



## Atonia Green Worley Transcript

LeDerick Horne (0:00 - 0:21)

The New Jersey Council on Developmental Disabilities provides information to help New Jersey residents with developmental disabilities and their family members. You can learn more about the council's work by visiting their website, [www.njcdd.org](http://www.njcdd.org). All right, everybody, welcome to the podcast.

LeDerick Horne (0:22 - 0:54)

I'm LeDerick Horne and I'm really excited I'm here with Atonya Worley. We've gotten to know, what has it been? Has it a year and a half we've gotten to know each other?

Yes, that's about right. And she is an amazing individual, amazing advocate. And in sharing these stories about the Black IDD experience, I knew she was one of the people that we wanted to be able to talk with and learn from.

So, Atonya, can you start out by just telling the audience, how do you describe yourself? Where are you from? And what do you do for work?

Atonia Worley(0:57 - 2:13)

So, yeah, describing myself, I would say primarily a caretaker. I'm an advocate, I'm a caretaker, a mom, a wife, a giver. I'm a giver.

I grew up in East Orange and Orange. We moved around a lot. We were poor.

And I've always been a caretaker. Um, even when I was younger, I had to care for my mom. She's mentally ill.

And then as I became, went into college, I had to adopt my brother. I was 19 and he was six. So I always was a caregiver.

And then I had a family, I grew my family and my son, who is the youngest out of four, um, was diagnosed and then I had to be a caregiver to him. So that is been my chief role from a small child. So, um, yeah, I became a parole officer.

I worked in the criminal justice field for over 30 years and that was caregiving as well.

LeDerick Horne(2:13 - 2:14)

Right. Right.

Atonia Worley(2:15 - 7:07)

I, although the, the role was to get them, the people that were the offenders, the ex-offenders, when they came out to comply, they needed a lot of services. You know, it wasn't just comply or you go back to prison. Um, sometime we were starting from the ground up where they came out with absolutely nothing.

So that was a caregiver job. And I always saw that job as, uh, before the grace of God, there goes I, I could have been one of those offenders. So, yeah.

So I worked in the criminal justice for 30 years, um, in a criminal justice field. And then I retired in March of 22. And then I started volunteering in the, uh, uh, disability field, um, for an organization that works with autistic families, marginalized autistic families.

So I volunteered and that just parlayed into many different roles within that, uh, volunteerism. Okay. All right.

And then, um, you, you, you, I think you've already touched on it as far as your connection to the IDD community. Maybe you can go into a little bit more detail. You said that your son was diagnosed.

Can you talk about what he was diagnosed with? And then I'd love it if you can give any advice to, uh, black family members who have a loved one who maybe has just received a diagnosis. Right.

So at age two, my son was diagnosed with autism. It was devastating for us. We knew absolutely my husband and I absolutely nothing about autism and the, uh, developmental pediatrician who gave us the diagnosis was cold.

She said, this is what it is and deal with it. As we were crying, you know, trying to figure out what was the next steps. Um, for me, the, what I would tell parents and what I did, I found a support group immediately.

And that was a lifesaver. I went to a parent support group. Um, I met these wonderful parents.

They gave me direction. Um, I started to, uh, obtain resources from this organization called at the time. And that is, it was a outreach hub for parents with families, with children with autism.

And they turned me in a direction to different resources. They kind of referred me. I started accessing those resources, early intervention started coming in, um, all the jargon, the IEP things that parents don't know when you're thrust into this world.

Um, they helped me with that. They helped me navigate the school system when he turned three and, um, we went from there, but yeah, uh, he was diagnosed. We had to fight the district to remove him and put in fight for an out of district placement because they did not have an appropriate services or program for him in district.

And remember this was, this was early two thousands when, uh, insurance did not pay for services. Nothing was out there. Hardly.

You had to create it. Um, we created a program for him in ABA program for him, a therapeutic program in our home. Um, we went broke doing so, you know, we had to max out our credit cards doing that, but we saw the benefit of the more he gets at an early age, the better the outcome for his life.

So, but it was a journey. And I would say that parents from that support group helped me with that journey. They supported me.

They referred me. And from that support group, uh, me and a group of those families opened a school for autistic children that is still in existence. Oh, wow.

What's the name of the school? It's Garden Academy. It's in West Orange.

We started in Mabelwood, but now it's in West Orange and I am one of the founders of that school. Oh, awesome. Awesome.

Okay. I'm learning things. I didn't even know that.

Okay. Yes. Yes.

I've been a worker bee for a long time. Can you, can, can you, can we roll it back to that support group? Um, if you, if you remember, how did you connect with them?

And I'm, I'm thinking about all the conversations that I've had with family members who walk into some of these spaces. And, um, oftentimes I've, I've found and heard that they're, they can be very white spaces, right? Like there aren't oftentimes a lot of these support groups where you have sort of a meaning representation and really vocal Black, you know, Black membership, can you just tell me like what, what, like how you connected to that group?

LeDerick Horne(7:07 - 7:09)

And then what was it like showing up in there?

Atonia Worley(7:10 - 8:51)

Right. And, and slow me down. Cause I could be all over.

So slow me down because it is important. The question you're asking is very important. When, when I contacted Kozak, once my son had the diagnosis, they told me that there were support groups all over the state.

And they told me what support groups was in my area. That's one thing. And also Kozak no longer exists.

It's now autism, New Jersey. Okay. So for someone that was diagnosed right now, they would contact autism, New Jersey, and they would let them know where the support groups are.

That's one thing. The second thing on the second part to your question, that space was absolutely predominantly white. Okay.

It was. However, as I sat there crying about my son being diagnosed, those women, and it was predominantly women supported me. So although it was a white space, I didn't care if they were blue, I needed direction and I needed support.

So the, the, it, you don't remember anything else. I say, you advocating for your child becomes paramount. If you don't advocate for your child, no one will not the school district, no one.

So although it was, it was a predominantly white space, they still embraced me and they gave me the information to this day. If I call one of them and say, Hey, did you do this? So do you have this service?

They'll tell me and they'll point me in the direction of where to go. There was an organization that one of the moms started called mom to mom, right?

LeDerick Horne(8:51 - 8:52)

Oh yeah. Yeah, absolutely.

Atonia Worley(8:52 - 18:06)

One of those women that I met how many, 22 years ago, cause my son is now 24. She started moms to mom and she, again, we talk about it. It was open to all moms throughout the state, regardless of your, you know, um, class or race or whatever.

And that's how it should be. So, uh, I would tell people you, you can't alienate yourself because it is, and it can be intimidating. I've been in many all white spaces that can be intimidating, but, uh, it was, it is paramount that you utilize anyone to get the information.

So yeah. And unfortunately, there's not a lot of, um, support groups that are predominantly for, for blacks, for us. There's just not, it's not, it's not existing.

You may see mix, but from my experience, I received more information from the white community and it's set up that way. I don't want to get into it, but you know what I'm saying? We're here to get into it.

Yeah. Yeah. You know, they, they, they have the resources.

It's not trickling down to us. And I would dare say that if it wasn't for that, my son would not be as far as he is now. He went to one of the premier schools in the state and it's because of me linked with these ladies.

Mom to mom is the support organization for folks with a variety of intellectual and developmental disabilities, right? It's not just for folks on the autism spectrum. Yes.

When it initially started, I think it was for parents who had children on the autistic spectrum, but then it expanded to all families with, with children with IDD. Yeah. And, um, and I just want to put the plug in as a part of what we're doing with these podcasts is, um, as we have these conversations, um, the, uh, many of the resources and the organizations and, um, you know, whatever we can share is going to be captured within the show notes of the episode.

So if there's something you want to, uh, you know, as a listener, want to, uh, research or, or find more info about just look into the description, look into the show notes, um, and we'll put, you know, links and whatever other information we can find so that folks can go and, uh, and seek out and, and chase after some of these things that, uh, that we're describing. So, uh, you mentioned, I guess it's now autism, New Jersey, uh, as a program that connects you to this support group. Um, what are some of the programs which, uh, helped you or, uh, which you think will be helpful for families to learn about, uh, to support them, uh, as they're advocating and, you know, and, and being of service to the people with disabilities in their lives.

Yeah. So really quickly, just to give some historical background, when my son was diagnosed in 2001, there were not many programs, right. As I said, one of the things that they had, they had programs through DDD.

There was no perform care. These other agencies that they have now, it was DDD and DDD was for everyone, right. And DDD is a division of developmental disability.

Okay. Cause I'm sorry. We, that's another thing.

We throw all these acronyms out. It's too much for families and people don't explain what they are. So with DDD back then in 2001, they had a different organizations that will help you with the application for DDD.

I cannot remember the organization back then that said, okay, mom, give us the information. We'll fill it out. We'll get back to you so that I didn't have to do that.

Cause remember I was running a full home program in my home. So that was one thing. It was in, and you know, what was being created?

It wasn't created yet. SPAN. Okay.

That's also a parent advocacy agency, SPAN, S-P-A-N. That was, it wasn't fully created. They were creating it.

Okay. So again, it was back then, then we would go see schools. ABA was starting to become popular.

That's applied behavior analysis. That was a methodology that was becoming popular back then. Wasn't, wasn't all the way, but there was some premier schools in the state that had ABA program.

So as a, when you're, you know, back then we would, we would tour schools. You would tour schools, see what was going on in school, see if you could replicate that. Right.

Fast forward up till now, you have SPAN is in full effect. You know, parents can access SPAN. It's a resource services.

It's a, you know, that's a great hub to get information, you know, with different things, guardianship now, now I'm in the adult world. So that's a whole nother piece. The, so they helped me.

Okay. They helped me. DDD was a great help back then for me.

Okay. In 2013, the state revamped DDD now became its own entity where it only helped primarily individuals with IDD over 21 and over, over. Okay.

And they created perform care. So perform care was created as a really, because what they do perform care primarily determines eligibility. And then they refer you out for services.

Right. So they started, I would say around 2013 and they deal with people with IDD under 21. Okay.

That's under 21. So for me again, back then there wasn't too much services. I had to find people who had the skill set to work with my son.

Now you can contact SPAN and they will refer you. You can call perform care. It's New Jersey perform care actually, and question them and apply for services.

Okay. And I know we'll get a bit more into perform care. Um, there's the, um, family resource network.

Okay. They helped me. They were out of Fairfield, but they're still around and they are throughout the state.

You can call them for resources in some direction. Um, that's off the top of my head. I would say for me, those were the organizations that helped me back then and parents, because they refer, they know information and they will refer you to this one and this therapist and call this agency.

There's many more ABA agencies out there. Now, um, you have your care management organizations, which are under perform care that you can contact, you know, there's, there's places like the son's place that are independent organizations that help families in our communities, um, with services. Wow.

Okay. Excellent. Excellent.

And again, um, take a look at the show notes. We'll link to, we'll link to, uh, all those references. Um, so you, you mentioned perform care and gave us sort of the history of, um, its creation and how it was formed and to be a real service for basically young people.

So like from birth on, right? Like if someone has a child, who's yeah, it's supposed to be okay. Um, if you call for children under three, they really want you to contact early intervention.

Okay. Cause early intervention deal with your chop before school, before school age, which school age is three. Right.

So they want you to call early intervention, New Jersey has the early intervention program and they're supposed to come in and provide services. Then perform care would jump in. Um,

however I've called perform care for families that are under three and they won't turn you away for services.

So we met each other through the perform care navigation work, which is a part of the grant that a brother, Bill Davis and I received from the New Jersey council on developmental disabilities. And, um, through that initiative, we were helping families to get through that perform care application. Right.

And so, uh, in mentioning it and, and, and talking about how supportive the perform care can be, can you, can you maybe just talk a little bit about why families should go through the process of applying, um, give them a heads up to what the application is like, because it can, it can, it can require

LeDerick Horne(18:06 - 18:15)

a lot to get through, but just really, you know, maybe a little bit more about what perform care is and why folks should go through the process of going through the application.

Atonia Worley(18:15 - 19:55)

Okay. So, um, I started volunteering with, uh, uh, organization called the science place to help families navigate all of the systems, welfare perform care division of developmental disability. But as the Derek, as you were saying, perform care was extremely daunting and parents would not finish the application.

Also, you could only do it on a computer. You couldn't do it on a, a cell phone. And many of the families don't have compute.

They don't have laptops. They don't have a tabletop computers and there's a technological divide. Okay.

So, um, I volunteered to help parents now perform care. The state has this system they created the program. The organization is under the department of children and families.

Okay. That's the chief organization in the state department of children and families under the department of children and families is CSOC, which is children's system of care. Okay.

Now the children's system of care, they um, Oh my God, the word just escaped me. They, they created perform care. Okay.

What is not created. They partnered with perform care to again, determine eligibility. Okay.



So families, this is part of the state is the new Jersey has a system in place where families can get services for their child.

LeDerick Horne(19:55 - 19:57)

And what are some of those services?

Atonia Worley(19:58 - 31:25)

Some of the services, some of this, and we'll talk about the services and then the application. Some of the services are, um, in home therapy. Okay.

You can get in home therapy, out of home therapy, substance abuse, um, care, substance abuse services for the child. You can get crisis services. Okay.

If the child's in crisis, they will send out a mobile response team. That's supposed to be expedient, come out and assess the child and dispatch services like immediately. Okay.

You can get that. They pay for camp. They pay for moderations on the home.

If the child need a ramp for the home, um, I know a family who just got a fence for the home because the child is in a Loper likes to run out. So that's why you want to access services from perform care. Okay.

Because, um, you can in the services, let me just talk about the application. The services are based on the diagnosis, not based on the parent's income is based on a diagnosis. And for those parents who don't have income, they can also do the application for Medicaid.

Okay. They do both. So once you access the application is a four part application.

The first part is primarily demographics. Okay. Um, all the information about, um, is the child a citizen.

Now that's an issue I ran into, which they're trying to resolve because they weren't taking families who were not citizens. Okay. Who, um, what's, what's the word there?

They not a green card, but they, they, they had, they couldn't prove citizenship. So they weren't taking those children. I know they're trying to resolve that.

So the first part of the application is, is all of that. The diagnosis, the, the doctors and the whatever, um, medical, uh, facilities, the child was connected with the psychologist and all of that. And then, um, they don't, uh, they don't even ask for the parent's income or anything on the application.

That's the first part. The second part is the functionality of the child. So it talks about toileting and communicating.

Um, and they're asking about behavior, all of that information. And then the third part is the HIPAA part, just to say, you know, um, your information is protected, protected. And then the fourth part is the acknowledgement.

And then the very important part is that you must send documentation with the application, all supporting documentation, any diagnosis from the pediatrician, the school, any, and parents, you know, some of them don't know any assessments that audit or evaluations that are done by the school. You must ask for a copy. You have a right to copies of everything that the school, not just the IEP, because perform kid don't take the IEP, which is individualized education.

Um, yeah, program that is more, more, I'm so used to just saying it, you know, again, people may not know what these acronyms are, but they don't take the IEP. So you have to have the evaluations, the evaluation from early intervention. They come out, when they come out, they do an evaluation, ask for a copy of that.

So you can attach all those things to the perform care application. If you do not, they won't move your application forward. Right now, the other issue we ran into is once that is all done, we submit the application, we submit the documentation, you may not hear anything.

And then we start calling, I will call on a three-way, Hey, what's the status of the application? You know, you would get a little bit of the runaround, but again, in the end it's worth it because you can access services. Yeah.

Yeah. And, um, and just to be fair to them, uh, as part of our work, we were, uh, we submitted recommendations on how to improve the application process. And I I've heard from at least two different sources that those recommendations, many of them have started to become a reality and some of the ballot barriers and challenges to filling out that application are beginning to be removed.

So, um, that's really good to hear. Yes, it is. And I was also a part of the, the, um, the group that we met to revamp that application.

It was, it was too long. It was redundant and they are shortening the application. So, uh, and you can access the application on one more than one device.

So I was very happy to hear that as well. Awesome. Awesome.

Now, as your, as your son gets older, um, and isn't as, and is making this transition to adulthood, what are some of the challenges that you're preparing to face now? You and your, your, your family, your husband, your extended family, what are you, what are you preparing for next? Well, again, and I'm going to repeat this in regards to just linking with organizations and support groups, because when he was about to transition and they call it aging out of the educational system at age 21, you don't know what to do.

You know, there, there, there needs to be a roadmap starting at like 17, 18, what you need to do. So, um, again, I was extremely blessed to have people in my life to say, Hey, at 17, 18, you need to start the guardianship process. Okay.

Um, my son is, is limited, limited, uh, verbally. He's not nonverbal, but his, his, his vocabulary is very limited. Uh, he communicates.

That's been a challenge. Social socialization and communication has been a challenge. So we sought guardianship early on 17.

By the time he was 18, we had guardianship. You also have to apply for social security if you don't have it, but it's a difference when you have it. Um, uh, when they're under 18, it's on your, it's on, it's based on your income.

When they're over 18, it's just based on the, the, the, uh, the young individual, the young adult at that point. So we have to apply for social security because you cannot get services from DDD unless you have social security, because once the young adult is approved for social security, they automatically get Medicaid. Okay.

And Medicaid is what sustains DDD, which is division of developmental disability. So all these things, like I said, the roadmap to get to where you want to be guardianship, social security. So you can have Medicaid and then you apply for DDD and then they start to pay for services for the young adult.

Okay. So we did all of that. When my son aged out at 21, June of 2020, it was the pandemic.

And it was really hard because when your child so used to being in educational program, they lose skills. Okay. They start to regress a little bit.

It was harder for us because it was the pandemic. We were home. He had absolutely nothing, everything stopped.

And we have him very active. He was in Taekwondo and swimming and skating, and we couldn't do anything. So it was really hard on us.

And so now my son is 24. We still struggle with socialization and communication. So self-sufficiency, that's our chief worry right now that we're worried about him as we get older and transition him being self-sufficient and cared for.

As I mentioned earlier, I have four daughters, his older sisters, and you don't want to burden your children with caring for their brother. But the reality is that I expect them, even if he's in a situation where he's on his own in a supported living program where he can live on his own or with a roommate, I expect them to check on him and be present in his life to make sure that he's okay. But that's what us older parents now think about as they get older and we get older.

I hear a lot of parents saying, we can't die. We don't want to die because you worry about the care of your adult child once you transition. So we worry about him being self-sufficient and we work on now self-sufficiency skills where he can manage himself, bathe himself, care for himself, make food.

We started now with a food program where he can make things. He can work the toaster. He knows how to work the stove.

We talk about safety, fire safety, stove safety, and we're doing this with supervision. Now, can he do it on his own without supervision? We didn't get to that point yet, but those are some self-help skills.

We're working on all of that. But the challenge, because he doesn't communicate, the other fear is if he's hurt, he can't tell me. If someone hurt him, he can't tell me.

That's always first and foremost in my head and very hard for my husband and I. In the way in which your son does communicate, has he conveyed to you, is his vision for independence in line with the vision that you and your husband have for his independence? We try to, I said to my husband the other day, I said, do you think he's happy?

And he said, I would like to think so, but you don't know. He can't tell me what he wants. A lot of time with individuals on the spectrum and they're nonverbal, you have to watch the behavior, because the behavior is a telltale because they can't tell you.

He knows how to say no. But if he's anxious, if he's overly anxious, that's a sign to us that something is going on with him. And anxious meaning he'll pick his fingers, he'll scratch his face and scratch his body parts, things till he's bleeding.

The other day, he scratched his face. I don't know what was going on. So yeah, that's what we have to look for.

But he's very active and he likes activity. So we put him in specialized basketball, soccer, and just to expose him. So if he don't like it, we'll take him out, but we want to expose him because we don't know what he likes.

So he'll ask for basketball and different sports. So we put him in ice hockey, right?

LeDerick Horne(31:25 - 31:27)

Because he loves roller skating.

Atonia Worley(31:29 - 33:35)

He's been roller skating since age six. He loves roller skating. If you take him, we go to Branchbrook, which you know, that's our place.

It's predominantly Black. Our music, the R&B, and he loves that. So he'll skate for two hours straight.

He won't get off. I'm waiting. Sometimes because I can skate, I'll go out and get him.

He loves skating. So I said, okay, let's try ice skating. So the first time we went, I don't know if you ever ice skated.

I know nothing about ice hockey. I will say I put some ice skates on whether I was actually skating. I said, no, I did a lot of falling.

So, all right. So ice hockey, I know nothing about ice hockey. We know that it's a predominantly white sport, right?

And it's no different in the special needs world. It's predominantly white. So we go in, it's in West Orange, and you have to be layered.

It's so much equipment. I'm like, what? It's the arms and the legs and the skates.

That's just one piece of nine things you have to put on. So he's looking at me like, what are we doing? So we're putting on everything and he can skate, he can roll and skate.

So he got on the ice and he was a little shaky, but the skate, he picked that up right away. Now the game, understanding that you have to get the puck into the goal, that's a whole nother piece. And there, of course, is a special needs team.

They understand. So for the first two times he wanted no part of it. I'm like, do you want to go back?

No. But then he wanted to go. Now he loves it.

It's been two seasons and he's waiting for it. He's like September ice hockey. I'm like, yeah.

So I mean, again, just to expose him. And now he really, he loves it. We, the first year they traveled and they go to games all over.

LeDerick Horne(33:36 - 33:36)

They serious.

Atonia Worley(33:37 - 35:19)

They go to PA, they go to New York upstate. We didn't do any of that the first season. I'm like, I'm not doing that.

Right. It's too cold. Anyway, I'm freezing.

Okay. I'm laying there watching him. I'm freezing.

So we, we, this year though, for 20, for the 23, 24 season, we did do, we did long Island. We went to one, one game. We went, we took him to long Island.

And again, he doesn't know the technical part of the sport, so they put them on. He just skating around. Well, again, to their credit, they are so patient.

And the coach came to me, he is such a nice guy. He said, don't worry about it, mom. Cause you know, I'm like, oh my God.

And he said, don't worry about it, mom. He'll get it eventually. You know, so the rest of the team was trying to get it, get it in the go, you know, make a goal, just skating around.

It was fine. So, but again he's like, he's a sport. He loves sports.

He won't watch it. He'll watch it with my, my husband. I don't know.

He's sitting there bored, watching baseball and all that. But he, he's, he loves to engage in sports. He loves sports.

So we know that's one of his, his loves. We just continue to expose him to different things and figure out what he likes. And again, you know, work on those skills, those self-sufficiency skills though, to make sure that at some point he can be somewhat self-sufficient with supervision.

LeDerick Horne(35:20 - 35:26)

Yeah. Yeah. Shout out to all the black hockey players, black hockey families.

Atonia Worley(35:28 - 35:44)

And there is, I'm telling you, there's a few of us. No, no, no. And I, you know, I can't recall any names, but I know that, you know, in the history of hockey, there's been some brothers out there.

But I have to say, when you were saying he was just out there skating, there's a, I forget who did the standup, but like, oh, don't let the brothers start playing hockey.

LeDerick Horne(35:44 - 35:49)

Cause we'd be just be a brother out there skating with no, with no stick, just waiting to get into something.

Atonia Worley(35:50 - 35:50)

Right.

LeDerick Horne(35:52 - 35:58)

Are there any other services or organizations that you think the audience should know about?

Atonia Worley(35:59 - 37:30)

Yeah. So my son attends a camp that is run by the ARC of Essex County. And the ARC is an organization that is throughout the state and they provide services.

They have camps, they also have schools, you know, so parents can look into those for the younger children and adults, they have schools and services. I hear they also have housing, right? So they can look into that as well.

And again, it's throughout the state and they also have Saturday programs. So they have arts and crafts they offer. And I know Essex County ARC does, but I don't know when the other ones like Morris County and some of the other counties, but you can, the parents can research that.

So the ARC is a good resource as well. Yeah. And so the ARC is one of these legacy disability rights organizations.

And, you know, the podcast is going to be published. So I don't know where actually folks are going to be listening from, but yes, we're in New Jersey, but the ARC is all over the United States and they may be international, but I know they're all over the United States. And there's a lot, they do a lot, particularly our chapter here in New Jersey.

So yeah, definitely take a look at the ARC's website. They've got programs sort of throughout the continuum of a person with IDD's life that provides a lot of different supports. Yeah.

Through the grant work, we've been able to connect with them on a few different occasions and it's really amazing the different, the variety of programs that they provide.

LeDerick Horne(37:31 - 37:42)

As we close up our conversation, is there maybe one or two pieces of advice that you'd like to share with the Black community who are listening to this episode?

Atonia Worley(37:43 - 44:37)

I know it is exhausting, this journey, it's exhausting for parents. And if you're a single parent, it is exhausting to try to manage it all, you know, and advocate. But again, number one, you have to advocate for your child or your young adult or your adult.

You can't leave it to the system and you can't leave it to the educational system. Because I was a parent who thought, oh, you know, the school system got it, but they don't. They don't.

They're inundated like we are with all the children. And they're sometimes, you know, kids fall through the crack, unfortunately. But I've met some really good educators, very good educators, and some that were overwhelmed with the system too.

But as a parent, you have to advocate, you have to know what's going on, and make sure your child has the correct services to improve their quality of life. That's it. You have to.

The more they get when they're younger, the better their quality of life will be as they get older. Because you want them to be able to self-regulate. You don't want them, you know, when my son was completely non-verbal, couldn't express anything, would just drop to the floor and roll.

You know, we're in a supermarket, he's screaming and rolling. You don't want that as an adult. That's hard to manage when they're 18, 19, they're bigger than you.

Everyone is bigger than me, because I'm short. And you're trying to manage that, okay? You have to try to get those services.

Now, I know it's exhausting. It's exhausting. But that is, it is extremely important to advocate for your child.

And they're going to get tired of seeing you. They're going to get, but you have to do it. That's number one.



And to link with organizations and support groups. And get with these parents who've been there, who know where to go to get services and to get help. Don't be afraid to ask for help.

Don't be afraid. It's daunting. As you say, it's daunting.

I wouldn't lie and tell anyone that it's easy. It's a hard journey. And it continues to be hard.

After 21, it's hard. And then you try to, now organizations are coming up for parents who don't have siblings, where their children don't have siblings, to watch, to care for the child when the parent transition. Right, right.

Yeah. So that would be my advice. Awesome.

Awesome. Can I actually, before we close out, can I just roll it back? It was something that I wanted to mention, or just sort of see if I can get you to reflect on.

This vision of your son being either independent or in a supportive living environment. Where did that vision come from? I don't know if I've mentioned it on other episodes before, but I think the reality that a lot of Black families have is that as we're growing up, we know there's that cousin or aunt or someone that kind of lives in that room down the hall at your grandma's house or what have you.

But it seems like you've got this really robust idea of how your son could be living independently, like still having, of course, the connection to family, but also being able to live out and be active on his own terms and doing things that he enjoys. Where did that come from? Did you meet someone who, you know, like their child was living that way or what?

I have, again, met many parents now that I'm in the adult world. I've seen different living situations and we've researched. There was a community in South Carolina that are building a community just for the IDD community to live independently with support.

So it's out there. And as I speak to different parents about what they want for their child, now that I'm talking about the adult parents now, dealing with just the adults, not the younger children. Because honestly, when I was in that world, you're not thinking about adult.

You're thinking about right now, what can you do? So anyway, with the adult world, I'm researching. I'm looking at what are the options for my son?

The first and ideal option is that he live with his sister. Okay. But if I'm not here, I can't, you know, I won't be here to make the decision.

If I'm, if I'm transitioned and I'm passed, they're going to be making the decision. So I just want to give them options like, okay, maybe we consider this and give them the knowledge now, like my daughter, who's a nurse. She always say, mom, I need you to write everything down.

I need you to, you know, write your wishes down because anything could happen. You know, I could walk out now and something happened, but you have to do the research. So that came from, again, talking to parents, researching, what are, what are the options for the adults?

I also met with group homes. I saw a group home. I have a friend whose son is in a group home right now.

You know, some of them are bad. They're fighting right now to get cameras in the common areas of the group home. Do you understand that there are group homes with people that are not, non non nonverbal individuals with no cameras.

We have cameras in the daycare with the vulnerable children who may be, you know, childless nonverbal, but we're in group homes with also vulnerable individuals that are nonverbal with no cameras. So we are fighting and advocating that all camera, all group homes, at least in the common areas have cameras. So, you know, again, that group home setting that it is an option for some people as well for my son, I don't see that as an option.

You know, I think he will have the skillset to live independently with support with a roommate. And so I'm trying to, if, if he don't live with his sisters to create that, that option. Okay.

All right. Well, thank you so much for sharing your experience, your passion with the, with the audience. And it's, it's been great knowing you over the course of the time we've been working together.

And I just, I appreciate you again, taking time to sit down and record this episode. So thank you so much. My pleasure.

My favorite thing I can do to help. I will. And it's needed.

We have to pass the information on. So I thank you for doing this podcast. It's important.

It's very important for families. All right. Thank you so much.