, and on a monitor 24/7. She needs supplies such as breathing medications, stress hormone injections, and a suction machine with her at all times in case of emergencies. Developmentally, Asher is nonverbal, has limited communication skills and has poor fine motor, gross motor, adaptive, feeding, and sensory processing skills. She uses a gait trainer to help her walk and more recently is learning to use a wheelchair in the community.

I believe voting is an important aspect of citizenship, and Asher's medical issues and insurance needs have made me more



aware of the importance of informed healthcare voting. Protecting Asher's rights is a current and ongoing priority of mine. As a single mother of two daughters, I try to lead by example that as a woman our right to vote was fought hard for and gives us the right to help transform our future, as well as the future of our children. My older daughter, Tatum, has participated in voting. Though she herself does not have a disability, she cares deeply about her sister and is also learning to be an avid healthcare voter. As a parent advocate, I am a member of Little Lobbyists, which is a national advocacy organization for children with complex medical issues and disabilities. I value the support, guidance, and



"I believe voting is an important aspect of citizenship, and Asher's medical issues and insurance needs have made me more aware of the importance of informed healthcare voting."

encouragement from Tennessee Disability Coalition and Family Voices of Tennessee.

Our advocacy journey began in February 2019 at Disability Day on the Hill in Nashville, where I met with our legislators and shared our family's story. We met with Sen. Rusty Crowe, Sen. Becky Massey, and Rep. Matthew Hill. Our leave-behind information sheet was titled, "No one anticipates a medically complex child." In the process of taking our children to meet their legislators, there was a shift. A genuine concern, rather than a pile of papers coming across their desk for signatures. Each person we met with wanted Asher's history and to understand how we navigate everyday life despite her challenges. Our topic of education was the need for Tennessee to have a clear, attainable pathway to Medicaid services for children with complex medical needs and disabilities regardless of parent income.

Rep. Matthew Hill asked me to testify at the TennCare Subcommittee hearing in March 2019 about the significance of the Katie Beckett Waiver for children with complex medical needs and disabilities. In April 2019, a fellow parent advocate organized a rally to increase community awareness for the need of a Katie Beckett Waiver. Asher and I, along with many other Upper East Tennessee families, shared our stories about why this waiver is important. We flooded social media with #mykidtoo and arranged for news and newspaper articles to tell our stories. A Katie Beckett proposal began as Rep. Sam Whitson and Sen. Kerry Roberts sponsored HB0498/SB0476 respectively. After full scrutiny from legislative committees, The House voted unanimously on March 30, 2019; Asher and I were invited by Rep.

Matthew Hill to be present on the floor. The bill passed with a unanimous vote from the Senate on Apr. 1, 2019. Several families were invited by the Governor's office to attend a ceremonial signing on July 11, 2019.

I think it is extremely important to communicate with our elected officials. That is the only way they know what is truly important to their constituents. It is our opportunity to hold them accountable for their choices and the impact their votes have on their constituents' daily lives. At the end of the day, legislators may not be aware of the needs of their constituents. It is vitally important they meet us, they meet our children, they understand our needs, and that they truly understand the consequences of their active votes. Health care should be a nonpartisan issue, as it affects everyone, and we should be able to find common ground. For me that is making sure my daughter and other children like her have the tools available to maintain an adequate quality of life and to thrive. ■

Ethan



My name is Roddey. My wife Sarah and I have a daughter Melissa, who is 16, and a son, Ethan, who is 13. Ethan is in seventh grade within Hamilton County Schools. He was diagnosed with autism spectrum disorder when he was 5 years old. Ethan was non-verbal until the age of 6 and experiences sensory difficulties such as loud noises, texture of grass, and fragrances. When Ethan began school, he spent most of his time in the special education setting. As of second grade, Ethan was fully transitioned and has been in the general education environment full time with the help of an aide.

I believe voting is important. When a person chooses to vote, they are choosing to have a voice in the election. In general, being politically aware and politically active is important and allows a person to make an impact. Myself and my wife both vote. I believe that voting is important because it is the closest thing you can get to “a say.” Disability-related issues do sometimes impact my decisions about who I vote for, but these issues are not a make or break for me.

At this time, neither Ethan or Melissa vote as neither of them are 18 years old. I hope that both of my children will vote one day.



"I communicate often with our elected officials and believe it is important for others to do so—they are not mind readers and in order for them to know what we want, we have to be able to communicate that to them."

Regardless of having a disability, voting for anyone is a challenge. There is a lot that goes into deciding who you want to vote for such as educating yourself on candidates and policies. Though I hope Ethan will vote when he is 18, it is ultimately his decision. Also at this time, Ethan does not have an interest in testifying before legislators, which again is his decision. My daughter, Melissa, did testify before legislators as a part of the Chattanooga Police Department's "Take Me Home" campaign, which assists law enforcement during contacts with adults and children who have disabilities.

I am a governor-appointed member of the Tennessee Council on Developmental Disabilities and a governor-appointed member on the Council on Autism Spectrum Disorders. I spoke with a Congressman about veterans with disabilities. I communicate often with our elected officials and believe it is important for others to do so—they are not mind readers and in order for them to know what we want, we have to be able to communicate that to them. I have not encountered any challenges yet in educating elected officials on disability-related issues, and I hope that my work will make an impact.

I have not contributed my time or money to a campaign, though I have been involved in causes related to disability issues, including the Katie Beckett Waiver, which supports children with disabilities in receiving Medicaid thereby providing them with the opportunity to receive home care, regardless of their family's income. I have also been involved in the process of the proposed Medicaid Block Grant in Tennessee, which I believe would likely hinder low-income children and families,

including those with disabilities, pregnant women, and the elderly, from providing health care services. Additionally, I have supported various nonprofits that focus on disability-related issues.

I participate in Disability Day on the Hill, during which disability advocates from around the state descend upon Nashville. Individuals are given the chance to meet with officials about various issues that are important to them. Though I am not a member of an organization that advocates or lobbies for disability-related issues, I do educate others through my position on the Council on Developmental Disabilities.

I believe that there are ways to be civically engaged that do not involve educating and lobbying. Through my engagement with the Council on Developmental Disabilities and Council on Autism Spectrum Disorders, I have created contacts and speak with these people regularly. I often talk with our State representative here in Chattanooga, and have also spoken with the Chattanooga sheriff as well as Chattanooga police. I also think it is important to add that representatives are eager to talk to and hear from their citizens regarding what they believe is important. I have learned that communication is reciprocated, they often reach out to me.

Thirteen years ago I didn't know what autism was or anyone affected by it, and so I think it is important to educate elected officials on the effects that Autism may have in their community. I would like to encourage people to be themselves—becoming involved and communicating with elected officials is not for everyone, but everyone has a right to be engaged. ■

Anjali

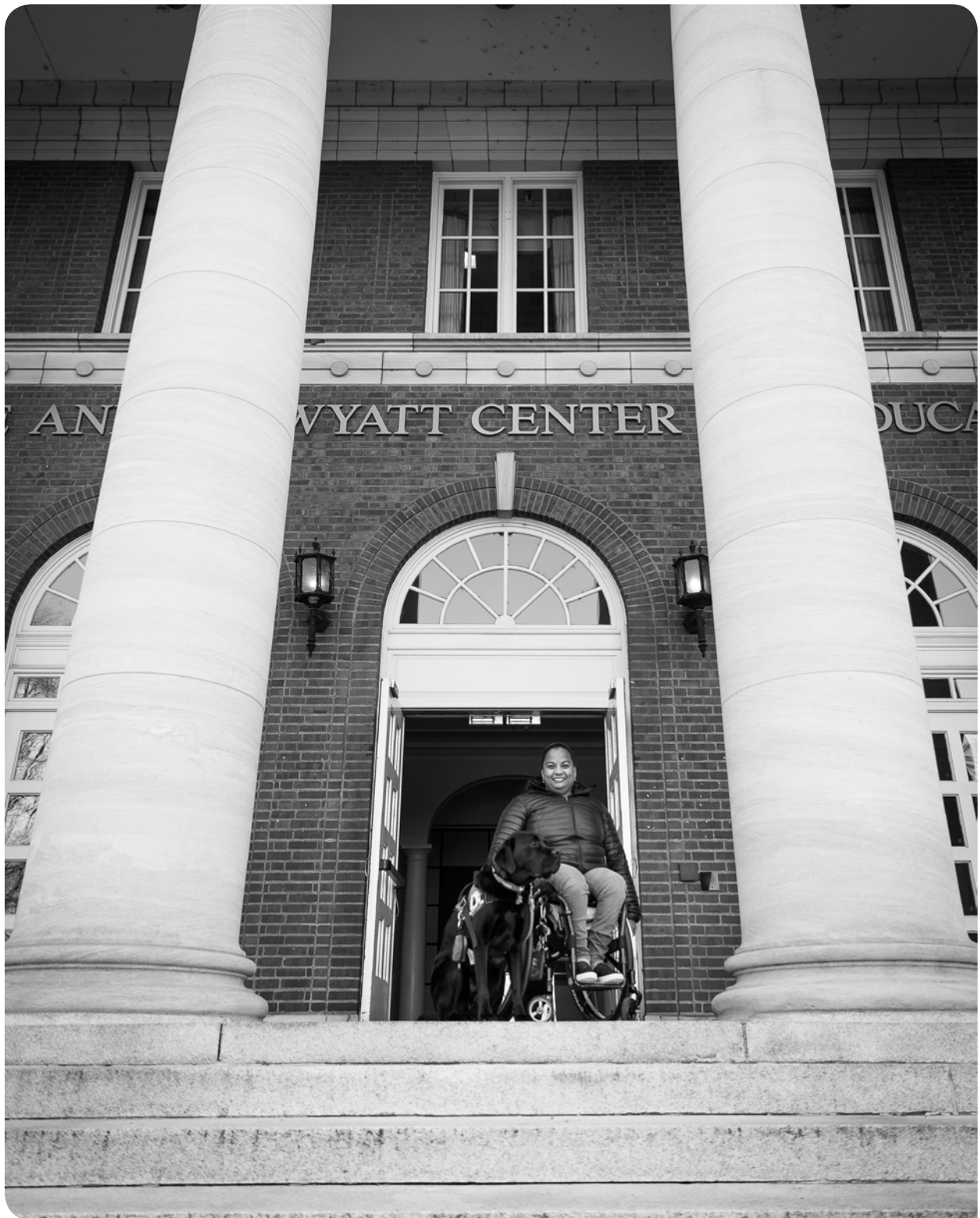
I am Dr. Anjali Forber-Pratt, an assistant professor in the Department of Human and Organizational Development with a joint appointment in the Department of Special Education at Vanderbilt University, Peabody College. This is my fifth year as faculty at the college. I am a full-time wheelchair user, and I have a service dog named Kolton. I participate in a variety of tasks, including teaching, research, and quite a bit of community activism. My research areas revolve around disability identity as well as disabilities and sports. I feel fortunate to be able to bring my interests into my work and to impact the disability community.

In terms of everyday life, my disability does not affect me that much, just because it has been there for as long as I can remember. However, there are times when I encounter inaccessibility, especially to places which I have not been before. In the Nashville area, one of the biggest physical inaccessibility has been scooters blocking the sidewalks. In addition to physical inaccessibility that I encounter, there is also discrimination in terms of people's attitudes towards disability. I do, unfortunately, encounter that a lot when I travel, which could lead to my being denied a ride on Lyft or Uber because of Kolton. This is often due to a lack of awareness surrounding service animals.

In addition to being a professor and a researcher, I am an advocate for disability issues. An activist. I did not seek to be one, it found me. An activist to me, is someone



who not only stands up for your rights, but also educates others. I have been fortunate that the adults in my life gave me opportunities to share my story since I was young. From a young age, I experienced multiple instances in which I had to educate others about my disability, and I feel fortunate to have been encouraged to use my voice and share my story. In addition, I was also involved in a four-year-long federal lawsuit with my school district when I was in high school that brought me into the disability advocacy work. Through these engagements, I realized that not everyone knew the different issues that those with disabilities face and that my sharing these stories were valued.



"In addition to physical inaccessibility that (I may) encounter, there is also discrimination in terms of people's attitudes towards disability. I do, unfortunately, encounter that a lot when I travel, which could lead to my being denied a ride on Lyft or Uber because of Kolton (my service dog)."

Due to my various involvement in sports and other advocacy work both locally and internationally, I was awarded the White House Champion of Change in 2013. It was incredible for me to not only meet but be honored by President Obama and be part of a roundtable on disability policy issues. Specifically, we focused on combating the unfortunate systematic barriers to people with disabilities in achieving and maintaining employment. It was a very powerful experience for me, being the youngest in the room and seeing how I can be involved in policy, knowing my voice was valued.

I am involved not just on the federal and national level, but also on the state and constituency level. I have been on several working groups with the Department of Transportation, giving input on the needs for legislation to address surrounding air transportation, particularly with service animals. In addition to transportation, I am also very much interested in health care and the challenges that are encountered among those with disabilities. Access to healthcare is fundamentally important, especially when you have a disability, because one's health can go from bad to worse very quickly. During the Healthcare Crisis a few years ago, I called Rep. Jim Cooper's office almost on a weekly basis to ensure that the issue is being addressed, and that it is keeping the needs of those with disabilities in mind.

One of the earliest challenges that I experienced here in Nashville was accessibility at the polling booth. When I bought my condo and moved to East Nashville, I was saddened to find out that my assigned precinct was inaccessible. It was an older church, and there is a step

to get up to the sidewalk, and then there is a super steep—not at all safe—hill to get into the basement of the church where the polling takes place. But, there was no way to indicate to the polling staff that it was not safe, that I needed help. It was a very frustrating experience that I did not want to just ignore. So, as a result of that experience, I have been working with Disability Rights Tennessee to address the issue of accessibility at polling centers. When I contacted them, they were actively gathering information from individuals within Davidson County who were experiencing the same challenges.

People with disabilities face various barriers, it could be physical or attitudinal in nature and I think it is important for those with disabilities to participate in advocacy work. I feel fortunate to have had the opportunity to use my own voice in my own advocacy work and I want to encourage other young people to do the same.

You can be an advocate simply by educating others about your disability or the difficulties you face because of your disability. You can be an advocate when you vote. We can vote and we need to use it as that is the power and beauty of democracy. Disability affects all of us in different ways, unfortunately it is not until it impacts one on a personal level that it will be on the forefront of their minds. Hence, it is our duty to teach them, to tell them how it affects us so that they understand. ■

Steven



My name is Steven, and I'm 33 years old. I graduated from Next Steps, Vanderbilt's inclusive higher education program for students with intellectual disabilities, in 2012. I've been working on Vanderbilt's campus for almost eight years, currently as the Alumni Coordinator and Recruitment Assistant for Next Steps. For the last four years, I've been living with a group of people of different abilities at Our Place Nashville's Friendship House. I was the first "Friend" to move in to the house. It's an awesome model of helping with affordable housing and other resources for people like me.

Although I don't think of them as disabilities, I have two diagnoses: a stutter and a learning disability. After joining the National Stuttering Association (NSA) and going to several NSA Conferences, I love stuttering. It's a part of me. In 2018, I got to meet Nashville Mayor David Briley when he presented me with the Award for Young Citizen from the Mayor's Advisory Committee for People with Disabilities. I earned this award based on my volunteer work with Saddle Up!, a therapeutic horseback riding program. In my spare time, I love fishing, boating, reading, and learning about history.

I first voted when I was 18 years old, so it's been several years now. I voted for Obama, which was my first presidential election. I knew what he stood for at the time and his different issues, so I said, "I'm gonna vote for him" and I did. When I voted, the poll workers were very helpful. I gave them my license and registration card. I did vote on disability issues specifically, but I can't recall any examples.

My family is very big on voting. My mom wanted me to always vote. I usually vote in all the elections, not just presidential. For example, I voted for a recent transportation plan. I think it is important to vote if you want to get your voice heard and your point across. Right? I say voting is 100% right on.

What originally got me interested in voting was my involvement in Next Steps and events like Disability Day on the Hill. I have gotten to participate in Disability Day on the Hill several times, both as a Next Steps student and as a staff member with Transition Tennessee and Tennessee Works. This is an event where people can gather at the Capitol in Nashville and talk to their elected officials, like their representatives and mayor, about different issues that matter to them. Having a time to talk to elected officials is important because it helps them understand where you're coming from and vice versa. Those days were really influential in getting me to vote and talk about the issues at hand.

While working at Next Steps, I meet with students before Disability Day on the Hill to help them prepare to talk to officials about various issues. I help our Program Director create a list of Next Steps students and their representatives to prepare for

Disability Day. I've also created videos about students engaging with their elected officials on Capitol Hill with Tennessee Works and Transition Tennessee. There's actually a video online that I made by interviewing the students on how they talk with their elected officials and asking them questions about the issues. Just getting their cool responses is awesome. I think our videos are almost like lobbying because they influence some political issues.

Elected officials should get their blinders off and pay attention to the issues at hand, including the different issues that people with different abilities have. It is very important to communicate with elected officials, especially expressing your opinion on what they stand for and the different ideas you like and you don't like. Aside from Disability Day on the Hill, I have also worked on videos about employment, so that is one specific issue I have advocated for. I have never testified before a committee, but in the future I would love to testify and tell the city that they don't help our local homeless very well.

My advice to others is go vote! Google the people you're interested in, learn their platforms, stages, hobbies, where they live, what government they're part of, and just learn. Right on. Right on! ■

Albert



Very few people have the ability to gain the attention of a room full of people. Albert, at 17, does so with ease. His eclectic style—tie-dyed socks and shirt, cuffed jeans, floppy hair, and sneakers—reflect his outgoing and humorous personality. Albert is an expert in hip-hop music. Music is his world.

As Albert's mother, I know he wants to access the recreational aspects of Knoxville with his fellow peers, make connections, and even aspire to attend college. If he does not receive ongoing support from his community and lawmakers, Albert will have difficulty doing so because of his disability.

When Albert was born, he consistently had seizures, a direct result of epilepsy. Albert underwent a hemispherectomy that removed half of his brain to slow down the seizures. After the operation, he developed hydrocephalus and had shunt surgery to protect him. In time, the shunt disconnected and left Albert facing an emergency medical procedure. Albert was harmed and left in a condition that has impacted his complete mobility, has required the use of an electric wheelchair, and taken away from the independence he desires. Albert requires complete, constant, and ongoing support to live his life.

It is important for elected officials to know about cases like this to change the rules, support, and funding to make accessibility more possible. Accessibility is a major problem we face in our city. It seems like the mall and movies are the only options for fun. Where we live, there is not a lot to do and sometimes we can feel isolated. There needs to be more inclusion for kids like Albert. We need major changes in education and engagement. We need to start early. Children need to know that Albert is not contagious and that people can come up to him. Albert is just a person who needs additional help. Situations like Arthur's could happen to anyone and I wish people would not be afraid of us.

Albert is not yet at voting age, we are somewhat a dynamic duo when it comes to civic engagement. We perceive voting as a basic right and responsibility of every member within a functioning society. Voting is our voice. When voting, disability rights are a major contributor to how we make decisions and ask for change from candidates. If a candidate does not see the extensive needs of our family, it sometimes affects my vote. Selecting a candidate can be extremely challenging, especially at Albert's age, because of his inexperience with voting. We need officials who really take care of people in need.

I stay informed by reading extensively, researching, attending town hall meetings, and speaking directly to candidates. I feel prepared with facts and good intentions. Albert likes to learn from going to events, using social media, through school, and hearing the voices of others. We have spoken with candidates in previous years to discuss topics surrounding disabilities. In doing so, I noticed candidates were

focused on other groups, but not necessarily the disability population.

We have attended Disability Day on the Hill and spoken to legislators. What a busy day it was! So many people are there to meet and you go from one office to another. It was an opportunity for us to say who we are, where we are from, and how we need support. It was so interesting to share our story. On this day, we met with a representative from TennCare. The representatives helped us work out some ongoing issues we have had with traveling and the therapies Albert receives. We met a senator there and spoke to him about medical marijuana. Access to such medications can help Albert with spasticity, his seizures, and ongoing pain. If more issues like this are important to us, we will visit the Capitol again to hold these discussions. We hope for change and that candidates can help with people that endure situations similar to ours. How are legislators going to know people like Albert exist if we are not there speaking out?

Recently someone told me, "As much as you want to engage with the people in the office, it is the people in the office that will help if they want to." We would like to speak more in front of legislative bodies and get more involved in campaigns. All together we could change the laws. It starts from these stories, it starts from the people. I will look for supporters wherever they are. I need to speak to these people to support Albert and people like him. We don't want to be silent anymore. We want to put our story out there and for people to know exactly what it is we are experiencing. It is time for the elected officials and people in power to be responsible, involved, and help us where we need it most. We need people to know Albert's story. ■

Lexi



My name is Susan and I live in Decherd, Tennessee, with my husband Jim and two daughters, Lexi and Kinsey. I am the president of our local chapter of The Arc, a member of The Arc of Tennessee, and People First.

Before moving to Tennessee, we lived in Georgia, where my daughter Lexi grew up. She is 20 years old and has a diagnosis of 5p- Syndrome. Later in life, she received a diagnosis of legally blind. Her communication is profoundly impacted by her disability. She accesses assistive technology to assist her with communication and vision needs.

Lexi has not allowed either of her disabilities to stop her from following her dream of

working with animals. She graduated from the transition program at her high school, then started her own business caring for people's pets. The name of her business is Happy Homebodies. She takes care of animals while their owners are away. Her business has been running for two years.

While in Georgia, I was fortunate to participate in the Partners In Policymaking Program. This program helped us learn how to speak with legislators and get our points across in different policies, forums, etc. We were constantly in contact with legislators regarding disability issues. We still do the same in Tennessee, because we know that is where change happens. Legislators may not be informed about the different disability issues. It is our responsibility to educate others. We also participate by signing petitions and through public comments. We know our votes matter and our legislators represent all of the voters.

We also believe face to face contact is effective when speaking with legislators. While in Georgia, Lexi was in class with our State Representative's son. We would have casual conversations during birthday parties regarding issues surrounding disability needs. He would attend our local parent support meetings and supported individuals with disabilities. Real relationships are important. Our family participates in Disability Day on the Hill every year, because it shows legislators there is a population of votes available to them and they need to listen.

I believe voting is one of the most important things a citizen can do. Lexi voted for the first time this year. She was a little nervous, but we helped prepare her by discussing different candidates and the importance of voting. We want her to know she has some control over her life and those who make decisions for her life. As a family, we were unsure of how she would access the area. I was allowed to walk to the voting area with Lexi and read the candidates to her and pushed the options she verbally chose. She finished, got her sticker, and was proud of herself for voting. She was able to make her contribution and her voice heard.

During our time in Georgia, we fought to change different policies, as well as, how things were presented. I remember filling out a form while applying for the Katie Beckett Waiver. The form had a box where you had to check that your child would qualify to be served in an institution if the Waiver was not received. As a parent, that is not a box

you want to check. After several discussions, meetings, and parent comments, that wording was eventually removed from the paperwork. Sometimes the small victories are huge. Not long after that, there was a movement to remove the term “mental retardation” from the law books!

Elected officials should be educated about different disability issues, because they do not always know what life with a disability entails. For example, they may not be aware of difficulties with transportation, employment, proper education, etc. If Lexi had not blessed our lives, we would more than likely not be as aware of disability issues. However, because of her, we have a responsibility to help make a difference and educate those in our communities. It is a wonderful experience to see her world and the world of others improve as a result of increased awareness surrounding civil rights and disability issues. The goal is access to a real life of her choosing. ■



Tom



My name is Tom and I am 23 years old. I have Asperger's syndrome, ADHD, and Obsessive Compulsive Disorder. My disabilities impact my life in that sometimes it is hard for me to be calm. I can be a bit impulsive, and sometimes I can act silly in inappropriate situations. Situations that are overstimulating, such as driving, can also be a challenge for me. Even the smallest thing can bother me, and reading social cues can also be difficult. However, I am very social and enjoy interacting with others.

I am currently the Vice President of Williamson County's People's First chapter. My role is to assist the president in any way

he needs, such as helping plan events and our monthly chapter meetings. I have also been asked to join meetings with local policymakers, and I occasionally get invited to be on policy-related panels.

The first time I became politically conscious was during the 2008 presidential election. I registered. I paid attention to which candidates had an interest and care towards the topics that I was passionate about in order to make my decision. I needed help from my parents with transportation, but I did my own thing while I was there.

I try to stay up to date regarding politics, because I believe an informed constituent is

a constituent that can vote more effectively. In my opinion, voting is one of the most important duties a citizen has. Personally, I pay attention to the news and the disability community, and seek advice from my parents. Although I would like to financially help the candidates that I support, it is just not feasible for me. I do, however, support by staying involved as well as being a voice for the disability community.

I attend the Disability Policy Seminar in Washington D.C. every year. This is a great opportunity for me to interact with Congressmen as well as discuss important topics with other individuals within the disability community. At these events, I put on my uncomfy clothes and try to refrain from displaying my most childish actions, so I can be a voice for those who don't have voices of their own.

In the past, I have had experiences with policymakers that were not always positive. One year, I was talking to a Congresswoman, and she treated me like a trained monkey. She looked at my mom, smiled and winked, and said, "It's okay." Everyone in the room saw it, and I felt very disrespected. Another time I was speaking to a Congressman and he was not paying attention, just nodding along. I don't think he realized that he wasn't listening, but I called him out for it. After I said something, he started paying more attention. Even through these uncomfortable experiences, I feel it is my duty to speak up.

There are a lot of political issues I am passionate about, including health care, accessible polling places, and transportation. These issues are especially relevant for those with disabilities. Disabilities aren't "one size fits all," and it is important

that our elected politicians recognize this and advocate for the disability community to ensure equal representation.

One important issue that I advocate for is accessible polling places. We really need to ensure that persons with limited mobility can still access places within the community, including polling places. I have a friend who is in a wheelchair. Not having a wheelchair-accessible poll would be really difficult for her. I also have friends who may need help with transportation or even someone inside the poll helping them know which button to press. It's important to have an interface that is accessible for everyone.

Another important issue is public transportation for all individuals, including those with disabilities. I have been working on a transportation initiative to continue funding for the Franklin Trolley. I also feel we need more public transportation in Brentwood. Even though I live in the city limits, the Trolley doesn't reach my workplace so I have to resort to using Uber and Lyft. I can ride by myself, but I do need my mom has to help me set up the rides and payment. It would be great to be able to rely on public transportation that I could use independently.

As I mentioned, I am passionate about civic engagement and believe that voting is one of the most important rights we have as citizens. I am actively involved in the disability community and pay close attention to important issues including accessible polls, transportation, and health care. I strive to be a voice for the disability community, especially for those who are not able to voice their opinions. I encourage all individuals to stay up to date with important political topics and to make informed decisions at the polls. ■

Adelaide



My name is Rondi. My family and I live on a farm in Dickson county. I work at Vanderbilt University Medical Center. My husband and I have three children: Madeleine, who is 10; Sawyer who is 9; and Adelaide, who is our youngest at 23 months old.

Adelaide has spinal muscular atrophy (SMA) Type 1. At around 4 weeks, we began noticing that she wasn't moving much and seemed really weak. SMA happens in about 1 in 11,000 births, and includes muscle loss that leads to significant difficulties with swallowing, breathing, and moving. Most children with SMA have a life expectancy of about 2 years, due to severe respiratory

problems. Adelaide requires intensive medical support, she is very weak, and uses a wheelchair. She recently started wheeling herself, but ultimately, she will need a power chair for mobility. Adelaide is G-tube dependent for feeding and nutrition. She is a source of joy in my family's life, but our family does require quite a bit of additional help due to her intensive support needs.

One day, we saw a news story about a similar family with a child with significant disabilities who was on TennCare. The family shared that they were about to lose insurance coverage because their middle-class income exceeded income

requirements for assistance. We reached out to the news station to thank them for covering this issue and told them about our family. The very next day we had news crews contact us to talk about not being able to access the nursing care we desperately needed. The news story prompted three front page articles in The Tennessean. One of those articles was placed on a Senator's desk, and our family went to his office in person to meet him.

This snowballed into our family attending other civic engagement events like Disability Day on the Hill, and forming a group of families deeply invested in advocating for their children with disabilities. February through May, our family travelled to the Capitol to testify. We brought Adelaide to each of these meetings, which means we brought her whole ICU wagon with all of her medical equipment. It also means we always had two adults because of the Adelaide's support needs. We suctioned her during the meetings and continued to show up day after day. I think this process was very powerful to our cause and showed the legislators the challenges we faced, increasing the visibility of our needs. In the end, our legislature successfully passed a path to Medicaid that would increase access for families struggling like we have struggled.

Social media was a powerful advocacy tool. I took to advocating via Facebook by posting a one-minute video talking about why this program was important for us. I tagged every single person I knew. When we showed up to the Capitol building on Monday, we learned that legislators had received between 10,000-15,000 emails and phone calls over the weekend in response to the Katie Beckett pushback story!

The experience of having legislators actually listen to us was an empowering experience, even though it was not an easy one. I believe it is highly important to visit legislators face-to-face. It truly is much harder to tell the families of those with disabilities "no" in person. Talking to your legislator personally puts a face to your name and tells a more impactful story, compared to a phone call or email.

It is also helpful to talk to and work with advocacy groups, as the members of these groups have been in the political arena and have their finger on the pulse of current issues. These individuals are well-placed to give invaluable advice to people looking to advocate. Advocacy groups are doubly helpful because they help you paint a picture of the problem, which is really helpful to legislators and helps you gain public attention.

One person, just like Adelaide, really can make an incredible impact on the world. Although Adelaide is not yet able to talk, her voice has most definitely been heard by the legislature. ■



Peach

My name is Peach. I am a rising senior in the Next Steps program at Vanderbilt University. I am also an intern at Employment and Community First Choices. I check e-mails, talk on the phone, self-advocate, and go out in the community. I have also worked at the Farmer's Market as a bubble tea server on weekends. I love music. I play the piano and go to concerts. A capella is my favorite. I live with my parents and am an only child.

I use a wheelchair to get around. It is easy to do so at Vanderbilt because they have elevators and the hills are flat. I can't use my right hand because of fine motor skills and cannot stand up on both legs. Typing is easier for me than handwriting.

I have been voting since I was 18 years old. The first time I voted was in Brentwood with my parents. It was easy for me to vote because the polls had accommodations for wheelchairs. Transportation is important to me, so I am a committee chair for wheelchair accessibility, like having ramps on public transit. I like voting for the governor because I think they can handle important issues like transportation, especially for kids with special needs. I learn about candidates through my parents, TV ads, and speaking with politicians during Disability Day on the Hill.

My parents vote with me, but my dad tells me to vote for who I think will run our state well. I work with Disabilities Rights Tennessee, The Arc Tennessee, and People First Tennessee. We all vote. I think it's very

important for people to vote if they are at least 18 years old. It's important because there are issues where people need help. People need to know what they need, how to get it, raise their voice, and say something.

I've met with Sen. Jack Johnson at Disability Day on the Hill and have been to his office to talk about transportation. I made a list of things that I wanted to talk about. My dad helped me practice an elevator speech to make points on what I wanted to talk about. He listened to me. Since I am on the transportation committee, I hope to figure something out with The Arc and make a game plan. We also talked about employment for kids with disabilities, getting the right jobs, and asking for accommodations. I usually e-mail or call elected officials, and see them at Disability Day on the Hill.

It's important to advocate for better transportation for people with special needs. If there are steps, you cannot exit the bus. It's hard when there is no elevator. Accessible parking is helpful when there is construction. Ramps are also very helpful. I have a friend who uses a walker and has a similar disability—she wants me to be an advocate because she knows that I will go out there. Besides voting, people can be civically engaged by signing a petition. We have one for wheelchair accessibility. Know your situation and speak up for yourself when you need it—don't be shy! ■



"It's important to advocate for better transportation for people with special needs. If there are steps, you cannot exit the bus."

Cyndi



My name is Cyndi and I live in the Pikeville, Tennessee area with my husband Glen. The two of us met in my hometown of Bloomington-Normal, Illinois. We now live in Bledsoe County as we fell in love with the area's natural beauty! We have two grown sons, four granddaughters, and one great granddaughter.

I acquired polio when I was just two years old during the epidemic, before there were vaccinations. I woke up completely paralyzed one morning and spent over two months in the hospital. I attended Kindergarten at Fairchild Hall, a school located

on the Illinois State University Campus with several other students who had polio, muscular dystrophy, and physical disabilities. In the fourth grade I transferred to the Illinois State University Laboratory School, which was a private school for faculty families and where I was mainstreamed full time.

As an adult, I would learn that the intense physical therapy I underwent all throughout my life actually did more harm than good. In 1995, I was diagnosed with "post-polio," which is a new onset of muscle weakness (affecting both voluntary and involuntary muscles).

I've seen a lot of changes during my time as a woman with a disability. There was no Americans with Disabilities Act until I was forty. I know there is room for improvement even now, but this law has made a huge impact in my life for the better since I rely on a wheelchair for mobility. Life has improved, especially with regard to physical barriers. Stores, street curbs, seating areas and restrooms are more accessible since the law went into effect. However, there is still so much more that needs to be done.

A recent event that has also changed my life for the better is being crowned Ms. Wheelchair Tennessee 2019. I was actually supposed to be a judge for the contest but I was encouraged to apply as a contestant by a friend! It is "out of the norm" for a contestant to be just shy of seventy years-old but I have embraced this role and am honored to have this platform to help create positive change for people with disabilities. Looking back on my "reign" it was an amazing year with incredible opportunities I never would have dreamed possible.

In regard to civic engagement, I have always been involved but my position as Ms. Wheelchair Tennessee opened doors to talking with our lawmakers. Recently, a woman reached out to me on social media about the fact that there was no automatic door at the Bledsoe County Court House. One rainy day she was stuck outside, getting wet. I called the Mayor's office and set up an appointment. Shortly after, I sat down with the mayor to express the concerns of the residents. The automatic door was installed within a couple of weeks. The city knew of the need and had intended to automate the door but ran out of money when they upgraded the rest of

the building. I stress to others with disabilities the importance of advocating with city officials. In my experience, lawmakers want to help but need to be educated to really understand the issue, find funding, and make it happen. If we do not make them aware, it will be ignored. This can be a slow process, but I keep the conversation going to ensure that it will happen.

I use a power wheelchair and it is important to me that I have the ability of active height, active reach, and the standing feature. This means my wheelchair will extend upward and outward depending on what I need to do. With these capabilities I am able to speak to someone at eye-level, reach shelves, get into high beds when traveling, and otherwise do things I am not able to do in a regular power chair. I am passionate about advocating for these wheelchair features to Medicare and Medicaid and help them see that these are essential benefits. As of now, these features are considered luxuries. I strive to make our lawmakers understand that these capabilities make it safer for people in wheelchairs and promote independence and a higher quality of life. I am hoping to visit Washington D.C. soon and meet with Medicare decision makers to make this a reality!

Overall, I strive to make our legislators aware that barriers strip those with disabilities of our independence. We fight so hard to live a fulfilled life like everyone else and in a split second we can be reminded that it's not that easy. We need our lawmakers to fight to remove these barriers for us. We need our lawmakers, government officials, and business owners to care and care enough to make the change. ■

About the Photographer

Jen Vogus is a photographer, educator, and parent advocate. She is also the founder of AbleVoices, a nonprofit organization that teaches photography to individuals with disabilities as a means for self-expression, empowerment, and advocacy. Jen is a graduate of the Tennessee Council on Developmental Disabilities' Partners in Policymaking Leadership Institute and a board member of The Arc Tennessee.

Jen became passionate about photography when she began taking pictures of her son who has intellectual and physical disabilities and does not communicate verbally. She photographed the things he was doing and what he enjoyed so he could share them with peers and teachers at school. It gave him a voice; sharing his interests and helping others realize all that he was capable of doing. The power of these photographs made clear to her their value as a tool for communication, empowerment, and advocacy. Jen's love for the technical, artistic, and humanitarian aspects of photography soon developed and has been a true passion ever since.

Collections of Jen's photographs have been exhibited at the Vanderbilt Kennedy Center, The Parthenon Museum in Nashville, TPAC (Tennessee Performing Arts Center), and Photofusion Gallery in London, England, among other venues.

Learn more about AbleVoices at www.ablevoices.org and follow along on Facebook and Instagram (@ablevoices). Contact Jen directly at jen@ablevoices.org.

About Us

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

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. vkc.vumc.org/ucedd, (615) 322-8240 or toll free (866) 936-8852

The Arc Tennessee

A statewide advocacy organization that empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime. thearctn.org, (615) 248-5878 or toll free (800) 835-7077

Photographer Assistants

Bryant Welch is a recent graduate of the Franklin High School Transition program in Franklin, Tennessee. As a participant of AbleVoices, he discovered his passion for storytelling through photography. Capturing scenic landscapes, majestic landmarks and finding unseen beauty in his work is deeply gratifying. Bryant hopes to eventually gain employment in the field of photography.

Ashley Shouse is a recent graduate of the Ravenwood High School Transition program in Brentwood, Tennessee and works in the after-school childcare program at Sunset Elementary School in Nolensville. Ashley became involved with AbleVoices during a Ravenwood High photography project and also participated in the AbleVoices summer photography club. She especially loves capturing sunsets at the peak of their beauty and her dream is to become a professional photographer.

Kyler Grissom is in the ninth grade and has an insatiable interest in photography. He is a peer mentor with AbleVoices and has a great appreciation for wildlife and nature photography. Kyler aspires to one day be a National Geographic photographer.

Eric Wilson is an avid photographer and likes to take pictures of everything! He started out taking pictures of mostly people, such as family and friends. But as Eric's eye has developed, he now takes pictures of anything that interests him, such as objects or shapes. Eric has worked at Publix as a bagger for over ten years and is dedicated to his job. Eric participates in the AbleVoices summer photography club and wants to keep being a photographer, taking pictures of things in a different way.

Sami Zinni is a recent graduate from Nashville State Community College and has an Associates degree in Web Design. Sami's interest in photography began in her NSCC Basic Photography class and continues as a participant in the AbleVoices and also as a board member. She has a side business as a neighborhood dog sitter and walker. She truly loves dogs and is referred to as the "dog whisperer" among her clients.



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