

ARISE Podcast 095 “

Host: Tania Anderson, ARISE CEO

Guest: Teresa Martinez, *Disability Rights Advocate, NY Connects Coordinator*
ARISE Cayuga County

TRANSCRIPTION:

Tania Anderson 0:00

Tania, welcome to the ARISE Podcast. I'm Tania Anderson, CEO at ARISE, and it's my pleasure to have with me today. Teresa Martinez, she serves as a disability rights advocate, and our New York Connects coordinator out in Cayuga County, where we have an office in Auburn. So welcome Teresa.

Teresa Martinez 0:31

Thank you for having me here.

Tania Anderson 0:33

It's great to have you here. You do a lot in your role at ARISE, but we're going to talk about something very specific, and that's your training as a family peer advocate. Can you tell me what that is?

Teresa Martinez 0:44

So, a family peer advocate is a advocate who works with families with a child with challenges and needs, they have a lived experience as a parent or caregiver of a child with significant social or emotional developmental medical or substance use or behavioral needs.

Tania Anderson 1:13

Okay. So, this is right in line with what we do is an independent living center, because as an independent living center. We are organized and directed by people with disabilities. We employ a lot of people who identify as having a disability, and a really important part of that is that, because we have lived experience as someone with a disability, when we connect with someone in the community, we can say, you know, I may not have your specific situation, but I've, I've walked in your shoes, I've had similar situations, so I can, I can really understand and have that extra level of expertise and empathy. And I imagine that your training as a family peer advocate is, is like that, but maybe a little bit different.

Teresa Martinez 2:01

Correct. Well, FP is similar to what we do here as an advocate, except for as a family peer advocate, they're required to have a lived experience,

Tania Anderson 2:13

Okay. And so, I take it then you have a child with a disability, or ...

Teresa Martinez 2:19

I do, I have two children. I have my oldest is 27 years old now, she who has children of her own and is going to school to be a special education teacher.

Tania Anderson

Wow, congratulations.

Teresa Martinez

Yes, yes. So, she has that lived experience and personal experience as well. And then I have a 16 year old who was diagnosed with ADHD. My older daughter was diagnosed she was on the autistic spectrum.

Tania Anderson 2:47

Okay, yeah, so and I have a good child with a disability. My daughter's 19, and she has a developmental disability, so we have that in common. So when you are working as a family peer advocate, what do you get special training for that? Is there special certification? How does that work?

Teresa Martinez

Yes. So there are certain credential, credentials, there's provisional, and then there's a professional. I've already received my provisional credentials, and now I'm aiming towards receiving my per professional credential.

Tania Anderson 3:23

And to get those credentials. What's involved?

Teresa Martinez 3:28

There is quite a bit of training, which is all free. It's through the families together New York State. The training is funded through OMH, the Office, Office of Mental Health class. You have to meet the criteria before you take the training. Once you meet that criteria, you're able to move on take the training. The training is actually called Parent empowerment program.

Tania Anderson 3:56

Okay that sounds super interesting to me. I've I as a parent, I've gone to a lot of trainings for my daughter, but it's usually about something about, you know, like the special ed system, or what kind of benefits she might be entitled to, or what sort of therapies might help her. This sounds like a different kind of training. What are some of the things that you're learning in this training?

Teresa Martinez 4:19

So, the parent empowerment program is a training that introduces advocates to their role and skills now, whether you have a role in as an advocate now or if you've had prior experience, and it gives you more skills to, in fact, effectively engage and empower parents and caregivers who take care of a child with challenge or needs.

Tania Anderson 4:48

Okay so this is not necessarily the substance say, in terms of you connect with other family where they've got a child with ADHD, you can say this is the nuts and bolts of how to deal with that. This is more about I'm a mom. I've got an experience. Let me, let me relate to you, connect with you, empathy, listening those sorts of, I'm going to say soft skills, but they're actually really important skills. Okay, so how long did this certification training? How long did it take?

Teresa Martinez 5:25

So, it took me about a week to do all the training. It's all online. It's similar to the training that we receive here through ARISE, but it's just focusing more on how to empower parents. It's more about parents and a caregiver and their families who have a child. And what challenges means.

Tania Anderson 5:54

I'm going to ask you a question where I think the answer is super obvious, but it may not be to everybody. Why is it important to empower families and parents of people with disabilities?

Teresa Martinez 6:08

Well, in my experience, when my daughter was first diagnosed, I had this fear of stigma and embarrassment. I was told, you're a parent, you know you need to you should know how to take care of her child, the rejection, not having the resources and tools on how to take care of my child with challenges and needs, how to provide for her, how to be able to help her through what she was in need, in need of. As a first time parent with a child in need, I just had this fear of reaching out to people, to organizations, and getting the resources that I need to be able to help her, then I think to

have that lived experience and have the training to help parents empower parents to know that you're Strong, you have that empowerment to be able to just reach out, have that voice for your child.

Tania Anderson 7:30

I think what you just said is so important, because there, there are a lot of times there's a lot of pressure on parents to not be perfect, but to be close to perfect, and to like you said, you're the mom, you're the dad, you're the caregiver, you know this child best, and for there to be a situation where you're like, I actually I don't know what to do, is hard?

Teresa Martinez 7:58

It is. I mean, to be able to partner with families and let them know that you've had that lived experience, and that's what they want to know. They want to know, because a lot of families think you're on the other side. You don't know. You don't have that experience. I may not have had a similar experience, but I have that experience. I've been on the other side. I know what it's like to feel like a failure, so to speak, as a parent, but as a family, peer advocate or an advocate, I think it's super important to let families know, parent know that you have that lived experience. You're here to listen. You're here to give them that empowerment to engage with their child, to be that advocate, to be that voice, for not only their child, but for their self as well.

Tania Anderson 9:03

And you know, our systems that are set up in the schools and the medical systems, they're really complicated, too. And I can see, just from my own experience, that you can just say, I don't even know where to start. I don't know what I don't know, and it can be really overwhelming to navigate. While you're navigating your emotional side about just recognizing that your child is different from other kids. Is that kind of been your experience, too?

Teresa Martinez 9:35

I really struggled with schools and, you know, trying to be the voice for my children, and trying not to focus so much on the stigma or the embarrassment, but to know that, you know, yes, I am a parent, but I don't have all the answers, And I'm reaching out for help. It's hard as it's to want to reach out for help, and, you know, let someone know that, hey, yes I'm a parent, but I still need help because I don't know where to start. I don't know where to begin. I don't have the tools, or I don't have the resources. So, when I ended up reaching out to get a family peer advocate for my children, was wonderful, because they were the voice for us at that time. You know, it gave me the confidence that I needed to know that, hey, yes, I'm a parent. Do I have all the answers? No, but can you help me? Can you give me the resources and tools needed to help my child just to be able to have someone that understood but have that lived experience their self, to know, hey, I've been there. I've

been down that road, and to have that partnership, to know that I have someone that understands it, empathizes with me, instead of going against me and saying, here, here are the resources and tools. No, I'm here to guide you, and I'm going to be here to help you every step of the way.

Tania Anderson 11:27

I'm in your answer just now, you mentioned, you know, stigma and embarrassment, which I get. I guess this does still exist in our society, even though you and I work so hard every day to make sure that people with disabilities feel included, because, I mean, the reality is, it's an arbitrary designation. Whether you have a disability or not. Everyone's got strengths and weaknesses, and society draws this line that says you're on one side, you've got a disability, you're on the other side. You don't when the reality is we, we all have disabilities and something right? Do you find that that embarrassment and stigma is still something that you discuss a lot when you connect with families,

Teresa Martinez 12:15

It's something I hear a lot from families, from individuals having that fear of reaching out and getting the help, and wondering if they're going to be rejected, and not knowing that because I'm on the other side, answering the phone if I'm going to completely understand what they are going through. So, I have had many calls with, you know, families, and the first thing that some people have said is, I've been rejected before. What makes you any different? And so, I will sit on that phone and explain to them what makes me different, what makes our organization different, you know, and making sure that they don't whatever the prior experience that they had with someone else, that they won't get that same experience here, let them know that I really do understand I have that lived experience. I've been there.

Tania Anderson 13:21

That's so powerful. What you just said, and part of me is just really heartbroken that people call and are in such a place that they are expecting rejection. But I'm also very proud of you, and basically what we do at ARISE in terms of saying you don't know us, we're with you, because we are people with disabilities. We get it.

Teresa Martinez 13:45

We're here. We understand. And that's what makes our organization so great, is that we do have that lived experience, and we still have that lived experience.

Tania Anderson 13:55

Absolutely. So, if someone's listening to this, and maybe they haven't reached out, or they're feeling maybe it's a parent or that just got the news that there's a so-called disability or issue with their child, and they're feeling maybe a little lost. What advice would you give them?

Teresa Martinez 14:16

Not to have that fear, not to have a fear of rejection or stigma or embarrassment and to reach out, because there are a lot of people that do understand that and have been there and that are there.

Tania Anderson 14:31

And you're a testament also to, I mean, there's our kids are going to be successful, even you've got this label that someone has a disability, but that doesn't define the person. And I know my daughter is very happy and making progress for her diploma, and she's successful. You talked about your two kids and they're happy and successful. Everyone's path is different. And it's, it's really, I think the work you're doing is so critical in showing families that you may have a different path than you thought, but it is. It doesn't mean it's a worse path. It's probably, maybe a better path. It's just a different path, and we'll take it together. Any parting words of wisdom for us? Theresa,

Teresa Martinez 15:25

Just, I want to say that is a pleasure working here. I am truly happy. Helping people is what I've always wanted to do. I've had a passion for. It's a great organization work for and knowing that I can use my lived experience to be able to help others.

Tania Anderson 15:45

It's wonderful. Thanks so much.

Unknown 15:47

Thank you. Tania.

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