Hidden Voices Ep. 3 - Parent Mentors & Advocacy

Shannon M. Turner 0:00

Yvette, how do you define advocacy?

Yvette Pegues 0:03

My definition of advocacy is just, gosh, making a way for yourself in the world and bringing others with you, and whether that's physically, mentally, emotionally or if that's kind of more socially or politically. For me, I would just say getting in the way and making your needs known.

Shannon M. Turner 0:30

Welcome to Hidden Voices, where we are uncovering the stories of Georgia's residents with developmental disabilities. I'm your host, Shannon M. Turner.

Shannon M. Turner 0:53

Everyone's got an origin story. Think about superheroes, they have origin stories for how they got their superpowers, but everyday people have their stories about what got them involved in a specific issue. What galvanized them, gave them strength, kept them going. For people with DD some areas in their lives call for advocacy to even function in the way they do for people without a disability. Yes, there's the all-important Medicaid waiver, but the need for advocacy starts so much earlier than that in a person's life. Are there integrated classrooms for people with functional needs in their school district? Do their families have the support and training they need? Do they have access to all of the medical supplies they need? Are they isolated? Or are people advocating for them to be fully integrated into the community? Today, we're going to hear about the amazing network of people with disabilities, their parents, and caregivers who have become strong advocates across the state. We'll hear about what can happen when you learn how to make the system work for you, or if it's not working for you, you work on making it work better for everyone.

Shannon M. Turner 2:01

I'd like to introduce you to my co-host today, Yvette Pegues. Yvette is a leader in the disability rights community, she herself has a developmental disability. Yvette had a career, was on track to receive an Ivy League education, she was a mom of two young kids. Everything was going along at this fast pace until she reached the age of 30. Then in a pretty quick succession of events, everything went sideways. Let's listen in as she tells us some of her origin story and how that turned her into the advocate she is today.

Yvette Pegues 2:34

My name is Yvette Pegues. I am the co-host for Hidden Voices, and today I'm talking about my having multiple disabilities. My disabilities range from mobility being in a wheelchair to cognitive, intellectual disabilities. And so, as an advocate, I fight for inclusion. Inclusion for those with disability difference in diversity, to be in the workplace, in the marketplace, in schools and part of the technology that is being created to support our entry into communities where we would otherwise deal with architectural and attitudinal barriers. My condition is called Arnold Chiari malformation. I have type one, there's like three different types. I didn't know I had it until I started having paralysis on the right side, and I went into emergency and I was an engineer at IBM traveling, was kind of on my way to getting this amazing college education that I had been praying about at Harvard. And my body started changing and after the emergency room visit, they said that your brain is falling into your spinal column because of a condition that causes a lot of swelling, it causes a lot of motor issues. And you need to redirect the CSF fluid in your brain to other parts of your body to keep it from pressurizing. So, it was basically like my head was a dam that was about to blow. So, I went into what they call a “decompression surgery” and that's literally what it does: it’s just moving things around, and taking bones out of my spinal column to make room for that fluid to pass through. And during that surgery, I was told that I had either a spinal seizure or some type of spinal dysfunction, and so I walked in and never walked back out. So, my life changed overnight, I couldn't go back to becoming an engineer. I couldn't take advantage of this fully funded scholarship to become an education leader, and I couldn't talk. There were so many things in that moment that I could do before walking into the operating room. The beauty is that I did get off the table, and because of my faith, the question wasn't, “Why me?” The question was like, “Okay, what now?”

Shannon M. Turner 4:39

Even though Yvette's disability didn't come on until later in life, technically it's still considered a developmental disability because it relates to a previously undiagnosed birth defect. These days, Yvette is involved in advocacy in a variety of capacities, and a lot of times she says her best advocacy is about helping people know what already exists through organizations such as Disability Link.

Yvette Pegues 5:04

I work alongside Disability Link in my effort to provide resources for others, because I don't think we need another resource organization as much as we need a map. ‘Cause the services are out there, I think federally, locally, and even nationally, there are resources available. I think the hardest part is putting them together, as opposed to just finding yourself kind of going around in circles.

Shannon M. Turner 5:27

One thing that sets Yvette apart from the other people in this episode is that she herself is the person with a disability. Our next two guests are parents of children with developmental disabilities. Yvette talks about how little understanding and advocacy there is for people who are parenting when they themselves have a disability.

Yvette Pegues 5:44

Being a parent, or parenting with a disability is not an area that's as supported as parenting a child with a disability. When I'm the patient and the advocate with the responsibility of being a wife and a parent, I now have to take my own child's temperature on a regular basis and how do I do that cognitively? And that disability didn't just happen to me, it happened to my entire home. It affected my marriage, it affected my parenting, affected me professionally. So, there was really no one person at any of those stages to say, “Yvette, here's what you do next. Here are some of the options.” Advocacy is a language, it's a culture, it's cultivating culture. It's a need. It's a purpose. And it's so many things that don't fit under the dictionary definition of it, that as I look back, I feel like it was just one big black hole that needed advocacy.

Shannon M. Turner 6:36

The next two families will hear from also experienced that black hole. The void of advocacy in the parts of the state where they lived, and into that void, they stepped forward with resilience and leadership.

Jerry Grillo 7:00

My son is a constant loop in my thought track. My son is the boy you can hear from outside the house or from the other room, making sounds that seem to have no form. My son is quiet, sometimes for hours at a time. My son spends most of his time inside, in his wheelchair or on the floor, watching movies, listening to music or stories, playing with me. My son is the boy with clenched hands held up in the air as if in protest, tight hands that close like vise grips because the part of his brain that says, ‘let go’ is on sabbatical. My son stands out in a crowd, even though he can't stand by himself. My son's diagnosis doesn't define who he is. Everyone is different and should be valued for their individuality, including people diagnosed with spastic quadriplegia cerebral palsy. My son sometimes has scratches on his smooth and brilliant face, some of them fading some of them fresh, because he can't quite control his hands, and because his fingernails often are really hard to trim close with those clenched hands. My son has a smile with no strings attached, a gigantic smile for you and especially for me whenever I enter his space, because my son inexplicably hasn't tired of his old man yet.

Shannon M. Turner 8:21

Now 18 years old, Joe Grillo lives in the small town of Sauttee Nacoochee, a town located in the lush, beautiful mountains of Northeast Georgia. He has cerebral palsy and spastic quadriplegia. He uses hand motions and sounds to communicate. Jerry works for Georgia Tech and is a writer, he keeps a blog about their lives. The words you just heard at the top of this segment were from a 2016 Atlanta magazine article Jerry wrote about his son and their lives together. Jane was a writer in her own right for a long time starting out her career as a journalist. You'll find in their story how those skills to investigate and articulate lead them to be poised to advocate, not only for their son, but for others as well. Jane tells us a little bit of Joe's birth story, which for their family was the first place of advocacy, right down to deciding who they would let into the neonatal intensive care unit.

Jane Grillo 9:17

Joe was a surprise before he was even a surprise. I mean, when we found out that we were having Joe, he was a surprise. [laughs] I just never felt good, like I felt fabulous when I was pregnant with Sam. We have a daughter, there's 14 years between our kids so I anticipated that I would again feel fabulous, but I did not. I was exhausted and tired. So I was about to go for my six month when they do the glucose test and all this stuff, and went into labor like three days before that appointment. So I was having people come in to visit and bring flowers and all this stuff, and meanwhile I was trying to grasp what was going on with this little two pound and a half ounce baby that was born at 26 weeks, and I didn't really even understand about prematurity - I just like couldn't even grasp all of that. So it wasn't like when people would come to visit and Joe was in the NICU, you know I sort of had to learn early on how to prepare them for what they were gonna see, and I started categorizing, like who could go see him and who couldn't based on if they could take it or not. So I had - that was, I guess, the beginning of my advocacy. I had to start figuring out how to dose people with the information about what they were gonna see and who Joe is, and almost take my whole maternal feelings out of it. So, 77 days in the NICU is a really long time and he was the smallest and the most fragile of all the babies and the NICU for a long time.

Shannon M. Turner 11:09

You might think from that long hospital stay the Grillo family would have emerged with a mountain of medical debt, but Jane told me that they were incredibly lucky to find the Katie Beckett program just after that.

Jane Grillo 11:22

Well, thank goodness for the Katie Beckett waiver. [laughs] Katie Beckett is named after a family, a young woman who had some significant disability and her parents fought to have a new Medicaid eligibility for people with significant levels of disability to stay in their home. Because before Katie Beckett if you wanted to be on Medicaid, you would have to live in the hospital or a nursing home, but Katie Beckett made it possible for people who don't meet income eligibility. In other words, we made too much money to qualify for straight Medicaid, but our son’s conditions were going to be so cost prohibitive for a middle class two working parent family that we needed the secondary support. So, we have regular insurance, and then Katie Beckett is secondary.

Shannon M. Turner 12:25

The place where families encounter the need for advocacy is often right away after the birth of a child with a disability or at the point of diagnosis. The need for advocacy continues quickly after that with finding, obtaining, and paying for the right medications.

Jane Grillo 12:42

I started going to all these places, so talk about a crash course in advocacy, right? Start with medication and insurance. Joe had this thing called infantile spasms, which is a kind of seizure. Like the medication for that the little tiny bottle was $2,000, and insurance wouldn't pay for it. We finally did get it and right around the time when we got approved for the pharmacy to get the meds for us, we got approved for Katie Beckett. So, it just kind of clicked into place.

Shannon M. Turner 13:20

Yvette and I talked about this. Can you talk about what your vision for our system of medication should be?

Yvette Pegues 13:27

My experience is that industry is about the stakeholders and not about the people who need the medication. It's not about the patients, it's more about getting the most profit.

Shannon M. Turner 13:38

And isn't it interesting that you don't see the people as the getting and receiving the medications as the stakeholders? Of course, they should be the stakeholders.

Yvette Pegues 13:45

They are the stakeholders.

Shannon M. Turner 13:46

At this point, the Grillo family has worked hard to get their systems and structures up and going. They're like a well-oiled machine. Everything's clicking along at a steady pace, and then just when you think they've planned for all contingencies...

Jerry Grillo 14:01

It was a cerebellar stroke. So it wasn't like a hemorrhagic stroke that, you know, where there was a bursting blood vessel or something...

Jane Grillo 14:10

What was interesting was it gave us a little dress rehearsal for disaster. So our daughter, yes, your big sister lives in Michigan, and she has the kind of job where she can travel pretty easily and still do her work. So, when I called her and said “Well, your dad has had a stroke,” she just said, “okay, I'll be on a plane and it's no problem. I can do what I need to do, and just be there to do whatever you need.” And we had discussed beforehand, hypothetically, what's going to happen if anything happens to one of us like when we're really old.

Shannon M. Turner 14:56

“We don't know what will happen in the future.” It's one of those things we heard over and over again through the story collection project. We learned that many families have created a micro board, which is a small group of people invested in providing structure and guidance in the life of a person with DD. They convene over the course of his or her life so that the family doesn't have to bear the sole brunt of that responsibility. To learn more, we recommend visiting the Georgia Micro Boards Association online, we’ll provide a link in the show notes.

There's fear of the unknown. There's sometimes desperation to find housing, funding, wanting to connect with other people who genuinely care about and welcome them in as part of the community. There's the advocacy and work you put into getting on the Medicaid waiver planning list, then actually getting a NOW or COMP waiver so the person can live their fullest life. And what does that look like for a person like Joe?

Jerry Grillo 15:52

Joe is an economic engine, you can't argue that I mean, and people like Joe, you multiply that, it's ridiculous. Think of the jobs that people like Joe provide for, and I think a lot of that is lost and swept under the rug in the fury to make political points that last a few seconds. Let's put it this way. Joe is the CEO of his own little micro-organization. He, in his lifetime has provided jobs for physical therapists, nurses, lab technicians. Don't get me started on doctors, pharmacists. Think of the people who are part of the healthcare spectrum, and Joe has had contact in some way or another with all of them.

Jane Grillo 16:36

If we put all those people in a room, if you count from the day that he was born until now I bet there would be 100 people in that room.

Jerry Grillo 16:44

Easily.

Shannon M. Turner 16:46

This is such an important notion. A lot of people want to portray people with DD as asking for a handout from the government, something they are not earning. But Jane and Jerry are flipping that script and saying, “Look this little bit of investment gets turned into real jobs for so many other people.” Fully funding the waivers for the 6,000 people on the planning list would mean not just a full life for those who need the services, but many, many jobs that boost the economy by hiring people who work with and for them.

Jane Grillo 17:20

Well, first of all they need to increase the number of NOW and COMP waiver funds that are available every year. There is just such a need in every community, but NOW and COMP is about support services for people with disabilities. It pays for a whole range of supports and services that people need to live in their homes rather than in a nursing home. There's so much need for these waiver services.

Shannon M. Turner 18:00

There's a lot that connects the Grillo family with the next family we’ll meet, the Ladd family. But one of the main things that connects them is how they stepped into the role of advocate. In so many of the stories we collected last year through the GCDD Storytelling Project, we learned that often after having a child with a developmental disability families would become involved in advocacy. Not only that, but many times one of the parents saw so much need in the system that she or he would jump their own career track and get involved in the field in a way that was completely unplanned or unexpected. As they learned more and more about the paperwork involved in filing Medicaid applications, they would create a service to help other families do so. Sometimes, they would join foundations related to their child's specific disability, but probably the most exciting trend is this network all across the state called parent mentors. Jane is a parent mentor for White County.

Jane Grillo 19:01

Today, I am a part of the Georgia parent mentor partnership. I serve as White County School Systems parent mentor, and I've been doing it for 11 years now. For the most part, it's about kind of forming a bridge between school and family. So I try to help the family, walk beside them, and help them get services and supports and, you know let them know, “Hey, look, you know, I'm here, I'm making it. You'll make it too.” Because I can sit at the table and say ‘I know exactly what you're going through.’ I can help teachers see the parent perspective as well.

Shannon M. Turner 19:43

So while Jane is mostly working at the local level with some connection to the statewide network, Anne went from being a local parent mentor to being a part of that mechanism that holds the vessel for the entire statewide network of parent mentors.

Jane Grillo 19:59

Parent-mentor partnership was developed to really infuse family engagement into education. And we know generally that family engagement increases outcomes for students. When a family has a child who receives special education services, there are some unique complexities and barriers that come with that. The Georgia Department of Education developed the parent mentor partnership, the parent mentors are actually parents of children who have received special education services or who currently do receive special education services. A parent talking to a parent is much different than an administrator talking to the parent of a student. In addition to that, they are real connectors in their community. So they know what's happening and they're able to make those connections between folks, so they're able to help families understand the school system and help people working in school systems really understand where those families are coming from and why they may be presenting themselves as they are. And also,put it through their lens and say, “Is there something we're missing? Is there something we haven't thought of?” in order to engage families.

Shannon M. Turner 21:11

Jumping career tracks and becoming a parent advocate is a major shift in life trajectory, like putting on the advocacy cape. But it doesn't have to look like this for everyone. Remember when we talked about origin stories and superheroes? Just like we all have an origin story. We also have a point of departure, the turning point is a pivotal moment that brings an opportunity to become a part of something bigger than ourselves. The moment has a huge impact, and galvanizes us to action. I want to be sure we're showing that these everyday people met extraordinary circumstances and demonstrated resilience. Often there were things about their life that came before and uniquely prepared them for this role, like how Jane was a reporter which developed skills both to research and to take things less personally, or how Anne was in the field of design which led her to approach the social services her son received from a holistic systems thinking perspective. Another way to think about it though, is that we all have this capacity because in the end, it's just your kid, your friend, your neighbor, and so you rise up to meet the challenge. It's just what you do when life, lifes.

Shannon M. Turner 22:37

Meet Anne Ladd. She is the family engagement specialist for the division for special education services and supports through the Georgia Department of Education. But the title that came first: mom, that title led to so many other things.

Anne Ladd 22:53

He's very handsome, he's got a great personality. He is very easy going, he's non-ambulatory and nonverbal, and has a visual impairment. So he's got a lot of physical needs, but he's got a great personality, and he's really a pleasure to be around. We enjoy hanging out with him.

Shannon M. Turner 23:13

That's Anne describing Matt, her son who was diagnosed with a developmental disability from a genetic disorder when he was still a little guy. Let's listen in as she talks about their journey toward diagnosis.

Anne Ladd 23:25

I took my son at about his five-month checkup and I said, “Hey this looks different, we're not seeing this, I'm concerned about this.” And the pediatrician said, “Don't compare him to your older child. It's fine. Give him some time, everyone develops at their own pace.” So we left that appointment, and within a couple of weeks, we knew that there was something more going on. So, it really took us reaching out to our extended family who connected us to a developmental pediatrician, and there was clearly something going on more than me being a paranoid mother. So shortly after that though, he developed a seizure disorder. It was however, quite some time before we received a diagnosis. And during that time, we began doing therapies and the things that you do, seeing doctors seeing various specialists, and they speculated that it was perhaps a mitochondrial disease. But here's another thing we were told, “Well, it's an invasive test, and costs a lot and really there's nothing you can do about it. So that's probably what it is, but just continue doing what you're doing.” We continued to push and did receive a firm diagnosis. We were pleased to know and have that confirmation.

Shannon M. Turner 24:43

So, for Matt’s family pursuing the proper diagnosis was a turning point, they had to become strong self-advocates. A lot of times when we interviewed people with DD and we asked them what their definition of advocacy was, they said it was simply standing up for yourself. If you have to pursue someone just to get the right and proper diagnosis, this might be your first place of advocacy. The next point of advocacy for a lot of people getting a Medicaid waiver.

Anne Ladd 25:12

Early on we got on the waiting list with Matthew probably when it was five or six years old. And it was getting hard, I mean it was just physically and emotionally hard. And so we were calling more often to check where we were on this infamous waiting list, and one day my husband Paul called and just said, “Look, you know, we need some kind of support. My wife is losing her mind.” They sort of ruffled through some papers and said, “Well, we've just gotten, you know, we're going to be giving out more waivers. And let's see, oh, yeah, we see Matthew's application here. Yes. Okay. We're going to work on that immediately.” And we just both were grateful but we both thought, “Gosh, what if we hadn't called that day?” Or what about the people who don't know to call or don't, you know the equity it felt unfair.

Shannon M. Turner 26:01

Yvette, can you tell us about your own experience with trying to get a Medicaid waiver?

Yvette Pegues 26:06

So I applied early on, I do not have one today. I am on what used to be called a waiting list. A list I have no access to, a list and I don't even understand fully or where I stand on this list. I didn't even know I needed it or Medicaid, or the Medicaid waiver, which obviously is not the same thing, until I started to have to pay for my own, my personal care assistant that would help me medically when my husband had to return back to work. So that's where I need it the most. I need it for the support and the insurance. I thought about reapplying, but what I've done instead is I've just adapted, which is sad but true of a lot of families because I either sit around and wait for the waiver, or I live. You know, my motto is, “You either live in pain or you die in pain,” and so I've chosen to live which is a hard decision. It's painful, but it's what my family needs and it’s what I need to be sane, to keep sane.

Shannon M. Turner 27:02

Being an advocate is kind of Anne's full time job now, not just for her family but for the whole network of families who have a child with DD currently in the state of Georgia's education system.

Anne Ladd 27:13

I think I was reluctant. I had no interest in working in the world of education. When I was in college, I thought who would major in education? I just had no interest in that. I look back at my own path and the opportunities that’ve come my way and kind of surprised that they've come my way and that I've walked that path that's those opportunities have been revealed, but appreciative and just to know so many incredible passionate people who want to take their own experience and, and really enrich the lives of others. I think that's another really valuable part of the fact that we're a partnership. We are all connected as well, and so everyone brings different stories to the table, which is so valuable because I don't have to be the expert on everything that comes my way or every question I get, but there's this network of people I can reach out to and they've had that experience or they've gone before me or, you know their concerns are different than mine. So, I think that's what really strengthens our group.

Shannon M. Turner 28:13

When it comes to that notion of expanding the network, we're going to come back to that idea of the importance of strong networks over and over again. When people know each other, know how to share information, know how to stand up not just for themselves but for each other, it's just so much more effective.

Shannon M. Turner 28:41

Yvette, what are all the ways we can advocate?

Yvette Pegues 28:45

Advocacy requires information, it requires that you're transparent with your experience. And that experience like you said, doesn't have to be specifically around disability. My experience has actually been partnering with organizations who do it professionally, who have the resources and a direct line. Just like with GCDD, I was able to show up at the steps of our local state capitol and speak with individuals who are making those decisions or have a part in moving those decisions forward. But then I've done something as simple as you know getting a manager’s attention and saying this doesn't work. Or don't ever say that we're grandfathered in, that's not a thing. And you know you're putting yourself at risk, or as simple as, gosh my kids from the age of maybe seven, would redirect folks who would speak to them instead of me because I figured since I was in a wheelchair that I couldn’t speak. So, it's about in my case being more linear, not just fixing your problem but making sure that that problem extends to other issues, circumstances, and individuals teaching others around you. And yes, sometimes that might be a Facebook post. It shouldn't be angry, it should be more like a response for inclusion.

Shannon M. Turner 29:50

And in terms of inclusion, Yvette talks about how the desire for inclusion sometimes comes before we build physical spaces that can accommodate inclusion.

Shannon M. Turner 30:00

You told me that you think that in terms of accessibility that there's the physical component, but there's also the social component, that people's attitudes really have to shift. And that maybe even comes before we make these physical changes. How do you think we should go about making those shifts in our society so that folks are not marginalized or invisible-ized?

Yvette Pegues 30:19

So, the attitudinal changes really do affect the architectural ones, because if you don't have the attitude of change and you're the person moving the needle, you won't even want to make change. There's other ways, right? There's litigation, there's threats. There's other ways to kind of force someone to do it. But I found that when you force someone to do it, it's either not done well, it's done to the minimum, you know requirement, and it's not really well received. So yes, the attitudinal has to come first.

Shannon M. Turner 30:46

This is an interesting thought experiment that Yvette is introducing us to: Which comes first, the chicken or the egg? If you want to work toward inclusion, is it most important to change hearts and minds first? Or is it more important to build a physically accessible space? Frankly, it works both ways. You have to make a building accessible for people to be part of the conversation, and you have to want them to be there in the first place to have an inclusive conversation. When Yvette says, “nothing about us without us,” this is a really important idea. And it harkens back to the folks who fought for the passage of the Americans with Disabilities Act. Remember in Episode One when Talley Wells described folks crawling up the stairs of the capital, pulling their wheelchairs behind them? That's a powerful image. Hopefully, one we won't have to see again.

Shannon M. Turner 31:39

Sometimes the whole idea of advocacy is daunting, overwhelming really. It feels like no matter what the issue, we're all waiting around for permission, for our marching orders, for a playbook to know how to become an advocate. And with issues of disability, you really don't have to, in fact you shouldn't wait for it to happen to you or your family or someone you know to get involved. You don't have to wait for it to become your origin story. Your origin story can start today, because more than likely, sooner than later, these issues are going to impact you and/or the people you love.

Advocacy is like a spectrum, a constellation of different kinds of actions. So, here's just some of what you can do: Start with strengthening and broadening your network by getting to know and appreciate people who are different from you and stay informed. When you're feeling grounded and ready to start taking action that will lead to tangible change, commit to building a relationship with your state legislators and hold them accountable to creating and supporting budgetary and policy changes on the state level. By the way, GCDD has advocacy training days that are powerful and effective and they are a great way to get involved. At the end of the day, what will get you ready for any kind of action is knowing the very human stories behind any issue. As Jerry says it's not really political at all, it's about seeing and meeting his son where he's at, as a human being with his own origin story.

Jerry Grillo 33:15

I mean one thing I would say is to stop politicizing people's lives and start humanizing people. It just drives me crazy how something like care for people who demonstrably need it the most, becomes a political issue.

Shannon M. Turner 33:40

Thanks for listening to this episode of Hidden Voices. We encourage you to check out our show notes for this episode so you can find and follow Yvette's work, Your Invisible Disability, find out more about the network of parent mentors across the state of Georgia, as well as see some of the cool stuff the Grillos have made about their family's journey. Tune in next time as we hear about the high school transition and inclusive post-secondary education programs and some of the ways that folks are creatively combating a dangerous trend known as the school to couch pipeline.

Shannon M. Turner 34:21

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