Hidden Voices Episode 5 - Housing & Transportation

Shannon M. Turner 0:10

The westbound elevator isn't working. It's the one that'll take you down to the MARTA platform at the Decatur station and it's under renovation because it kept breaking down. It was supposed to be reopened in a month, but one thing has led to another. If you're a wheelchair user heading west, you have to ride in the other direction for a stop, change trains, and come back through the Decatur station. On a normal day at peak times, this might take about 20 minutes of extra travel time, if it's the weekend when MARTA runs less often, who knows? Just because of one non-working elevator.

Shannon M. Turner 1:03

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 1:26

Today, we're talking about the opportunities and challenges around housing and transportation for people with disabilities. It hurts my brain to imagine just adding up how much of people's time is being wasted every single day because of things like this. The hours they have to be on the phone, getting to places extra early, hours and hours of paperwork, and doctor's appointments. Just imagine that this is how your time gets spent. It's like this huge and invisible tax, but this episode is not about that. Having public transportation is great, we need it, we need to fund it, we need to use it. Along with public transportation, new ride share services often help people with disabilities live more independently.

Shannon M. Turner 2:13

During the GCDD Storytelling Project, we got to follow along with folks as they took Lyft to their jobs and such. It really is a game changer, but sometimes in more rural areas where public transportation and even Lyft tend to be less of an option, or if you're a wheelchair user and the transportation services don't offer the vehicles needed, people with DD may be dependent on family members and caregivers to be their lift. The point is, people do have some options, but sometimes those options are limited and they definitely are informed by where they live, and where they live, well, that's another choice entirely. Housing, as we'll find, runs the gamut from living completely independently, to living with your family, to finding yourself living in a nursing home at a very young age, but first, let's start with how people get themselves around.

Shannon M. Turner 3:22

Parker Glick is a 30-year-old trans man who was born with arthrogryposis, which means congenital joint contracture. It derives from the Greek literally meaning curving of joints. Parker was born a twin in Korea and his twin, while inside his mother's body, received more of the available resources. Because he was being crowded out of the uterus, it did not allow his joints to form, his twin did not have any physical disabilities. These days, Parker's profession is working for an organization advocating for people with disabilities to find and secure independent housing. Parker himself as a wheelchair user, the fact that Parker is a wheelchair user trying to get him to come into the studio lead us on this wandering journey. We typically record on the second floor of a historic building in East Atlanta Village, which has not yet been renovated for accessibility. Okay, fine, we worked for a while to try to rent a different studio space. But most of the alternative spaces were not on reliable Marta bus lines.

Parker Glick 4:31

Too many buses are let out in the field, and they're not operable. Either the audio will be out and that doesn't mean that it's accessible because then now folks that are blind don't know where the heck we're going. Then the ramp is not working, oh, well, you know, my supervisor said to go ahead. We don't get any wheelchairs down this road. Does the road begin with a staircase and then end with one? Like, we obviously got here somehow.

Shannon M. Turner 4:54

Parker does not currently qualify for MARTA mobility. It's not that he doesn't qualify financially, MARTA mobility isn't based on how much money you make. It's strictly based on whether or not you have a proven disability. But that's the thing about this stuff, you have to get paperwork from a doctor and physically go down to the MARTA offices every one or two years to re-up your MARTA mobility services. They asked you to put yourself and your chair through this obstacle course in order to prove that your chair isn't going to get stuck anywhere or isn't too wide for the vans, etc. etc. And well, Parker's been a bit busy.

Parker Glick 5:33

So, what happened was I was going down closer towards Fellini's on Sycamore, and there's a small street side street called Berry Street. And so, I'm just there with my obnoxiously large headphones and riding along headed home then all of a sudden I get a like a blank screen. I wake up beside a tree, because that's I guess, where you wake up after an accident, and I felt like a glitter bomb had gone off out of my arms, my legs, you know. Thankfully not my neck or my spine because that was the first thing I thought I was like, “Okay, don't move.” I look up towards the sidewalk and I hear somebody I hear say, “Oh my God my car is totaled,” to which I wanted to be like, “Okay, well, I got hit by your totaled vehicle. So, can we get the human, you know, some help?” It's probably what was more so running through my mind, and what actually came out was probably like "help."

Shannon M. Turner 6:26

So, we wound up recording our conversation in downtown Decatur. All told it was probably an additional three or four hours of planning and conversations and logistics and ultimately, we were never able to find a way to get Parker into an accessible studio. It was just another glimpse we got into the constant maze of navigating the system folks have to go through. I will say though, that since we were hanging out in Decatur on a beautiful Saturday afternoon in late summer, rather than a dark studio, Parker brought along his good friend Charlie Miller, who also happens to be a wheelchair user. Inevitably, we wound up drawing Charlie into the conversation as well. He gave us some real insight about what a person who doesn't have a disability can do as an upstander rather than a bystander.

Charlie Miller 7:20

I had an internship in Atlanta. I was living in Gainesville, Georgia. So obviously, there's very limited accessibility in Gainesville, Georgia, and I’m very lucky to be able to drive but I didn't want to drive through Atlanta traffic. So, I went to the Gwinnett County Transit System. And when I went through there, it was like $5 a ride. Had a lift, your chair goes into the lift, you take them out to Atlanta, drops you off, right perfectly where I needed to be. So, one time, I was taken it and we get the bus stop, they come to get the lift out, and the lift stopped working. And like I'm like literally stuck, I'm like, I can literally see my building. I can see the entrance of where I need to go. And I was like, “Guys, you need to get me off this lift,” and they're like, “We don't know what to do, we're calling maintenance.” So, I call, I call my boss to let him know. So, he comes out and he sees me. He calls the fire department. So, we had to have the fire department get me off.

Shannon M. Turner 8:34

I asked Charlie how he felt about his boss's intervention on his behalf.

Charlie Miller 8:40

Oh, embarrassing the company was too relaxed about getting to the problem, so my boss is like, I got to push the envelope, he did it the right way. Transportation is our right.

Shannon M. Turner 8:53

Wouldn't it be great if everyone, especially the people who make our laws and build our infrastructure really saw transportation? Accessible, affordable transportation as a right for everyone?

Shannon M. Turner 9:14

You may remember Jake Ricks from our earlier episode about adaptive technology and support animals. Jake is in his mid 30's and lives in Ochlocknee in South Georgia, and is quadriplegic from when he dove into a shallow creek as a teenager. When we called him up to talk about Ollie, the dog who lives with him and supports his life, we discovered that Jake's a funny smart guy with a lot of exciting things to say about all sorts of different things, not just about disability. You should hear him talk about the 27-point buck he shot last year. One of the things we found most interesting is his take on transportation, both for his own life and for other people with disabilities. Jake has converted an old motorcycle and sidecar. The thing is in his wheelchair, Jake rides in the sidecar and his dog Ollie rides where the driver would traditionally sit.

Jake Ricks 10:07

Oh, yes, my motorcycle. Yeah, it's an older motorcycle with an automatic transmission, found it on eBay about 10 years ago and definitely had to have me one of those. We bought a box that will go on the seat on the motorcycle. So, Ollie I can actually ride on the box on the motorcycle side, and then I'm in the sidecar driving down the road. So, it's definitely a head turner because people at first think the dog’s driving, you know. It's pretty crazy.

Shannon M. Turner 10:32

On a more average day, Jake drives a van that has been adapted with a ramp in hand controls so he can drive it. And let me tell you getting a vehicle adapted and then maintaining those adaptations is one of the more expensive ongoing costs a person with a disability can face. I just want to note that we've already talked about some things that can rack up over time medications, having to get a new wheelchair every three years because bodies change, and the chair itself starts to break down, there's therapies. Now think about how expensive your own car can be, but think about if your car needs special equipment. Jake works for an organization called Lives Without Limits. Because he saw how complicated and expensive it is, Jake encouraged them to start including van adaptations into their mission.

Jake Ricks 11:21

We've since got into helping people with vans, we've had several vans donated to our organization, and then we can get those vans repaired or fitted to somebody else's disability and been able to put it out back in the community.

Shannon M. Turner 11:34

Listen, as Jake describes the van, its airline quality hand controls, and their maintenance.

Jake Ricks 11:41

Yeah, this was four-wheel drive full size one ton van. I got it my senior year in college back in 2004. Reason I got a diesel was so it would last a very long time because they are not cheap at all. It’s still running great, fifteen years later so far. Yeah, they're computerized like aircraft grade, you know controls that way it's safe on the road, you know, because the main thing with that kind of stuff is liability, you know, so, and obviously, it's all computerized with backup systems and everything. And I've never had a problem driving it, never have any problem with it, but the conversion on the van was $77,000. $5,000 just to get them serviced. Yeah, definitely not cheap.

Shannon M. Turner 12:22

One thing Jake told us about was the difference in how Florida and Georgia handle and support transportation for people with disabilities. It presents this interesting conundrum between going to school and getting professional training or going to work.

Jake Ricks 12:36

There is one weird thing about Georgia vocational rehab, but in the state of Florida under vocational rehab, they won't have to pay for a vehicle if you're in school, but they will have to pay for a vehicle if you're working, you know and try to you know, you have to have a way to work and because Georgia is actually the opposite of Florida. In the state of Georgia, if you're in school and college and don't have a way to get there, then they pay it so that you have a van. But after you're out in the workforce, after you graduate college, they no longer do any assistance as far as that goes, which is the boat I'm in, you know. I'm still driving the same van, you know, I knew after I graduated, I wouldn't be able to get help from VR.

Shannon M. Turner 13:15

The thing that's fascinating about Jake's perspective here is that he lives very close to the Georgia Florida line. So, close, he can really see how they do things, for better or worse in another state. When you live on a border like that, it makes it easier to think about whether the grass is greener on the other side. Whether you should even consider moving or maybe you just feel trapped where you are, maybe it's a toss-up, maybe you're not trapped, but you'd have to give up some things like your family or community. For Jake though, Georgia is his home and he works to figure out how to live his best life here for himself and for others.

Shannon M. Turner 14:03

Accessible transportation is a major determinant in being able to live a fully independent life. Having reliable transportation that you can utilize when needed can mean the difference between having a job and not having a job, being able to hang out with people easily or staying home. It can mean getting to church, the grocery store, your mama's house for Sunday dinner. Having the option to go where you need to, when you need to is one of the pieces of the puzzle that lets you have the choice for how you want to live a good life and provides the opportunity for living it. Another one of those choices is where you're actually going to lay down stakes. Housing is an enormous issue of consideration for all of us, but when you add in contending with disability to the mix, it becomes a whole other puzzle to solve.

Shannon M. Turner 14:54

Meet Evan Dewey. Evan is a 34-year-old man with down syndrome and by all accounts he is living one of the most ideal scenarios for people with DD these days. He and some of his friends from high school came together and bought a house which they converted into a kind of Independent Living Coop in Tucker, Georgia. They all have their own rooms in the house and the basement has an apartment where a staff member that they and their families have hired lives and helps to manage their very busy lives. It wasn't a straight forward path to get to the solution though. First, Evan's parents tried building an apartment in the basement of their house for Evan, but then his brother went off to college and Evan also wanted to live independently. So, then they tried getting him an apartment up in Dunwoody, which is a northern Atlanta suburb, in hopes that the distance might give him more freedom and independence. Let's listen in as Evan's parents, Jane and Brian talk with Evan about some of that wandering path he took in his 20's before they got to this awesome new solution.

Jane Dewey 15:57

We learned something valuable from that because he was in a - going into a home situation up in the Dunwoody area.

Evan Dewey 16:05

Yeah.

Jane Dewey 16:05

And so, we transfer, they transferred him to the Publix up in Dunwoody. We had started working part time I think at Publix. Before he graduated, we sort of got that transition going and he had a job coach, and then we had part of the waiver where people would come in and work with him in the home. And we had our basement done, so that he could try to live in the basement and see how that worked as far as a transition, and then when we were able to have a full waiver, we looked at opportunities for living outside of the home, and we thought Evan was ready. I'm not so sure he was ready at the time, and you know, and that's a difficult thing to decide because Evan wants to please people. He wants to say what he thinks they want him to do, and I think he thought that this was the next step, and this is what he was supposed to do. I'm not sure he emotionally was ready for it. So, we had to work through a lot of that, and then we made the mistake of putting him in a living situation with two other young men that he knew in Dunwoody and an apartment and then he had to start a new job with Publix, the transferred Publix, yeah, the transfer and it just it was I think a little too much he tried. He tried really hard to make it work.

Shannon M. Turner 17:27

The folks who live together in this co-housing situation have named their house Twin Magnolias because there are two Magnolia trees in the yard. And because as Evan's mom pointed out, magnolias mean dignity. The Twin Magnolias house has created a community and a family between the residents and the caregivers. There's this palpable feeling of home life there. The family talks about that home life at Twin Magnolias.

Jane Dewey 17:55

We've been really really lucky with staff and we've been here almost five years and have most of the original staff. So, the house has become really independent.

Shannon M. Turner 18:09

Evan has household chores.

Evan Dewey 18:12

It's the garbage.

Jane Dewey 18:13

Yeah. And then don't you have to pull the garbage up to the curb on

Evan Dewey 18:17

Mondays. Yes.

Jane Dewey 18:18

So, he takes the trash out every night garbage. And then I think the girls are responsible for recycling.

Shannon M. Turner 18:25

Brian and Jane gave us their closing thoughts on housing with Evan.

Brian Dewey 18:30

What more would you want to set things up so that your son or your daughter is independent and living their life?

Jane Dewey 18:40

It's almost intuitive. You know, you have to decide yourself: Are we ready? Is my child ready? Is my family ready? And really what would be the best opportunity for them? But that's all hindsight too, and you have to sometimes I think for those of us with kids with special needs. There's a fear of failing, but it's okay to fail because everybody fails, all of our other kids have failed in situations. We just feel more responsible. You know, when I look back over the history of what we did, I don't feel like we failed, we learned a lot.

Shannon M. Turner 19:21

Going back to that notion of dignity and the name of the house Twin Magnolias, finding creating or getting into a good housing situation is complicated. Some housing situations do and some don't protect a person's dignity. Medicaid waivers, as we've pointed out, help people find and secure alternative solutions. They're called a waiver though because the first priority for funding would be to keep people in an institution. If you have a family who will plan for you, who will fight for you, or if you have the resources and supports then you will likely stay out of the institution. Our next interviewee, her family just couldn't help out in that way.

Shannon M. Turner 20:15

Amber Davenport is 22 years old and lives in Macon, Georgia. She has the kind of cerebral palsy which leads her to be a wheelchair user. Amber’s life and support system turned upside down right at the same time she was graduating high school, her family was not able to step up and provide the care she needed. There are some really difficult issues with substance abuse, other kinds of abuse, and neglect embedded in this story. These issues led to Amber winding up in the hospital for two weeks last year and malnourished and dehydrated. When it was time to leave the hospital, where could she go? Amber’s in about the worst possible situation imaginable, at 22 she's living in a nursing home.

Shannon M. Turner 21:01

Where are we?

Amber Davenport 21:02

A nursing room, in Macon Georgia.

Shannon M. Turner 21:05

She's now been here for a little more than a year. Please note here that Amber is very smart. She got a 3.5 GPA in high school. She could go to college to pursue her dreams to become a creative writer or study theology with the right supports, but instead she's in a daily monotonous repeating loop of a nightmare. She describes getting up at five in the morning just so she can have some quiet alone time and get the staff's attention to help her with personal care before they get swept away by breakfast trays and such. She herself hardly ever eats breakfast because it's so gross and yet she says she's gained weight since she's been there because the food is heavy and greasy.

Amber Davenport 21:53

After me, they go and take care of 60 patients. We're two people per room. It's not easy, especially when you have a lot of total care patients, and a person who can't do anything for themselves. It's got to be hard.

Shannon M. Turner 22:14

Day in, day out, she sits there and reads her favorite fantasy fiction books, and hopes that someone will bring a well-behaved dog to visit the residence. Prays that this won't be one of those days when one of the other residents gets up in her face and wishes she could go ahead and start taking college courses through her phone.

Amber Davenport 22:34

Go to school and go to college and stuff.

Shannon M. Turner 22:37

What would you want to study if you went to college?

Amber Davenport 22:40

Probably Biblical Studies.

Shannon M. Turner 22:42

Oh, interesting.

Amber Davenport 22:44

And theology and that type of stuff.

Shannon M. Turner 22:47

Amber, do you have a Medicaid waiver?

Amber Davenport 22:49

No, not yet, not that I know of.

Shannon M. Turner 22:52

Amber has some advocates that are trying to help her file the necessary paperwork to receive a Medicaid waiver, which would be her ticket out, but it's a slow process. Starting with the fact that her family cannot locate her birth certificate. At the rate things are going she could be stuck there for another few years. One important and devastating fact that we run into several times meeting people with DD who reside in nursing homes is that being in a nursing home is itself disabling. Take Amber, she has the ability to walk, however, because nursing homes are not set up as places where people can live their most actualized lives at the level of ability they possess. She has only used a wheelchair since residing there.

Amber Davenport 23:39

It can get frustrating at times, but it’s okay.

Shannon M. Turner 23:43

Do you worry that because you're here and not being challenged to walk or given the opportunity, the equipment that you might lose that ability while you're here?

Amber Davenport 23:53

Maybe, but I'm real strong, like using a book bag and everything.

Shannon M. Turner 23:58

Amber has hope that she will get out, and she has dreams about where and how she wants to live when that happens.

Amber Davenport 24:06

I don't know somewhere quiet. Probably a house, because that would make more sense, since I'm in a wheelchair. I don't want to stay here in Macon, I don't like Macon.

Shannon M. Turner 24:18

Sometimes the best part of an interview happens when you're not recording of course you change anything to not have it happen that way but the fact is people just get more relaxed, become more themselves again when that recording button goes off. I was trying to help Amber understand the podcast what she was going to be part of by sharing her story so I played some of the episode about adaptive technology and service animals for her because it occurred to me that she and Kyleigh are kind of similar, they're close in age, have the same faith background and are both thoughtful and fun and girlish all at the same time. I watched as Amber held my phone and listened to Kyleigh's story.

Shannon M. Turner 25:06

This is a story of how Kylie is making the world, her world.

Shannon M. Turner 25:10

As she listened, Amber got this huge smile on her face like she got it. She really got that she was a part of a bigger story. But all the while I was watching her, I was putting all this stuff into the moment about how unfair it was that Kyleigh's life is so different from hers. After she was finished listening, I even said something like that. Like, “Do you ever get sad that you don't have things like Kyleigh has?” And she immediately said, “No, my life could be like that one day, I will have that one day.” As I drove away from the nursing home, I was like, yep, Amber doesn't feel sorry for herself. And as long as she doesn't, she will find her way out of the situation.

Shannon M. Turner 26:04

I learned recently that the word for power in Spanish, poder, has two meanings. It means both our traditional understanding of power in English, but in Spanish, it also has this dual translation of "to be able to." Ever since I learned this concept, I've been thinking about it a lot in terms of the central challenge that people with disabilities face. As we work together on these projects, our team really had to synthesize the historical, sociological, and current perspectives around why it is that people with disabilities are pushed to the margins, tokenized, silenced, and invisible-ized. We went to this training called Social Roles Valorization that helped us break the problem down into the simplest possible terms. Things we typically place high value on physical prowess, beauty, youth, intelligence, high dollar earning potential, are not usually linked to people with disabilities in our minds. That's why it's so easy for us to say, let a 22-year-old end up in a nursing home for any length of time and just shrug, or to let countless people have their time wasted every single day, because if we see someone as without power, as in the Spanish translation of “not able to,” then we also see them as not having the kind of power that you wield over other people. So, we just don't care enough to fix it. As you think about the people who are going out of their way for a broken elevator, day after day, month after month, remember, Atlanta was able to fix the collapsed I-85 interstate bridge in less than two months because that was important to everybody else, it was a priority.

Shannon M. Turner 27:58

Next time on Hidden Voices, we're going to talk about employment as a key part of the lives of many people with disabilities will learn about an important initiative called Employment First, which is helping more people find meaningful work.

Shannon M. Turner 28:20

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.