Shine a Light on Stigma Podcast

Transcript - Episode 8: The Lived Experience of Stigma – One Family's Journey

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.

Mia Croyle: Hello and welcome back to the Stigma Podcast. In this podcast, we're talking about the ways that stigma impacts people living with substance use disorder and those who love them. 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 Mia, and I'm here as usual with Brittany. And in a second, Brittany is going to introduce you to our wonderful guests for today. But before she does that, I just want to remind everybody that we have several podcasts prior to this. We have six previous podcasts, and please feel free to go back and listen to them. We think they've got some good stuff in there. And then I also want to remind our listeners that we love, love feedback. So please feel free to send any thoughts you have, any comments, any praise, any helpful suggestions for ways we could do better, or any suggestions for future episodes, guests you'd like to see, topics you'd like to see us address. And the way you send us that feedback is by emailing us at stigmapodcast, just all as one word, stigmapodcast@telligen.com. You can find us on either the Superior Health Quality Alliance website or the Telligen website, and you can also find us on your favorite podcast streaming services. And if you find us there, please subscribe so that way you won't miss an episode in the future. So with that, I'm going to hand it over to Brittany for some introductions.

Brittany Rodriguez: Alright, well, Mia, I always love hanging out with you on the podcast, so I'm glad to be back. And today I'm excited to introduce a couple that has an incredible story. It's really important, I think that we hear these type of stories as we've talked about in previous episodes, how just our exposure to real life and hearing the human story, that human connection is so important, especially when it comes to listening to stories of substance use disorder. So without further ado, I would like to introduce you to Janice and Darren. They are a couple out of Oklahoma City and they're very active in this community. You'll get to hear about some of the work that they're doing and how they're contributing to this area and really helping promote some best practices, really when it comes to offering services to people that really need it in places that they really need it. So yeah, without further ado, welcome. Thank you.

Darren: Thank you. Thank you so much. Good to be here. And thanks for doing this. I got to listen to some of them. It's great. You guys are doing great.

Brittany: Thank You. Yeah, we feel like total newbies as I've told you. So we always appreciate the feedback and getting to hear what people think about our different episodes and the things that we're offering. But as you guys know, since you got to listen to some of the episodes, is we always start off by really asking people is your, why do you do this? What makes this topic of stigma important to you guys?

Darren: We were the parents of, I don't know how you say that. Our son passed away a year and a half ago due to a fentanyl overdose after three months of him being in a inpatient treatment center and doing great and seeming to be really on board with it all. It wasn't twenty-four hours after he got out that he was found dead. He was at a halfway

house, and he was found dead there. So for whatever reason, he was not able to resist the temptation once he had just a little time out on his own. As far as us getting involved with this, there was really kind of no question that we needed to do something. And since he was a cook or a chef, depending on which restaurant he was in, he spent all of his time in restaurants and bars because you work nonstop at those. And over the years, he got involved with opiates and because of that, that's where we wound up.

So because of that, so it became apparent that we needed to do something to try to help the community because all of his friends were into the same thing. We don't have a lot of contact with his friends that he had then, but when we did initially, they're all trying real hard to get off of this to try to stop doing this. And so if anything, he serves that purpose in helping them realize that, oh s***, this is not the way to go. And so consequently, we decided that it would be a great idea to make sure that every bartender that wanted to and every club manager that wanted it would have Narcan on hand in case somebody had an incident there. And so beyond that, we also have the drug testing kits, and we get 'em all through Shred the Stigma in Oklahoma City. So Drew [Cook] kind of embraced this.

We don't do exactly what they're doing [Shred the Stigma] because they work with direct users individually, and we're just making sure there are supplies there in case someone needs them. But it's been rewarding, and I guess we'll get into this a little bit more, but over time, I've realized when I first started bringing them into bartenders, there was some resistance. They were like, well, no, wait a minute. And now the minute I say the word, they're like, oh, thank you very much. So the education just in what six or seven months has done some good because they know who I, or they know what I'm doing. They don't know who I am, but they know what I'm doing,

Janice: They know what Narcan is,

Darren: And they want it. And invariably, two or three people at the bar go, Hey, do you have any more of those drug test kits? Wow. But boom.

Janice: So I imagine we'll be doing this for quite a long time, but one thing we learned with being around Andrew, in restaurants, it's very easy to, if you like illegal substances, it's very easy to find them in restaurants. And so a lot of times we just feel like that's the best place to reach people who might need these supplies for us anyway, it's something that we can do in honor to honor Andrew.

Brittany: I think it's unique. Oftentimes you hear about them being offered in schools or at different clinics or at homeless shelters even. But as you guys know, Andrew was fully functioning. He was going to a job, he was coming home to a family. He is doing all of these things. And so those people who are also in those places, it's really important to reach.

Darren: And by way of explanation, he said that it got to where his back hurt so bad, he felt at 33 that he was getting old too quick. And so that's where this came in. It helped him feel better. He could go to sleep quick, he had to be back to open in the morning, and that's where that use started. And it made sense for him at the time.

Janice: But apparently it was aggravated very quickly. And by, I guess it was probably November of 2021, and we were all living in the same household because, because with the pandemic, he'd lost his job, he'd been on unemployment and things were pretty bleak for him. And I discovered that he was not just using Oxy, he was smoking it. So he was getting huge doses of Oxycodone. And it just so happened that when he got out of rehab and decided to use one more time, it was fentanyl, it was a fake drug, it was fake Oxy.

Brittany: Which you hear about all the time these days, fentanyl is becoming the seemingly drug of choice, and not even by choice, that's the wrong word, really. People think they're getting one thing and they're often getting something laced with fentanyl or that fentanyl is a part of it without even knowing it.

Darren: And then we don't know that that was the case with Andrew and Narcan at the bar wouldn't have saved Andrew. But it's just something we can do, it makes sense. It's something we can do and it kind of makes sense to us somehow.

Mia: And fentanyl, I mean, to me it's so insidious because really when you think about it, what someone with a substance use disorder is doing when they take drugs is they are trying to manage their disorder. They're taking drugs

to manage their substance use disorder. There are other ways that we hope more stable and healthy ways to manage their substance use disorder, such as medications for the treatment of opioid use disorder that we hope to shift them to. But when you think about other healthcare conditions, imagine if the medications you were taking to manage your diabetes, you had a fifty-fifty chance that maybe it's going to be the insulin you need, but maybe it's going to be something that'll kill you. Maybe it's going to kill you. And so it really, it's hard to think about fentanyl and some of the other things that are now being laced into these medications as anything other than just completely terrible. I'm struggling. I'm at a loss for words.

Darren: That came up over the past two years more than anything else. It's just terrible, terrible. In Andrew's case, he was also bipolar. And so managing his bipolar with medication was something that went on all the time. And to speak in generalities is a hard way to go. But in Andrew's case, he had a real hard time finding a psychiatrist that wouldn't just give him anything he asked for any reason he wanted it. And Andrew was manipulative because he had a substance abuse problem. And even when I'm in the psychiatrist's office yelling at them for him having had an overdose, they're like, okay, well alright. We didn't get much help that way. And he wasn't looking for that much help for them. Towards the end, he was looking for something else he could abuse.

Mia: And I love the idea how you found a spot where on one hand it honors Andrew, and these are spaces that he spent most of his life in restaurants and bars, and it really meets people where they're at. Like you said, a lot of our efforts to distribute Naloxone and get kits available and such are in some public spaces. They're in schools, they're in healthcare settings. Our public library has one, but that's not necessarily where people are in the community. That's not necessarily where people might physically be when they have an emergency. And so just getting those resources placed in those places, I mean, I admire that so much that you're out in the community having those conversations with restaurant manager after restaurant manager and bartender after bartender. Just those conversations can start to change the world and you're your little piece of it. And then that you're putting something directly helpful in there. The fentanyl test strips, the rescue medication, you are basically saying, we don't want anyone else's child to die.

Darren: Right. Well, we don't want anyone to have to pull a double shift because somebody can't make it in that night in the restaurant or it's helpful all the way around.

Brittany: Yeah, I had a question just, you hinted to it earlier about how even in the last six or seven months you've watched this shift happen. So I was going to say, what has been your experience or how do you feel like the conversations are changing? Are people just more open to talking about it or…

Darren: People are definitely aware now. I mean, we have the bus stop benches, we have the signs, we have that kind of thing. So people are definitely aware of it a lot more. When I first went in, I only had two people just refuse it, just say, Nope, we don't have that kind of problem here. Had another guy say, I think they probably get what they deserve. Old guy that owns, what's that place up on 39th? And I said, well, then you don't need 'em. I mean, it's fine, you don't have to have 'em, but I'm just telling you, but I don't know if this is on topic. I don't want to commodify Andrew's death. I don't want to go in and say, my son's dead, so you have to do this. So I try to approach it that way, which probably takes longer, makes more of a conversation. But over time people are just like, oh, great. I've been wanting to do that. Is the response that I get now. I wish I'd had this. Thank you so much. We've had people that, yeah, we had a situation the other night, or it wasn't the other night, it was a month or so ago, but someone had to call an ambulance and it happens. I was in a club one time and they were saying over the speaker, no sleeping in the club. It's like, okay, but I'm sorry.

I'm focused more on the kids that work there. But if someone is in the place and goes down, then obviously we want the rescue medication to be available to be there for, and I hope that they remember when it's there. I thought about making little boxes with use me kind of thing.

Janice: I was in New York City recently. Now that I'm retired, I'm a photographer. And so I go to these workshops and I was in New York for a street photography workshop and I went into a bar and sat down how you meet people and figure out what's going on. And right behind the counter, right behind the bartender was a supply of Narcan. And I was so thrilled and pumped. And she said, it's everywhere in New York City. We all know that we have to have Narcan in bars and restaurants. So we're getting there in Oklahoma. We're getting there.

Brittany: Yeah, I think you're exactly right. The park bench is the billboards, the conversation happening. There is a shift that's happening in the last year. I feel like, especially within our state, which I know Mia, you can kind of give perspective from where you're at even. But I think it just points to what we've said all along is the more exposure and the more we're talking about it and the more we're normalizing these conversations and instead of avoiding them, it really is impactful.

Janice: But with Andrew, we had worked many years to keep him employed and keep him fed and housed and hoping that one day he would be able to kick this substance abuse issue that he had.

Darren: I knew so many kids from, I graduated high school in the late seventies. I knew so many kids that went down a similar path to Andrew, spent decades there and then pulled themselves together and got back. So I said, I kept telling myself, Andrew's so much smarter than my friend, this guy or that guy or that guy. He's going to make it one day he's going to wake up and go, what has changed is the drug. It's the drug.

Janice: Not substance use disorders, it's the drug and the lack of health care to treat it.

Darren: Maybe so.

Brittany: Yeah, I agree. I think it's access, which is what you guys are actively addressing. And then really we hope that these conversations, the more we're talking about, the more that communities are talking about it, that it does influence policy. And we're kind of seeing that, I don't know if you guys have heard about, there's a new reversal drug that was just approved called OPVEE, and it's interesting because it has a longer half-life apparently. And so where Narcan with fentanyl, oftentimes we're having to give it five or six times because the fentanyl's half-life lasts so much longer than the Narcan. So it's interesting that they're still research happening that drugs are still being created because hopefully, I think the case is, and the argument is, is that by giving this newer reversal, opioid reversal drug, that it lasts longer. And so we're giving people more of a chance. Oftentimes that's what we're seeing when it comes to fentanyl overdoses, is that okay, they're fine, they're fine, they're fine. And then they drop again.

Janice: And then yes,

Brittany: Because it wears off.

Darren: Because it wears off.

Brittany: And so I think it's interesting, and not that I don't know enough to endorse drugs at this point, but at the same time, I just think it's encouraging that because it means that people are thinking about it, that people are acknowledging that this is a problem and that it's not necessarily going away. And so what are we going to do about it?

Janice: Right, exactly. Exactly.

Darren: I don't know if this is interesting or not, but one of the things that speaks to that I think, is that my eighty-six-year-old mom has been the one with the least amount of stigma to cast on this situation. Her neighbor behind her who's retired has a fentanyl problem and is battling that, trying to get off it, manage their pain and that sort of thing. And so she has been okay with it, which surprised me not how it went at my house when I was a kid, but she's a doting and some would say enabling grandmother. And we were all in it together with him. And she has been, it's been pretty interesting to see her just accept all of these ideas. Oh, you go out and pass that out to intravenous drug users. That's a fantastic thing. And so I think that encourages me that everybody can understand this.

Brittany: This is a concept that should be able to be talked about by everyone because it actually impacts everyone. And that's another thing we also often are talking about is that we like to think that someone with substance use disorder looks a certain way. They're a certain type of person, and it's such a lie. It is not true.

Janice: Every drug user is someone's kid. And that it could be that parents have done all they can for 'em and they still choose to use, but there's got to be some way to reach these people and at least keep them alive. So they have the choice. They have a chance. Yeah. Yeah.

Mia: That's what alive is always our goal. You can't do anything else. People can't get into treatment. People can't make changes if they're not alive. And you mentioned the word enabler, and we had talked briefly before we got on the podcast just about some of the ways that you as parents were sort of advised or treated throughout this process. And I wonder if you're willing to share a little bit about that and sort of, because I think it certainly speaks to some of the stigma that families experience as well.

Darren: I don't want to make it sound like we've been at odds with the field of psychiatry and the field of recovery, but Andrew started out in high school and did two years, I think during high school, active in A.A. and all of that stuff. And I had a little problem with how it was one way and no other way, this is the way you have to do it or you are going to fail. And they would scare him into thinking that if anything happened, any backsliding, anything like that. And it was only over the years that when he would be involved with A.A. that there was a lot more empathy because it seemed like there was a lot less leaders and more participants, and so it became a little bit more democratic or whatever.
We felt that even though they do this all the time and everything that the rehab, what do you call those places? Recovery center that Andrew went to for three months, they kind of had a blanket feeling that your family's mad at you. You have got to do this on your own. Don't look for the support anywhere. If you don't do this on your own, you'll never be able to do anything on your own. And of course he's 33, so we weren't down there very much. We only got to go down there a couple of times and one of those times was to pick him up. But they were telling him, even then, it's like, hey, these people are mad at you, and you need to pull your s** together. We were never, and we were like, no, we were never mad. We're never mad. He goes, well, they ought to be. I mean, those were his last words.

Janice: They had convinced Andrew that he had to handle everything on his own, and I think he was overwhelmed. We tried to back off what we were supposed to do back off, but then he was dead. I mean, just like that. We didn't have a chance to even help him if we wanted to.

Darren: We didn't have a chance to screw up his post-recovery. We just didn't. So anyway, I feel like that at some point we will analyze a little bit more closely and we'll realize we're looking for a place to hang some blame. But at the same time, it sure felt like that last moment put up a spike of contingency or spike of, what's the word I'm looking for? Kind of put us at odds with

Mia: The system.

Darren: And so that...

Janice: Kind of put us at odds with Andrew and where in the past, we had always been there when he needed help, and it felt like we were not able to help him. Wouldn't have changed anything probably.

Darren: No, no, no. It was out of our hands. I mean, it was way out of our hands.

Janice: He made his choice, and that's the way it is. But really back to treatment. I mean, I think that if that was going to be the theory that we were enabling him, I wish I'd known that earlier and I wish I also had a chance to talk to the therapist and say, Hey, this didn't work for us. And there's a reason why that was not working for us with Andrew. What worked with Andrew was trying to get him stabilized, trying to get him back to work, and then being there for him when he needed us to bail him out or whatever, to bail him out. And because bipolar disorder is not something that most treatment centers are willing to deal with. I mean, they have no clue what the bipolar brain, how it operates, and it's just Andrew had so many strikes against him.

Mia: Yeah, it seems like it's hard to find places that can really treat the whole person. When we think about psychiatry isn't really, at least in your experience, wasn't well equipped to deal with the addiction parts or the substance use disorder parts. And then the substance use treatment centers weren't very well equipped to deal with the mental health part.

Janice: Exactly. There are treatment centers probably out there that could have dealt with them, but they were $30,000 and up. I mean, I was laughed at on the phone. I'd say, do you have treatment and is it covered by insurance? And they would laugh at me and go, oh, no, no, no. It's $30,000 up front. That was it.

Mia:

Yeah. And I mean, that's stigma as well.

Janice: Yes, it is.

Mia: And the other thing that just really I hate in hearing your story is that you were made to feel ashamed of the way you parented and the way you loved your son. And we've talked about how sometimes people try to motivate change in people using substances through shame and how that doesn't really help. That doesn't work. That's not been proven an effective way to motivate someone to make changes. And in fact, it works the opposite way. And it sounds like you've experienced that on your level as well as family members and as someone who loves someone with a substance use disorder and trying to help them that you were also, they tried to use that sort of lever of, let me wedge some shame in there and see if that lights a fire under you and under your child. And it doesn't seem, this is why we're such advocates for evidence-based treatments, because we know that that doesn't work, and yet we still see it and it's tragic.

Darren: And especially amongst the youth folk that we would, I remember one guy we met, and we only had one meeting with him, but he was going to help Andrew out, and his choice of to introduce himself was to take Andrew to shake his hand and then pull him up out of the chair and stand this close to him and just give him the skunk-eye basically. And until Andrew looked away and it's like, ah, this isn't going to work, we'll see you later. It just wasn't for Andrew.

Janice: Andrew was a very kind-hearted person. He would take anybody in. He was known to take homeless people into his house. I mean, he never met anybody that wasn't his friend and that he wouldn't help. But when it came to him needing help, it just seemed to be always elusive. He never could find the right help that he needed.

Brittany: I'm glad you just said that because the one thing I wanted to ask you, and I'll even give you another chance to say something, is I wanted to end the podcast or wrap up the podcast by asking you what you wanted the world to remember about Andrew, because it's really important that our listeners as well as all of us, remember that he's a human, and that was not defined by his substance use disorder, but by who he was. And so you gave us a little foretaste of what he was like, but I just wanted to give you a chance to tell us, if you could tell the world one thing to remember about him or one thing you think he would want the world to know, what would it be?

Janice: Well, I can tell you that we had a funeral service, and then we had a memorial service where we had people come up at one of the places where he worked here in Oklahoma City. We had a big party basically, and we had people go up and tell Andrew stories, and we heard the most amazing stories of how he helped people. He taught people how to cook, he helped them get jobs. He was always helping out somebody who was down on their luck. I mean, I remember from the time he was four years old, he was like, mom, there's a homeless guy. We got to give him some money now. He was the most kind-hearted, generous person you could ever meet, and sweet as he could be. He just had mental health issues he couldn't quite deal with.

Darren: It came up more than once that he would hire somebody who would wind up having to fire him later. But he was always trying to, he hired a fifty-five-year-old woman to work in the kitchen who'd never worked before and said, we're going to show you how to do this. And she's still there as far as I know.

Janice: In high school, he was preparing for a talent show with some friends, and they had a little walk band going, and he thought it would be fun to, because he knew the janitor the school sang. He had the janitor sing with them.

Darren: So he made it happen. He was that kind of guy.

Darren: What we are doing now is some of his friends have made up a couple of different kinds of stickers with his face on it. One is the Grateful Dead steely with Andrew's head up where the brain goes and one's just a little square that says, Rest Easy, Andrew. And we have made it our mission to put it in the bathroom of every bar in town. So when you see a little guy, little guy, he's got, yeah, he's all over the country, really.

Janice: We've taken him to Portland and New York City.

Darren: You're going to go to New Orleans next week.

Janice: It's just another way we can honor, and we've had people say, I saw Andrew's sticker on the wall and it's great. It's like, now I know what to look for.

Brittany: That is awesome. Well, thank you so much for sharing your story. I know it's not easy, but it's important. It's really important that you guys keep talking about him and you keep talking about this issue, and so it's really grateful that you guys were willing to share with us.

Darren: Thank you for having us, you guys are doing great things.

Brittany: Awesome. Thank you. Well, Mia, I guess I will wrap us up today.

Mia: Yeah. I just want to say I'm so honored to have got to spend some time hearing about Andrew and about the great work that you're doing. So thank you. It really is a privilege for you to share his story. Thank you.

Brittany: Okay. Well, you guys know where to find us and on any of your platforms, we just want to remind you to go ahead and listen. Go back and hear the other stories and subscribe. And like Mia said in the beginning, we love hearing from you guys and from anyone who's listening. So if you could just shoot us an email, we'd love to hear what you think or your story as well. You can do that at stigmapodcast@telligen.com, so feel free to reach out, and otherwise, we will see you next month. Thanks so much.

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