

WEBVTT

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00:00:01.409 --> 00:00:08.070

All right thanks cat and good afternoon. Everybody welcome to the and new webinar for December.

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00:00:08.070 --> 00:00:16.919

As, you know, the topic for the webinar is around peer support and I have shared many times over the years. How important that I believe pure support is.

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00:00:16.919 --> 00:00:21.809

And I say that, because peer support came at a very critical point in my life.

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00:00:21.809 --> 00:00:27.929

And I am so very grateful to have had the opportunity to speak to another mom when I needed it. The most.

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00:00:27.929 --> 00:00:37.229

For this webinar, I have invited Mary Turner and Stacy guilty to join me to also share their perspectives around peer support as well.

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00:00:39.030 --> 00:00:44.969

And on today's webinar, we're going to hear from the 3 of us and hear our peer support stories.

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You will learn where peer support can be found, and we'll give you a few resources where you can connect other families and individuals to peer supports as well.

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00:00:53.429 --> 00:01:01.320

So, I'm going to go ahead and get us started and just kick off the conversation. This is a picture of me and my daughter, my youngest daughter.

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I'll just tell you my story and most folks know that I am a mom.

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00:01:06.030 --> 00:01:12.810

I have 2 daughters, and my youngest daughter has developmental disabilities and this is her in the picture with me.

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00:01:12.810 --> 00:01:18.959

Shortly after she was born, I began to suspect that there were some health concerns.

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00:01:19.224 --> 00:01:33.415

As time went on, she continued to struggle in many areas and then began, not meeting some of the critical developmental milestones. However, her pediatrician, at the time has kept telling me that I was being too overly cautious.

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00:01:33.775 --> 00:01:37.314

I needed to stop comparing her development to that of her older sisters.

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00:01:37.620 --> 00:01:43.680

And we would leave and come back and we continue with these same concerns throughout her 1st year. So.

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00:01:43.680 --> 00:01:48.629

At her 1 year checkup that same pediatrician.

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00:01:48.629 --> 00:01:52.439

Very briefly told me without any delicate touch.

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00:01:52.439 --> 00:01:58.049

There is something wrong you need to take her to a neurologist and have tests done.

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00:01:58.049 --> 00:02:06.450

And so, before I left his office, he gave me the number to children's hospital, and he told me that I needed to call and make that appointment.

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00:02:06.450 --> 00:02:09.509

On that day, if I could, so.

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00:02:09.509 --> 00:02:12.960

You know, boom, you know, there, I was instantly frozen.

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00:02:12.960 --> 00:02:17.969

I swear I could not move. I couldn't speak for a few minutes.

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00:02:17.969 --> 00:02:23.039

I really couldn't do much of anything and stuff is really the word that I would use there.

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00:02:23.039 --> 00:02:29.849

Like, something out of a movie where it feels like you've been transported out of real life momentarily.

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00:02:29.849 --> 00:02:36.719

I, I really felt like a ton of bricks had just been dropped on top and I did not know what I was going to do about it. So.

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00:02:36.719 --> 00:02:41.159

Everything and I've seen everything came to a halt.

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00:02:41.159 --> 00:02:54.840

And changed in that 3rd, and just sitting here today, talking to you about that, uh, those feelings and emotions of panic and numbness kind of come right back up to the surface. And you just don't forget something like that.

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00:02:55.914 --> 00:03:10.284

So, after I gathered myself together, got my emotions in check, I'm gathered our stuff and headed home. I made that appointment at children's hospital the very next day, and my husband, and I prepared to take her to that. 1st visit.

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00:03:10.379 --> 00:03:16.590

Still completely be filtered by everything that had had just happened and what we had been told and.

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00:03:16.590 --> 00:03:22.199

It was actually fear, which is probably the best word to describe the fear of the unknown.

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00:03:22.199 --> 00:03:27.270

You know, not knowing where, where you were headed, what we were dealing with, we didn't know.

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00:03:27.270 --> 00:03:31.259

Where are her future actually was was headed.

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00:03:31.259 --> 00:03:39.419

And now we had to sit and wait for that 1st appointment and it really felt like we were sitting on a ticking time bomb.

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00:03:40.500 --> 00:03:44.460

So, fast forward about 2 weeks later, I was still in a fog.

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00:03:44.460 --> 00:03:49.889

In 1 afternoon, now, the blue my phone rang on the other end was.

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00:03:49.889 --> 00:03:54.569

This person has said, you know, you don't know me, but someone shared.

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00:03:54.569 --> 00:04:01.139

Kind of what you and your family were going through and I just wanted to reach out. She said I'm a mom and I have walked that journey.

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00:04:01.435 --> 00:04:11.395

Now, remind mining you that I lived in a very small town at the time and so news traveled very quickly and this was Pre text, Pre, Internet, Pre messages.

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00:04:11.395 --> 00:04:17.545

So word had traveled by mouth that we were experiencing some challenges with our youngest daughter. So.

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00:04:18.870 --> 00:04:32.009

If I remember correctly, I just kind of began talking to her through tiers and describing our situation. And after I composed myself a little, we were able to have a really good conversation.

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00:04:32.009 --> 00:04:45.538

And that phone call actually lasted probably an hour and a half almost 2 hours long. She probably had no clue what she was getting into and probably wondered who she was really talking to on the other end. But.

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00:04:45.538 --> 00:04:52.379

Her reaching out to me, when I was in the greatest Nate need gave me a new vision.

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00:04:52.379 --> 00:05:04.798

And most importantly, it gave me hope and in fact that mom and I formed a pretty good relationship, she encouraged me to go to workshops, go to conferences, get involved with trainings.

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00:05:04.798 --> 00:05:09.418

And she introduced me to different advocacy opportunities.

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00:05:09.418 --> 00:05:14.338

And she accompanied me to my daughter's 1st meeting.

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00:05:14.338 --> 00:05:24.329

Um, basically held my hand and walked me through step by step what I needed to do, and I just cannot express enough. What a blessing.

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00:05:24.329 --> 00:05:27.358

She was and what that call meant to me.

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00:05:27.358 --> 00:05:31.108

I am so grateful that she took the opportunity to reach out.

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00:05:31.108 --> 00:05:37.108

Um, you know, I finally felt connected, I felt like I could see some direction.

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00:05:37.108 --> 00:05:43.678

I finally felt like someone else in the world got it and someone understood where I was.

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00:05:43.678 --> 00:05:58.074

In this new journey, and that I was no longer alone. I think that was so important. You know, I remember reaching out to my family and friends as well and unfortunately they weren't able to really relate to what we were going through. They were there to.

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00:05:58.709 --> 00:06:07.079

Kind of help walk beside us and and help us out along the way, but they really weren't able to understand what I was going through. So.

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00:06:07.079 --> 00:06:12.238

Um, and I remember her saying to me on the phone that, you know, it may not be what you expected.

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00:06:12.238 --> 00:06:16.619

But it's going to be okay there's, there's other ways to look at this. So.

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00:06:16.619 --> 00:06:22.168

And that's not the only time that peer support has been a true blessing to me over the years.

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00:06:22.824 --> 00:06:36.923

As I continue my journey as appearance, and being the caregiver alongside my daughter, I continue to find that pure support is 1 of the best supports. I have available to me. I love feeling like, I have found a tribe so to speak.

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00:06:37.228 --> 00:06:42.238

That I can reach out to someone who can relate and to folks who understands. So.

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00:06:42.238 --> 00:06:49.678

Anyway, I know that I'm not the only 1 who has shared those kinds of experiences. I know my story is 1 of many.

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00:06:49.678 --> 00:06:59.009

Peer support is very beneficial to so many people in so many different situations, whether it's having a child with a disability or.

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00:06:59.009 --> 00:07:09.749

Unique health challenges, or someone who has just received a challenging medical diagnosis. He might think of like breast cancer. I've had friends and family members.

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00:07:09.749 --> 00:07:15.569

And I know that therapy or support in those situations have been extremely beneficial to them.

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00:07:15.569 --> 00:07:24.718

I would say that having support from the peer or a mentor can be absolutely beneficial and very much life changing. So.

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00:07:24.718 --> 00:07:36.959

Enough about me, I'm going to quit sharing now and I'm going to turn it over to Mary Turner so that she can share her story in perspective as well. Mary if you're ready.

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00:07:36.959 --> 00:07:49.559

And thank you, Lisa so, my name is Mary Turner obviously, and I am the mother of 3 children. I, my 2nd child was born at 24 and a half weeks of.

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00:07:49.559 --> 00:07:59.423

Pre, uh, choose premature, so we knew from the get go that a 1 pound 8 ounce baby girl was going to have some challenges that she went through life.

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00:07:59.843 --> 00:08:00.413

Um,

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00:08:00.444 --> 00:08:03.264

I can't tell you how many times the doctor well,

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00:08:03.264 --> 00:08:03.624

actually,

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00:08:03.624 --> 00:08:17.064

I can tell you 7 times the doctor called us and told us that we needed to plan for Sarah to no longer live and 1 time they told us that we needed to plan on institutionalizing her that she would never quote unquote,

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00:08:17.064 --> 00:08:17.934

be normal.

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00:08:18.178 --> 00:08:33.149

1 of the most difficult times, though, was when they Sarah was in the, and the doctors came to us and told me told my husband was there with me and told us that.

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00:08:33.149 --> 00:08:38.908

Sara was splendid and that she was a failure to thrive baby.

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00:08:39.264 --> 00:08:48.384

Being 30 I had no idea what those terms management and all I knew is that it sounded particularly on ominous.

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00:08:48.833 --> 00:09:01.703

And the doctor explained that for Sarah, every breath that she took, it was like, someone that took 8 times, the amount of energy of somebody who was not didn't have a splintered chest.

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00:09:02.183 --> 00:09:14.394

And really what they were saying is that her ribcage couldn't expand, like everybody else's could and her lungs were damaged and I remember thinking, okay, I can do this. I can do this.

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00:09:14.938 --> 00:09:19.198

But a friend called someone who I had met when we were in the Nick unit.

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00:09:20.004 --> 00:09:23.124

And I don't know how she knew to call me on that particular day.

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00:09:23.364 --> 00:09:38.153

I would guess it was probably divine intervention or maybe somehow she got word we were going through a very difficult time and she called and it was interesting because they brought the phone to me at my daughter's bedside again

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00:09:38.153 --> 00:09:39.984

kind of an unusual situation.

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00:09:40.553 --> 00:09:44.933

And she asked me if I was okay. And I said, yeah, yeah. I'm okay. I can do this.

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00:09:45.028 --> 00:09:50.129

I'm a little bit of a stubborn German, um, and I remember just.

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00:09:50.129 --> 00:09:59.818

Thinking pull up your big girl Penny's, Mary, you can do this and finally she said, Mary, can you really do this? Or do you need a friend?

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00:09:59.818 --> 00:10:09.239

Well, that turned on the water works for me and I said, yes, I need a friend and she was there and probably 15 minutes.

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00:10:09.239 --> 00:10:16.374

It was someone who'd gone through something similar to this day. She and I have remained very close friends.

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00:10:16.644 --> 00:10:26.964

I can't tell you how many situations she has walked through with me when we've been faced with difficulties with Sarah and her healthcare and her disabilities and so forth.

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00:10:27.563 --> 00:10:41.964

She attended a with me similar to Lisa's experience where they, we wanted something for our child that the school district wasn't really willing to to invest the time and energy and money in.

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00:10:42.323 --> 00:10:54.864

And I remember being her, squeezing my hand, and holding me tight. Whenever the principal said, you know, if you make this decision, then the responsibility for Sarah's up to, you can't.

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00:10:55.168 --> 00:11:05.938

Can't lie, I kind of laughed at that and I said, well, Sarah's responsibility has always been up to us. So we went ahead and fought the front and got what we wanted from the IAP.

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00:11:07.553 --> 00:11:20.844

However, the thing that I think is most critical to here is that we all feel like, at times were on this journey alone. And at times we'll have different people reach out to us and want to take a walk beside us.

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00:11:20.874 --> 00:11:25.344

But it's the people who've had that lived experience that know the most.

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00:11:25.619 --> 00:11:35.903

What it feels like, when you're alone and afraid, and you're hoping you're making the right decisions and I was very blessed to have that person walk along. Beside me.

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00:11:36.354 --> 00:11:49.043

I've always said that if I was going to do a doctor at dissertation on anything, it would be on connection and collaboration and having people who can walk with you in some of those life journeys and the difference.

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00:11:49.043 --> 00:12:02.094

That it makes whenever you have that connection versus when you are trying to walk that alone, primarily, because you don't know what else to do, but just to keep putting 1 foot in front of the next foot and moving forward.

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00:12:02.964 --> 00:12:05.063

I was grateful for my peers.

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00:12:05.094 --> 00:12:14.033

I've been able to be appear for other people been able to attend with other people and really the whole point of it is to be able to help them,

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00:12:14.033 --> 00:12:21.563

have their voice and advocate for what they need for the children that they have it that they're involved with in their lives.

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00:12:25.104 --> 00:12:35.364

Thank you Lisa. Oh, thanks, Gary. And you're you're so right. I appreciate you sharing your story. The lived experience is what really helps make that difference.

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00:12:35.394 --> 00:12:43.823

Um, again, like I said, you know, I had family and friends that were by my side, but not really able to relate to some of the feelings I was having and.

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00:12:44.068 --> 00:12:47.129

The fear that I talked about, and that that.

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00:12:47.129 --> 00:12:53.879

Moment of panic that I went through. Um, it makes a difference. The lived experience is really beneficial.

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00:12:53.879 --> 00:12:59.278

I think Lisa, sometimes that I'll be quiet. Let's Stacy talk. I think sometimes.

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00:12:59.278 --> 00:13:04.408

When it's a family member, they, they're so confused about.

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00:13:04.673 --> 00:13:17.573

Things and so feeling your pain, but in a different way that they don't know how to be the kind of support that you absolutely need. Because they haven't been in the same shoes. They've walked with you, but not the same shoes.

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00:13:17.573 --> 00:13:25.163

So they'll say things that they hope are encouraging, but often they're not particularly encouraging. It's just kind of a.

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00:13:25.678 --> 00:13:29.369

They meanwhile, but they don't always have the right.

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00:13:29.874 --> 00:13:44.783

Again, a lived experience, right? And, you know, from a grand parent's perspective, you know, my mom has shared, you know, not only was I seen my granddaughter go through some challenges, but I was watching my daughter and her family go through those challenges. So, she got the double, right?

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00:13:44.874 --> 00:13:51.533

And not knowing what to do is, you know, she's talked about how she helped felt incredibly help with at that time too. So.

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00:13:51.989 --> 00:13:58.589

Having the peer support was a big help and then me actually flipping it around and helping her. So.

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00:13:58.589 --> 00:14:02.908

Anyway, so thank you very much for sharing Stacy. Are you still there?

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00:14:02.908 --> 00:14:12.688

I am still here. Great. Well, I know that your stories is a little bit different, but, um, you have a very impactful story about your journey as well. So if you want to share.

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00:14:12.953 --> 00:14:26.094

Okay, thank you. Um, my name is Stacy. Dokey and I'm I'm a fam, a mom of 4 I have 2 boys and 2 girls, and my 2 boys, um, have an autism diagnosis. My oldest son is 25.

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so this is kind of his little bit of his story in our journey. Um.

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00:14:30.989 --> 00:14:41.879

And, like, Lisa said, my story's a little different, um, when I started my journey with my oldest son who's now 25, I didn't have any peer support or to be honest, any support at all.

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00:14:41.879 --> 00:14:47.759

My son had been given multiple diagnosis, but nothing really fit.

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00:14:47.759 --> 00:15:01.739

Um, I worked for a local school district at the time, and they sent me to an autism training and about halfway through it was like, a 4 day training and about halfway through. I'm like, this makes sense. This is my child.

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00:15:01.739 --> 00:15:12.869

So, we, you know, I researched on who to see what doctor to go to. Um, I remember getting that diagnosis and thinking, okay, we have it. But now, what do we do with it?

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00:15:12.869 --> 00:15:21.899

I worked very hard after that to educate myself on, not only autism, but the 504 progress are.

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00:15:21.899 --> 00:15:32.698

Process because our 1st was a disaster. I had no support with me. They were talking at me using all of these words that I did not know what they meant.

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00:15:34.193 --> 00:15:48.293

I worked very hard to get the services. My son needed the journey through all of that was rough, but it taught me to be an advocate. And later in life, when I had my other son, I was more prepared when the process started with him.

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00:15:48.599 --> 00:15:53.339

I now have the ability to help others through their journey and to help navigate this.

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00:15:53.339 --> 00:16:01.859

System and to not let another parent feel lost in an meeting, or a doctor's appointment, or any, any things surrounding their child.

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00:16:01.859 --> 00:16:08.818

All of this experience set me up for the career I have now as a family support program coordinator.

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00:16:09.053 --> 00:16:23.903

And I have a team that helps parents every single day with that peer support. Because, like Mary said, you know, you have family around you, but it's not the same. They might be helping you through your journey. But they do not have that hands on.

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00:16:24.178 --> 00:16:27.389

Every day what? It's like, journey.

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00:16:27.389 --> 00:16:39.389

Um, so peer support, I believe in that 100%, it is, is the best thing. And now now I have it cause I knew where to seek it.

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Um, but back then I didn't, so I'm so glad that these kinds of things happen.

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00:16:45.418 --> 00:16:52.139

That connects all of us, Lisa. That's that's the story.

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00:16:52.283 --> 00:17:03.774

Great. Thank you very much. And you're right it's the connected it's the networking where you feel like you're in your like I said earlier almost in your tribe of of, like, minded folks. Right? So right.

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00:17:04.344 --> 00:17:10.673

Let's take a few minutes and talk real quickly about where people can tap into different peer support services.

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And Mary, I know you're the director of the Missouri family family resource center at and Casey.

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And I know that there's a great emphasis on supporting families there. Can you give us a little more information about what is and what is available there around peer support.

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Absolutely, so Missouri family to family has been around for over 30 years.

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Actually, every state has a resource center that came about as a result of a legislative process when John f Kennedy was president and but they take on different forms throughout the States.

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They could be called a parent to parent association or family voices, or a, you said University Center for disabilities and we are under the University of Missouri, Kansas City.

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00:17:57.173 --> 00:18:09.834

You said so we're in the Institute of human development division. So, what we are is we have several different what I call pillars to our services, and I'm going to be super brief.

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00:18:09.834 --> 00:18:17.453

So I can get into the brief to the peer support component. You can call us and get an immediate information and referral services.

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That's usually a 1530 minute phone call where you need to know where to go in your community or in the state to connect with the resource for a family member. So you have a plan.

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00:18:28.794 --> 00:18:37.943

You know what you're doing, you just need some additional information on where to go next. Then we have what's called navigation navigation is always done by peer support.

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00:18:37.943 --> 00:18:51.653

And so that's someone who has a lived experience that is trained, and we put them through 3 or 4 different trainings before they can become a navigator and a navigator will help. You really start developing a plan.

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00:18:51.653 --> 00:19:04.794

I'm using the charting the life course tools. And this is typically, when someone just gets a new diagnosis, they don't know what they're being faced with. They have no idea where to turn, or how to find out some information.

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00:19:04.794 --> 00:19:11.003

And so our navigators spend more time with you to help you to understand a little bit more about the,

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00:19:11.003 --> 00:19:17.304

the diagnosis or diagnoses that you've received both developmental and,

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or physical or mental health diagnosis,

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00:19:20.423 --> 00:19:23.604

and then help you craft a plan for moving forward.

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00:19:23.604 --> 00:19:25.493

Then we have what's called.

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Peer support and peer support is.

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00:19:29.034 --> 00:19:41.213

Kind of our cream of the crop, if you will. So this is someone again, with a lived experience who will help you do the navigation piece, but they will follow along with you anywhere from 1 week. 6 weeks.

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00:19:41.243 --> 00:19:45.534

8 weeks, 12 weeks, as long as a year's period of time.

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00:19:46.078 --> 00:19:59.844

Agreed upon by the both the peer mentor and the family, they'd been matched with in order to really help you get moving, solidly on all the plans, because you may start with knowing 1 thing that you need to do.

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00:19:59.844 --> 00:20:09.713

And then, as you get further and further into understanding the diagnosis, you may have come up with additional things that you need to face and to build plans for.

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00:20:10.288 --> 00:20:15.834

In addition to that, um, peer support that we provide in the navigation and information and referral.

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We also do training both for leaders and we do education for our constituents and stakeholders and other professionals as well as family members.

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00:20:28.798 --> 00:20:39.203

And to get our help, really Lisa has up on the screen, the best way to contact us is through the website that you see there, or to call us.

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00:20:39.233 --> 00:20:42.834

And and I will put my email in the chat,

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00:20:42.834 --> 00:20:51.413

and you guys are more than welcome to contact me directly through email and we will connect you with the appropriate response either information,

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referral navigation,

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00:20:52.884 --> 00:20:58.193

or connect you with a peer who can be that emotional support and walk beside you,

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00:20:58.523 --> 00:21:01.614

they are trained on how to do an process.

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00:21:01.913 --> 00:21:12.084

They're trained on the resources in the community and they're trained just to be a listening ear to teach you some advocacy advocacy skills for yourself and your family members.

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00:21:13.949 --> 00:21:25.858

Well, that's great. Mary, thank you so much. It was a great overview. Um, I would definitely encourage folks to go to the website and check out the information that's there or to call them just visit with 1 of the navigators that you have on staff.

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00:21:25.858 --> 00:21:29.969

Missouri family the family has been has been part of.

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00:21:30.114 --> 00:21:41.213

My life, my family's life for many years. My daughter's 33 so I can remember way back when it 1st started and that was the place to call because Internet didn't exist at that time.

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00:21:41.213 --> 00:21:49.253

So, we would call family to family and get some of the resources that we needed and make copies and share with other families that we knew as well.

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00:21:50.098 --> 00:21:59.634

Um, oh, yeah, go ahead. So I should have said, um, just so everybody knows we have peer support throughout the entire state.

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00:21:59.814 --> 00:22:06.263

Um, we have 400 peer mentors that are trained and so we do match based on.

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00:22:07.048 --> 00:22:15.088

Not only the demographics of the diagnosis, but also the region of the state, the person is living in. I'm sorry I didn't mention that before.

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00:22:15.088 --> 00:22:21.209

Yeah, and I think too if I remember correctly, I mean, you guys are also connected to a national.

167

00:22:21.209 --> 00:22:24.269
Family to family, so that if somebody would happen to.

168
00:22:24.269 --> 00:22:36.148
Call in and be looking for a very specific, uh, maybe a diagnosis. That's a very rare situation. And wanting to connect you guys could go even to a higher level and connect on a national.

169
00:22:36.148 --> 00:22:39.269
A platform and reach out to.

170
00:22:39.503 --> 00:22:52.433
Correct like a national. Absolutely. Yeah. We, we are on multiple lists and so if we can't find someone locally, because for instance, it might be a very rare or unusual diagnosis.

171
00:22:52.794 --> 00:22:57.594
Then we go into our pool of supports with the national organizations throughout the nation.

172
00:22:57.898 --> 00:23:00.959
Cool. That's great.

173
00:23:02.273 --> 00:23:12.233
All right, so Stacy, I know that you worked for a behavioral health organization, and your organization also serves a lot of families you serve individuals of youth as well.

174
00:23:12.894 --> 00:23:23.634
You mentioned that you were the coordinator or the program coordinator for the family support provider services. Can you give us a little more information on that and how someone might tap into that service.

175
00:23:24.233 --> 00:23:39.023
Yes, to get into our family support services, you have to have a case manager in our youth program, and we work pretty much hand in hand with them. Um, while they work with the child, we work with the parent. Um, we do a lot of.

176
00:23:39.328 --> 00:23:51.179
Meetings a lot of resources, um, just kind of walk them beside him, you know, trying to get the, the child, the services that they need.

177
00:23:51.179 --> 00:23:55.949

Um, they do have to have in our program, they have to have Medicaid.

178

00:23:55.949 --> 00:24:00.538

Um, but, yeah, we just we pretty much have a, uh.

179

00:24:00.538 --> 00:24:04.229

Huge thing of what we can do.

180

00:24:05.278 --> 00:24:10.409

And because your system, or your organization is in the Kansas City area.

181

00:24:10.409 --> 00:24:20.878

I went ahead and added the map because there are community mental health centers all across the state. There is a link at the bottom of that PowerPoint slide where you can click.

182

00:24:20.878 --> 00:24:25.169

And go to what you see on the on this slide, you will come up with a map.

183

00:24:25.169 --> 00:24:30.749

And you can enter in your county and find what community mental health centers in your area.

184

00:24:30.749 --> 00:24:33.868

Do all mental health.

185

00:24:33.868 --> 00:24:36.898

Centers have on on board.

186

00:24:36.898 --> 00:24:40.469

Yes, I think every 1 of them has, at least 1.

187

00:24:40.469 --> 00:24:48.388

Okay, so there's a perfect peer support right there. Um, it might be in your right in your backdoor even so.

188

00:24:48.388 --> 00:24:54.538

Where in our efforts, we have to have that lived experience um, that is our.

189

00:24:54.538 --> 00:25:01.798

Our main requirements to be able to do the job is having an, having the lived experience.

190

00:25:01.798 --> 00:25:06.419

True and they go through 3 days of training to be, um.

191

00:25:06.419 --> 00:25:13.949

Certified so to speak, so they go through all kinds of training with Stacy and another team of FSP leaders that.

192

00:25:13.949 --> 00:25:19.499

Bring them up in the system and help them work better with the families that they support. So.

193

00:25:19.499 --> 00:25:27.628

Right. Great. So I'm going to add, um, the division just.

194

00:25:27.628 --> 00:25:34.949

Not too awful long ago also added family, peer support services through the partnership for hope waiver.

195

00:25:34.949 --> 00:25:41.249

It's not a service that's up and running completely yet. So it's open for development.

196

00:25:41.334 --> 00:25:56.183

I've added a quick link here on the slide. There's a waiver fax sheet you can check out and we also did a presentation about family, peer support services. There's a recorded webinar and a Q and a page there for you to check out as well.

197

00:25:56.183 --> 00:26:06.624

So, if that's something you're interested in, and you get services through the division with the support coordinator, you might bring that to their attention and, um, investigate that a little bit.

198

00:26:08.213 --> 00:26:20.574

Um, so we've just shared some places where you guys can find for your support, but there's also other places that peer support could be in a more informal way. I know that my support coordinator.

199

00:26:20.634 --> 00:26:35.423

Um, and my daughter's support coordinator over the years was very instrumental in the connecting families together. They knew the other

families of the community, and sometimes I would reach out and say, hey, if you've got another family in the area, please feel free to give them.

200

00:26:35.423 --> 00:26:36.983

My name my number.

201

00:26:37.318 --> 00:26:40.439

And I've made connections that way over the years.

202

00:26:40.439 --> 00:26:46.169

And Stacey, and Mary, you guys can chime in here if you think of something else to add to.

203

00:26:46.169 --> 00:26:52.378

Another place you might consider is reaching out to some of the provider agencies that are in the area.

204

00:26:52.378 --> 00:27:02.364

I know many folks have peer support services. There. I know. There's some in St Louis. I know there's some around the Kansas City area for sure. Down in Springfield.

205

00:27:02.453 --> 00:27:14.003

Um, some of those provider organizations have support groups for families. That'd be something else. You can reach out to you because that's a a natural place for peer support to to begin to develop.

206

00:27:16.078 --> 00:27:19.618

Um, some of the large organizations that I think about is like.

207

00:27:19.618 --> 00:27:27.298

The down syndrome Association, um, I happen to know somebody who receive services from them and luckily.

208

00:27:27.503 --> 00:27:40.644

Now, in today's time, those families don't even have to leave the hospital without support the down syndrome folks that the association will reach out to the parents that maybe have just given birth to a child.

209

00:27:41.034 --> 00:27:49.824

And those families actually go home already having some peer support opportunities in place. So that's pretty cool. I'm glad that's a a great step forward in that area.

210

00:27:50.219 --> 00:28:04.679

Um, I've also talked to some health care folks, our doctor or family physician. I've always reached out to her and again, given her the permission to share my name and information with other families that she comes across.

211

00:28:04.679 --> 00:28:15.749

I have always spent a little bit of extra time at our appointments, telling her about some of the resources that I'm aware of, and making connections to some of their families in that that manner as well.

212

00:28:15.749 --> 00:28:22.259

School systems obviously good places you run into the same folks in the hallways if you're.

213

00:28:22.259 --> 00:28:29.189

Child, it gets any kind of special education services you might be running into some of those other families in that same arena.

214

00:28:29.189 --> 00:28:35.578

I know when my daughter was in school, the special education teacher that she got services from.

215

00:28:35.578 --> 00:28:45.838

Actually set up monthly meetings for some of the families, and lots of families got connected in that manner and we stay connected outside of school related events. So.

216

00:28:45.838 --> 00:29:00.749

Good place to meet other families the last, but not least is always the social media. There are so many online opportunities to connect to folks that are.

217

00:29:00.749 --> 00:29:01.199

Again,

218

00:29:01.193 --> 00:29:04.044

might be experiencing the same diagnosis that you are,

219

00:29:04.344 --> 00:29:04.644

uh,

220

00:29:05.183 --> 00:29:05.963
different things,

221

00:29:05.963 --> 00:29:12.594
even assistive technology if you have questions that you might want to ask of folks that use different technology,

222

00:29:12.594 --> 00:29:18.594
there's places for that there's places for individuals with disabilities to make pure connections as well.

223

00:29:18.594 --> 00:29:20.723
You know, people 1st of Missouri is 1 of them.

224

00:29:20.999 --> 00:29:29.038
Um, so I would say if you're a support coordinator or provider staff, and you've listened to this webinar.

225

00:29:29.038 --> 00:29:40.888
Please please do not forget that adding peer support services to the list of things that you can offer families and individuals and these are some of these are at no cost. So you can just reach out.

226

00:29:40.888 --> 00:29:45.808
Is there a family? The family is 1 of them just get those families pointed in the right direction.

227

00:29:45.808 --> 00:29:50.788
So, Mary Stacy, do you guys have any last minute thoughts you want to share.

228

00:29:53.699 --> 00:30:08.578
I would just encourage everyone my experience in being a peer support person for other family member is you get as much reward as out of being a peer support as the support that you give to another person. So.

229

00:30:08.578 --> 00:30:16.673
Don't so if you get to the point that you're ready to be your fear support, let us know, and we'll help, you get connected and how to become 1 of those.

230

00:30:17.003 --> 00:30:25.554

But if you're in a situation where you need a peer support, or you're working with family members, who need of peer support, don't hesitate to contact.

231

00:30:25.648 --> 00:30:31.318

Any 1 of us in the panel, because we definitely want to fill that need in our communities.

232

00:30:31.318 --> 00:30:41.638

Absolutely, I absolutely agree with Mary. It is. The most rewarding thing I've ever ever did is is to help families because you do feel so alone.

233

00:30:41.638 --> 00:30:45.148

And if I can help with that, it's the best thing ever.

234

00:30:45.384 --> 00:30:52.554

Right. Good point. All right well, I want to say, thank you to Mary and Stacy. Thanks so much.

235

00:30:52.554 --> 00:31:02.753

I've enjoyed hearing your stories and I always enjoy hearing your perspectives and sharing your information and resources with us and to everybody else on the call. I just want to say.

236

00:31:03.028 --> 00:31:10.259

The next webinar will be scheduled for January 25th.

237

00:31:10.259 --> 00:31:15.778

From 1230 to 1 so thank you all for joining us and have a good new year.

238

00:31:15.778 --> 00:31:19.991

Thanks everyone. Thanks, Lisa. Thanks, Lisa.