Hidden Voices Episode 6 - Employment First

Shannon M. Turner 0:00

So, you just want people to know that you want to say to them let me work.

Tira Harper 0:09

This is America.

Shannon M. Turner 0:21

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 0:44

In my early 20s, I moved through a rite of passage, I embarked on a wandering journey trying to figure out myself and my future. When I graduated from school with an English degree not wanting to become a teacher, I was faced with a job market that was less than friendly. This was before the days of the internet. So, I have these vivid memories of walking around the mall in the tiny Appalachian town where I grew up, filling out one application after another by hand, painstakingly writing about my meager job experience in tiny little boxes. Within two years, I had about 20 jobs. None of them that I particularly like or want to do, nor was I gaining experience to launch me forward. I worked in a bar, temped, did some substitute teaching, lived at a camp, worked at a video store, worked at a bar, you get the picture. But the real problem, I struggled mightily during that time because my vocation was not matching with my sense of purpose. The jobs I had weren't meaningful to me and I don't mean meaningful only in the sense of deep soul level fulfillment, meaningful also includes meeting the needs to sustain my life financially or a job that had the potential to grow into something better. That period of time led me to be in all these jobs where I had no sense of myself and I certainly had no autonomy. My capacity for self-direction felt really limited.

Shannon M. Turner 2:08

Now, there's this stereotype for the typical job that's socially acceptable for a person with developmental disability. Examples for these jobs are, grocery store bagger, bussing tables at a restaurant, a greeter at Walmart, or something similar. These types of jobs can and do have meaning for people, but there's a social glass ceiling that adds arbitrary limitations on how people with disabilities work, and what types of jobs are available to them. Especially if they have an intellectual disability, and sometimes those jobs don't give the personal autonomy and choice over their life. Today, we're talking about the importance of employment opportunities for people with developmental disabilities because employment is an important pillar in healthy actualized life, just like transportation, housing, and education.

Shannon M. Turner 2:57

First up, we're traveling to the middle of state, Macon, Georgia, where the foothills of the Appalachian Mountains give way to the flat plains, and also where you're most likely to meet big storms which cause big tornadoes. Here we sit and visit with Nanditha and her mom Nalini. Nanditha Isaac, or Nandi for short, is a 36-year-old woman with down syndrome and vision impairment. Nandi runs her own business where she scans people's old pictures and turns them into electronic files for archives, she calls it Scan with Nan.

Nanditha Isaac 3:31

My business is a little bit different than most of them, most of them are run by machines and I do it by hand. I like to take pictures, as you see, and I like to look at them very carefully, and I sort them for good quality pictures, in order to scan them, save on a computer, and put on a flash drive. I can save memories and I just love to save people's memories.

Shannon M. Turner 4:00

This is the thing that makes Nandi's business so desirable for people who are wanting their memory saved with care. She sorts all the pictures by hand. She deliberates over each one to decide its merits as a scan-able picture. She truly loves what she does. Nandi got the idea for her business after a tornado swept through Macon. Her mom Nalini shares that origin story and talks about Nandi's journey to finding her purpose in preserving people's memories.

Nalini Isaac 4:27

That's when there was a tornado really, and she realized that there was a need for scanning that people needed to be able to save their memories. When the tornado struck, it struck us that you know, we got to do something with that. So, we actually sat down with Nandi and talked to her, we told her, we’ll support her with these things, you know, we will support you financially, we'll support you with teaching and learning but you have to report to work like it's a job. You have to dress up and come sign in, do what you're assigned and sign out, and it was a contract because we didn't want it to be something that's a hobby. It was a job. So, Nandi agreed and we started on this journey.

Nanditha Isaac 5:05

Homes can be rebuilt but we cannot recreate the memories they once had. I love taking pictures. I do it as a hobby. My new hobby is Scan with Nan and that's how my small business came to be, and that's how KABOOM! It started.

Shannon M. Turner 5:27

When Nandi started her business nearly 10 years ago, she learned how to scan photos at big box stores, and that brought its own challenges.

Nanditha Isaac 5:35

Before I started this business, I went to two different stores. I learned that I was scanning them. The machine didn't work and it destroyed the pictures, the documents and I didn't like that.

Shannon M. Turner 5:52

Do you have a job coach?

Nanditha Isaac 5:54

Not right now. But I used to have a job coach. It's even helped me get more orders coming in.

Shannon M. Turner 6:03

What other help do you need to run your business?

Nanditha Isaac 6:06

I need help with marketing and following up with emails, invoicing, collecting payment, like filing and business forms, etc.

Shannon M. Turner 6:20

As a true entrepreneur, Nandi has other jobs on top of the Scan with Nan business she created for herself. In this job, Nandi is training the very professionals that are providing services to her community. Direct support professionals assist people with disabilities as they complete their daily activities, with this position, not only is Nan continuing to help others in general, but she is now able to give back to her own community. She's helping other people who have disabilities have better quality care, and ultimately live more independently themselves. Like so many participants Nandi's life is made all the more better by having a Medicaid waiver. Here she explains what kind of waiver she has and how it supports her life and pursuits.

Nanditha Isaac 7:04

There are two types of waivers, I did have the NOW waiver. Right now, I'm still working with a COMP waiver. Not only does this waiver support my life, also helped my mom and my dad, my family, and my support staff. I do have a team of staff to help me to live independently, go out of my own community, and help me to network, in order to expand that for my life, for my small business, it would change the huge outcome for me as well. It will change my life and ours. To me my support decision making is very important because of self-direction, I like making my own decisions with my support staff. I love the fact that I make my own decisions, and sometimes it comes from me, not from anyone else.

Shannon M. Turner 8:05

Nandi is a great example of matching a person's interest and skill with her work. With support, she's able to work in a vocation where she feels fulfilled, and Nandi is passing it on.

Nanditha Isaac 8:16

I'm actually a self-advocate, and I love helping people without a voice to come out and come up and to use your voice. Just two worlds there is the community and the disability world and I believe those two have a strong connection. I believe those two need to come together and make a better change, for good because we are just like you, because people with disabilities cannot be judged the way they are, because they had their lives. They want to be self-employed. That's the reason self-employment is very, very important, using their gifts, using their skills, using their talents, and their own time. They can make a change and start doing things on their own. This is my passion. I just love people who have a development disability and who don't have a voice, and I help them. And I just love advocacy.

Shannon M. Turner 9:33

From Nandi, we head out to meet Chad and his mom Kelly who live in Canton about an hour north of Atlanta. Kelly has been slowly working to renovate their small house to make it more and more accessible to having her and Chad staff flow smoothly together. On this day, Chad and Kelly have just returned from a quick getaway to the beach.

Shannon M. Turner 9:52

Hi, Chad.

Chad Roberts 9:53

Hey, I'm good. Thanks.

Shannon M. Turner 9:57

The computer-generated voice is Chad using his assistant communication device. Chad Roberts is a 26-year-old man with autism and bipolar disorder. The way that autism affects Chad's body makes communication different, both in the way that Chad communicates and in his desire to sit down with us and just talk. So, we mostly speak with Kelly, which is fine, she has the story to tell us. Kelly starts us off from the beginning with his early childhood and how his disability was received by professionals and their own family.

Kelly Roberts 10:29

When he was born, we noticed things about six months on, I kept mentioning to the pediatrician and being ignored and being told that I was doing too much for him, his brother was talking for him and, and things but Chad never gestured, he never pointed, he never babbled. When he was about one and a half, almost two, I decided I would change pediatricians, and I did, and on our first visit, he handed me a pamphlet. "17 Characteristics of Autism" and he left the room Chad had 15. So, although he would not formally diagnose Chad, he sent us to the Marcus Center. They did a week-long evaluation, and came in the room to tell me everything, what Chad was never going to do. He was never gonna work. He was never gonna have a friend. He was never gonna ride a bike. He was never gonna play baseball. He wasn't going to learn anything, but we should send him to school, because we would need a break. It felt pretty defeating at the time. I was married, had been married 15 years, my ex-husband and I. He wanted to put Chad in an institution and made me an offer that day, “Either he goes or I go.” So, I'll say goodbye to my husband in my marriage for 15 years and set on becoming a single parent with two children with one having a significant disability. I know the doctors were wrong that day. I set out to prove them wrong about everything. I think I've proved them wrong on everything except for writing a check. I don't think Chad's written the check, but he does cash paychecks every week, and I think that's a lot more important than writing one.

Shannon M. Turner 12:08

Today, Chad has four paid jobs and a couple of volunteer positions at church and in the community. As a result, he happens to be one of the busiest humans on the planet. His journey to this point has not always been easy. You probably notice Chad speaks via an augmentative device called a Dynavox, but as Kelly will tell you, his early life was very challenging before they found a communication system that worked for Chad. He would get frustrated and act out. The acting out itself was often compounded by how people reacted to Chaz behaviors, and in turn, how people reacted to Chad often had limiting effects on his life.

Kelly Roberts 12:48

They were very negative behaviors, he was very aggressive. At one time, I had 27 holes in the walls, he's broken my arm, my rotator cuff in two places and I walked in the emergency room and I was like, "I think my son just broke my arm," and he did, but you know, the funny reaction I got about that was everyone got so mad at Chad. And everyone, everyone just thought he should, I should, he should get punishment. He had to go to an institution. But when I was nine years old, my sister broke my arm, and nobody thought she needed to go to an institution. Nobody thought she needed to be punished. We didn't talk about that every year for 10 years. We got over it. And she did it on purpose. She knocked me off of a teeter totter, and I mean, I was in the hospital for a week.

Shannon M. Turner 13:33

So, we're at this point with Chad, he has some significant behavioral issues and people have gotten hurt before, these things are true. If we take them at face value, the end of the story does really seem to be institutionalization, or, at the very least, not a life that includes gainful meaningful employment interacting with the public. Chad's story doesn't end here, in fact, it began turning before this big situation with the rotator cuff. His story started to turn with the big gains in communication that were made.

Kelly Roberts 14:05

It's made such a huge difference in Chad's life and my life. It's made such a huge difference. When Chad can communicate his wants, and needs, it just takes away the anxiety from him, used to be the doctors had to walk out to my car to see Chad, and now he's laughing in the waiting room. They're so impressed with how well he's doing now with this device.

Shannon M. Turner 14:28

These differences are huge. And it's really important that the difference is felt by Chad and seen by the outside world. It's what starts to crack open the realm of possibilities for what Chad's life does and could look like. So, communication was the first important turning point for Chad. The second: work.

Shannon M. Turner 14:48

Do you like to work?

Chad Roberts 14:51

Oh, oh, yeah.

Shannon M. Turner 14:53

Oh, yeah.

Chad Roberts 14:54

Oh, yeah.

Shannon M. Turner 14:56

As Kelly will tell you, they learned early on that work is so important to Chad, that it made a huge difference in his overall happiness.

Kelly Roberts 15:03

Check out his first job when he was 14, he had a teacher that could see past the behaviors and got him his first job at a law office, and I really kind of thought she was crazy, because he was so loud and disruptive, but we worked through that the lawyer was great. The receptionist was her daughter in law, so, they knew Chad before he went in. And Chad really enjoyed it. I mean, he was taken out a couple of times for being disruptive, but gosh, he's had that job since he was 14. And he probably hasn't had any trouble in 10 years. He does what they call, the jail mail. And it's for people who get arrested, and the lawyer, attorney, solicits business for court representation. So, he matches the correspondence to the letter to the envelope, and voc rehab tri fold letter folder that was one of the supports they provided and he folds the letters and puts them in the envelopes and then takes them across the street to the mailbox and mails them.

Shannon M. Turner 16:06

So, his first job that he started when he was 14, he still has it. That's some employee loyalty. But now Chad actually has several other paid positions as well, including cleaning for a gym and a chiropractor and working in the kitchen at Pizza Hut. One of the things that makes all this possible for Chad is that he has a job coach named Reggie. Let's hear from Reggie what it's like to go to work with Chad.

Reggie Mack 16:28

No matter how like complex it is for him, he's still he's able to accomplish what needs to be done. Whenever we're working at Pizza Hut, I don't know what they do when we're not there. It’s just packed. So, it just shows, if his mind is set to do it, he's gonna do it.

Shannon M. Turner 16:46

Again, that job coach Reggie helps Chad keep working. This is one of the places where the Medicaid waiver and using it to its fullest potential can make a huge difference in someone's life because Chad has a job coach who goes to work with him, he helps Chad stay on track and negotiate his work life, but it's important, he's not doing Chad's work for him, and he's keeping Chad's professional life, just that, fully professional. It's the kind of accommodation you might ask for in any other situation. If you had carpal tunnel, you might get a special keyboard, or if you had trouble filtering out your noisy coworker, you might get some noise cancelling headphones.

Kelly Roberts 17:25

You know, there's been some hiccups in the road, it's all about the supports that he's had. I mean, it's so much more than just a job, you know, for Chad. It really gives him purpose and meaning, he gets to ride the bus to his jobs. It's about the only thing he gets to do independently, it really does give him a purpose and a sense of belonging, and he's building relationships with people that he wouldn't have if he had been sent to a day program or they were just congregated, segregated settings and didn't have the opportunities that he has. He has one-to-one support through Medicaid waiver and we self-direct all the services except for supported employment. He's got a COMP waiver through Medicaid, and his one to one support is based upon his needs that we've done evaluations, and when he goes out in the community, he always has one-to-one support. In the community, he volunteers at pretty, quite a few different places. He has a volunteer position at Reinhardt University with the football team. He volunteers when he has time at our church to help the custodian, he also has his own ministry through our church. They found out, someone in my Sunday school class found out that Chad like to rip paper and so our church started they have a big hamper, and people put papers in it on Sunday when they come to church and Chad does during the week and shreds the papers and then takes them to the animal shelter and they use them to line the cages with.

Shannon M. Turner 18:52

What a lovely match between someone's interest and skill and a need in the community. With it we all have the ability to live in that intersection, Kelly tells us about her advocacy work and the work that Georgia is currently doing.

Kelly Roberts 19:06

Right now, I have focused my advocacy on a couple of different services that are in the COMP waiver. Supported employment, I think is the most important service that our state offers. I just went to a forum, and our state is doing some amazing things and has some great goals set. Within five years, they want to have three times as many people doing supported employment that are with disabilities that are now receiving it. But there's so much more than just getting a job. You know, it's all about the supports what for that person, and like for Chad, if he gets a job, the week before he starts, we’re driving there every day, we're taking pictures, we're talking about it. We'll get out and walk the building, and we just really, you know, try to plan and do that. As far as being in advocacy, I've been able to help several families in our community and get into services. I'm really happy to say that I've been able to do that and I try to reach out and help as many families and share what we've been able to accomplish.

Shannon M. Turner 20:05

That state forum Kelly is referring to is a Georgia Employment First effort. At the core of the Employment First movement is the drive to match a person's livelihood with her interests and skills as anyone should get to do. Through this series, we've explored how life for people with disabilities has changed substantially in the last 50 years, thanks to court cases and evolving resources and perceptions. If you do not have a person with a developmental disability in your life, you might not be aware that there is a huge national movement for those folks to have the opportunity to get out and work, like to have significant work that's driven by their own interests, skills, and passions. Everyone deserves to have work that's meaningful and challenging. The Employment First movement is a national movement to do just that, a call for a framework for systems change that is centered on the premise that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life.

Shannon M. Turner 21:05

In 2018, here in Georgia, we passed a bipartisan bill which established employment as the first and preferred option for all people who want to work regardless of their disability, and this legislation was backed by research that shows that states that have embraced Employment First policies show encouraging results. The state of Washington, for example, has the oldest such policy in the country and as of last year, 86% of people with intellectual or developmental disabilities are getting state funded services and are either working or preparing to enter the workforce. When the bill passed last year, that number hovered around 13% in Georgia, the United States Congress is also taking steps to implement Employment First policies. The transformation to Competitive Employment Act is making its way through the House and Senate and seeks to expand opportunities for integrated employment while phasing out subminimum wage certificates that allow people with disabilities to be paid less than the federal minimum wage. Chad wants to work, it's his whole life. Everything about his life hinges on his ability to work.

Kelly Roberts 22:12

I would really want to, like, take a hard look at Chad and imagine if you have somebody that you love in your family like this and what you'd want their lives to be like. He deserves every opportunity that other people have. I can only do so much. I have pushed the doors open for Chad, I've advocated and got the doors open, but Chad Roberts has done the work. He's the one that shows up and does the work and he's proven it to us over and over how work is important to him.

Shannon M. Turner 22:46

From Chad, we had to meet Tira and his assistant Barbara. We meet them in like Lithonia, a suburb east of Atlanta about 20 minutes outside of the city, sitting down in a conference room at his day program, KES, Tira and Barbara seem glad to have the opportunity to talk about their lives and how they work together.

Tira Harper 23:05

I am trying to be more independent

Barbara Branch 23:11

Independent, independent

yes

he’s trying to be more independent.

Shannon M. Turner 23:16

Tira Harper is a 35-year-old man with cerebral palsy who lives in Lithonia Georgia. Most days during the week he touches in at his day program KES with Barbara Branch, his community living support assistant, but then the two of them get out into the community as much as possible. When we meet with them on an early spring morning, they are just getting started on their day. Tira and Barbara's relationship transcends the norm. You can tell it's been forged with trust and caring. They are truly a team. When they're out in the community, they are getting things done. Tira disability affects his speech. As a result of their long relationship, Barbara understands him and serves as his translator. Tira tells us what his life is like and how he and Barbara fit as a team.

Barbara Branch 24:01

Every day, he wants to go to the library. I take him to the Value Village, Goodwill. These are the places and the choices that he decides where he wants to go. And I take him out in the community, Walmart so a lot of things, doctors’ appointments. All these things, we make sure that he gets on.

Tira Harper 24:20

I am up on everything because of Ms. Barbara.

Barbara Branch 24:28

He says, "I am up on everything because of Ms. Barbara."

Shannon M. Turner 24:32

Tira is known and welcomed in the community happenings all around Lithonia. In fact, a lot of folks refer to Tira as the mayor of Lithonia.

Barbara Branch 24:40

He has several plaques that they have awarded him with. He also has been in two plays, and have awards, you know, been involved in a lot and he'd be so happy but

Shannon M. Turner 24:55

Tira has been working or trying to work his whole adult life. When we first met him about a year ago, he was helping out of the local tire store, moving inventory around and doing general tasks. Tira enjoyed being there and working, however, he wasn't always getting paid for that work. Things changed for him in the year since we met and he moved up to being paid, then he worked for a while, but it was short term summer work.

Tira Harper 25:22

I worked at Martin Tires.

Barbara Branch 25:31

At Martin Tires, he works there. They let him work on the weekend on a Saturday, rolling the tires, they look at him also as a liability. You know, you are working around tires when you change tires and stuff like that, but being that people in the neighborhood know him. They let him roll the tires and they pay him and they do he always wanted a job but he definitely going to need someone to be with him.

Tira Harper 25:56

I want a job but I need help.

Shannon M. Turner 26:02

Tira has been trying to work for years to land a job at Wakefield, a local grocery store that would be so conveniently located as it sits across the town square from the Lithonia City Council offices, the library, and not far from his home. For a while he was even volunteering there too, bagging groceries for free to try and get a foot in the door.

Tira Harper 26:22

I really wanted to work in Wakefield.

Barbara Branch 26:27

He said he really wants to work in Wakefield. That's a supermarket.

Tra Harper 26:31

Well, it’s right there

Barbara Branch 26:35

He said because it’s right there.

Tira Harper 26:36

Its a lot better on me

Barbara Branch 26:42

It's a lot better on him, it's closer to home. This is what he's trying to say is he knows everybody

Shannon M. Turner 26:50

Sounds like a good fit, right? Well, even with Barbara’s support, Tira gets nos from jobs he'd like to have. Tira has been viewed and subsequently treated as a liability. And that has been a common theme in his life. This sort of prejudice and stigma. Well, it's a poignant example of what the Employment First Movement is working to change.

Tira Harper 27:13

I would be a liability

Barbara Branch 27:15

A liability that's what he's saying. I know I'm a liability but don't nobody want to hire me. I tell him, Tira, I keep telling you, you can't talk like that with me. I don't use that word. I don't like that. Cuz you can do it. You can do it. You got a brain. You got this. You got that. That's how I talked to him.

Shannon M. Turner 27:33

Tira, do you ever get tired of people telling you you're a liability?

Shannon M. Turner 27:38

You say that enough that it makes me feel like you just been told that so often that that's becoming

Tira Harper 27:44

All my life.

Barbara Branch 27:45

All his life.

Shannon M. Turner 27:46

Tira is loved and known in his community, benefits from a primary support relationship from Barbara, and has the drive to engage and succeed in his life pursuits that rivals students in their first year of law school. And Tira's experience is an unfortunate example of what happens when not everybody gets on your train. In Tira's case, that train is his desire to have meaningful work, and his struggle highlights how hard it is to fight that uphill battle. If everyone sees you as a liability, and not as an asset, then how are you going to get a job?

Shannon M. Turner 28:24

Tira? What do you want people to know about your life?

Tira Harper 28:28

I am a good guy, and I want to work but I need an opportunity.

Barbara Branch 28:44

He's a good guy. He just needs opportunity, you know, and he'll help anybody.

Shannon M. Turner 28:57

Our next episode of Hidden Voices will be the final episode. This season, we're going to take a 360 look at where we are now through the beautiful, complicated lives of Callie and Michael. These are two stories that will reveal how we're doing in the state of Georgia and how far we have left to go.

Shannon M. Turner 29:22

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