

Shine a Light on Stigma Podcast

Transcript - Episode 9: Understanding the Connection Between Trauma and Stigma in Substance Use Disorder

Note: The Shine a Light on Stigma Podcast is produced for the ear and designed to be heard. This transcript is intended to augment the recording.

This podcast is part of a series that explores ways to eliminate stigma and help people with substance use disorders access the medical care they need. Produced by Superior Health Quality Alliance and Telligen, Quality Innovation Network-Quality Improvement Organizations under contract with the Centers for Medicare and Medicaid Services, an agency of the U.S. Department of Health and Human Services.

Brittany Rodriguez: Hello and welcome to the Stigma Podcast. In this podcast, we're talking about the ways that stigma impacts people living with substance use disorder. We aim to inspire and empower our listeners to shift away from the culture of stigma towards one that promotes healing and recovery in a supportive and respectful way. I'm Brittany, and I'm here with Mia, along with our guest Sara today, whom you'll get to meet soon. But you may have noticed we've been on a bit of a break. I've been just a little busy, and so we wanted to take a second to introduce why. I'm happy to announce that I was able to welcome a new little girl to the world, baby Eleni. And I've been out on maternity leave, so I'm happy to be back.

Mia Croyle: We're happy to have you back, Brittany.

Brittany: Thank you. Well, Mia, would you like to introduce us to Sara?

Mia: Yeah, so I am so thrilled to bring as a guest, Sara Jesse to talk with us on the podcast today. Sara Jesse is the community health manager for public health Sauk County in Wisconsin. She helped found and direct several substance use-related programs, including the Sauk County response teams, which is an EMS peer support home visiting program that it works to enhance linkages to care. Also, the Sauk County Overdose Death Review team, the Sauk County Partnership for Prevention Community Coalition, the Support People and Empower Recovery Coalition, the Sauk County Harm Reduction programs, including Narcan and Fentanyl test strip distribution. Sara also works on community health assessments and plans for other health focus areas with a special interest in health equity, social determinants of health, suicide prevention, and adverse childhood experiences. Having lost her sister to opioid overdose in 2007, she's a passionate advocate for harm reduction in primary prevention services. So your bio sort of referenced this a little bit, I imagine, but as you know from listening to previous episodes of our podcast, the first thing we always ask our guests is to just tell us a little bit about their, why is this work important to you? Why is the issue of stigma a compelling one for you? So we would love to hear your why, Sara.

Sara Jesse: Thank you. And I love this question because it really invites me to share and rededicate myself to what is most important to me, which is in a word, healing. I'm really in this for the healing of humanity. It's a lofty goal, but it's my experience that we really are connected as humans on this planet, and these moments of healing are nothing more than the awareness of that joining coming into our minds. It's a

moment where we release our fear, where we release our judgment about ourselves, about the other person and our hearts open, and this is what I'm in it for. It's really been my mission since I was 21. I made it my mission. I was like, oh, I'm here on this planet for healing. That's what I'm here for. It's for my own healing and the healing of others. So it's a great why that gets to stay with me throughout my whole life. It's been with me over 30 years now, so that's what I'm here for.

Mia: Well, we're glad you're here. And having worked alongside several of the programs listed on there, I can say that the work that you do and the work that you empower other people to do really does touch many, many, many lives. So we're glad that you tapped into that early and hang onto that through your career. Before we started recording, we were talking a little bit about something that you said is always sort of a very interesting point and something you think about often in regards to stigma, which is the connection between trauma and stigma. I'm wondering, can you say a little more about what you mean by that connection and where you see those connections being?

Sara: Absolutely, and I think it would be best served to share more of my story. I know as you introduced me, you mentioned my sister dying of an opioid overdose. Elizabeth died when she was 37 years old, and she was addicted to Oxycontin. That was a big part of her overdose. And her story I feel is like that of so many other people in that she experienced so much toxic stress from early childhood abuse. There was abuse that was sexual, physical, emotional. There was neglect, there was a lot of mental health problems, were a lot of mental health problems in my family, lots of substance use problems. So all of that stress really led to her making what I think is quite a reasonable decision to turn to substances for some relief. And where I feel this really feeds into the conversation around stigma is I know that every single person I work with would move heaven and earth for my sister when she was a child.

Sara: I mean, they would see her suffering and they would skip their lunch break, they would work unpaid overtime. They would do anything to help my sister because at that point she was a victim. But when she started using alcohol when she was 11 and used it so much that she needed her stomach pumped for the first time when she was 11 years old. And at that point it was like, what are you doing? Why did you make this choice? And we can step back and say, wow, this is an individual who is in so much pain that this is a logical choice for them to find relief from that pain in whatever way they have available. And we know a lot of people who have substance use disorder start using at a very tender age like my sister did. And when they use, they talk about their experience of like, oh my God, when I first tried alcohol or when I first smoked marijuana, I felt like I could live in this world.

Sara: I felt like things were okay. And to me that signals their brain was so saturated with this toxic stress from childhood adversity that when they tried the drug for the first time, it was an experience of being comfortable in their own skin for the first time. And so of course they repeat that experience. And again, it's quite reasonable to want that. And also thinking about how this is a child whose brain is far from being fully developed, it's really hard not to make an emotional choice that gives you some release from pain and discomfort. But you fast forward a few years when my sister started experimenting with other drugs, cocaine, marijuana, people's empathy starts to go down and down and down. And then we start saying, this was your choice. This was your choice. To become addicted to a drug and to unpack that I think is quite complex because as humans, we really want to make quick decisions and move on.

Sara: We love thinking quickly. And so, it's really easy to just judge someone, okay, I've solved this problem. It was your choice, end of story, and now we can move on. And I can keep my own idea of who I am intact, and I don't have to really think slowly and challenge my own beliefs. So, I think to undo stigma, we really need to train ourselves. And I think it's an inside job that starts with me first to really take a look at our own discomfort, our own stories that we tell ourselves as Americans. I think we're very saturated in this model of individualism that if you are unhealthy, it's your own moral failure somehow. And it doesn't

have much to do with your environment, doesn't have much to do with all the things that are outside of your control. So we're really getting into a psychological place where we want to be in control as humans, we don't want to admit just how out of control so many things are. And in order to really break down stigma, I think that's what we need to do is start telling ourselves maybe different stories. And I can give an example of that if it's helpful.

Mia: Yeah, I think an example would be great, but I just want to pause for a minute and think about some of the gems of wisdom you've already dropped. I mean, I love this idea of really working on combating stigma being an inside job. And it strikes me that we yearn for simplicity. And like you said, we like to go fast. We like to diagnose the problem and then fix it. And a lot of the things that are really challenging our society right now aren't simple problems. They have these layers upon layers of complexity, and we don't like those kinds of problems very much because they're not easy and quick to do. But I also love the hopefulness that you're portraying in that these things can be unpacked, they can be worked through, but we have to slow down to really allow ourselves the spaces to do that.

Sara: And we also need to maybe relinquish our own hero stories, the story of me in that I did this through my own grit and determination. It's a beautiful story, but it's not true when you really look at it, it's just not true. And I think that's something we're grappling with so many social issues right now as a country. So it is a super exciting time.

Mia: Yeah, I love, one of the phrases I heard recently that I just have really loved is I didn't make good choices throughout my life. I had good choices. And that one, I mean, that's one of those ones that your brain just goes pow. Because it's, like absolutely. I had a menu of options, all of which would've been good choices available to me. And there are people who don't have that. There are people whose menu only serves up what we would call bad choices.

Sara: Exactly. And so much that is due to brain science and things we have no control over. So when someone says, oh, look at the bad choices they made, they overdosed. And frankly, some people I know would say they deserve to die from their bad choice. And it's like, oh my God. But what choices exactly Mia was their brain offering to them when they've been saturated in trauma? It's like, did they choose the trauma? Did they choose their brain's cortisol levels and how long those cortisol levels would stay high? Did they choose how their brains would respond to substances when they first tried them? No way. You didn't choose all that.

Mia: You didn't choose any of that. Yeah, right.

Sara: Absolutely. So this is a question that I get asked sometimes. It's like, well, Sara, you grew up in that family with all that adversity. How come you turned out? Or I hear the flip side of, like, well, I grew up in a family with all kinds of hardship and I never made that choice. And for me, I spent a lot of time unpacking this because, frankly, I felt pretty guilty when I was in my twenties. And I was like, wow, how have I made it this far? I don't know if I mentioned I'm one of nine children, so I'm one of the youngest of nine. And I was seeing all the trouble that my older siblings were in with substances, with criminal activity, with severe mental health challenges. And so I started looking at that, and what I found were all things that were outside of my control.

Sara: Like birth order. Birth order is a big deal because not so much of the order exactly, but because a dysfunctional family system needs people to stay in pretty rigid roles. And even if your family isn't that dysfunctional, you might find it's really hard to break out of the role that you've been handed. My sister, Elizabeth, who died from an overdose was four years older than me. And the family needed at that time a scapegoat. They needed someone to blame when the family was questioned, like, what's going on in this

house? Oh, well, Elizabeth has these substance use problems and Oh, okay. And it doesn't invite a whole lot of further inspection. So she was the scapegoat, the one that could be blamed for all the families dramas. And my role next in line was caretaker because the family needs someone to try to hold it together.

Sara: And combined with that, I had a little bit of the hero of the family as well that I did well in school. And so my parents could say, look, we're fine. We have a straight-A student. And they did that with my sister, who's a lawyer, and my sister, who's a doctor. They were held up in these hero roles. So I really saw, wow, if I had been born before my sister and the family a scapegoat role, that could have been me. I firmly believe that. I mean, maybe there was a little bit of my personality in there as well, but that's also not in my control what personality you have. And then I have kind of an interesting story in that I was born, when I was born, my family lived in East Orange, New Jersey, which at the time was nearly all black. It was an all-black neighborhood that was deteriorating rapidly.

Sara: And so my older siblings attended a school district that was really scary, that really was challenging. It was hard for them to focus on studies. They had to walk to school past houses where there was prostitution, where there was injected drug use. It was rough. And my family was able to move in 1975 to a very exclusive, nearly all white neighborhood, and I was only two at the time. So I got to really benefit from that district, that school district. And so I feel I am the direct result of white privilege. Our black neighbors could not leave that neighborhood. Redlining was still in effect during that time saying where I moved to was very exclusive and very hard to break into. That's part of my story that I realized in the last several years, like, oh my God, without that school district, who would I be today? I would've struggled mightily in that school district. So you can say, well, I could also give an individual story and say I started 12-step programs when I was 21 and worked them. It was a full-time job and really dedicated myself to this work. And that's true too. But there's so many other factors that made me who I am today that really were not an individual story at all. It was things that I was given and that were out of my control.

Brittany: I do think that just listening to this, it's so impactful, but this is a story of empathy. I feel like as I'm listening to this, I'm thinking, okay, you're exactly right. This is textbook of things that we're seeing every day in this world. And even this morning I was giving a training on stigma and naloxone, and every time there's this slide that I talk about of what influences addiction or substance use disorder, and the two biggest factors are environmental and biological. And you hit the nail on the head exactly in your situation what those were, right. And for me it's just pulling out empathy. I'm just thinking, man, it's heartbreaking to listen to that story. And you're exactly right. The whole concept of it could have been me.

Brittany: It puts you in a mental space to be able to do this work. And I think, I guess, so that's my question for you as we're kind of starting to move towards, what can our listeners do here? What are we asking? If we were listening right now, what do we want to be asking them to do? And so I'm kind of curious to hear what you have to say. If you had to give someone advice, be like, this is what I think should be your next best step so that way you can be a better part of this solution when it comes to substance use disorder. Yeah,

Sara: I think number one, thank you, is to start challenging our own stories, our own stories in which we're the hero and we fought individually and everything because easy to tell a story of everything I have is due to my own hard work. And to really start unpacking that and going, is it really? I think that's very helpful in this cause because then yeah, you can enter into spaces. When I used to do Narcan trainings at the jail, I would tell the story of my sister and I would say, I could easily have been her. I could easily be in your shoes. Roles could be reversed here so easily I could be in jail. Absolutely. Just a few things had changed in that scenario. So leading with that kind of thought and that kind of we're accepting that kind of powerlessness in a way too, or lack of control that we have.

Sara: It's hard as a human, but I think it's needed. So that's kind of the inside job part that I think we all can do. And then how do you unpack this when it's quite complicated? There are some simple phrases that I like to use. One of my favorites is that the opposite of addiction isn't sobriety, it's human connection. Because that points like, oh God, that's what we all yearn for is that human connection. Even if we're acting like it's the last thing we want, it's really what we want deep down inside is to be seen and valued and understood and to be joined with. Another one that I say often is trauma is the real gateway drug. It's not alcohol, it's not marijuana, it's not tobacco, it's trauma. And to talk about just how much that toxic stress can change the way that the brain is structured, the way it functions. ‘

Sara: And that of course leads to that's not in our control and hopefully opens hearts to and minds to people who are really struggling now. And of course, I don't want to make it, so on the side of, it's not a choice because of course there's choice in there as well. I don't want to take away that individual agency that we all have, but I think we really overplay that individual agency both in the stories we tell ourselves about ourselves and the stories we tell about other people because it's easier and it makes us feel good, but it's not really sharing in that humanity, which is what we all really, really want at the end of the day.

Mia: Yeah, I think we've talked about this in past episodes, how connection can be such a difference maker for someone struggling with substance use disorder or for someone looking to develop that empathy and really make a difference in this area, just that connection can be everything.

Sara: And if this is new information to you as a listener, maybe you want to look into adverse childhood experiences or ACEs and learn about the studies that have been done. But if it's new, it might really open your eyes because they show time. And again, how the more adversity you have in childhood, the more likely you are to have problems with using substances to have substance use disorder to use. Injected drugs mean, and the relationship is this very steep curve. If you have five or more types of this trauma, you're like 10 times more likely to struggle with substances. So it is really impactful.

Brittany: It is really interesting science, and I remember the very first time I learned about ACE scores, it was mind boggling. It truly, like you said, it can be really impactful. So I will actually try to link to that or to at least some type of educational source that we can put. If you want to go learn more, we can add that to our description for the podcast today. But Sara, thank you for sharing first of all your why and just how you've gotten here. There have been so many things that I've thought that should be on a mug somewhere that could be a T-shirt, but really, they're just these one-liners that have been really eye opening and even just I've had my own self-reflection during this time of thinking, I need to remember that for this situation or for that relationship that I have with someone. So thank you for sharing that and we want to continue having this conversation.

Brittany: But for today, I'm going to go ahead and wrap us up and we will definitely be hearing more from Sara if you've enjoyed this episode. So please continue following. And as you know, we've referenced quite a few previous episodes and so please go back and listen to those. There's a lot of impactful messages there from ER clinicians to family members to people out in the community that are really in the weeds this work. And that's a big part of our strategy when it comes to stigma is really just exposure and being willing to have these conversations. So please go back and give those a listen. We also would love any feedback that you could give us or any, I guess really anything you'd like to say to us or to our guests. We're happy to pass that along. And we would love to hear from you at StigmaPodcast@telligen.com. And that is T-E-L-L-I-G-E-N, and we do get those, and we love hearing from any of our listeners. You can find us at any of your favorite podcast streaming services, so subscribe so that way you get a notification and don't miss anything. And hopefully, there won't be as long of a break between the next one. No more maternity leaves for me anytime soon. So thank you for joining us and we will talk to you next time.

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