

Countering the Opioid Crisis: Time to Act Podcast

Episode 2: Stigma, Addiction, and Health Care

Guests: Edna Boone and Dr. Charlene Dewey

Host: Ruth Katz



Narrator: Welcome to Countering the Opioid Crisis: Time to Act, from the National Academy of Medicine and the Aspen Institute. This podcast explores the most critical drivers of the opioid epidemic and key strategies to stem the crisis. Host Ruth Katz leads the Aspen Institute’s Health Medicine and Society Program and co-chairs the National Academy of Medicine’s Action Collaborative on Countering the U.S. Opioid Epidemic. Here’s Ruth.

Ruth Katz: Addiction is often viewed as a moral failing or weakness rather than what it is—a chronic relapsing disease. More than 3 million people across the United States have an opioid use disorder, and four out of five of them go untreated. Why is that?

Among many reasons for this huge gap in care—perhaps one of the most impactful and least talked about—is stigma. People with substance use disorders may be stigmatized by their family, their friends, their healthcare providers; and they might even stigmatize themselves. To get people with addiction the care they need, we must focus on removing stigma as a barrier.

With us today is Edna Boone, a health information technology expert whose family has experienced addiction and stigma up front, and Dr. Charlene Dewey, a professor of medical education and administration and professor of medicine at Vanderbilt University Medical Center. Both are members of the National Academy of Medicine’s Action Collaborative on Countering the U.S. Opioid Epidemic.

Edna and Charlene, welcome. It’s great to have you here.

Charlene Dewey: Thank you Ruth. It’s great to be here.

Edna Boone: Thanks, I’m happy to be here.

Ruth Katz: I want to start by hopefully getting us pretty much on the same page here, and that’s with trying to get a basic understanding by what we mean with the concept of *stigma*. How would you guys define that, and how do people experience it?

Charlene Dewey: I’ll take that one first, Ruth. First, we think about stigma in the basic definition of something like a mark or shame, or some form of discredit—like a stain, so to say. Basic definitions would say that it’s like a diagnosis of a disease. It’s something that people put on another individual, thinking something untoward toward them. And addiction is a chronic relapsing disease. It’s not really a moral failing or something that people view as a personality deficit, so to say, but that is where the root of stigma actually comes from.

There are probably several different misconceptions around substance use. These can result from a number of different factors. Some of them might be rooted in the historical and racial precedents of the war on drugs that was set way back in the 70s, when it was more of a criminal kind of process. We still see addiction or substance use disorder as a criminal act for many individuals, and that’s a form of stigma.

Addiction isn’t really a choice. This is a process that happens when someone has a genetic predisposition, and they try a substance, and then their brain adapts to it. So it really is not a choice, even though people see it as a choice. “Oh, they can just stop that. They should just stop using that substance.” That’s not really what it’s about. People might have a

predisposed risk, but it's really a process that they end up developing. Sadly, it's when they're struggling the most, when they have an addiction or substance use disorder, when they're treated the most poorly. Rather than giving them the help that they need, often they find out that they're being chastised or stigmatized because of the condition that they have, which is a chronic, relapsing brain condition and not one of a stain or mark on who they are as an individual.

Ruth Katz: So, Charlene, is there more to it than that? You used the word *behavior*. Are their stigmatizing behaviors in addition to stigmatizing language that we need to be looking out for as well?

Charlene Dewey: Yes, Ruth, absolutely. We think about language being one of the major components for sure, but there are behaviors and attitudes that are manifested in a variety of different ways. Sometimes they're conscious, sometimes they're unconscious, and there are those biases that people develop over time. In the healthcare arena, so to say, if someone is stigmatized because they feel like the healthcare provider says that they can't really be competent or make their own decisions because they're using a substance, then that is a behavioral kind of approach. There are definitely behaviors, there are definitely attitudes.

Again, using some of the terminologies that we have used in the past—and I think a lot of people are growing out of these but they still exist right—like “dirty” if they're still using a substance or “staying clean” when it seems like somebody might be in recovery. All of those are attitudes, words, behaviors, and actions that subconsciously or consciously contribute to stigma, which are negatively impacting our patients who are trying to deal with a substance use disorder.

Ruth Katz: Charlene you just mentioned, and I mentioned in my opening comments that health professionals themselves may engage in stigmatizing types of activities. You would think health professionals and health workers would know better. Why would they do that?

Charlene Dewey: Well, first, I have to say that healthcare professionals are normal people. They all grew up in society, just like we did, and their experiences might influence how they're going to actually engage with someone who has a substance use disorder. When they go to medical school, they might already have preconceived notions about what substance use disorders are. Those are going to be due to social depictions within media, cultural conversations that they've had, or maybe the lack of conversations that they've had around what substance use disorders actually are. And so, when they go into training, we actually have to somewhat untrain them first and then retrain them into understanding and appreciating substance use disorder as a medical condition that actually needs treatments and interventions.

What we also know is that they're going to have experiences. Depending on who's teaching them, they might have negative experiences or positive experiences. If we have healthcare professionals who are training them who they, themselves, have had positive experiences, then they're more likely to demonstrate those positive experiences with the students that they're teaching, whether it's physicians, nurses, PAs, whatever.

But if the students also experience negative experiences from faculty that use a stigma, or maybe they see negative examples of the outcomes of treating substance use disorder—those can all be impacted because there aren't enough treatment centers, enough good treatment programs or people who can treat them like addiction-medicine doctors—if all of those really start to develop more of a negative, compared to a positive, experience for that student, then by the time they get to residency program, or by the time they finish residency program, they, themselves, will only reinforce the stigmatizing beliefs that they came into medical school or nursing school with. They might also have even worsening negative attitudes, biases, or stigma around substance use disorder because of those experiences. And of course, we know that's going to end up leading to negative impacts like reduced access and quality of care for the patients and delayed detection and referral and early treatments.

Ruth Katz: Edna, let me ask you this question. Charlene has just described, in general, the kinds of behaviors we might see, the kind of language that people might experience, and what health professionals learn in medical school that may even set them up for this kind of behavior. You and your family know all about stigma firsthand, both stigmatizing language and stigmatizing behavior. What was that like for your family? Talk a little bit about your own experience.

Edna Boone: Sure. You know I go back to the definition of stigma and think about that “mark of shame,” “discredit,” “a stain.” My family was hit pretty hard by this several years ago. We lost two young men; that was really difficult to go through. It's difficult sometimes to talk about. I think about the anonymity of both myself and the people in my family. I have to also look inward and say, okay, I've got my own stigmatizing language and behavior.

I've experienced the shame of stigma even just talking about this. Even in a closed meeting of the NAM's Opioid Action Collaborative I felt real pressure to change my language—to use the term *opioid* addiction rather than saying *heroin* or *fentanyl* addiction—and then to make sure that folks knew that the folks in my family that were afflicted had gone to college and had graduate degrees. This behavior, this is the language that we use around this disease. It's definitely clouded my frame of reference, and I know that when I speak about it.

Then I think about, okay, in my healthcare career, what have I experienced? I remember early on, when we had electronic health records that I worked on, we started to realize that we can use the data in these systems to prevent medical harm and try to help patients. What we started to do is watch the patients that come to the emergency room and those that come to urgent care centers that are seeking pain prescriptions, and we wanted to flag their medical records on the computer so that we wouldn't write any new prescription. This was kind of like, we're going to stop the drug traffickers. I thought about it the way we treat shoplifters when they're being followed around a store.

Our ultimate goal was to not harm the patients by providing more medication. The focus and the behavior ended up being trying to catch someone and blame that patient rather than the focus of an opportunity that they need care and we can get them into the system and treat them. Instead, again, this shames and discredits those in behavior and in language.

I do want to get back to language, because one of the things that we talk about, and this is a mouthful, but there's this pivot to person-first, recovery-centered language. Words matter. They reflect our attitudes toward people that have this disorder, and if we use stigmatizing language or behavior, we can interrupt them from seeking the care they need. Or, we can cause them to have worse outcomes just because they are perceiving, perhaps, that their peers who have cancer experience thoughtful, considerate care. It's more than just getting your feelings hurt; it's a serious problem, and we need to treat it seriously.

Ruth Katz: It can have a real detrimental effect. Back in the day, I can remember when growing up that my parents, certainly my grandparents, if there was a diagnosis of cancer in the family or even among friends, nobody would say the word. They would refer to it as, “She's been diagnosed with the ‘big C,’” which was stigmatizing in its own way.

Addiction, of course, as both of you have spoken about, that's a disease too. But there seems to be a different sense of how we think of cancer than how we think of addiction. I want to get into that in terms of the stigmatizing effects, but before we go any deeper into that problem and think about potential solutions, can we step back just a little bit and talk about how we actually got to this point?

Charlene, you mentioned the war on drugs, some of the other activities or issues that have been around for a long time. How did we get to the point that the medical condition of addiction has in essence become a mark of disgrace? How did we get there? Edna, can you start us off on that?

Edna Boone: Sure. One of the things we have to look at is how do we structure care and health care? We have separated addiction care, and really mental health care as well, as a silo. So much so that healthcare professionals don't necessarily feel it's their responsibility to treat or even consider treating people that have these ailments. These silos have further perpetuated the stigmatizing language, behavior, and everything that we've been talking about.

We also have separate regulations around prescription medications for opioid use disorder from “normal” prescriptions. You need to have formal training and waivers to prescribe medication for opioid use disorder, but no formal training, no waivers to prescribe opioids. It's this topsy-turvy, how did we get here, and how do we get ourselves out?

Ruth Katz: Let me ask you both this question. Does race, poverty, or even wealth also somehow impact or play a role in SUD stigma?

Charlene Dewey: Yes.

What's interesting is if we go back again—like we talked about the historical aspects of the war on drugs and how patients were seen as derelicts of society because they were using substances, or couldn't hold down jobs, or things like that—they were criminalized. It was taken through the process of being tough on them, getting them into jail, so that they can get off of substances and everything like that. That is where we started. What we need to think about over time is, where have we come?

Early on, even in history, we just didn't have really good understanding, Ruth. There's plenty of people who will still say the word *addiction* all the time. I tend to actually use *substance use disorder*, because the DSM-5 only lists substance use disorder. It doesn't...

Ruth Katz: Charlene, let me interrupt. What's the DSM-5?

Charlene Dewey: That's the diagnosis-management diseases for psychiatry and all the mental health conditions, in which it lists substance use disorder, or an opioid use disorder, an alcohol use disorder...

Ruth Katz: So it's the bible that lists various diseases and conditions and explains it, and *substance use disorder* is included as one of those.

Charlene Dewey: Exactly.

Ruth Katz: Got it.

Charlene Dewey: It doesn't even use the word *addiction* in there, and so I actually have learned to stay away from that.

If I use myself as an example here as the history: I've been in medicine for over 30 years now. When I first started, I actually started off by helping smoking cessation because of it being a part of a modifiable perspective for cardiovascular diseases, or like heart attacks, strokes, things like that. Over time, as I had experience with other patients who had different substance use disorders or with great addiction medicine or general internal medicine doctors who took care of patients with addiction disorders, then we learned over time what to do better.

Where we are today as far as definitions, as far as treatment, as far as access and resources, it's very different than what we had back in the 70s. We're kind of trying to untie that knot. We got into it for maybe some of the best intentions, but it didn't last that way and it's evolving.

What we get back to now with the race and the socioeconomic status is that earlier on, what we saw was more socially disadvantaged patients, or minorities, or ethnically diverse individuals being more criminalized for substance use versus when it became more of an epidemic when a Caucasian population started having complications or side effects from opioid use and or inadvertent deaths. You can see just how, from lowest socioeconomic to higher socioeconomic, or racial background from minorities to majorities, it made a difference in how people looked at it.

Ruth Katz: And, of course, now we refer to the opioid situation as a crisis, whereas we didn't refer to some of these other addiction problems earlier as a crisis.

Following up on that, race and poverty can affect stigma, as in this case. What about in terms of ages? I assume that stigma is experienced by people of all ages, but do people of different ages experience stigma differently? Edna, I'm going to ask you to jump in here because, again, reflecting on your own experience—Can you give us any sense if there's a difference in how young people versus old people may experience stigma?

Edna Boone: Well, sure. There's some of the obvious: Cognitively, you don't have a mature person. You've got emotional, psychological peer pressure. They're adolescents, and young adults are really vulnerable to substance use. When does it cross over to substance use disorder? They might be predisposed.

What is available to them? And there's a lot of issues around confidentiality. Can they talk to their healthcare providers about this, with their counselors or their family? Are people going to refer them to treatment, or are they going to be ostracized? Again, we get back to some of the communities of color, and we get back to criminal, legal issues with police. Then there's the whole concept of consent when we think about the prescriptions of opioids; a lot of times you hear about sports injuries, and these young men now in their late 20s and 30s started in high school. These are the things that are with us.

And then it's not always recognized. I mean, I think we're doing a better job than we were, but it's still out there. It's not as easy for them to get help as it is for those that might be of legal age.

Ruth Katz: Charlene, you're a clinician. What's your experience with old vs young, if you will?

Charlene Dewey: That's where the silos start to come in again. We have young people being taken care of by pediatricians. I'm a general internist, so I don't see anybody unless they're considered an adult. You have that chiasm of what happens when someone, as Edna just said, who maybe had a sports injury and started using an opioid for a very legitimate medical reason, becomes dependent on it or develops an iatrogenic dependency. Then, they're transferring over from their adolescent years into their adult years. That's the most vulnerable population for opioid use disorder, actually—the adolescents and the young adults. In the older patient population, while it still exists, it's almost minimal.

What we know is that younger people, either from their predisposition genetically, from their cognitive development that aren't ready to handle certain decisions yet, or are experimenting in an appropriate way but are predisposed, that is the population that's most vulnerable.

Like Edna said, their access is different. They might have stigma, and fear, and friends saying one thing, parents saying another thing, school programs saying one thing. They can't access care, unless their parents are with them if they're under the age of 18, as an adult. So they can't make decisions on their own, but yet they might be using substances. It becomes a little bit of a variety of different things that pose as barriers for those young individuals to get into help and get the help if they need it.

Ruth Katz: Stigma can affect people of all ages. We've talked about race and poverty; those things may experience stigma differently as well.

And health professionals themselves may use stigmatizing language or exhibit stigmatizing behavior. Edna, what do you think about this?

Edna Boone: I think about is the patchwork. The reality is—you've got this expertise at Vanderbilt, and I think at many other health systems that are looking at this, who are really trying to move the needle—but the reality is we have this patchwork in middle America. And where there's rural America, we have huge gaps. This is where we have some of the needs.

What's the experience of someone who's experienced that several different times? It's that even within the recovery community there's a disparity, not just in terms of language but in what treatments are being offered. My own family experienced this. You go in, and some treatment centers will say they will offer the medication listed for opioid use disorder and some don't.

There is a body of scientific evidence that says we should be doing this, and we've got insurance companies in the mix, and we've got stigma. And some of that does come from the providers: "I'm not ready and I'm not comfortable to use this prescription on this patient that needs it." You've got some of the academic centers working through this, and then you've got the reality on the ground. Again, I think stigma is at the root of many of these things.

Ruth Katz: Yes, you often hear that health professionals will say, “If I provide this kind of help, I’m just furthering the addiction problem.” Charlene, you started say something. I’m sorry I interrupted you.

Charlene Dewey: I was going to say to Edna, of course my heart goes out to her and to anyone else who’s been in that same predicament. She’s absolutely right, because there are gaping holes in training and resources.

The medications for opioid use disorder or medical assisted treatment, unfortunately, right now we have process that physicians actually have to go through a special training in order to prescribe buprenorphine or treatments for opioid use disorders and there’s a criteria that they have to meet in order to prescribe it.

But that’s one of those things that actually becomes a barrier and almost becomes the stigma with it. If we as healthcare providers can’t actually prescribe the medicines to help those individuals who actually need it, and can’t get the training to help them understand why and how... As healthcare providers, we can and should be helping these individuals.

Edna Boone: I’ll throw one more thing on that. I know we’re talking about more healthcare providers, but then let’s make sure the insurance companies are covering it. If it’s not covered, people are not getting the care they need.

Charlene Dewey: Absolutely.

Ruth Katz: Of course, that’s stigma of a different sort, the decision not to cover it. You guys have given us a really good idea of the nature of the problem that is stigma itself: what it is, how we got here, and how it works today.

Let’s turn for a moment to look at big picture solutions. Can you give us some examples of how stigma has been successfully dealt with within the context of health care?

Before you both jump in, let me go back to a comment that I made earlier about the “big C.” We used to talk about cancer as the big C; we don’t do that anymore. We talk about cancer, and we even talk about the treatments, and having real discussion about it. Are there other examples out there that you can share with us of how to deal with stigma successfully? Either one of you, jump in.

Edna Boone: I feel like probably the most obvious one is AIDS and HIV. I’m sure listeners remember, but individuals, including healthcare professionals—because I know, I was working in hospitals when this was happening—they were afraid to touch people that had AIDS or HIV. They felt they might catch it. Even though the science taught us otherwise, the facts were not enough to change the public opinion. Once AIDS was stigmatized that you might get it, it really took this huge tide to turn. We had organizations like Act Up; the AIDS quilt came into DC; you had people like princess Diana who visited AIDS patients in the hospital; Rock Hudson from a totally different generation, it came out that he had had AIDS; and then you have Ryan White from the youth, just fighting to attend.

Ruth Katz: A reminder for our viewers, Ryan White was a young boy who contracted AIDS, and as Edna said, wasn’t allowed to go to school. He was completely shunned and ultimately died of the disease. There’s a major piece of legislation in Congress that’s named after him, the Ryan White Act.

Edna Boone: The collective actions, they created a seismic shift around AIDS. We saw that. There was systemic change. We don’t talk about AIDS in that fashion anymore. It’s time; we got to now make that same kind of shift around the way we stigmatize substance abuse disorder.

Ruth Katz: Charlene, are there are other examples? HIV, AIDS is a good one.

Charlene Dewey: Mental health in general, sexually transmitted diseases, which we now actually call sexually transmitted infections, and like you said, cancer. Those are all really good examples.

As a community, we have to look at those things that we do that give good messages or messages that help humanize things, as opposed to letting people wallow in fear or bias about something like mental health or cancer or sexually transmitted diseases.

I think it's certainly a place where we can start recognizing that substance use disorder is a chronic disease process. It's a process within the brain; there's a genetic basis for it. If we start with that, maybe we can start to shift some of the stigma that people are experiencing because of the lack of understanding or fear around substance use disorders in general.

Ruth Katz: I don't want to let you go without asking one final question to really help our listeners. Because it seems to me each one of us has a role to play here in trying to address the problem. Let me ask each of you, in closing, what is the one suggestion or idea that you would tell our listeners that each one of them could do in their everyday lives to prevent the stigmatization of individuals with substance use disorder? What's the one thing?

Edna Boone: Oh, for me, it's just people speaking out. I think it can make a huge difference in spreading awareness to friends, family, and certainly health colleagues about using person-centered language when we talk about addiction. If you think about a loved one that you might be stigmatizing right now, everyone needs to speak with care and thoughtfulness. We need to change that language and our behavior now.

Ruth Katz: Charlene.

Charlene Dewey: So for me, I think I'm going to address healthcare providers in general to think about embracing a reflective position, asking themselves what is there that I can do that's going to be different by not placing judgment, good or bad, on individuals who have substance use disorders. How can we as healthcare providers actually find better ways of helping our patients in the success of managing a substance use disorder, and really all conditions. It definitely starts with us as an individual, reflective practice. I have this saying that says, "Be part of the solution and not part of the problem."

Ruth Katz: Thank you Charlene. Thanks Edna. It's great to have you here.

Edna Boone: Great to be here.

Charlene Dewey: Thank you, Ruth.

Ruth Katz: Edna Boone is the health information technology expert and Dr. Charlene Dewey is a professor of medical education and administration at Vanderbilt University Medical Center. They are both members of the National Academy of Medicine's Action Collaborative on Countering the U.S. Opioid Epidemic.

If you're interested in diving deeper into identifying and addressing stigma surrounding opioid treatment in the United States, register for the virtual [Stigma of Addiction Summit coming up on June 10](#). There's a link in this episode's description to that program.

In upcoming episodes of Countering the Opioid Crisis: Time to Act, we'll explore racism's role in the opioid epidemic and the changing nature of pain management. Be sure to follow us in your favorite podcast app. And make it easier for others to find this podcast by giving us a rating on Apple Podcast.

Thanks for joining us. I'm your host, Ruth Katz. Be well and stay safe.

Narrator: Ruth Katz is Vice President and the Executive Director of the Aspen Institute's Health Medicine and Society Program. She Co-Chairs the National Academy of Medicine's Action Collaborative Countering the U.S. Opioid Epidemic.

The conversations in this podcast build on the ongoing work of the NAM Action Collaborative. The Action Collaborative is committed to developing, curating, and disseminating multi-sector solutions designed to reduce opioid misuse and improve outcomes for all who are impacted by the opioid crisis.

To learn more about the Action Collaborative, please visit nam.edu/opioidcollaborative.

Our theme song was composed by Benjamin Learner and Joshua Sherman and recorded at Old Mill Road Recording in East Arlington, Vermont. The Aspen Institute's Pearl Mak created our logo. Our podcast editor and producer is Shanna Lewis. Special thanks to the Aspen Institute and The National Academy of Medicine.