Hidden Voices Ep. 2 - Adaptive Technology & Service Animals

John McCarty 0:08

For the first 20 years of my life, I had only behavior as a way to communicate.

Shannon M. Turner 0:21

Welcome to Hidden Voices, where we are uncovering stories of Georgia’s citizens who have developmental disabilities. I'm your host, Shannon M. Turner.

Shannon M. Turner 0:43

What are the trends and issues that people with disabilities, especially developmental disabilities, face today? If you missed Episode One, I encourage you to go back and listen as it's a great introduction to things like, what is a developmental disability? And the landmark national case Olmstead which started here in Georgia and set the precedence nationwide for how people with disabilities live their lives today.

Shannon M. Turner 1:06

Today we're going to meet three people at three phases of life, with three very different disabilities: autism, cerebral palsy, and spinal cord injury. In each case, these folks are able to communicate and live more independent lives thanks to some amazing adaptive technology and support animals.

Shannon M. Turner 1:27

Okay, so back in the day, you may remember, it was totally fine to leave your kids in the car. Like people did it all the time, and my dad had a job where he would frequently have to pick us up from school or what have you, and his job was not done and so he would leave us in the parking lot at Walmart or a hospital while he went and did things. We had this new car, it was a Mazda CRX, and you could fold down the backseat to get into the trunk. So, my sister and I were sitting there on this fairly mild day, it wasn't too hot or anything. We didn't have anything to read, and we got kind of bored. And I at the time had seen a series of different TV shows and movies where people had been kidnapped and thrown in the trunk of a car, and I always thought that seemed fascinating and terrifying and just really interesting to me.

Shannon M. Turner 2:19

So, as we're sitting there, bored to tears, I looked at my sister and I said, “I'm going to climb in the trunk of the car, and I'm going to show you how to let me out, I'm just going to sit back there for about, I don't know, 30 or 60 seconds just so I can see what it feels like. And I'm going to knock and I want you to let me out.” And so, I walked her through the process of clicking the thing and letting the seat down over and over and over again and made her do it like three times. So, I got back there and I felt what I wanted to feel which was the darkness and the heat, and then I knocked. And she had immediately forgotten how to let me out. So, I said, "try again, remember how I showed you." She said, "No, I can't do it." And I was so upset, then the panic started to set in, and it got hotter. We both started to cry. And then we started to knock harder on the outside of the car. And obviously, since I'm sitting here telling you this story today, everything worked out fine. Someone walking by the car heard us crying and screaming and knocking on the side of the car, and they let me out. And then they went inside and told my dad, so, we got in huge trouble. But I'm telling you that because for those brief moments, I was able to experience what it's like to be really stuck, to not be able to get out of a situation in the same way that the people that we are about to meet know what it feels like.

Shannon M. Turner 3:49

These folks, either because of an injury or a birth injury or something about their body has kept them inside unable to communicate or move for a very long time. And then because of whatever reason, they've found their way out. The ability to communicate has opened a door for connection with others, and opportunities to live more integrated in society. But I want you to imagine this too, what if it lasted an hour, a whole day? What if it lasted 17 or 18 years? Thousands of people live every day like this, and if the dread you felt in those few moments, like I felt, they feel like a lifetime. And yet, for the thousands of people who live in this reality, they are also living intensely rich inner lives. They are writing essays and poems, debating politics, and formulating all sorts of opinions. They're even coming up with snarky comments that you just can't hear. And then one day, a connection happens, a bridge is built, and that bridge is like the knock on the car, and that is technology. And now all of that stuff that exists in their secret world comes out, and you know just what you've been missing.

Kyleigh Kramlich 5:07

One person changed my life, his name is Bach.

Christine Kramlich 5:11

So, Bach met Kyleigh at camp, and Bach as a device user himself, and Kyleigh really at camp with Bach discovered the power of her voice. That it was power, not just answering mom's silly questions, but that she had something that she really wanted to say.

Shannon M. Turner 5:31

We're in Lawrenceville, about 35 miles northeast of Atlanta in a wooded neighborhood speckled with solid looking houses that fly flags denoting the turning of the seasons fall, winter, spring in the heart place of suburbia. And this is where we find Kyleigh.

Shannon M. Turner 5:59

Kyleigh Kramlich is 16 years old, she has significant cerebral palsy that affects both the way and the speed at which she communicates. But backing up - when Christine, her mom, was pregnant with Kyleigh, she had something that was called a uterine abruption, which means that for an undetermined amount of time Kyleigh was outside her mother's womb, but she was still inside her mom's body. It's a really dangerous situation and both of them almost died. Her CP makes her body stiff, all over, and while she can eat, she loves to eat in fact, she uses a G tube which is an external tube surgically placed in her abdomen to help her get enough nutrition. Kyleigh's home is a full on assistive technology wonderland. When you enter Kyleigh's World, and it says that right on the wall, there are paper skeletons hanging off the lights because Halloween is her favorite holiday, like she celebrates it all year long. Kyleigh does not use verbal communication but communicates through a device attached to her power wheelchair. She moves her eyes back and forth to symbols on a tablet and it dictates for her.

Kyleigh Kramlich 7:08

Cat. That is my cat.

Shannon M. Turner 7:09

It's important to know with both Kyleigh and John, whom I'll tell you about next, we've edited things way down. For every sentence you're hearing, it's actually taking them three to four times longer to articulate what they have to say. What Kyleigh and John are trying to say is valuable and it's worth the work, from you. They're giving an enormous effort and they're paying attention to you too. And they're funny.

Christine Kramlich 7:33

What's the first thing he taught you how to say?

Kyleigh Kramlich 7:37

Doo, Doo, Doodoo. [laughs]

Shannon M. Turner 7:42

This is the story of how Kyleigh is making the world, her world. Kyleigh's mom calls her communications device, The Talker, but Kyleigh likes to call it Sunshine because it has a bright yellow frame around it. These days, Kyleigh's world also uses Alexa so she can turn the lights and TV on and off,

Kyleigh Kramlich 8:01

Alexa, living room on.

Shannon M. Turner 8:03

Sometimes Kyleigh is better at telling Alexa what to do then her mom is which causes no end of hilarity between the two of them. But if someone comes along and physically turns off the light switch, Kyleigh can no longer tell Alexa to turn on and off her lights. Her bedroom door is robotic and is controlled by her device, Sunshine. When we visited Kyleigh, she showed us how it works and more importantly, why it's important for her to be able to control the door.

Christine Kramlich 8:31

So that would be open and if we tell it to close. [cat meows] Wow. [laughs] It’s like nope, can't come in kitty kitty. No coming in for you.

Shannon M. Turner 8:47

Make sense, she's a 16 year old girl. She doesn't want her parents to just walk in on her unannounced at any time. Then there's the elevator created out of a renovated closet that brought in a huge increase in Kyleigh's living space. She uses it to get from the first floor to the basement into Kyleigh's World.

Kyleigh Kramlich 9:06

She had a table.

Shannon M. Turner 9:12

Listening to Kyleigh use her device, you can tell when she starts to get tired. Her eyes don't land on the right symbol, so she starts to say words that she didn't intend. Words like table or hamster pop up, glare on her screen can also keep her eyes and the symbols from properly connecting.

Shannon M. Turner 9:31

Alexa must have been like a game changer for you.

Kyleigh Kramlich 9:34

Yes, she is amazing. My eyes are tired.

Shannon M. Turner 9:40

Kyleigh recently got a new chair and when it arrived, it was missing the most important button, the one she uses to move herself around. The one that enables her independence. Whatever the reason for this mistake, a worker having a bad day or a lack of quality control processes, when you have a disability the stakes are just so much higher than if someone made a mistake while making your coffee. Mistakes made that affect people with disabilities can have rippling effects that last months or years and take enormous efforts to correct. Other mistakes can cut deeper though. At Kyleigh's old school, she had to ride the bus over an hour one way to attend a school that was actually designed for students who have mobility issues, and she hated it.

Christine Kramlich 10:28

Do you want to tell them why it is that you didn't like the school that you went to and why you wanted to leave?

Kyleigh Kramlich 10:34

Kids were fighting and saying bad words.

Shannon M. Turner 10:37

But she didn't just hate it, her parents felt she was languishing. Not being pushed to use her brain the way they knew she could. Then one day, the breaking point came.

Christine Kramlich 10:47

One day she came home from school on the bus where she is the sole child who rides the bus and her knuckles were very bloody and it was smeared all over the window, looked like a crime scene. And that was the last straw for me. Kyleigh's body doesn't always cooperate with her, so there were some bolts next to her on the bus, and she just was running her knuckles over it repeatedly, repeatedly, repeatedly. So, by the time she came home, all of her knuckles were just torn open, and it was really, it was a really bad day. And there was an aid on the bus, and just Kyleigh, and a driver. And so, you would think that, between two adults and one young lady that she would be safe and taken care of and when I saw that she wasn't, that was not okay with me. We had a choice, we could use money for a lawyer or money for a private school and we opted to go the private school route. Now we're not just surviving there, I would say you're thriving, don't you think, Kyleigh?

Kyleigh Kramlich 12:02

Yes, I love it.

Shannon M. Turner 12:04

Kyleigh is really flourishing at her new school and her ability to communicate is the vehicle that makes this possible. This technology was not available for someone like Kyleigh 20, 30 years ago. It not only makes a difference in how Kyleigh communicates, but in the relationships she's able to build. I asked Kyleigh what it was like before she had her device. And she said, it was really hard, and her mom Christine said, “See that, that right there, words like ‘really’ we didn't have that nuance before.”

Christine Kramlich 12:36

When Kyleigh really got her device, that's when her personality could come through. Things that she could communicate on a basic level were basic. But when she can say "that boy is so cute," and when she can say things like, "because," to me, those are such powerful things to be able to say. Now she can say, "I love you because,” and I love you has been there but the ‘because’ is what really makes my heart smile because now I can hear what's really in her, in her brain and in her thoughts.

Shannon M. Turner 13:23

Communication is game changing, but it's not a promise of an open door. Kyleigh school is challenging yes, but the future still lives in hopes and dreams. Now, 45 minutes away from Kyleigh, lives John McCarty, who has autism, and he lives in Roswell, Georgia. He was ready to go to college, so he had to take the GED, but no one would let him take the GED because he needed someone to sit right next to him and help him communicate his answers.

Shannon M. Turner 13:52

For the first 19 years of his life, John was unable to communicate with the outside world. Now, in his mid 20s, a lot has changed since he's been able to communicate with others. Like anyone, John was a curious kid. He craved exploring and connecting with family and friends, but misconnections ruled the majority of his efforts. There was the time he wanted to learn how to bake. So, he went over and took the mixer out of the pantry, but no one knew what that meant. John spent every morning sitting by the radio listening to NPR, his mom thought that he just liked the rhythm of the sounds of people talking. But he was listening.

Shannon M. Turner 14:31

Frustration and distance were the fire for a communication method search, and they did finally find a way to communicate. John and Joan went to a training together where they learned to use a simple letter board. Even though the board is a simple tool, John had to learn how to control the muscles in his arms to point at letters. And then with enormous patience, they began the process of using the board to communicate together. John refers to November 8, 2014 as his Independence Day. It was during this training when John started to be able to truly speak for himself. And Joan, through that training had to learn how to turn over the lead to John, like letting him drive.

Shannon M. Turner 15:14

So, this one night while they're out to dinner during the training, she says, "All right, John, what do you want to talk about?" So, he starts spelling, and N E T I. And she's learned in the training if he starts getting off on the spelling of a word to just reset the board and let him start over again. N E T E, she resets the board. N E T A. Then it dawns on her. Clearly, he knows what he's trying to say that maybe he doesn't know how to spell it, or maybe I don't. So, she gets out a piece of paper and a pencil and she just says, “just go, just start saying what you're trying to say, and I'm going to write it all down”. And this is what she does today, actually, when he has a really long passage of things to say. “Just say it all I'm going to write down and we'll figure it out after you're done.”

“Netanyahu is in the news today.”

Joan looked up, and that was the first time she realized how much of her son she'd been missing in the first 20 years of his life. Now there are only a handful of people who are trained to use the letter board to help John communicate. John explains the process as Joan reads from John's board.

John McCarty 16:25

At this time, the spelling I do is only possible through a communication partner who has to be trained. The way to think about it is like a dance. To be a proficient dance team, both partners need to have a significant amount of training and practice and need to practice together. That's just how it is with me and those who act as my communication partners. Because it is a long and intense process, I have few communication partners.

Joan McCarty 16:55

Mom, Dad, he has one brother, and three sisters, so that's six people. So, Austin is a partner and then his cousin. So, what's that? So, 6, 7, 8, 8 partners.

Shannon M. Turner 17:10

Even though they can communicate now, the journey is not over. In fact, the communication board set them on a new, more difficult journey. Joan says that a lot of people don't trust this method. She says they've even referred to it as voodoo. Along with the board carrying suspicion as to its actual authenticity, using the board is physically exhausting for John. Joan reads and explains the process.

Joan McCarty 17:34

It's slow and physically exhausting, but it works for now. Sometimes very rudimentary things work best. Of course, they see this and want to make it something else. We've tried a lot of different things. We've tried numerous, Dynavox, we've tried typing, like talking keyboard, we tried picture systems. We’ve tried it. He was 19 years old when I got to this, so it wasn't like we never tried anything. But we tried a lot of different things and they never worked. We made the wrong assumptions, and the assumption that this makes is that it's his motor. There's nothing wrong with anything but his motor. The fine motor that’s speaking is the fine motor capability of your brain, and so your gross motor is easier to train. So you just train your gross motor to point at these things. This is what Pearson’s not getting. I can't put it there, so that he can point because he sometimes needs the prompt. I need to take that like this, and put it back, that's a prompt. I need to go like that, put it back, it's a prompt. I need to say “go, you got it.” Those are all prompts. It’s not that he doesn't know what his next letter is, it's that his body can't get him there. And as you'll notice, the more we do it the more exhausted he becomes, the more I have to prompt.

Shannon M. Turner 18:58

So, this partnership, this dance that John does is sort of like if you spoke a really unique language and only eight other people in the whole world knew how to speak it with you or translate it for you. The fact that not everyone supports the partnership it takes for John to speak it's like society is again disabling John. Primarily, once they figured out that John is a pretty heady guy, once he was able to express himself, of course, he wanted to go to college. But he kept getting turned down to take the GED because it would require someone else to be there to help him take the test. At one point, they were ready to file a lawsuit. In the end, John has decided that not attending a post-secondary education program worked out for him, because a whole world of experiences has opened up for him. He's being asked to speak all over the state. He's got a fellowship, Joan reads:

John McCarty 19:52

I have been on an unexpected journey. The GED thing didn't work out, that's the good news. I have spent the last year getting paid to present about my life. I was just awarded a SARTAC fellowship to present about the supported decision making, which is an alternative to guardianship for people with intellectual and developmental disabilities.

Shannon M. Turner 20:17

John continues to explore supported decision making and how to advocate for others like himself.

John McCarty 20:22

It was then that I started to realize that my life was about to become a journey filled with more hope than I had ever dared to dream of. I have freedom to have control over what happens to me.

Shannon M. Turner 20:37

So, what's next for John? When John and I first met, it was a little more than a year ago, and the first thing he said this time was "you would not believe how much my life has changed in the last year." So, as I was getting ready to go, we were reflecting on how much his life could change in the next year.

John McCarty 20:54

You know, it's like if you just think about where we were a year ago, just who knows what I'll be doing.

Shannon M. Turner 21:04

Now we're going to head due south in Georgia to Thomasville and we're going to meet Jake Ricks. When Jake was 15 years old, he went for a swim in a nearby creek with all of his buddies. It was a hot summer day in July, just two weeks before his 16th birthday. He already had his car in anticipation of getting his driver's license. He felt invincible. He says, “I dove into the creek, like I’d done with my buddies so many times before.”

Jake Ricks 21:31

I was just swimming at creek with a bunch of buddies and dove in, and landed on top of my head just hit wrong and shattered C5, my C35 vertebrae in my neck, and it paralyzed me from the chest down, so I’m quadraplegic.

Shannon M. Turner 21:44

So one thing that's interesting about the way that Jake's life worked out is that he's pretty sure he wouldn't have gone to college if he hadn't had his accident.

Jake Ricks 21:51

Things have had to happen in life and I'm glad I went to college, I loved the experience and figured out I was a little bit smarter than I actually thought I was anyway. [laughs]

Shannon M. Turner 22:00

Jake has made a fully independent life for himself where he gets out and hunts, helps to take care of his family's rental properties, and participates in his community. Some people even call him the mayor. He works for an organization called Lives Without Limits, which helps other people with disabilities get outdoors and do all sorts of things like hunt and fish. As Jake will tell you, they also help people make adaptations to their homes and vehicles.

Jake Ricks 22:26

Yeah, it's called, Lives Without Limits. We were actually part of a national chain back in 2008, was when we first got started. My boss that I actually worked for her in a therapy company whenever she got me interested in hunting and stuff again, which I had done some with my dad. My dad was, was really inventive and really, really resourceful when it comes to that kind of thing. I grew up dove hunting and deer hunting in South Georgia. So, he made me a rig, my first rig that I used to shoot a shotgun with and everything so. She wanted to, you know, start something up so we can take people with disabilities on hunts. There's a lot of places to hunt here in South Georgia. So, just kind of work out that we would, you know, have places donated and people would donate, and then we since also ventured out into doing things like building wheelchair ramps for people on their houses. We partner up with Habitat for Humanity with that here in our area, and also since got into helping people with vans. We've had several vans donated to our organization, and then we could get those vans retired or fitted to somebody else's disability and been able to put it right back in the community.

Shannon M. Turner 23:27

One of the things that makes Jake's life most possible: Ollie. Ollie is Jake's support animal who came to him through a program called Paws with A Cause.

Jake Ricks 23:35

I got him in December of '08 actually. Haven't slowed down much, but yeah, he's a he's a really good dog, a really good companion. Basically, anything I drop he can figure out a way to pick it up if I need him to. Man, you'd be surprised, you never know when you get in a tight, you know. I mean, he's actually helped me quite a few times. I've dropped like my cell phone in my van, and if you can imagine the crazy scenario, like your door getting stuck or something in the van and then you're not able to, you know, get out or something and need to call somebody. And then also, he knows how to open and close doors, hold the door while I'm able to pull through it. He's certified legal to go anywhere with me, you know, just like a seeing eye dog, it’s basically the same certification they have. So, he's a really amazing animal, though he really is. Paws with a Cause is a really great program, and I didn't have to pay anything for him. He always loves to go, he's always ready to go and stays right there beside me whatever I'm doing.

Shannon M. Turner 24:36

Now, we've heard from Kyleigh, John, and Jake about how assistive technology and service animals made their lives fuller, but these types of accommodations are expensive and access to them can be limited. Now let's talk about how people with disabilities actually acquire the freedoms that come with assistive technology. One of the things we'll come back to over and over in this show is that Medicaid waiver. Medicaid waivers are the thing that help people live independent lives out in the community. Problems accessing waivers start from the very beginning. For example, as we learned from Episode One, it's problematic that they're called waivers in the first place, because funding is initially directed toward keeping a person with a disability in an institution.

Jake Ricks 25:22

Anytime somebody has a catastrophic injury like I've had, or even a lifelong disability, it's all about quality of life as far as support systems and programs. You know, these kinds of programs that are in place, you know, we hear about budget cuts everywhere and everything, and that definitely needs to be in an area where we don't need to do any of that, you know, in my opinion. In all honesty, you know, a lot of people some I mean, some people even with my type injury, could end up, you know, without these programs may end up in a nursing home, which would end up costing the state or costing, you know, the government way more money than what it does now, it just makes sense that these home, that these homecare programs are in place and help take care of people because most people want to stay home anyway. You know, people want to be able to be in their community and independent and anytime there's programs that can help keep somebody in the home is definitely a good thing.

Shannon M. Turner 26:14

Because she's still a teenager, Kyleigh has the Katie Beckett waiver, which is a program that was specifically created to help parents take care of children who have extreme medical and physical needs. As soon as she's 18 though, she'll need a Medicaid waiver in order to be able to get out of her parents’ house and live independently. Some people start applying for Medicaid waivers for their children when they are still very young because that's how long the waiting list is. There are currently 6,000 people in Georgia on the wait/planning list. John does not currently have a Medicaid waiver and that's one of the reasons he is still living at home at 23. With a waiver, it would really help him and his parents so he could get out of the community on his own, perhaps train other people on the letter board and not have to rely on his family to communicate as much. Jake has the ICWP - Independent Care Waiver Program, which helps people who tend not to have intellectual disabilities. These are people who don't need as much support to get out into the community or who wouldn't need say, a job coach with the things that they very much need to live independently.

Jake Ricks 27:20

You know, I wouldn't have the independence I have and the life I'm able to have if it wasn't for that. I'm actually under the Medicaid program called Independent Care Waiver in Georgia. It pays for some of my nursing care and stuff like that. I mean, if I didn't have nurses to help me get out of bed every morning, I wouldn't be able to do anything I do, you know. It pays for some of my medical supplies every month and then it also pays an agency that pays for nursing care to come into my house. You know, help me get up, personal hygiene items, take a shower every morning, and then also help me get into bed at night. I'm pretty independent once I get in the chair, but as far as you know, in and out of bed, things like that, I definitely have to have help with it. And without that help, I mean, that burden would be on my family, and I mean I just wouldn't be able to, you know, take as good of care of me as I get now, because of programs like that I'm able to, you know, that's why I'm able to do what I do.

Shannon M. Turner 28:10

Once he's up and dressed and on his way, he's a completely independently functioning human until nighttime rolls around. Thanks to Ollie's help, of course. Assistive technology and service animals are like the hammer and screwdriver in some people's toolbox of support. And in some cases, make a way for connection and communication to happen at all. These assisted mechanisms need investment. Wouldn't you want access if it were you who needed to speak? Once a person has the tools to speak, you never know what they might say?

John McCarty 28:41

You may think I'm just another pretty face, but I'm going to make a real difference for people with disabilities. [laughs]

Shannon M. Turner 28:53

I think you’re right.

Shannon M. Turner 28:55

Join us next time as we explore the importance of advocacy in the lives of people with developmental disabilities and learn about an exciting program that sets the state of Georgia apart: the network of parent mentors.

Shannon M. Turner 29:17

This episode is dedicated to the memory of Dawn Alford, the Public Policy Director at GCDD, who sadly passed away during the time we were working on this series. As a tireless disability rights advocate for seven years at GCDD, Dawn moved the needle toward creating opportunities for people with DD in all aspects of their lives. She had a personal passion for canine assistance. Along with the other great organizations we mentioned in this episode, please check them out as well at canineassistance.org.

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