NJBLACK DISABILITY INITIATIVE

Keena Fitzhugh Transcript

Intro (0:00 - 0:18)
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.

LeDerick Horne(0:18 - 0:58)
Hello everybody, this is LeDerick Horne and I'm really glad that you're able to join us for another episode of the podcast. I have a great guest here today, Kina Fitzhugh, who I was introduced to through Jade Pollack, who's our connection, our liaison to the New Jersey Council on Developmental Disabilities. Jade is a big fan of yours, Kina, and so she said that we had to talk and we had to make sure that you were a part of these podcast conversations.

So I think maybe just to get us started, if you can just begin by telling the audience just how do you describe yourself, where you're from, and what do you do for work?

Keena Fitzhugh (0:59 - 2:22)
Okay, well, thank you to Jade for speaking so highly of me. I do appreciate that. I am fond of her as well.

Currently, I am a caregiver to my daughter. Previously, I was an executive director for financial aid in the higher education industry. I'm a mother.

I'm a woman. I'm a person. I'm a human being, a lover of life.

More recently, I have been so fixated on my role as a caregiver, but in conversation with a friend of mine who also has a son who is disabled, we've been discussing how to show up in the world as more than just a caregiver. So my focus is more so on that, how I show up and identify as more than just a caregiver while still celebrating the fact that I do have this responsibility to care for my daughter. I'm grateful for being a mother.

I'm that is how I came into this community. The IDD community is from my daughter, who is now 21. She'll be 22 in August.

LeDerick Horne(2:23 - 2:34)

And I know your connection through Jade is that you work as a cultural liaison for the NJCDD. Can you just talk a little bit about what you do in that role?

Keena Fitzhugh (2:35 - 5:03)
Correct. So in that role, it's a formal title, but the way that I approach it is not so formal. In my meetings with, for instance, my daughter's nurse has a disabled son.

He is 10, I do believe. So in conversations like that, just out within the public or people that I know, I share this information about the council. I share the information about the different resources that I've been afforded the opportunity to come across and talk about my story, talk about my journey, the struggles, the success, the wins, the lows and the highs, right?

Because it's not just, you know, I'm out here sharing all this wonderful information and you're going to get the information and everything is going to just be processed efficiently and quickly and the journey won't have any bumps. So I share that. I say, you know, here's this resource.

I'm not saying that it's going to be easy. You may have to follow up. You may have to make phone calls.

You may have to build a community of support to help encourage you along the way. But here is some information that, you know, I've been afforded to have to share with other people and also, you know, on the council and what that has meant for my life. And I go way back in the council.

I sat on council number eight for about a year and a half, many, many years ago when my was four or five. So I am familiar with the resources and the information that's disseminated out into the community, but also just making sure that people who are marginalized or who do not have the opportunity or access to that information in different ways have some non-traditional ways to get the information. And that's where I come in as a cultural liaison where it's in my passing.

It could be, you know, going to church. It could be out in about, you know, at the mall, you know, just having, I had a very in-depth conversation with someone who had a nonprofit agency to help give shoes to people who couldn't afford shoes. And we talked and we had a conversation.

I shared my information. She shared her information. And it was a beautiful experience because that was more information to provide to someone who didn't have the information or the knowledge, but could now take that back and share with someone else.

LeDerick Horne(5:04 - 5:12)

Wow. Okay. And you, you mentioned a few things there.

I just want to highlight. So you said that you sat on council eight, that's the regional family support council.

Keena Fitzhugh (5:13 - 7:36)
I did many, many, many years ago. That was actually, I don't know if I shared too much into my story. I was 21.

I had my daughter. I had a placental abruption. I did not know she was going to have severe cerebral palsy.

I didn't even know what cerebral palsy was. She was born. She didn't have oxygen.

That lack of oxygen caused her to have brain damage. That brain damage resulted in severe spastic quadriplegic cerebral palsy. Later on in her life, about 15 years later, she then developed or because it's a genetic disease, Crohn's and colitis disease.

She is totally dependent on me. And through that journey, I went through the process of being angry. I went through the process of saying like, I'm 21.

How am I going to care for, you know, a child, a special needs child, which I didn't even have the language for, you know, I didn't have the language for it. I just was like, okay, I'm in the hospital. I have my daughter.

The doctor says to me right away, she's going to be disabled. There are programs where you can put her, you know, if you don't feel like you can take care of her, because she is going to need extensive care. And you're very young.

And at that moment, I said, no, I said, I don't know what all this is. I don't even know what it's all about. But I know that she needs to be loved.

If for nothing else, if I love her, I am going to learn how to care for her, I am going to learn what her life is going to be. And I'm not going to say that today, I just had her. And she had to be transported to Our Lady of Lourdes in Camden.

And she stayed there for about a month and a half to receive oxygen and medications to help her with her seizures and epilepsy. And during that time there, there was a program that actually helped me to understand what exactly I was going to need to care for her. So that transitioned into me taking her to Camden to a neurologist.

And then the neurologist...

LeDerick Horne(7:36 - 8:15)
I don't want to interrupt you, but the... So I'm really caught up on, you mentioned you didn't have the language. And I know that that is such a barrier for so many of us.

It's acquiring the language of disability. And I think that helps us to really frame what our expectations can be for ourselves, for others, for our loved ones. And then you mentioned this program.

I don't know if it still exists or not, but if you could just maybe talk about in sort of this stage in your story and your journey, how you started getting some of that language to really understand what the next steps are going to be for you and your child.

Keena Fitzhugh (8:15 - 13:49)
Sure. So originally I didn't want to say my daughter was disabled. I didn't want a handicap placard.

I didn't want anything that made her separate from... Because I already had a daughter. She was three.

So I had a typical three-year-old and then an atypical daughter who now I have to identify in some way or label in some way. So during that time, it was special needs. We're going to call these people special needs.

And I'm like, okay, well, that sounds a little bit better than saying that she's disabled because it just gives her a different characteristic than saying, like, oh, she's not able to do something, but she just is in a special category. And so there were little things that I had to do for myself, mind tricks for myself. For me personally, everyone in this journey that's either disabled or caring for someone who's disabled, they may approach it differently.

For me, it was, okay, I need a handicap placard, but we're going to call this Kiki's VIP. Kiki's VIP allows us to, we can park where we need to park so that she can have access. And so when I was at Lourdes with her and the program was like around the corner.

So we like Walter Rand Transportation Center. And then like up a little bit on the corner, there was this program and I would take her there for her first year. And they actually helped me with neurology.

I didn't know that she needed to see a neurologist. I didn't even know that there were cerebral palsy doctors or, you know, she was on a feeding tube and I had to give her an NG feeding tube. And I was just like, what is an NG feeding tube?

What are all these things? And so along the way, I truly believe that there were people who were placed in my life to help me to understand exactly how to care for her without all of the frustrations that could come with one, just caring for her and then two, not knowing how to access what we need to take care of her. And so from there, I have a friend and I will mention her name because I'm very, very fond of her.

She is like dear to my heart. My best friend, my friend Octavia called me and she said to me, I was taking her to CHOP because that's where the program said, okay, take her to CHOP. So I'm going to Philly.

I'm pushing her wheelchair. During this time, the front street bridge, I believe was like being demoed and we're like crossing the street and it's all this traffic. And I'm like, I don't know if I can do this because I don't know if I can drive from New Jersey with this barrier trying to take care of her.

And she said, I'm taking my son to DuPont. They have valet parking. And I said, that's where I'm going.

And it was a wonderful, it was a wonderful transition because when I started taking her to DuPont, there was a team, there was a team of care that I received for her. So she saw a cerebral palsy doctor. She saw a neurologist.

She saw a GI doctor. She saw ortho. There were resources for me.

What do you need as a caregiver? What do you need as a parent? What are some of the things that we can do to help ease the load?

And they never told me no for anything. And I appreciated that because later on in my journey, I saw how some of the no's impacted me when it really shouldn't have, when it shouldn't have been such a barrier, but they actually laid the groundwork for giving me the confidence to say, I'm not going to accept the no, because I know that there are things that I can do in order to get the yes for what my daughter needs. And so that's where I started to learn the language.

That's where I started to gain my confidence as a parent, learn the resources, her actually transitioning into early intervention because before early intervention, she was at Voorhees Pediatric Facility. And before that, I was trying to take her to a daycare that didn't even have the supports that she needed because I didn't know that there were daycares that could care for children or babies that had such severe disabilities. And I came across that by having a conversation with the director at the daycare center who did the research for me.

She didn't know, but she said, you know, we have your other daughter. I found this program. It may be something that you want to take Keandra to because they are better equipped to take care of her.

We don't have the resources that I don't want to see her not get what she needs. And so that's when she transitioned to Voorhees Pediatric. She was there and they helped me along the way with a lot of the information and resources.

And then in my school district, when she transitioned to early intervention and Damien O'Shea, and that was something that, you know, I was very grateful for. And again, my friend who I mentioned saying her son is a year older than my daughter, this is what I received. This is what I see.

This is what I heard is coming down the pike. Ask about this. So I had people who really poured into my life in such a way for me to take care of my daughter, which made the journey a lot better, which made me want to be that for other people.

LeDerick Horne(13:50 - 14:07)
Wow. Just curious. Is the Octavia Octavia Nash?

Yes. Okay. So I've, I, so I've known Octavia for two years now was part of the work that I've been a part of for the, for the council.

She was actually one of the first interviews that we did for the podcast. So.

Keena Fitzhugh (14:07 - 14:12)
Oh, wow. She did tell me she was doing a podcast, but she didn't tell me it was this podcast.

LeDerick Horne(14:13 - 15:49)
So, so for, for the listeners, they'll actually get a deep dive on Octavia and, and that's amazing the way that the, the stories connect. And, and I'm also, as I'm listening, I'm thinking about how between the, the two of you were, were telling a very South Jersey black and disability story, right. With the resources and the connections that are done in South Jersey.

And I, and I'm mentioning that because it's, it's been one of the critiques that I've heard and my team has heard repeatedly is how we need more services and more attention placed on South Jersey. Yeah. So I'm, yeah, yeah.

Small world, you know, small world. That's a, that's a, that's amazing connection. You know, you mentioned you mentioned daycare and I think one of the points that we need to do a better job at is connecting with providers of daycare so that they're aware of the different services that are out there for young people and families that show up because sometimes it's those daycare providers who are like the folks who even recognize that there may be a developmental, a developmental delay. And so I, I don't know if, you know, I know it's been quite a while, but maybe through some of the work you do or your, the connections, maybe you can maybe speak about the value of, I don't know, like maybe it's accessible, accessibility within the daycare system, or are there, you know, inclusive daycares that are available that maybe you, you know about.

Keena Fitzhugh (15:51 - 19:45)
So one of the things that's interesting, I was speaking with my daughter's nurse who she does, as I mentioned, she has a son who's disabled and we were discussing, I don't know that the daycare facilities that are currently operating as daycare facilities will even have the capacity or are even required to have the capacity. I know that there are separate, like I said, my daughter went to Voorhees Pediatric Facility who had a medical day program for babies all the way up until, you know, she turned three and they do have it even beyond, but it was my option to allow her to go to her school district for early intervention. I think that it would take a daycare facility to one, have the sensitivity to understand because they have so many metrics and rubrics that they have to adhere to for the state to even become a daycare facility.

And then to take on, you know, either a baby or, you know, a toddler that does have a developmental disability or disability, it comes with a responsibility and it comes with the need to have sufficient resources. And so that is a conversation I've been having with my daughter's nurse because one of the daycares that her daughter was going to, who also has some needs that they didn't want to do it. You know, they didn't want to accept her.

They didn't think that they could actually do it in an adequate way or, and, or just didn't want that responsibility. So I do think it's something that we should have more of and, and of quality, you know, of quality though. Like my daughter, she is 21.

She aged out of the school district. I opted not to send her to any day programs. It was my personal choice because I just didn't feel that the day programs that were available would be adequate for her disability and the severity of her disability and how I care for her at home.

I didn't want it to be such a huge difference between when her pamper gets changed, how clean she is throughout the day, what kind of social engagement she's receiving. Is she getting her therapies? Do they have enough staff, you know?

And so that's why I opted to actually retire from my career, if you will, and become a full-time caregiver to her. It feels better to me as the parent and as a caregiver that I have my eyes on her. She has a very fragile life and I want to make sure that I can extend her life for as long as I can with good quality care.

And I just felt like I was the person who could give that care the best. Not everyone has that option. She, you know, I am paid through two different resources that through the pandemic, although the pandemic was hell for a lot of people, especially for, you know, people like me.

One of the things that came out of that was that a parent could become the support worker and be paid to care for their loved one, which was a huge relief and benefit for me because I really didn't know what our transition was going to look like out of the school district into the adult world. It hasn't been easy. I think the adult world is light years away from even the kind of pediatric care that we received.

And I'm doing some work right now with her doctor to try to bridge that gap a little bit better because it's not as coordinated as it could be in the adult world, and it should be.

[Speaker 4] (19:46 - 19:47)
Yeah.

LeDerick Horne(19:47 - 20:43)
Yeah. Can you talk with me a bit about sort of those early days, you're a young mother, you've already had a child, now you've got a child who's born with, you know, pretty significant disabilities. And, you know, the doctors are in your ear saying one thing.

I'm worried about, I'm wondering about what the conversations were like with your family, you know, and particularly, you know, the Black family. Our dynamics can be varied, you know, kind of just depending on what your background is. But I'm wondering, was there anyone in your ear who was kind of leaning you in one direction or another, someone who was helpful, maybe someone that maybe was giving advice that wasn't helpful?

Is there any kind of like story that you could maybe share about the family support early on for you?

Keena Fitzhugh (20:44 - 25:11)
So my family structure is unique. I did receive support from my mother. She lived with me for 15 years.

She, it actually morphed into a support role. When she moved in with me, it was kind of like, I was helping her to do some things for her life. And then she really took a liking to caring for my daughter, and her heart opened up to care for my daughter.

So she is still to this day, one of my main supports. She has always been supportive of making sure that Keondra is taken care of or helping me to take care of her. Now, in my family, outside of that, I don't think that they understood the magnitude of what it is to care for someone who cannot care for themselves, and how much energy goes into that and what I don't have to give to someone else.

And so there were a lot of demands that were put on me just because in my family, I was the person who would research, would find, would seek, would be organized, be dedicated, you know, try to follow something through. And so oftentimes, my family pulled on me for resources, they pulled on me for help. And not that they wouldn't help me, because I received help too, but I just received the help in a different way.

And I struggled with that because we were a very close-knit family with my mother. My mother, I grew up in Section 8 housing. My mother did not have a high school diploma.

My sister and my brother dropped out of high school. I had my daughter, my oldest daughter when I was 17. And I was doomed to be a statistic, basically.

I didn't have, you know, going through high school, being pregnant at my junior year, my guidance counselor basically was like, you're not going to college. And so in my family, as I mentioned, because I was the person who could see the bigger picture, I could make a plan, I could try to see that plan to fruition, assert myself in a certain way. One of the things about being a young Black woman, mother, 17 years old, is that people don't want to listen to you.

They don't believe that you, you're young, you know, you must have made a poor decision because you have a child and you're not an adult. But when I had my daughter, I moved out of my mom's house, I said, you know, I can't stay in this environment and excel and win. I knew that, I knew that.

And I worked really hard to put myself in a position where I could expose my daughter to a different environment. And so because of that, you know, I left that environment, my family, they believed in me, and they believed that I could be a person to help them achieve the goals that they want to achieve. But it came with a heavy load, because when people have an expectation that you will do something for them, or you can do it, if you say no, then it's, well, why are you saying no, I know you can do it, you know, you can't loan me money, I know you have it, you know.

And so it almost became where I wasn't recognized as a caregiver, you know, they just saw me like, oh, she's just taking care of her children. And I'm like, no, what you don't understand is when I'm caring for a three-year-old and a newborn who is severely disabled, I, it's taxing. It's taxing.

And my daughter cried for the first five years of her life because she had spasticity in her muscles. And I didn't know that. And I would say like, she's crying, she's, you know, she's not sleeping well.

And one of the conversations was that her diagnosis wouldn't come until she was after one years old. So even though I had all these resources, and we were going to the doctors, we didn't receive a formal diagnosis of what her condition actually would be or is until after she turned one.

LeDerick Horne(25:12 - 25:47)
What about advice to families now? And I'm, I think maybe one angle to take initially is if you're a family member, and there's some, you know, a mother, whether it be a young mother or, you know, or someone who's older, who has a child who has a disability, maybe is recently diagnosed, what's the, what's the kind of support you would, you would ideally want to receive? Like, and, you know, can you frame that as advice for, for families who've got like a newborn person with a disability who's become a part of the family?

Keena Fitzhugh (25:48 - 30:12)
Yes. What I would say is first, make sure that you are cared for. Make sure that you are cared for as a person.

We cannot give what we don't have. And so if you are not at least nurturing or trying to become sufficient in, in yourself, and what will strengthen you, you will not be able to give to another person. I, I know it, I've tried it.

It doesn't work. You just have to, and you cannot feel guilty about that because when you are full, when you have what you need, you can then give out to your loved one or to your child that you have this responsibility to. Also be assertive, you know, be assertive and show up how you show up.

I know oftentimes I would feel because I was a black woman and I was a young mother and I'm caring for my daughter, you know, severely disabled that I have to make sure I'm polished, make sure I'm speaking, you know, eloquently, you know, not basically code switching even in healthcare, because I don't want them to look at me and say, she's not capable of taking care of this child or already having a preconceived notion of who I am and how I show up in the world because of my skin color. And if we're talking about being black and being in this community, I will say that what I've learned is that you need to show up how you show up. You need to be assertive, regardless of what you feel a healthcare provider may feel about you.

You need to assert yourself for your child and always ask, ask for help, ask for resources, make sure that you let it be known that, you know, this is exactly what you are requesting. This is what you're asking for. Be aware of who you're speaking to, make sure you get their names, make sure you get their titles, make sure you ask what exactly is it that this person is going to be able to do.

There's so much more, but in the supported role, I think that people, I know for me, I would have wanted for my family and for people I interacted with to just give me a little more grace because everyone wanted something from me, but I wasn't able to always provide it. And then it became distinct from certain people, you know, and then because I'm trying to, I'm like, oh my gosh, like, I'm not a good person because they asked me to do this and I just really can't do it. I had to let all of that go.

And I will say, I've only done that within the last probably five years because I just literally had nothing else to give. So once you get to that point, it's like, even if I'm consciously doing it, even if I'm saying like, this is how I'm going to be or not, if I don't have it, I cannot give it. And it's going to be that way, regardless of me actually making the decision or it just happening by default, because I just don't have it.

I don't have the energy. I don't have the time or the resources. The other thing is to make sure that you use all of your resources.

You know, I signed up for email listings and this is going back 20 plus years. We weren't really using email so much. I received a lot of paper mail, but I signed up for, you know, mailers, emails, documents, you know, things that were happening in a community, different agencies.

There's a lot of agencies that have resources like the ARC, um, family support council, you know, um, even just your social services office. I would go there and say, I need a listing of the services that you provide, um, or two one one, which came later on.

LeDerick Horne(30:13 - 30:17)
Um, can you explain to people what two one one is?

Keena Fitzhugh (30:18 - 34:23)

So two one one, um, the, the way that I have used it is basically for everything. But if I wasn't clear on something, um, you could call this number. You would actually speak to a representative.

You can explain exactly what it is you're doing, whether you need food services, disability services, Medicaid, or, um, even heating and utility assistance, um, disabled assistance, whatever it is that you think you need, or may, you may not even know how to explain, you know, what it is that you need. They will help you connect you to those resources. Um, and usually I would also ask for a New Jersey resource, um, book, excuse me.

I believe they have it online now and I would read the New Jersey resource book, you know, even if it was something that I did a few nights that we just peruse and see what is available to me. Um, what is something that maybe I don't know I need it, but they offered a service for it and I could use it. It could make my life easier.

And that's one of the things I'm all about in, you know, caring for my daughter. I am always trying to make our lives easier. I'm always trying to be innovative in how we can have our needs met and determining what we need and imagining what that looks like.

And I never accept no for an answer. Right. I don't, I write letters.

I, I'm like, okay, well, let me call, you know, and see and explain what it is that we're trying to do, you know. Um, and I think that's been my biggest asset for myself is that I do make my presence known. I do, you know, even when I was in college, I had my, I was a nontraditional student.

I had my children. Um, I would go to my financial aid office. I'm like, this is what I need.

I don't know if you offer it, but I don't have a sitter all the time. I need to study, you know, and I could bring my kids to class someday. It's like, I wouldn't miss class.

I would be like pushing my, my door for class, you know? And my professor was like, I understand. I'm just like, I just can't, there's things I want to get out of my life.

And I just don't want to settle for, I can't because of my condition or I can't because I don't have, like, I just have to figure out a way to make it happen. And if that means, you know, connecting with different resources, building a community, um, it's something that I'm not afraid to do. I used to be, um, and that's what I'm saying when you said for new mothers, you know, um, what would I suggest?

I used to be, but if, if I could share that earlier on, if someone could share that with me, that you don't have to be afraid that you can assert yourself that you are okay, you know, that, you know, you don't have to be polished every single place you go. That takes a lot of effort. That takes a lot of energy.

Sometimes you just have to show up as you are. You love your, your child or the person you're caring for right now, the immediate need may be to just get what it is that they need. And it's okay.

If you know, like my daughter had COVID, I had to go to the hospital. I had a scarf on my head. I had Crocs on.

I hadn't showered in two days. Cause I was like up with her, but I noticed how I was received. And originally the way that I was communicated to, sadly to say was poorly until I opened up my mouth and I started to speak and I started to assert myself.

And then it was okay, this mother, she knows what she's talking about. Make sure you listen to her because she knows about her daughter, but it shouldn't be that way because you don't know what someone's journey is. You don't know.

And I, and I felt it. So, and I feel I have a pretty good perception of people is that it's because I showed up that way, but I'm tired. I had COVID myself.

I'm going to, I'm not going and fixing myself up and being pristine, just for you to receive me and give me the kind of care that I'm deserving of regardless of how I show up.

LeDerick Horne(34:24 - 37:28)
Right. Wow. Wow.

There's so much that you said there. And I just want to kind of highlight some of it just for the, for the listeners. So I think one of the things that stands out to me is you were talking about being a college student and like bringing your child to, to, to class and the consistency of being okay with asking for help and asserting to the people around you, particularly, you know, like people who are in paid positions to be helping students like, Hey, here's the kind of help that I need.

What, what do you have? And I love the, I think it's from, from, from many black folks, it is just a part of the experience of pursuing higher education or any kind of social mobility is that it's going to look different. It's not going to look like it on TV.

Right. We have to be, we have to be okay with that difference. And that's particularly true when you are, are either a person with a disability or you're supporting a person with a disability.

And then I I'm also hearing and I think it's a consistency. And I, again, I just want to point it out to the audience that like, you can't just be like a passive parent here, right? Like now on your off time, you're doing the research.

You're just perusing through research just to see what is it that, that, that you can find. And I think it's it's a bit of an indictment to our society that, you know, being, having a child with a disability, which is a natural part of just being a human being, there are those of us who are born with disabilities that you should have to do all these extra steps on your own to be able to provide the support, but, but it's the reality, right? Like, and then like, and if you're going to thrive and if you want your child to be, to thrive and live up to the, to the highest of their potential, that, that extra work is just something that unfortunately we, we have to do.

And I'm loving the, the, the way you're expressing this tension between, you know, be yourself, you know, be yourself, right. And be your whole self, right. And then also realize that that's going to rub some people the wrong way.

I mean, I, it makes me think of, I remember going to my grand, well, my grandfather to a lawyer's office and my grandfather worked at one of the major medical, medication producers in New Jersey. And there was a lawsuit associated to being in the manufacturing facility. And I remember walking in, I was my grandfather's driver.

I took him everywhere. So we're, we're in this office and I'm a young man. I got my locks, you know, I'm sure I didn't really know what I was walking into.

And, and this guy starts asking my grandfather questions. And then, and then at one point the conversation shifted to me and I responded. I remember this attorney saying, I didn't expect that voice to come out of your mouth.

And I remember that, that being like, and, and, and, you know, and like in hindsight, I was like, I'd love to hear what you thought my voice is going to sound like. Right, exactly, exactly. But it is not on us to take on these, these other people's ignorance or their biases or their prejudice, right.

Like we show up.

Keena Fitzhugh (37:28 - 37:34)
No, but, and, and I'm sorry not to cut you off. I'm sorry if you didn't complete your thought.

LeDerick Horne(37:34 - 37:35)
No, no, go ahead, please.

Keena Fitzhugh (37:36 - 42:03)
But it's almost mandated on us in our, in society. And I think that's where, that's where I had to stop because I can't make myself more palatable for you because you don't have to do that. The world bends to what you decide is going to be the curve for that day.

And for me, I couldn't do it anymore. I had to say, I'm a young black mother. I'm, I am a woman, but I'm educated and this is my culture and this is how I show up in society.

And I'm okay with that. The same way that we accept any other cultures that enter into our communities. We also have to be aware of how we are accepted as black people for our culture, for what it is.

And once I stopped, you know, I'm just like, sometimes I'm not going to be as tactful if I'm upset. If I'm upset about something that's happening with my daughter, my tone is going to be different. And I used to say, I can't show that I'm upset because I don't want to be deemed as aggressive.

And if I'm deemed as aggressive, then I'm not going to be heard. And how unfair is that, that you don't get to express that you are upset about something that a process didn't. And I'm not saying you, you're cursing people out, throwing chairs, you know, being disrespectful.

I'm just saying that you have the opportunity to share your frustrations in a way where what is recognized is the frustration and not the person who is actually expressing the frustration. And I see that all too often. I worked in higher education for over 20 years, as I mentioned, I was the executive director.

And I worked with people who didn't look like me, but our students look like me and I saw how they were treated. And, you know, and I will say if a white student came in and they were upset about something, they didn't get their refund check, they didn't feel as though, you know, they were being treated or a process that they felt was not something that they should have had to adhere to. When they entered the office and they voiced their frustrations and they were upset, they were met with compassion.

They were met with empathy. What is it that we can do to fix it? And when students who look like me, when black students showed up, it was called security.

They're being aggressive. They, you know, but I just saw another student come in and you had their refund check for them. Now this student you're calling security because you feel that they're being aggressive, but where's the threat coming from?

Is the threat actually coming from the student or is it because you feel that you are being threatened by your own judgments on what this person may be? And that's when I started to say, you know, this isn't, it's not fair for us to have to do this in a way. I shouldn't have to go outside and say, now let me make sure the way I present myself is exactly this way, because this is the only way that I'm actually going to be able to receive, to be met or to receive acceptance or actually be communicated to with some type of kindness.

And I just don't think that, I just didn't want to do it anymore. And I'm a person where I am going to assert myself and I am going to express my frustrations if I feel that there are frustrations to be expressed, because sometimes there are, sometimes the processes are convoluted and sometimes the processes are not as clear and adequate, or there isn't any support to help you through the process. Even with my daughter transitioning into DDD as a 21-year-old, the process was just overbearing and complicated.

And there was no one to help until you get your support coordinator, you know?

LeDerick Horne(42:03 - 42:13)
Can you talk a little bit about the transition into adult life? So you're, I'm assuming your daughter was getting support through PerformCare?

Keena Fitzhugh (42:14 - 52:08)
Yes. So originally my daughter was getting support through DDD. Then sometime during a transition period, DDD branched off and PerformCare then took on everyone that was, I believe 21 or 20 and older, 20 and younger, excuse me.

And so that was a process, right? Because it was like, if you still want your services, you need to call in, you need to say, you know, this is what you need, because if not, you're not going to be part of this program anymore. And I will say in conjunction with all the other resources and support we were receiving in that pediatric world, I understood that that is the way her life was going to go.

That was the process that we were going to have for the duration of her life. I'm going to have a team of doctors. I am going to have these resources.

People are going to respond to me in an efficient time. If I need a letter for something, they're going to give it to me. That is what I received when she was at DuPont.

We didn't wait for many things. I asked for something. I had the script.

I asked for a letter. We had the letter. I needed to get an appointment.

There was an appointment. And that's what you expect moving forward, right? That's what I thought.

That's what I thought. What I will say is during the time that she was 17 or 18, Rowan University started the RISD Center. She was a patient of a GI doctor who also the main doctor for that office branched out to become the doctor at the RISD Center.

So I was hearing like the RISD Center is going to be a place for the adult care. And in my mind, I was like, okay, it's going to be just like DuPont. I'm going to have everything I need.

What I found was that it's not that easy. In the adult world, it's very different. They are actually, I'd say like assimilated as a loose term into the adult world as just patients.

The distinction of the quality of care that's needed for people like her is not there. And so when I take her to the doctors, it may be she's just treated like me if I go to the doctor. And I'm just like, I don't get that.

Where's the team? Where's the communication between everybody? And it just wasn't there.

And so that transition, okay. So during the time that she was at DuPont, that's what I was used to. When it was time to transition her out of DuPont into the adult world, I started two years prior.

So I started looking at what kind of resources would be available to us, what I would need to do as a parent. Do I need to have legal guardianship? How am I going to be able to communicate for her needs?

What are the resources that we are going to need? All of that. And I still will say it wasn't the best process.

Although my process went smoother than others because I had the desire, the energy, the will power, if you will, to be proactive in it because I just didn't want to be behind because I know what it felt like to be behind. So her in school, they would send information home about transitioning into this adult world. It still is different from anything I could have imagined.

And so that transition into the adult world for her doctors for, you know, I was looking for a cerebral palsy doctor. It's a physiatrist. It's not a cerebral palsy doctor.

So I'm just like, okay, well, what is that? And how do I get that doctor? Thankfully at DuPont hospital, when they are aging out, there is a transition team that actually we meet.

And that meeting is about two hours. And we talk about all the things that we're going to need. What it's going to look like.

Did you choose a hospital? Do you know the doctors? Did you think about this?

So I was able to get some prompts as well to help me with that transition, but still nothing like what I thought it would be even going to a hospital, transitioning her from performed care into DDD, a nightmare. And it's a shame because why so what happened? I believe that there is a disconnect.

And I know that they know that it's a disconnect. I just don't know that one of the things that I'm actually going to be working on. And it's something I'm in a program right now for my master's degree at American university for us legislation and healthcare compliance.

And one of the things that I noticed when I was going through the process was that there from the time you apply for DDD, until the time your child or your adult child becomes 21, and they get their tear and they get their acuity and you know, you get a budget. There is a separation because the support coordination, you do not receive that until two months prior to their 21st birthday. So from the time you're applying for DDD with all the documentation that they want, the doctor's letters and legal guardianship, you don't have someone assigned to you.

You don't have someone that you can call and say, am I following this process correctly? What other documents would I need? Some people didn't have the doctor's information, you know, didn't have legal guardianship didn't even know they needed legal guardianship for people who are like my daughter, for other people who can maintain some of their rights, it would be a different conversation.

But for my daughter, she is completely and totally dependent on me to care for her. So I needed to have legal guardianship of her. And so going through the process, people are just telling you stuff, your daughter is, you know, this is her tear, this is her acuity.

I had to research what is that? Let me read the policies and the procedures. I'm going to read the CFR, you know, I mean, but who knows that I only know that because I have a higher education background, legislation was my expertise, writing policies and procedures for a school.

So like anything, money comes from Medicaid, you know, and so there's rules attached to it. So I'm like, okay, let me look and see exactly what I'm going to follow the paper trail. And then following the paper trail, it will show me exactly how I need to navigate this process for my daughter.

But what about the people who can't do that? What about the people who don't even know that they could have a DDD budget for their loved one? It's a defeat process, I feel, because if you feel at a certain point, and I had to do it, you're calling, you're emailing, you're asking questions, you're not always told the same information.

Someone tells you something and the other person says, oh, that was wrong. It should have been told to you this way. If you circle people around enough who already have that burden of caring for another person, and I'll get back to burden as well.

If you already have that burden of caring for another person, you are not going to feel empowered to wake up and say, now I'm going to make 25 phone calls today. It's just not anything that you're going to want to do. You have to have so much energy, strength and fight to keep going.

And I just feel that the state knows that people are going to apply for DDD. Support Coordination Agencies, there's thousands of them. And they tell you, you pick your Support Coordination Agency.

Okay, so I'm going to call all of these Support Coordination Agencies and try to figure out one. I'm going to do this by myself. And so for me, I would like to see a support advocate from the time that your child needs to apply for DDD.

Someone who can actually walk you through the process and tell you the things that you need. And for me, I will always say to anyone, keep all your documents, make sure you tell your doctor's office, I need either if you don't have electronic, I need a printout of my medical history. I need documentation for all of the appointments.

Do not miss appointments. Make sure you if you can't reschedule, you know, all of these things are important. Because when the full picture is being processed, those are the questions that are going to be asked.

When is the last time that you saw a doctor, even if my daughter had just been to the doctor, and she had to go back to the doctor, because they wanted a form filled out specifically within 30 to 60 days, you know, and some will and her back to the doctor when she just saw the doctor. It's like things like that, that, you know, it's, I don't know if it's designed as a deterrent, but that's what it's evolved to.

LeDerick Horne(52:08 - 53:27)

Because, you know, and I don't think and part of the work that I've been a part of is actually providing in person support to help folks get through the perform care application. And then an outcropping of that has been to help a few of our families to get through DDD as well. And I don't think I don't think folks appreciate what an asset just like time is and the resiliency to read through all of this documentation, and then all of the sort of built in supports that aren't oftentimes available to many people in the black community of having the child care and that freeing up enough time for you to make those 20 phone calls.

And I mean, just all of it, you know, and it's all kind of wrapped up in needing just a whole lot of resiliency because of Yeah, the system, it feels like it feels like you need to be like you have to have a background in higher education. And yeah, and if and if not, you're not going to be able to code through all of those forms and deal with the bureaucracy needed to get to get the supports that your young person's entitled to.

Keena Fitzhugh (53:27 - 55:58)
And I just know that that's a shame. And when I mentioned, you know, going back to the word burden, for, for many years, I cringed at the word, you know, if I said like, Oh, you know, I don't want to call my daughter a burden. And through therapy, because I've been in therapy now, going on almost eight years, what I learned is that, you know, in me saying that I'm not saying that she is a burden, but the care that comes along with what has been assigned to her life is burdensome in the way that I have to care for her.

And so it's almost, you know, like now, there's this discussion of, you know, you say disability, are you saying special needs? Are you saying differently able? Are people happy with that?

Well, which disabled person wants to be disabled, called disabled or which one wants to be special needs, you know, and so it's the same, I feel for, as you grow in an understanding, then you decide, you know, how you want to explain what it is that you're going through. So for me, I do say it's a burden, because all of what goes into caring for her is very burdensome. She, in her life, is a beautiful life, and I love my daughter, but had those things not been done to take care of her life, I know that I wouldn't have as much stress, you know, if I didn't have to make all the phone calls, if I didn't have to make sure that she got a new wheelchair every five years and make sure Medicaid sees the assessment and says whether or not she qualifies and getting a new feeding machine and feeding bags, Pampers, you know, I mean, I have five different agencies I have to work with every month in order to get her the supplies she needs just to take care of her.

And then I have to be the person who actually does the care. And I also have to be the person who makes sure she has her doctor's appointments. I would like to have more support in terms of the other person who was responsible for making her with me, but that just doesn't come out that way.

And I can't waste so much of my energy on trying to persuade or explain why something like that is necessary. And so, yeah, it can be burdensome. It is tiresome.

LeDerick Horne(55:58 - 56:04)
But what I'm hearing, not to cut you off, but what I'm hearing is the burden is not your child, the burden is the system.

Keena Fitzhugh (56:04 - 58:19)
Exactly. It's all of the things that have to be done, you know, in order to and it's, it's funny because it's like, I'm paid from two different programs to take care of her. And I always say how grateful, how forever grateful I am for that.

But nothing streamlined, you know, I go out of one system, and then I go to another system. And then I have to have three different visits, you know, from the nursing agency, from public partnership, Amerigroup, and from the Support Coordination Agency. And everybody's asking me the same stuff.

And I always say, you don't have like a one app that you can just go into and say, Not a single database somewhere, right? And they're saying, no, we're trying to move towards it. And I just, you know, like, it's just another thing.

Like, I just, Amerigroup was just here and did the medical assessment. Now public partnership wants to come and talk about it. And I get it, it's Medicaid dollars, you want to make sure that you know, you're being a good steward over the funds, there's no fraud and abuse.

I get all of that. But when you are looking at documentation, I just feel like you're getting the same stuff that the other person is receiving. There should be some type of universal way that everyone can just go in and get what they need, and then tailor it to what it is that you specifically need for reporting purposes or for documentation or whatever it is.

But it's just not that easy. And that's where, you know, as parents, I'm in a parent support group on Facebook. And I, you know, I empathize with a lot and sympathize with a lot of people because many of the questions that they have are just very basic questions that they can't even get an answer to, you know, or their own holds, you know, for for long periods of time.

And, you know, for me, I just, I just, you know, put myself in that position to say, even if I may not feel my best that day, I still have to do it because it's what's going to keep our lives together and make our life easier.

LeDerick Horne(58:21 - 1:00:02)
We've already gone longer than I thought, than I thought we would. No, no, no, there's no need to apologize. And just, I appreciate your, your openness, your transparency.

And not only into talking about your own journey, but but also being honest with folks around just like the challenges and the struggle of getting through this system. Um, and then also, you know, what you've talked about as far as like, making sure you're caring for yourself. I heard I heard therapy, I'm a person who's gone through therapy.

And I'm, I you know, I think I think all of us should at least go to one session. But I know particularly, you know, I'm dyslexic, I have a learning disability, I went through a self contained special ed class for most of my time, when I was in school and early on, but in special ed my entire time through school. And, you know, particularly if you're dealing with the reality of what it is to have a disability, and I use the word disability, I'm a person that uses the word disability, that it's a lot to be able to untangle and to navigate through and to understand and to compartmentalize when you have to and, and incorporate in other ways.

And so that care piece, I think is really important. Maybe just as we close out, so you've shared a lot of a lot of resources that you've talked about through through your journey and the resources that you've shared with other family members. Is there maybe, you know, if you can maybe talk about the state of New Jersey, but also maybe specifically Camden County, are there one or two resources that you folks really should be aware of?

Keena Fitzhugh (1:00:03 - 1:00:15)
I did mention for public partnership, and for the PPP program under Medicaid, I do believe that that is a great resource for people.

LeDerick Horne(1:00:15 - 1:00:23)
Can you break down what PPP stands for? Just so I try to I know it going through COVID. But just yeah.

Keena Fitzhugh (1:00:24 - 1:00:26)
Let me get it correctly.

LeDerick Horne(1:00:27 - 1:00:27)
Yeah.

Keena Fitzhugh (1:00:35 - 1:02:23)
So the PPP program is the personal preference program in New Jersey, you could request that program through your Medicaid provider. In my case, it's a mayor group. So I contacted a mayor group.

Might I mention, I did not know about the PPP program. My daughter had a nurse who said to me, I received this paper from my other client, I think you can be paid to help take care of your daughter. Never saw it before, didn't even know it existed.

Right. So that's something that I also feel the way in which the communication is distributed, even from the larger, you know, companies like New Jersey Family Care could have told us that that's something that you know, is possible. But yes, the PPP program, personal preference program, basically, you could act as a PCA for your loved one, and be provided the PCA is a personal care assistant, which means that you would take care of that person.

And they're allotted a certain amount of hours based on their need. And you could be the person that is actually paid to provide that care to your loved one. The other one is catastrophic illness.

I think that's something that people don't, may not know or may not have heard of. I actually had my van, my modified van reimbursed for payment that I bought for my daughter a few years back before she turned 18. And that they were able to reimburse me for my van up to a certain amount and also any health expenses, medical expenses that are outside of the scope of what your health insurance provider may pay for.

LeDerick Horne(1:02:24 - 1:02:31)
I'm smiling because you got me with the Kiki's VIP. I'm imagining the van being Kiki's limo.

Keena Fitzhugh (1:02:32 - 1:03:15)
Yes, yes, I had to do that. I had to tell myself like, I mean, it's crazy, though, right? Like you have to play those little mind games, like with yourself to be okay, sometimes.

And, and yeah, that's what, and so my daughters, they say now, like, you got Kiki's VIP. Even when we went to Disney, we had a flash pass, you know, and we were able to just go onto the rides and stay in like where, when it's hot, they had a section for us to sit and have air conditioning for her. And it was just, you know, I didn't know that they had that.

It was something I reached out for, right? And asked, you know, my daughter's disabled, I'm visiting Disney, what are some of the things that could be available to us?

LeDerick Horne(1:03:16 - 1:03:19)
So, yeah. Are there any other supports that you would recommend?

Keena Fitzhugh (1:03:20 - 1:05:42)
I did have some written here. Social workers at hospitals, if you are at a hospital and you feel as though there's a coordination of care that you need, you can reach out, ask for a social worker to come. I've gotten things like, I've been in a hospital with my daughter for weeks at a time.

I've had my meals paid for. They actually coordinated the care for her nursing to restart. Any type of supplies that we needed at home, medical equipment, durable supplies, things like that, I think it's good to ask for.

Some people don't know that they can ask for a social worker to be of assistance to them. Also, if you feel as though the care that you're receiving at the hospital is not adequate, you can ask for the steps to report that or, you know, how you can file a complaint or make a change for who the care provider is at the hospital. So, I do think that that's good as well.

We mentioned perform care for, maybe for FSS services. I received that for my daughter, which was a reimbursement for respite care where I could choose a respite care worker and they would reimburse me for up to 20 hours per month or 60 hours within a quarter to use at my discretion to help me with my daughter. Attend fairs.

Attend fairs, attend any of the... One of the ways that I found my daughter's support coordination agency was that I went to Independent Living's fair that they had, and I said, I'm just going to walk around and see what resources they have that are available. And I picked up something from everyone.

And when I got home, I said, over the weekend, I'm just going to sort through this material and see what's available. And I actually found some really nice things, what they help with, housing supports. There were some things I needed for my electric bill.

They were able to help me with that. And so, yeah, just really being mindful, you know, of what is available, research, Google. I've Googled a lot of stuff.

I just type in what's on my brain, how do I get, and certain things pop up and then I research it further and actually use that to build my community resources for other people.

LeDerick Horne(1:05:44 - 1:05:55)

You know, as we close out, you've already given a lot of advice, but is there maybe just one sort of closing piece of advice that you would want to give to members of the Black community who are listening to this episode of the podcast?

Keena Fitzhugh (1:05:57 - 1:09:33)
Yes, I do. I actually have some, because I wrote them. I said, what would I want to tell people?

Remain confident in your ability. Seek knowledge and ask for help. Take time for yourself.

And this is from the caregiver perspective. Even if it's, you know, some people say, I don't have any time for myself. I don't know where I can find it.

I used to hide out in my bathroom and try to shower one, although I wasn't in it because people would leave me alone. And I would just take, you know, 10 minutes to decompress and do some breathing work. I also recommend that if you are on Spotify, there is an artist that I love.

His name is Stephen Halpern. It's actually just instruments, wind instruments or chimes that you listen to, no words, and you can decompress and take a few deep breaths. I like to put a little lavender, you know, in the shower and let it steam up.

10 minutes, you know, for yourself. Any way that you can get it. I used to not do that.

And, you know, as I mentioned, my friend Octavia, she said to me, you have to start doing it some type of way. And I was the person to say, I can't, I don't have it. I can't, there's nobody here.

And I found it after I laid my children down, everyone was quiet. I was able to take some time for myself. Get everything in writing.

Keep all your documents, whether it's paper or electronic. Take notes on your phone. One of the things that I have found to be really of benefit is taking my phone in the shower and sitting it on my window sill.

And so when I'm showering and something pops into my head, I just open up my notes and I jot it down really quickly and say, at least it's a prompt for me to come back to. Or make a list item with little bubbles and, you know, select it off as you complete those tasks that still need to be completed. And ask for help.

Ask for help when you need it. Sometimes people are not going to be helpful, but you never know. My aunt, who cannot take care of my daughter, like she can't physically take care of my daughter, but she does come and sit with my daughter sometimes.

She can do up to an hour, two hours if I get her cared for and she's quiet and she can stay in her wheelchair. She can come and sit with her for two hours while I run to the grocery store or, you know, even if I take a moment for myself, go for a walk. So sometimes you may think the person who may not be able to help might be able to help.

So just always, you know, reach out. Ask for help. Use your community resources and build a community.

I think that's something that's really important, too, is if you can build a community of support, someone you can talk to. One of the things that I appreciate, we mentioned therapy. I do suggest that.

I know people, you know, may think that it doesn't work, but for me, it provided an outlet and it also provided an unbiased alternative support where I could just get everything out that I wanted to talk about and not feel as though like, oh, I'm talking to my mom about this. Now she has the worry, too. Now she, you know, feels downtrodden because I'm sharing, you know, all of my frustrations.

If I can get it out in therapy, I'm lighter and I've already done the work to work it out. So I don't really need to impede on anyone else's keys or time to do that for myself, to try to, you know, emote. I mean, emoting is a beautiful thing.

If you need to cry, if you need to get it out, get it out, get it out and make a plan and then move forward.

LeDerick Horne(1:09:34 - 1:09:38)
Wow. Kena, thank you so much for your time. Thank you for sharing your story.

Keena Fitzhugh (1:09:38 - 1:09:40)
You're welcome. Thank you for having me.

LeDerick Horne(1:09:40 - 1:09:42)
Oh, no problem. Thank you so much.