Hidden Voices Episode 7 - Where We Are Now

Pam Moore 0:00

There is an army of experts in this state, and they are mamas, and they are daddies, and they are grandmas, and other supporters who have lived this life.

Shannon M. Turner 0:20

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 0:43

During this season, we've been painting a picture of a system in which people with developmental disabilities live their lives. Depending on what stage of life they're in, whether it's early childhood or going to school or adulthood, involves mountains of paperwork, doctors and therapy appointments, schools, IEP meetings or job coaches and supervisors. Think about any issue that you might be involved with that you are following in terms of being an advocate. There's this structure that supports folks at local, state, and national levels. It's not just true when it comes to disability, but it is especially true here, that there are laws that are made without a lot of insight from people who are living the life that they affect. The thing we've learned all along the way is the value of education and self-advocacy with ally advocates in the lives of people with disabilities. It's not just about a single piece of legislation, a single program, or even a single person who will go to the mat with you over and over again. It's about all of those things coming together to form a network of advocacy. And when you think about that word, network, think about its roots. A net that works. Folks need a net that will catch and hold them. So, what happens when very little of those resources are available to a person? What does it look like when the system completely leaves you behind? At the top of the episode we heard from Pam Moore, one half of a mother/daughter advocacy team. They live in Comer, Georgia, a rural area 25 minutes outside of Athens. You get there by driving through rolling green hills and farmland and then when you think you must be lost, you turn on to a small road that then becomes their homestead. There's this cute little trailer that has birdhouses and flowers all around. They have converted this place into their haven.

Pam Moore 2:45

Are you glad to be outside?

Shannon M. Turner 2:50

Due to a stroke while she was still in utero, Callie has spastic quadriplegic cerebral palsy. She also has seizures, vision impairment, and a number of other medical issues. A few years ago, Callie's family discovered she could communicate by answering yes or no questions by looking up or down. This was a game changer for them. Remember John from our earlier episode about assistive technology? As Callie is now in her 20's she can express her personality and even explore a potential life of independence like she never has before. In the fall of 2017, Callie and a small group of her most ardent supporters came together to conduct a facilitated process called The PATH which stands for Planning Alternative Tomorrow's with Hope. It helped them unleash this whole world of Callie's interest. Pam picks up the story from here:

Pam Moore 3:43

The purpose of developing a path is to, yes, it was very important to you Callie, is to bring Callie who was known as the focus person, and allies, supporters, family, friends, whoever you invite together to talk about Callie's hopes and dreams and vision of what her life can be and what she wants it to be, and then you go through a process of jumping from the ideal, which is known as the North Star, where you're headed to where you are now. And then you systematically figure out what needs to happen to help Callie get to that good life that she's envisioned for herself with our help.

Mary Griggs 4:35

Michael, I love you.

Shannon M. Turner 4:40

This is Mary Griggs, who is talking to her son Michael. Michael is a 34-year-old man living in Jonesboro, Georgia, who has hearing impairment from an illness in his childhood and who has an intellectual disability.

Mary Griggs 4:52

It makes him happy, be happy when he sees children run around playing. And Michael he's a rusher too, because he does a lot. He comes in and turns the lights on, and he pulls out the song books, the books and stuff. So, he does that, and helps with the trash and he does a little something.

Shannon M. Turner 5:12

When he was a baby Michael contracted a cold, which then led to meningitis. Michael was in the hospital for three months, and even though it was a touch and go situation there for a while, he came home seemingly healthy.

Mary Griggs 5:26

That's when they said that he had meningitis, also his speaking and hearing. I think he was turning about a year, about a year because he's getting ready to say “Mama,” he was saying, “mmmm mmmm Mama.” I know I heard Mama.

Shannon M. Turner 5:42

Between the time Michael was born, his illness and starting school, there was not much opportunity for Michael to participate in some of the early intervention programming that would have benefited him. Early learning programs and occupational therapies would probably have helped him tremendously but these either weren't available to him, or there was not much outreach to Mary, and identification of his disability.

Shannon M. Turner 6:13

Remember all those things we mentioned that we've been exploring throughout the season? They are the pillars of living your best life as a person with developmental disability, housing, transportation, education, supported employment. Now, there's the saying in the storytelling world, "the universal in the specific." As such, we're going to take these two stories of Callie and Michael, and look at how they highlight how a situation can play out in two very different circumstances, where two people with and without resources are or are not supported by the system, and we're going to do that by flowing through the life cycle. First comes early intervention, their programs like, Babies Can't Wait, that help with that stage and after that comes education.

Michael's Teacher 6:59

M I C H Can he spell his own name? No.

Shannon M. Turner 7:09

Michael did go to the Atlanta School for the Deaf for many years, but he emerged with only a few signs.

Pam Moore 7:16

I don't think they did too much. I don't think they did too much with him, or spent that much time with him, because I went and visited, just to see what they were doing but they must, he was just like in a little corner.

Shannon M. Turner 7:30

When we first met last year, we took an ASL interpreter with us to help with the conversation. We didn't get very far with the interpreter and Michael, it was unclear if Michael was able to understand the interpreter or if he was just choosing not to engage. Michael and Mary seem to have created their own sign language, which mostly consists of wants, food, I want to leave, I want to go to my room. He doesn't seem to be unhappy, as his mom says he's content to sit back and watch.

Shannon M. Turner 8:02

What does it look like when you have resources to navigate the educational system and to stay at the plate batting for your child?

Pam Moore 8:10

We did our best to work collaboratively with our school district. I mean, my background was in education too, so, you know, I didn't want to be that parent that was always confrontational, but at the same time, I knew what she needed, and so probably the entire time you were student Callie, I was there as your advocate.

Shannon M. Turner 8:28

What Pam will tell you is that they were working in a system that ultimately supported them and wanted them to succeed.

Pam Moore 8:35

But we did have a supportive school district they just didn't know how to do. And so, part of my role was helping them figure out what it was going to look like to have a student who had really significant medical needs. Somebody it wasn't just the G-tube that you could teach a teacher or a para how to pour food into, but these were actual skilled medical needs that had to be monitored and addressed the whole time she was in school.

Shannon M. Turner 9:01

As I went all over the state interviewing folks for the Storytelling Project, "I didn't want to be that parent," came up over and over again, in our conversations. Parents who had that notion that speaking up would be a problem, but ultimately, they just had to because they learned that the squeaky wheel gets the grease. But there's this huge crack that kids fall through when the resources or knowledge to be a squeaky wheel are not available, and I want to turn your attention to this program in Georgia called GNETS.

Shannon M. Turner 9:33

GNETS, which stands for Georgia Network for Educational and Therapeutic Support is this controversial program that is specific to this state. Started by a psychologist, some people really like it and think it's wonderful, successful, forward thinking. However, an extensive investigative journalism article last year showed how very problematic it has become by revealing issues of abuse such as tying down, isolation, and even hitting students. The worst part of it was that it was almost exclusively serving African American boys, and had developed a reputation for where you get sent if you have supposedly behavior issues.

Shannon M. Turner 10:12

Remember how we talked about Olmstead in Episode One? Well this has become the new version of separate is not equal. Remember, we're making our way through the life cycle. If they missed early intervention programs, then education is their first interaction, a publicly mandated one with the system. As a person with developmental disabilities comes close to graduating from high school, their family begins the long and arduous process of applying for Medicaid waivers. So, remember those waivers we've been talking about them a lot. There's the alphabet soup of options COMP, NOW ICWP. As of this recording, there were 6,007 people on the waiting/planning list to access one of these waivers and only 250 new people a year gain access, and the number of new slots added each year fluctuates with each legislative session. Lawmakers sometimes open up more slots, there was a time when over 1,000 new slots were being opened up each year, and then some years only 100 new slots will be opened. Once you have a waiver, you have it for life. The difficulty comes in with the amount of new slots open for a year, currently 250, and the number of people on the waiting/planning list, 6,007. Your chances of getting a waiver in any given year is relatively low. The Hidden Voices team did a bit of math and we figured out that to fund the entire waitlist, it would cost each taxpayer in Georgia $49 a year. $49 a year. This would provide every person with a developmental disability on the waiting slash planning list in Georgia with the majority of services they need. Both Michael and Callie have a waiver and it helps out a lot.

Mary Griggs 12:05

Well, when he came home, he had nothing to do so he stayed up in his room. I've been trying to get him in this day program for a while, and it was about, oh lord, about five or six years before we got this thing done. It took so long, you know, they kept, we had to keep calling people and then they would have us going back and forth back and forth. So, we've got a waiver, well, I had to get that waiver.

Shannon M. Turner 12:30

Michael's waiver allows him to go to a day program where he has interaction with his peers and some supportive activities. There is, however, more potential within Michael's waiver that is untapped. Due to the complicated waiver system and lack of outreach from the state. His waiver continues to be underutilized. Callie's waiver, the COMP provides for a lot of the supports we've mentioned before so she can have the nurse and CNA support, get out into the community, and participate in all sorts of activities. It also helps her mom be able to work. Otherwise, well, we'll tell you about that in a minute. As complicated as it is to get a waiver, understanding how to manage the waiver and navigate the services becomes an additional hurdle. We spoke with many parents who said they wound up feeling like they needed degrees in social work in order to navigate the system. Some of them even started their own consulting practice to help other parents just fill out paperwork. These interrelated intricacies such as health professional shortages, transportation, housing, education and the like, can become stop signs in the full utilization of a waiver. Now we're going to move on to housing, and waivers are again an opportunity for people to live their fullest life and assist with things like independent living, job coaches, and transportation. Mary and Michael have been working to get their own housing for quite a while now.

Mary Griggs 13:56

I'm tired of living the way I'm living

Shannon M. Turner 13:58

I know you are.

Shannon M. Turner 13:59

This process is long and complicated. Mary last heard it will be another six months until they are eligible for an apartment. Currently they depend on housing from a friend. Callie currently lives with her mom. Since she went through the path they are starting to think about and plan for her to have an apartment in Athens as she loves the city life. She wants to be able to go to concerts and the movies much more often than she can now, she even has a boyfriend who comes to dances with her. There's so many new models being created around helping people live fully independent lives from community co-living such as Larche to host homes and full co-ops. They're also still over 200 people still institutionalized at Gracewood, including some children. As we discussed in our episode about housing with the story of Amber, a 22-year-old woman in a nursing home. There are uncounted individuals with disabilities that are residing in nursing homes. These facilities have become the new under the radar institutions where we park and forget about people like we used to back in the day when we had asylums. We just have a long way to go here, folks.

Shannon M. Turner 15:12

Callie has staff that come in and hang out with her throughout the week, often two staff at once a nurse and a CNA. They strive to hire CNAs who are close to Callie's age and who likes some of the same things that she does. They go to town and Callie's renovated accessible van all the time. Michael has a caseworker who picks him and Mary up for their doctor's appointments, which helps a lot, but Mary broke her leg last year and since then, it's greatly impacted her ability to walk and walk is what they do, all the time.

Mary Griggs 15:45

We'll walk to Family Dollar, it's right up the street up there. We'll go there, he loves to go to Family Dollar because you love them cars.

Shannon M. Turner 15:51

How far is it to the Family Dollar?

Mary Griggs 15:54

About an hour.

Shannon M. Turner 15:55

Walk?

Mary Griggs 15:56

From here to where we got to go, I would say about an hour.

Shannon M. Turner 15:58

There's not really bus transportation out this way, is there?

Mary Griggs 16:01

Yes, it is. Still got to walk about an hour to get down there though.

Shannon M. Turner 16:07

It's really important to note here that public transportation is mostly confined to our major metropolitan areas, and it's often unreliable wherever it is. This is one of those areas where we struggle as a state, no matter who or where you are, but if you're a person with a disability, it's just put on blast.

Shannon M. Turner 16:27

The next pillar for many people with disability is employment, even supported employment if they need a job coach or other kinds of supports. There's a national movement and priority right now for updated employment policies, and the Georgia legislature recently created an Employment First council to look at how businesses can have integrated work environments and policies that recognize and include people who have disabilities traditionally viewed as significantly intellectual disability. At the moment employment is not on the close radar for either Callie or Michael, but Callie's love of fashion has led them to new conversations about how that could possibly factor into some consulting or other work. For Michael, there are some options for employment, but connections with some key people and organizations need to be made first. With the right supports, Michael could explore entrepreneurship or look for opportunities to carve a position that fits with his abilities, interests, and skills.

Shannon M. Turner 17:35

If the only way to change the system is through advocacy, how does that even look from within a broken system? It happens on many levels, the personal, organizational, and systemic. In looking at Callie and Michael stories in connection to each other, I want to take a moment to look at empowered and disempowered advocacy. Callie is maximizing her waiver, but there are still major challenges. There's a shortage of health professional support workers everywhere, but remember Callie lives in a rural area, and people just don't want to drive an hour or more to go to work. So that makes the problem even worse.

Shannon M. Turner 18:13

For Michael, because the system does not make community based service information plentiful and access simple. He and his mother face hurdles trying to prepare him for the future. To make planning for it a possibility, they need stronger advocates working on their behalf in order to secure the services needed. I need to take a minute here to call out some complexity. Mary is a great mom who like her son is also living with a disability. Mary is unable to work and has applied for disability benefits herself and has been waiting for quite some time for approval and to access them. One of the challenges stemming from Mary's learning disability is that she feels stuck in how to advocate for both of them in their current situation. She said that Michael has been given hearing aids but the day program won't let him bring them home in the evenings. She needs assistance navigating systems that other parents have said they needed a master's degree to make work for them. The practice for organizing and filing names of medications, caseworkers, and agency notes into volumes of notebooks is a daunting one that has become the status quo and a system not built to easily and equitably help all of those in need. So, what I'm trying to convey to you is that Michael and Mary cannot do this alone. That's why we're trying to encourage you to become an advocate and ally as well.

Shannon M. Turner 19:45

This moment is a call for people to care and get involved, to voice their support and resources for Disability Advocates and supportive candidates and policy to just pay attention. I get it, people daunted by advocacy. But at the same time, one of my favorite quotes comes from this DaRa Williams song from the 1990s. And she says, "When I chose to live, it was no joy. It was just a line I crossed," and I feel like sometimes it can be that simple. You really can just pick up a phone, call your legislator and say, this is what I believe, this is what I support, and they will listen to you. You get a little bit more interested, and then you get a little bit more involved, and you find you get a little bit more effective. You don't even have to be the parent or family member of a person with a disability, but you can listen to those folks because they make the case for how their advocacy work can be so very effective.

Pam Moore 20:49

I'm really thinking about a state senator who sat in that chair because he came to our home and he met Callie and he just got to know us a little bit, realized that there's a whole other world out there that he really didn't know about, and it was doing the best that he could, but he really got insight into the people that his decisions were touching. That's a way that that army of experts could maybe be a real assistance to decision makers, is if a question is coming up, ask the people it's going to affect.

Shannon M. Turner 21:29

So just like I mentioned, that policy gets created without talking to the people that that policy would affect. We as allies and advocates have to ask the people whose lives are being affected before creating policy. In the end, we have to stay informed and stay involved.

Shannon M. Turner 21:54

We live in a world that's trying to tell us that we have huge differences between us that we should build walls around ourselves. One of our differences is between people who see the world as being interdependent, and people who see us as a dog eat dog world, of, "I've got mine and you get yours," it's the myth of the bootstrapper. There was this moment that happened a few times when I was talking with these parents all across the state, where they admitted to me that in any other circumstance, they would not have wanted to ask for help, that they really did believe in their family taking care of itself, but at the end of the day, that was impossible. When they had a child with a disability, everything changed, even if they didn't believe in asking for governmental support, the realization that the Medicaid waiver provides necessary supportive services that people with disabilities have a right to access started to shift the thought narrative from, the waiver funding being a handout, to the recognition that funding the needs to be efficiently and easily accessible, and that this funding for people with disabilities is supposed to be a legal guarantee.

Shannon M. Turner 23:09

Now, I want to take a minute to talk to you about Callie's journey. Callie falls into a category known as medically fragile. A medically fragile child is defined as a child whose medical conditions or health problems require 24-hour supervision from a skilled nurse. Often, they are not able to care for themselves and need help with basic activities such as bathing and feeding themselves, regardless of age. Callie was determined to be medically fragile early on in her life, and she's not a child anymore, but the definition of being medically fragile still carries with her. When she was very young though, Pam was left with the lion's share of responsibility for Callie's care, which left her reeling, and completely unsure of how to move forward. So, in the same way that we started our season talking about Lois Curtis, a rock star, with total name recognition in the disability community because of her involvement in the Olmstead case, here we are now finishing up with Callie, who is too, because Callie and Pam had to take their case to court. They kept running into this situation where they were being turned down for services that Callie's doctor had recommended, ordered, and mandated, and eventually it went all the way up the chain where there was this landmark case that was named after Callie. They said it was no longer appropriate for insurance companies to turn down people for service based on what their doctor had said, but now I want to tell you about what's happening to Callie and Pam right now, as in what's happened since we started talking to them for this podcast. Callie got really sick, and she needed IV antibiotics, and they also were experiencing another one of their nursing shortages. So, I chatted with Pam on Facebook messenger to find out what was going on, and this is what she said:

Pam Moore 24:54

It's a long story, but bottom line is our nursing provider doesn't have adequate staff in our area. So, when someone leaves and no one stays forever, we're left in the lurch. It's bad. Callie is recuperating, but an equally almost huge challenge is lack of staff. This week, I will be Callie's nurse for 97 hours straight. Prayers appreciated. It's truly disheartening that Callie can't live her best life because of a broken system.

Shannon M. Turner 25:37

What else does Michael do when he hangs out up here?

Mary Griggs 25:39

Nothing.

Shannon M. Turner 25:41

Nothing? He just sits? He doesn't watch TV or . . . ?

Shannon M. Turner 25:49

As he sits alone in his room, playing with blocks and cars, there is a silence that surrounds Michael. Not the silence that comes from the fact that he is deafness but from spaces around him that have not filled the way they are for other people. The harder you dig; the silence becomes very loud. One wonders how Michael might have fared in a different situation with more access to resources, more people joining with his mother and helping her to advocate for him, for them both really. Even in the quiet spaces, when we try to engage him in conversation, he would look away. Is that simply what he's become used to? How many people have looked away from Michael at every stage of his life? We have very little insight of what Michael does all day at his program because they wouldn't return our phone calls, and again, this is a complicated story. I just want to take a step back and say, choosing which stories to tell and how to tell them is such a place of power and privilege. It would be easy to fall into a narrative that Mary is not managing Michael's care herself or that she could do a better job of advocating for what's happening to him at school or at his day program, or that she could try harder to get him into a better housing situation, that the caseworker is the problem, or that their church should be doing something on their behalf, because that's what makes it easy for people to look away from them. It's important to remember that Mary herself came up in a system that didn't support her or her disability. This system has moved through some progress but still is fraught with class and race oppression. These are things that play out over and over again in people's access to housing, transportation, education, and healthcare. Mary has an eighth-grade education, has no access to transportation to speak of, no supportive family. She feels she has very little voice herself, she's a good parent, but she is lacking things you need in order to be a true advocate. So, what can we do about it? Well, you could sit around and wait until you have someone in your family with a disability. That would be like looking away. There are so many things to be an advocate for. But I think we've proven why it's important to continue to pay attention. We become the ones who are part of that network. The net that works. Think about Michael, every time you try to engage him, he looks away. He won't look you in the eye look anywhere in the room, but at you, no matter how hard you try. We have to do better for him. We have to make sure that he knows we're looking at him, that someone is paying attention.

Shannon M. Turner 28:47

Hidden Voices is sponsored by the Georgia Council on Developmental Disabilities. This podcast is part of a series of stories called the Storytelling Project, a collaboration between L'Arche Atlanta and GCDD. You can find out more about GCDD’s advocacy at gcdd.org. And about L'Arche Atlanta's community of people with and without disabilities at larcheatlanta.org that's L-A-R-C-H-E atlanta.org. Other strategic partners are Resurgence Impact Consulting and Story Muse, made in partnership with FRQNCY Media. I'm your host Shannon M. Turner. Irene Turner is our Executive Producer, Enna Garkusha is our Producer, DonTae Hodge and Cooper Skinner are our Sound Engineers. We are recording at Listen Up Audio in Atlanta, Georgia.