

## **Podcast # 098 The Joe Family Foundation**

**Host:**

**Tania Anderson, CEO of ARISE**

**Guest:**

**LaToya Jones**

**Founder & President**

**Joe Family Foundation for Disability Advocacy Inc. (<https://thejoefamilyfoundation.com/>)**

### **JFF transcript**

**Tania Anderson**

Welcome the ARISE podcast on Tania Anderson, CEO at ARISE.

It's my pleasure to have with me today, LaToya Jones, who is the founder and president of the Joe Family Foundation for Disability Advocacy Inc.

Welcome Latoya

**LaToya Jones**

Thank you.

**Tania Anderson**

We were talking a little bit before we started recording this about the foundation that you started.

And I I bet you a lot of people listening to this may not have heard about the Joe Family Foundation.

So, you can you just give us an overview about what you're doing?

**LaToya Jones**

So, the Joe Family Foundation for disability advocacy is a vehicle for individuals who strive to achieve all of their abilities.

The foundation was birth from a support group that we originally started.

My son, who is a traumatic brain injury survivor, he is now 20.

When he was nine years old, he had a stroke and a TBI.

After going through our traumatic experience with him, we decided, and he really was pivotal in a decision that we needed to help people who've been through traumatic experiences like ours.

The Joe Family Foundation itself has been around for a few years as a foundation, but we've been operating as an advocacy organization and support group since probably NyShaun was 10 years old.

**Tania Anderson**

10 years.

**LaToya Jones**

Yeah, yeah, yeah.

So, we we've really been it, but, you know, it started off as, you know, me, and our family just wanting to help people.

People don't know what they don't know.

They don't know what their rights are or what their abilities is as educated as I am as a mom, I still have barriers to being able to achieve what NyShaun needed.

You know, people don't know that there's an OPWDD process.

How do we get through the front door for our individual to be able to be recognized as a person with disabilities to receive more services?

Individuals don't understand how involved they could be with the IEP processes with our school districts.

So really, we set the vehicle up to help families, help families with youth young boys 13 to 25 years old because that is where we saw the gap.

Those are the ones that were, you know, going for middle school to high school and then to college and not a firm plan of what can be what they can do for their lives, you know, besides going into maybe a program.

But maybe they want to do a career or something else, but not knowing how to navigate that space.

So that is why, you know, we started the foundation and it was something that I promised my son and my two daughters I would do just seeing them struggle from what happened to my son being able to find creative opportunities to do peer-to-peer mentorship, to do like, uh , you know, healing through arts therapy is what our program is called.

And it's where we mirror arts with music and motion and creativity to get individuals, siblings and families to connect to their feelings.

And it's not, you know, always bringing therapists in to talk to those folks because that's not what they want.

It's just bringing therapists in the room to hear to listen to the conversation to see how they can help.

But we started all of this just because of the barriers, the blocks, the things that we experienced as a family, and we felt no other family should have to feel like that.

So it first started off, you know, what those things, uh implementing programming, small programming, one of the things that NyShaun, Nadia and Alana wanted to do was, again, make people feel good on holidays.

So, one of our biggest partnerships first was with Syracuse University. Their health services office.

We did a love box campaign where we put together shoe boxes for individuals and then we partnered with one of our centers here and donated those to youth and crisis.

The year after where my children attended after school program, we as a family cooked Christmas dinner for all of those children and then donated books and gifts to them.

But we had the opportunity to sit down with them as a family and actually pass the dishes around and had conversation because we knew some of those kids would be missing it that next weekend for Christmas.

### **Tania Anderson**

There's a lot there that I'm just going to pause for a second because Latoya, that's amazing.

So, what I'm hearing is that you had a personal experience when your son had a traumatic brain injury, and really you have just not just carried that forward, but to crave this whole movement.

And the thing that I there's a lot there, but the thing that I think is really important for folks to listen to is the whole concept of pure support that you're talking about.

And, you know, I don't I'd go around a lot of different places and I'm the mom of a daughter with a disability and you are so right that for families and individuals and a lot of times it's parents of school age kids are younger.

We don't know the system.

It's a super complicated system.

We don't know even what to ask.

And having that peer support of someone who has walked that journey, even if it is not the exact same journey, it's similar enough that we can help each other out to navigate.

Would you say that's one of the core principles of what you're trying to do with the foundation?

### **LaToya Jones**

Yeah, so we want to make sure that we have peer to peer support with the individuals, but also be inclusive again, of people of all abilities.

So, they might be individuals that have disabilities, but we also have friends that push in that don't have disabilities.

And I think that's important because one of the issues we had when, you know, Ny first returned to school was a lot of criticism from his peers because they didn't understand his experience.

They didn't understand his scars.

So, I always think it's important to include everyone in that period of peer-to-peer concept, but also not leaving out our siblings, right?

Because our siblings of our children also experienced those hurts in that trauma.

So, we also shape opportunities for those siblings to get together or have time because what I found over the years is those children feel like they're forgotten about. Because we give her so much energy to the person that does need our support as parents, but then we have two or three other kids that are like, hey, you know.

**Tania Anderson**

I'm still here. Right, yeah, at ARISE we have some programs specifically designed for siblings as well because what you said is so true that, you know, the child with a medical condition or disability just they need more time and attention and the parents and the caregivers fulfill that obligation and the siblings are sometimes feeling a little left out or they're trying to navigate with their own peers, you know, why is your brother or sister different?

What's going on here?

I loved the fact what you said about the inclusive nature of the work that you're doing because, especially with kids, they're just really curious and they want to understand what's going on with their peers and we should welcome those questions and not be afraid.

You know, disability is not anything to be afraid of.

It's just the spectrum of being a human being, and that's what you're trying to do.

**LaToya Jones**

Definitely.

**Tania Anderson**

Wow.

So, tell me a little bit about the art component of some of the programming that you're doing.

**LaToya Jones**

So that component started off with like pop-up opportunities for individuals so at different abilities to be able to get their energy out.

We found around COVID time that people and their children were bottled up.

People couldn't go to program during the day.

So now, you know, because of the individual not understanding the isolation, then there's behavioral issues at home with the caregiver, with these folks with disabilities.

So, we started building that program and then now we do the same.

We don't have a brick or mortar.

Unfortunately, we used to host these events on Fridays where we would pop up and the pairs would get together.

They would do something around the Arts or gaming within our space.

So, we continue to do that, have pop-up experiences, push into some of our Syracuse City school district and other districts if they're interested, and we connect with the families.

Again, it's open to all abilities, but we target our classrooms that have special needs individuals, and we try to work with those families so that those people feel more included in activities that are going on.

But at the same time, if there's a need for us to think about needs that they might need as a special need parent or caregiver for their individual, we can help navigate, you know, those needs with some of our partners through like a wraparound service method.

So that has been powerful in connecting things.

And one of our schools that we work with a lot and kind of adopted is McKinley Brighten school.

And we would like more partnerships like that, right.

Because we don't need to reinvent anything, or we don't need to reinvent the population they're there.

We just need to go where they are.

So, I'm firm believer that we have to go where people are and that is where our classrooms are.

That is where our teachers might need the help.

We do have educators that are specialized in special education, but that doesn't mean that they understand our people or our folks with different abilities.

It doesn't mean that they understand that autistic child that might be having a meltdown in classroom and it may be just because they do work on the carpet better than sitting in the chair.

So, we're just here as a resource to help, you know, the schools, the community as a person in a family that have personal experiences and how to work with folks with different abilities. But also, how to be inclusive and understanding being educated and not just be responsive to things that might happen in their space.

So being able to form partnerships and push into events into schools that helps with some of those things.

### **Tania Anderson**

Right. And so, you're saying we and I I know you a little bit and you're a dynamo as a single person.

But so, who is we?

Is it is a group of volunteers?

What is your network look like through the foundation?

**LaToya Jones**

So, I always say we, I always say it's not a LaToya show, you know?

It might have come out of a root of hurt and trauma that I experienced and, you know, as parents of special needs individuals, you experience that every day when you look at them and you think about what they could have been if this didn't happen to them.

So, I say we because we do have a community, we at JFF, we have an executive board.

We have, you know, advisory board members and then we have special friends that really enjoy the work that we do in the community.

We have, you know, partnerships that we that allow us to push individuals in.

We work a lot, as I said, with Peyton.

We do some work with him in a community and collaborate with CNY Adaptive Design.

We are friends and partners with Dr. Nienke Dosa at Upstate, because, you know, as I said, we are open to work with folks who are in need.

So, if you as a special needs provider or organization feels like your individual or your family needs us, reach out to us.

They may be already getting services, but maybe they need a support group or a one on one with someone they feel like that they can talk to.

**Tania Anderson**

Right.

And there's that peer piece again.

**LaToya Jones**

And that's where we come in at. So, I do a lot of one I ones when families I refer to me.

I'll take a mom or caregiver out for coffee. And a lot of it is just to listen.

They want somebody to listen at what their struggles are or what they're going through.

And then that next part is seeing how I can help them navigate some of those issues with the things that I've learned.

So, I always say we because we do have, you know, great supporters that are offline or or you know, behind the scenes, but they work with us.

Another one is Derek Carr. I believe he's now with SUNY ELC, but he's been pivotal in the work that we do around Home for the Holidays.

And it's an annual event, a distribution event that we host every year and we open it up to not just folks with disabilities, but all abilities.

**Tania Anderson**

And you had mentioned earlier that you've identified some specific gaps in the community in terms of people needing either the support or the peer outreach you mentioned middle school, age boys in particular, are there other gaps that you're seeing that you're trying to connect with specifically?

**LaToya Jones**

So right now, I feel like a 13 or 25 gap is huge and specifically working with boys, that is what we target.

But our services are not just for that population.

They're open for everyone.

And it's not just targeted to TBI individuals.

So, if your child is autistic, special needs, someone, a person doesn't always have a physical disability and a different.

Yeah, a visible disability.

We're open to you because really all it is for us to be a resource and build that relationship.

And as you know, that as a parent of someone special, it's hard.

It feels like you're on an island by yourself, but there's really people out there and you don't know it until you have a podcast, or you do something, and you get to meet those people.

We have systems in place and things to help people.

But if folks cannot see themselves in those organizations or identify those services or have the education to know that those services are there, then they don't know what they don't know and they they're not going to outreach to those services that might be implemented into the community.

**Tania Anderson**

Right. No, it's so true that it can be an isolating experience to have experience with a disability or have someone you love with a disability and there's also an element of grief that goes through that you mentioned as well.

And but there's also, I mean, I have found that an element of celebration in terms of we're all it's all just an expression of being a human being and a person, whether it's somewhat like my daughter who was born with a disability or your son who acquired one as a child.

They are still wonderful valuable people.

And I I wouldn't trade that experience for anything even when it's been a difficult experience.

And I I bet I'm going to presume you would probably say the same because the growth you've been able to experience as a person is really magnificent.

**LaToya Jones**

Yes.

And that is what I taught my kids.

That's what I taught my son.

We grieved.

We had trauma, and now we celebrate.

We help people.

So that celebration looks like NyShaun being able to do whatever he wants to do.

He could want to climb the moon.

He's going to climb the moon, right.

Right now, he's at OCC and he's working on photography because that is the passion. But we just make that adaptive for him, right?

So that he can enjoy what he does.

We celebrate that by continuing to be advocates and good humans, by not, you know, classifying and putting people in the blocks that live with disability, but engage in them in everyday life, you know, making the community more walkable for them.

You know, things like that recognizing their here.

And they have a voice.

We celebrate that annually, you know, as a family in a community with our home for the holidays event.

And we work with that all year to be able to bring in donations of things for our families just to come and shop, right?

To have that experience, you know, we're in a date and time where any kid doesn't get that experience.

So again, we'll be hosting that this year and we're going to celebrate that with our families and we're going to allow them to come in in our concept this year for home for the holidays is books, blankets and board games.

**Tania Anderson**

You are going old fashion.



**LaToya Jones**

Yes.

And because we have to take it back to family, right?

Families at home when we have folks that are born with different abilities or they, you know, get the different abilities during their lifetime, we struggle as a family with that.

My oldest daughter struggles with that and it's kind of like uh when the soldiers get PTSD because her experience and I was seeing her brother die.

So as a family unit, we have to bring family back.

We always say that we have to bring the village back.

And so this is how we bring the village back, pushing into our community, offering annual events that we host, making them desirable for families to want to come to, letting the children engage and being tired of whatever's going on.

If it's them going up to pick a book or a board game, if it's the pie, they're taking, or the cake mixed so they can bake it in the kitchen when they get back home for the holiday.

It's really all about family and through any struggle. Blood related or not, you need a family structure.

**Tania Anderson**

Absolutely.

And I couldn't agree more that building that community, whatever it looks like, is critical to everyone's success and everything you're doing, I commend you for it.

It's so consistent with the philosophy and mission of ARISE in terms of peer supports and inclusion and the power of people with disabilities just thank you for what you do.

So people who want to know more, our website is [ARISEinc.org](http://ARISEinc.org) and we're link to each other and what's a web address that you can share with folks who want to learn more?

**LaToya Jones**

They can look for us at the Joel Family Foundation just Google the Joe Family Foundation and we'll pop up and you all know that, you know, I'm in the community.

So, if you see me out, if I'm even doing anything, just ask.

I'm always open to talk to families.

I'm always open to do one I want with caregivers.

If you need to get in touch with us, find us.

We will loop your individual and with peer-to-peer support.

Our fellas these days they love gaming, so they have created a space also for them to come together and game.

And I think that's a good fellowship for them to be able to do that.

So, if you need to get in touch with us, you can find us there.

You can also find us on Facebook under the Joe Family Foundation, and we also still host space for our support group on Facebook, which is the Brady Boy support group.

**Tania Anderson**

All right.

Well, I don't know when you sleep.

But thank you for taking sometime today to talk with me.

Thanks for everything that you do.

I really appreciate it.

**LaToya Jones**

Thank you for having me today.