Raisa Habersham 0:00

Ryan, I wanted to ask you, how do you feel that Royce has changed your life?

Ryan Howell 0:06

It's been awesome. It's been so awesome, since he changed my life.

Raisa Habersham 0:19

Welcome to Hidden Voices, I'm your host Raisa Habersham. Join me on my journey to learn more about the experiences of Georgia residents with developmental disabilities guided along the way by my co-host and mentor, Derona King.

After hearing Nick's story, I was devastated. And I was angry, angry, knowing there are young people with disabilities caught in a system that seems designed to keep them trapped in nursing facilities. A system that seems designed to exploit the people it's supposed to care for a system that robs people of their autonomy. I mentioned in the last episode that my grandmother was in a nursing facility at the end of her life. Talking to Nick made me wonder what kind of treatment she had actually endured during her time there. Has she been well fed? Did nurses respond properly when she called for them? How will taking care of what she really I've never asked my dad about it. In the year since she passed, I've avoided those hard questions and tried to focus on the happy memories instead. Still, I wonder what someone in next position could do. He's determined to find a system designed to work against him. And he already works with an attorney. But what gives me the most hope is that Nick has become his own greatest advocate. I talked to the owner about Nick's situation and what could be done? What happens in a situation? Right, next? You know, is there anything being done about a situation? Or is there anything that can be done at the state level?

Derona King 2:14

So at the state level again, next, another number, there are around 6000 people in the state of Georgia who are on this list to get a Medicaid waiver? So, again, we go back to commoditizing people? And the answer is complex. But what what we do know is the answer is not just we have to wait for the state, we have to wait for the system to fix this. It's a dollar and cents games until we can convince our systems that the human beings are more important than the dollars. It's an uphill battle.

Raisa Habersham 2:54

You know, Nick seems to be his own advocate and his situation. What can one do? If they are next situation? How can advocacy help?

Derona King 3:08

Advocacy is an opportunity for people to have a voice for themselves, the most important thing that can happen is for people who are in his circle for people outside of the system, to continue to help him raise his voice and to advocate with and alongside of him to consistently and repeatedly go at the system for help.

Raisa Habersham 3:28

You know, I'm frustrated for Nick. And I imagine people listening are also frustrated on his behalf. You know, what can they do to become advocates or activists, for him or someone like him?

Derona King 3:44

We know I think if we deflect our corporate consciousness from my tax dollars are going so that some expert can make the right decision for nit to really begin to assuming some knowledge base of what is happening for people who are living in experience like Nick, Nick is not an anomaly. Nick, is status quo. Nick's experience isn't some outside experience of waiting for five hours for someone to to get him out of bed. It's almost standard operating procedure. For example, hidden voices is offering a solution by opening up opportunities for people to learn what the lived experience is for people with disabilities.

Raisa Habersham 4:43

I love that you said that because I think a lot of times people do tend to look at certain issues as this is not a me problem. And that's a problem in and of itself. And the more reflective people can become and the more they realize, you know, it's more than just me. I think we'll see more inroads. I hope we'll see more inroads.

Derona King 5:12

It really is a changing of attitude for the community for the society, on how we perceive people with physical or intellectual or mental health differences. We need more typical people aligning themselves with people who are considered Other than that, and we need to see each other for our gifts and capacities, rather than what we think those differences are. That's the protection, that's the safeguard. That is what Nick does not have, he hasn't had a personal visit in at least nine months. So the safeguard is gone. So the answer is, again, that to the same answer, you have the power, I have the power as just an ordinary citizen, I don't need to have a dictate or regulation or prescribe anything to have a relationship with someone, like people with disabilities are entitled, according to the ADA and the Olmstead decision to freely given associations, Nick doesn't need permission from the facility to have friends. It is a right, it is a human right.

Raisa Habersham 6:23

What could the future look like if you know more people committed to being active advocates?

Derona King 6:30

As a taxpayer, just imagine, if the tax paying citizenry of the state of Georgia, collectively rose up and said, the way we engage or treat people with disabilities with our state dollars, is unacceptable. And as a voting citizen, I'm no longer going to vote for people who want to push people with disabilities to the bottom or the edge that we're no longer going to accept people were being treated with hand me downs and what is left over. I think that could change for the positive what the future could look like for all of us. But the beginning step is being made aware, which of course is what this work is doing. It's being made aware that things are not equal. So we are the answer.

Raisa Habersham 7:28

Nick’s situation made me wonder if there are other people who advocate for themselves the way he does. Derona suggested I speak with Eric Naindouba, a 16-year-old student from Clarkston with cerebral palsy. Originally from the Central African Republic, Eric and his mother Nestorine, fled the country and came to the U.S. when Eric was small. Ben Krysiek is Eric’s caretaker and is helping Eric communicate during the interview. Even though Ben is paid to be in Eric’s life, they have a mutually beneficial relationship.

Ben Krysiek 8:03

Every single day that I come here, he cheers me up, every single day. And that's how I would describe a relationship. It's just that simple. I was really nervous when I started working with Eric. I was, I was because I'm gay. But I told him, he asked me one day I was like, Hey, are you gay? And I said, Yeah, and he didn't care. And that was that. But I was shocked by the love and the respect that he gives me. So I think it's been consistently a crazy fun relationship. And then it's been a very, like, loving and honest relationship and friendship. So it means a lot to me. And I haven't even told Eric this, but especially after, before I was working with him, I was an English teacher in Nagasaki, Japan. And, um, I, I, I had some pretty interesting experiences where I had some co-workers, the first week that I started there that out in the office, I felt really sort of betrayed and not safe, but I feel really safe when I'm with Eric.

Raisa Habersham 9:29

I think that sort of goes back to the intention behind mutually beneficial relationships. Yeah, for sure. Eric has an advocate named Cathy Frankel who supports Eric self advocacy efforts. Kathy was a physical therapist at Eggleston hospital when she first met Eric and his mother. She felt compelled to help Eric and his family who were recent refugees. We can hear Kathy talking more about Eric's story in this video.

Kathi Frankel 10:01

Unfortunately, when he was born, it was under a lot of duress. And he suffered some brain damage. And he now has cerebral palsy. But he's very smart. But his body, he can't control his muscle movements. The magical thing about Eric is with the right supports and the right people, he's going to make a lot of progress.

Raisa Habersham 10:30

Kathy has been there for Eric when he's had to advocate for himself. Like recently, when he wasn't given the option to go to college as part of his IEP plan.

Ben Krysiek 10:41

When Eric had his transitional IEP, going from middle school going into high school, one of the things that he was asked to fill out was this paper. But on this paper was asking questions about things like, you know, what are your plans in high school? Like, what do you do at home? You know, what do you do on the weekends? Like do you participate in after school activities? And then what do you plan to do after high school? And there weren't preset options that were filled in, like living in a group home or living in all these different types of living environments. Do you plan to live at home with your family? Do you plan to get an apartment? There was nothing about going to college on this paper. There was nothing about it at all. And I remember I talked with you about it, Eric, obviously. And what you were saying, I know you talked about it a bunch because I knew you were upset, and I was upset and then Kathi was upset. But your current OI, orthopedic impairment manager/teacher, whose name is Ms. Seal said, that's ridiculous. College needs to be an option on this paper.

Eric Naindouba 11:58

The paper only said a little bit.

Raisa Habersham 12:19

Eric's network of support is crucial in enabling him to more easily advocate for his needs. For instance, it was Kathy who encouraged Eric to start a weekly Meetup group at refuge coffee as a way for him to connect with his community. with Ben support, Eric would meet at the coffee shop every Saturday sharing space with people and building the bridge between stranger and friend. This allows for Eric to meet new people engage in discussion around advocacy, and mentor others on how to be strong advocates.

Unknown Speaker 12:50

You said, Kathy, and you decided you wanted to make your own advocacy, right? And so, I started helping you when I started working with you, right? And then I helped you decide that you wanted to do a meetup every weekend once a week at Refuge Coffee, right?

Eric Naindouba 13:19

Yes.

Ben Krysiek 13:19

Okay. And, well, not just somebody a lot of people knew you when you were there, right? There were a lot of people that knew you. Yeah. Everybody. When you meet people, or how do you help them become better advocates, especially at the coffee shop? What do you do with them? What do you tell them?

When you're with somebody, you shouldn't talk over them or step over them or try to make decisions for them. You just need to help them make decisions for themselves right?

Raisa Habersham 14:06

Much like Eric, Ryan Howell has had to learn to advocate for himself. Ryan lives in Southwest Atlanta and likes to draw comic book characters. His artistic abilities are a passion he shares with his Citizen Advocate, Royce Bable, who was in the performing arts program at Tri-Cities High School in East Point, Georgia. The two met in 2015 through Derona and Citizen Advocacy. At the time, Ryan had just lost his job and Royce was coming back to Atlanta after traveling through Southeast Asia. While Ryan has a passion for drawing, his interests span beyond that.

So outside of drawing and your artistic abilities, what other interests do you have Ryan?

Ryan Howell 14:53

I play, play video games all the time.

Raisa Habersham 14:57

What's your favorite video game to play?

Ryan Howell 15:00

Like racing, wrestling. It's kind of fun. And there's a lot of movies on Hulu.

Raisa Habersham 15:09

Do you have a favorite movie?

Ryan Howell 15:11

Yeah, just got done once a Bombshell.

Raisa Habersham 15:14

Bombshell? I haven't seen it, yet.

Royce Bable 15:16

It was good.

Ryan Howell 15:17

Yeah, it was good on Hulu.

Royce Bable 15:19

Mm-hmm. Yeah. Check that out. We were just talking about, about that. Yeah. So Ryan, you like, you like, you like comic books. You like video games. You like movies.

Raisa Habersham 15:29

Before becoming Ryan’s citizen advocate, Royce had heard about the organization through a friend who sits on the board. But what really drew Royce in was the opportunity to expand his thinking beyond his own lived experiences.

You know, I have to ask Royce, I know, you mentioned that you and Ryan had a lot of things in common, what made you decide to be a citizen advocate?

Royce Bable 15:52

I’ve been able to get a, a really different perspective about his experience, just in like, what it—you know, just to understand how he moves through the world, and then how someone like him moves through the world, and opportunities that are not afforded to him just because of their situation, whether it’s, you know, something that they’re born with, or something that, you know, financial situation, or what have you. It’s a totally different existences. Because on the surface, yes, we’re both black men around the same age, from the same part of town. But we’ve had very different experiences in the world. And that’s been the most eye-opening thing for me, is just to understand his experience.

Raisa Habersham 16:40

And so Ryan, what have you learned from Royce?

Ryan Howell 16:45

Well, get out of the house, have fun and make new friends.

Royce Bable 16:55

Yeah. Like, I'm always encouraging Ryan to, um, to get out and just go have fun or do something that he wouldn't normally do. So I think we've kind of bonded over that as well.

Raisa Habersham 17:08

Before the pandemic, one way that Ryan and Royce spent time together was at the cultural and live events that Royce hosted, where Ryan could mingle with other people who shared his interests. But there was one particular incident that was scary for both of them.

So Royce, how do you play a role in that and ensuring that Ryan has a say in his autonomy, him wanting to be independent, but still respecting his personal space and ensuring that no one does take advantage of him?

Royce Bable 17:37

Yeah. I think, um, the way I've tried to do it is invite him into spaces that I can control, at least that I can at least have some sort of control in some way of the environment, and then just kind of let him do his thing. Like, any time he's either come to a party of mine or come hang out, like he does his own thing, which is great. And then he'll be talking to my friend, or you know, doing something, but still, I trust everyone in that space. But there have—there was one particular incident where I thought it was controlled, and it wasn't controlled... and it gave us a little, a little bit of a scare.

Raisa Habersham 18:15

How did you feel about that, Ryan? That incident?

Ryan Howell 18:19

It was good. A little unsafe, but I got used to it. And I did—that's when, that's when I was down at the Lil Wayne concert. I thought I had a... first time I heard a gun, fireworks up but it sounded like gunshots, anyway.

Royce Bable 18:42

Yeah, but you know wasn't so essentially want to walk her through what happened?

Ryan Howell 18:47

Yeah. I was having fun, seeing Lil Wayne, minding my own business.

Unknown Speaker 18:53

So he was helping, he was supporting my team. I used to work at a festival here called A3C, and he was, he was basically serving as my assistant that day.

Ryan Howell 19:00

I was recording Lil Wayne.

Royce Bable 19:02

Yeah, he was recording Lil Wayne, who was about to perform, who was the headliner, and then go-

Ryan Howell 19:06

And then, first off, people was trying to [inaudible]. First off, I heard fireworks going off, and I'm like—but it wasn't. It turns out I found the hard way that they were gunshots going on. I thought that security got this, got it taken care of. Didn't got it taken care of. They had put a sign that said "No guns" to line up.

Unknown Speaker 19:31

So basically, he was helping me out at the at the at the concert that day, little one was the headliner. He was in front, he was recording Lil Wayne set. And in that moment, something happened where people thought there was a gun at the festival and there In fact, there wasn't everyone just started to run and without knowing what was going on. So people got trampled people were like, our entire full tech house on the Sunday of the performance, cleared out in a matter of minutes.

Ryan Howell 20:01

It was all over the news.

Royce Bable 20:03

Right. And then we lost each other. So, Ryan, that was the scary part.

Ryan Howell 20:08

I had to wait. And the worst part to see yourself made it out there alive.

Unknown Speaker 20:13

So it was, it was like chaos, and everyone was running. People were being trampled, climbing over fences in the middle of downtown Atlanta. I had—didn't know where Ryan was.

Ryan Howell 20:22

I was running so fast anyway. Yeah.

Raisa Habersham 20:26

It’s the kind of moment that can send anyone into a tailspin. But it was also the moment when Royce realized that Ryan can take care of himself.

Unknown Speaker 20:35

Hm. Yeah, but when that happened, I realized that Ryan actually, you know, knew what to do. And that he, you know, he—that's who I was freaking out about the most. I was like, I have no idea where Ryan is in this sea of chaos. And I was kind of responsible for him. But then it took me a minute, and I was like, oh, a logical—the logical thing to do would be—

Ryan Howell 20:59

Then my instincts started to kick in.

Royce Bable 21:01

Yeah, your—his instincts kicked in. And he ran back to the car. And that's where I met him.

Ryan Howell 21:08

Mm-hmm. I just want to make it out of there alive.

Unknown Speaker 21:11

And that definitely showed me that like, Ryan definitely knows what to do. So I don't, I don't really fear for his safety. I don't.

Raisa Habersham 21:24

Do you think that that particular incident kind of shaped you more as a citizen advocate?

Unknown Speaker 21:31

Yes. Yeah, it did. Um, I mean, that was a real test. I was like, I really didn't know what was going on in overall. And then especially with Ryan, so it definitely helped me. I mean, it was a test on our friendship, too, because Ryan was pretty shaken up about it. And, and so then I kind of felt responsible, but I think you got over it. Right?

Ryan Howell 21:54

Yeah. I faced my fears, so I faced my fears.

Raisa Habersham 21:59

The incident brought Ryan and Royce closer together, and made them realize how important they are to each other. Ryan, I want to know, can you tell me what Royce means to you?

Ryan Howell 22:11

He's like a brother to me. So, he's been there for me from day one.

Raisa Habersham 22:19

So he's like family for you at this point?

Ryan Howell 22:21

Yeah. And we're gonna take that seriously. It's been awesome. It's been awesome since he changed, since he changed my life.

Royce Bable 22:34

In what way?

Ryan Howell 22:35

In a positive way.

Raisa Habersham 22:38

One final question. You know, I know you touched on this a little bit, Royce, but, you know, what do you think you're learning by being Ryan's citizen advocate?

Royce Bable 22:49

What am I learning? I'm, I'm learning a lot. I'm learning patience. I'm learning, um, perspective. —I'm learning how disadvantaged he is. And what I mean, I don't mean like, Ryan in particular. I mean, Ryan, in particular, but also anyone else who's in his situation. You know, I see that this society is not set up for them fundamentally, you know, and it's very, it's frustrating for me sometimes, because I have perspective. I think that's something for me that has been a resounding lesson is that, you know, just the perspective to understand how much everyone else needs to be putting in and how much more we all need to be doing to make this world more equitable, really, because there's so much more. This is only—you know, my relationship with Ryan is only the first step. And it's only the entrance to this type of thing. And it's the way I'm, I've committed to making a difference. But there are so many more people with experiences like Ryan that don't have normal interactions with people or consistent interactions with just society. And I think it's incumbent upon us to really make more of an effort to do that, and to reach out to people who may not have this, who may not have situations that are equivalent to ours.

Raisa Habersham 24:19

What do you think others should do to be more inclusive?

Royce Bable 24:24

I think the first thing, I don't think anybody learns without perspective. I don't really think that people—just going out and doing community service or something one time, doesn't really give you the consistent perspective that you need to understand why people are disadvantaged. And I think one thing that I encourage all my friends to do and that I would continue encouraging anybody to do is just make some sort of a relationship with someone. It doesn't have to be formal. And that's why I like Citizen Advocacy, because I don't do well with formality. And it's allowed us to create our own thing. But I think that people, to make the world more equitable, need to do something to get out of their comfort zone in order to understand why the world is not. Because I think people don't even have a perspective as to why this world is not equitable. They just understand that I can do this, or I can pay for this. And I can walk up these steps, or I can go in here and swipe my card and do this thing. But there are so many people that haven't even made it to the bus to get to that place where you just got in your car to drive. They can't even go to the bus because they can't walk to the bus, or so many things before you, before, you know, you've already reached step six, and they're still on .5. And that, I think it's important for people to align themselves in a real way with someone that comes from a totally different situation to really understand someone else's perspective before they can act, because you can't really act without understanding why you're acting.

Raisa Habersham 26:01

Speaking with Eric and Ryan left me hopeful for the potential impact of advocacy. And getting to know Royce showed me what it can look like to be a true citizen advocate. Ryan and Royce’s relationship reminded me so much of Garrick and Nazir from Episode 1. These were real, authentic, and genuine friendships. Throughout these conversations, I’ve seen time and time again how much value these relationships can bring to someone’s life. No man is an island, and I’ve come to realize that the mutual nature of their relationships is what makes it so strong. I felt like I could finally articulate to Derona the growth that I’ve had on this journey.

I'll start with Eric, I think what stood out for me for Eric was the fact that he speaks for himself. He's going to advocate for himself, he's going to speak up on his behalf you're in, there's no telling from one like him, no. And he has an attitude. But it's combined with the fact that he has people in his life, who deeply care about him and support him. But the fact that he's just very much a proponent of his own self advocacy, and that of others, is the change that we all hope we can be in the world, from my viewpoint, at least, because he's not just being mentored. He's mentoring someone else, who he then hopes will mentor someone else. And it just very much reminded me of the conversation with Nazir and Garrick and how Nazir, yes, he's being, he has a citizen advocate. He's being mentored. And he's doing the same thing with those that he knows. And it creates a positive cycle of ensuring that yes, somebody is being an advocate, but also that they're having this inclusive mindset. And it brings me to Ryan and Royce and Royce's comments about perspective. Because you have to be able and be willing to change your perspective and see through another person's eyes in order to get to that change.

Derona King 28:23

Raisa, I think you made it. I think you crossed over from where we began, right? I just heard you say, thinking about where where we started, of breaching to this point of going, Oh, this is really just about two people benefiting one another, based upon more the things that they have in common, rather than the things that are perceived as different. But the fact is, there is no special training for Royce. There's no special technical thing that he needs to know, he just needed to be a human being open to another human being.

Raisa Habersham 29:10

And caring. You know, I think about the event that Royce said he hosted and that Ryan was helping him. And when chaos broke out, you know, his immediate concern was for Ryan, like, "Oh my god, did he make it out safely?" You know, he was very concerned. But his perspective also changed. It was almost as if initially, yes, Ryan is a friend. But he also looked at him as a friend he needed to protect when he had to come to terms with the fact that, "Ryan is his own person, and his instincts will kick in.

Derona King 29:52

I think that was a pivotal moment in the in the direction even though the relationship of Royce recognizing this man can take care of himself, in many ways that people don't give him credit to. The only way to really get that perspective clearly is to get up close and personal his words where you know, you're not going to get that in the, in a one day volunteer kind of a thing, which is great, every please, people who are listening, go do one day volunteers, people need you. But that's not relationship building. And it would be very difficult for meaningful advocacy to happen for Ryan, if voices role was to drop by, you know, just once a month, right. Or if he was on some type of check in clock and do your do your duty and report back something to someone. This is literally about two guys getting to know one another. And both of them experiencing the vulnerability that human beings experience when they get up close and personal to one another, over the long haul. So they're, you know, they're at the beginning of a journey that some people have been on for 30 or 40 years, and citizen advocacy relationships. Imagine the significant change that will occur in each of their lives and another decade, and the influence that will have on the community around each of them. They're modeling to their community, what inclusion looks like.

Raisa Habersham 31:36

And you know, for me, that's so it's refreshing in the sense that I think about black community and the images that you do see in the images that you don't see. And you don't often see in our community, the interaction of you're able bodied, non disabled black person, and a person with disabilities. And it also creates this image of it does not affect black people, or it affects them differently. But seeing Royce and Ryan's relationship it is modeling for their community. I think it means a lot to me, having grown up in southwest Atlanta, and, you know, just knowing the kind of neighborhoods that we have, and seeing their relationship and seeing what an inclusive community could be, and should be, and looks like.

Derona King 32:34

I think that if we consider we've mentioned this previously, as well, 20% of the population when everybody versus the person with a disability, this little significant number of that percentage, were supported and empowered by neighbors to exercise their right, because you're going to vote, you're going to advocate for yourself, you're going to vote in your own self interest. And there would be a change there. So there's there's lots of room for us to grow, at every level at the personal level. And then at the at the larger level at the state, county state and the federal level for people with disabilities to have their voices heard. But it begins with individual people understanding this kind of upside down society that we live in, that does not it does not play fair for people with disabilities, voice use the word equitable, it isn't equitable. And at the grassroots level, I think that's where equity begins.

Raisa Habersham 33:35

I always try to learn something anytime I'm talking to someone anytime I'm interviewing someone, and just giving them that opportunity to tell what's going on in their personal life. I think for me, it's important because you're literally giving a voice to people who have gone almost unseen, or practically unseen. Society has told people with developmental disabilities, either directly or inadvertently, that they don't matter. And this offers a platform for them to say up Wait, Yes, I do. And to highlight some of the barriers that have been in place for people with developmental disabilities. So I think for me, it's important that we tell these stories, so that perspectives can change. Once you at least bring it to someone's attention, and they start listening a little more, that's when that perspective can change. And that's when someone will actually have more gumption to interact with someone with developmental disabilities and actually get to know that person like they would a neighbor or even better than a neighbor, a friend. There shouldn't be an attitude of you're caring for them. As if you work for them. It should be you're caring for them because You love them. Because to that same extent, someone with a developmental disability is then gaining perspective from you and your experiences. So you're not just expanding your own mindset, as a citizen advocate. You're also helping to expand that person with developmental disabilities mindset that they can become more than what society has said this is available to you.

Derona King 35:28

Okay, thanks, Raisa. What a great journey. Thank you for allowing me to take the ride with you.

Raisa Habersham 35:38

At the beginning of this journey, I didn’t know what to expect but I hoped I would gain a better understanding of those with developmental disabilities. I learned the many ways in which they are segregated from their peers in education. And I learned about how nursing facilities work against people with disabilities seeking their independence. But I also learned the importance of self advocacy in situations that work against people with developmental disabilities. And I’m still learning. I think constantly about what an equitable society would look like for people with disabilities. I also think about how I can center more people with disabilities in my reporting. But more importantly, I’m learning how to be a more inclusive person by challenging my own conscious and unconscious assumptions. I invite you to continue your own journey by building relationships with people with disabilities in your own communities. I also invite you to be a part of the community that made this season of Hidden Voices possible. Become a grassroots advocacy member with the Georgia Council on Developmental Disabilities. Join L'Arche Atlanta, a community of people with and without disabilities, sharing life together. L'Arche's community events bring together people of all abilities for times of fun and friendship. Find out more at www.larcheatlanta.org. Citizen Advocacy invites you to get to know your neighbors and discover the unique gifts we have to share with each other. Contact your local Citizen Advocacy office in Atlanta and DeKalb, Macon, Athens, and Savannah to see how Citizen Advocacy can help connect you. Find out more at www.citizenadvocacyatlantadekalb.org or email us at citizenadvocacyad@gmail.com.

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