After the Fact | The Long Journey for Reasonable Opioid Care

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TRANSCRIPT

Frances McGaffey, associate manager, substance use prevention and treatment initiative, The Pew Charitable Trusts: When someone takes the brave step of wanting to get care, there often isn't care available that meets their needs.

Erin Davis, manager, communications, The Pew Charitable Trusts: In what other world do we take away lifesaving medication from a patient who doesn't comply with treatment protocols to a T?

Jordan Scott, digital advocacy and organizing coordinator, Pennsylvania Harm Reduction Network: And I remember trying to explain to them, like, you made me wait. I've been dope sick for days. Of course I went out and bought more heroin.

Brandee Izquierdo, Ph.D., director of behavioral health programs, The Pew Charitable Trusts: People want to turn back time, but we're also seeing opioid deaths decreasing. So why would we go back?

Dan LeDuc, host, The Pew Charitable Trusts: Welcome to "After the Fact." For The Pew Charitable Trusts, I'm Dan LeDuc.

Today we're talking about opioid use disorder and the challenges of getting treatment.

Please note that this episode references addiction and self-harm.

Brandee Izquierdo: There are a lot of reasons why it's hard to access treatment. Stigma is a huge driver, and stigma leads to discriminatory practices.

Dan LeDuc: Brandee Izquierdo and her team at Pew focus on policy that can help people get better access to treatment for substance use disorder. Their work has changed and expanded over the years to meet the growing need.

Brandee Izquierdo: I started in direct services, and I think it's important to provide some context around that because I'm a person in long-term recovery from substance use and mental health, as well as the criminal legal system. You have this

level of empathy and compassion because you've been there. It can be an extremely daunting task getting people access to those services. So I quickly learned that policies around accessibility were barriers, which is why I got into policy to begin with.

Erin Davis: I think the public knows overdoses are still rampant. The number is unacceptable. What I don't think people realize is just how hard it is to access treatment for people who want it.

Dan LeDuc: Erin Davis works with Brandee and the rest of the behavioral health team at Pew by communicating the research to the public.

And it's important work when more than 2 million Americans suffer from opioid use disorder—but only 1 in 4 people in need of care receive it.

Erin Davis: When people don't have access to treatment, people can be desperate. Withdrawal is a terrible, terrible thing to go through, and they just want to be well. And so, we've got to make that connection. When someone says they're ready for treatment, it has to be ready immediately, and it's just not today.

Frances McGaffey: When it comes to opioid use disorder, the medication you get often depends on where you're getting care. So, there's three medications: methadone, buprenorphine, and naltrexone. Methadone's the oldest. We've been using it in opioid treatment programs since the '70s. We've got decades of research showing that it's safe, it's effective.

Dan LeDuc: Frances McGaffey also works in behavioral health at Pew. She leads research to support state and federal efforts to expand access to substance use treatment.

Frances McGaffey: Opioid treatment programs are the only places where people can get methadone for the treatment of opioid use disorder.

Dan LeDuc: Opioid treatment programs, or OTPs, are commonly known as methadone clinics. They're brick-and-mortar locations where people are required to get their dose. But before the pandemic, if you were trying to start methadone treatment, you had to show up at an OTP every day.

The Pew team started trying to change this to allow for more "take-home" doses, which would make it easier to access the treatment.

And the good news is that the number of overdose deaths over the past year is the lowest in four years, according to recent CDC data. So, what ended up changing? And what still needs to happen?

Frances McGaffey: If people want to use methadone because that's the best medication for them, they might have to go every single day for months and months. And then they often face stigma, even from the people who are supposed to be providing that care. Nonjudgmental care is so important.

All OTPs, all across the country, have to comply with a minimum set of standards set by the Substance Abuse and Mental Health Services Administration. On top of that, states can create their own rules, and they can be much more restrictive. So, a big factor in accessing methadone is the state that you live in.

Dan LeDuc: And to add another layer, the treatment centers themselves can create their own rules for people accessing the care.

Brandee saw firsthand the challenges in accessing methadone when she was working in direct services.

Brandee Izquierdo: If they don't have transportation or if they live in a rural area, that's very difficult.

I was working with a woman who was pregnant, who was on methadone. Not having that access to that lifesaving medication created a safety issue for her, but also her unborn child, and knew if she didn't get that medication, it was life-threatening.

So, every morning I would get up at the crack of dawn. I would take a state vehicle, and I would pick her up. And then I would drive her over an hour away. And then from there you had to sit in the waiting room and wait for your name to be called. And then you have to drive an hour back from the program that you just drove an hour to, to get to work.

If you cut your finger and you need to go to urgent care, you know that you're going to get the stitches you need from urgent care, and you know that you are going to have those stitches before you leave. However, if an individual is looking for substance use treatment, it's a totally different story.

Dan LeDuc: It *is* a very different story. We spoke with a woman from Pennsylvania about the challenges she experienced in seeking treatment in the past. Jordan Scott is now an advocate for people navigating the complex issue of addiction. And she has a story to tell.

Dan LeDuc: Jordan Scott, welcome. Thank you for being with us today.

Jordan Scott: Thank you for having me.

Dan LeDuc: I was hoping we could just start by you telling us of your personal story where you realized you had some substance use issues.

Jordan Scott: Like a lot of other people I know, I struggled with mental health. As a young child, I think around like 10, 12 years old, I started engaging in self-harm. I started dealing with suicidal ideation and experimenting with different kinds of drugs. But combined with not being able to access care, because of the issues with our system, you know, there were periods on and off—over 12 years of just on and off chaotic or problematic drug use.

And I would do the normal go to detox, go to AA or NA, and that cycle just repeated for years. And I would always kind of have this thought in the back of my mind of, well, you know, clearly it has to be something wrong with me because it's working for all those other people. So I'm the one that must be defective here.

And I got onto methadone in 2010, I believe, and my experience with methadone was really short because of the clinic system. I lived in rural southeastern Pennsylvania. There isn't public transportation. I didn't have a car, so I was reliant on family and friends, and sometimes even walking, which was a two-hour walk to the clinic.

When I had my intake process, you know, I went there thinking I would have an intake, like a normal doctor's appointment, and I would get started on methadone that day. And that's not how it happened. And I went through withdrawal for almost four days before I finally got my first dose of methadone.

And I remember getting my first dose and they weren't even going to give me that first dose because I had opioids in my system. And I remember trying to explain to them, like, you made me wait. I've been dope sick for days. Like, of course I went out and bought more heroin.

Even though it's been so many years, I still remember the attitude of the staff that day of like, well, I guess we'll let you have it. Again, having to be at the clinic every day. Clinic hours, at least at my clinic, were very early. You oftentimes have to stand outside in line in the rain, in the snow, in the heat, being watched by security guards. The constant being asked, you know, to give a urine screen, being watched while you give a urine screen.

I remember from the day that I started on methadone, and for the very short two months that I was on it, every week when I met with my counselor, all she wanted to know was, how long do you plan on being on that? So, like many other people, finally I was just like, this isn't worth it. It was a hundred times easier to continue using heroin than it was to engage with the methadone clinic.

Dan LeDuc: Wow. Wow. You decided it wasn't for you. So, what happened for you next?

Jordan Scott: What happened next was just more of the same. Wash, rinse, repeat. Cycle through periods of chaotic drug use, really profound mental health episodes, periods of homelessness, multiple suicide attempts, up until when I was 26 and I went to treatment for the last time.

Dan LeDuc: And when you went to treatment for the last time, is that because the treatment started working for you?

Jordan Scott: No, not at all. It was really more of not wanting to continue with the same cycle, it was another holiday season that I wasn't getting to spend with my family and I wanted something different.

Dan LeDuc: You've been through a lot. Talk about what you're doing now. As I understand it, you are an advocate for people getting methadone even though it wasn't—the system at the time wasn't working for you.

Jordan Scott: I think my advocacy comes from the fact that things haven't changed.

If we look back into the history of methadone, or if you look back at the Nixon era, it wasn't approved as a response to a health issue; it was approved as a response to a criminal behavior issue.

Frances McGaffey: Opioid treatment in the United States has been complicated.

Dan LeDuc: Methadone was invented in Germany in 1939 because of a shortage of morphine. It was approved for use in the U.S. by the FDA in 1947 and was used for a variety of symptoms, including pain control and cough suppression.

Frances McGaffey: There was a recognition that more treatment was needed, and so, it made sense to scale up access to methadone. When it started, people were able to access it pretty easily.

Dan LeDuc: Before 1972, doctors could prescribe methadone from their offices, and patients could pick it up at a pharmacy.

Frances McGaffey: As the use of opioids increased, our approach to methadone changed.

Audio of President Richard Nixon: America's public enemy number one in the United States is drug abuse. In order to fight and defeat this enemy, it is necessary to wage a new all-out offensive.

Dan LeDuc: President Nixon spent hundreds of millions of dollars on enforcement and also created programs to treat drug use in the United States.

Audio of President Nixon: And it will be nationwide in terms of a new educational program.

Dan LeDuc: Overwhelmed, most programs were forced to provide less costly services on an outpatient basis, which became the primary setting for addiction treatment.

Frances McGaffey: Historically, OTPs have been really concentrated in Black and Brown communities, looking at it as a crime reduction measure, not to improve people's lives.

So, methadone can reduce criminal behavior and interactions with the criminal legal system by reducing the severity of someone's opioid use disorder, but we don't have evidence that you need a strict carceral treatment system to get the good results you want with reducing criminal behavior.

We've institutionalized a belief that people who use methadone to treat opioid use disorder can't be trusted.

Audio of President Nixon: In order to defeat this enemy, which is causing such great concern, and correctly so, to so many American families, money will be provided to the extent that it is necessary and to the extent that it will be useful.

Brandee Izquierdo: When it's based on fear, we want to regulate it and make sure that we have provisions around it. And that fear needs to be demystified. And how do we change policy? And how do we make it more based on science?

Everyone said, well, it takes a long time to change policy. And then COVID hit. And then all of a sudden, we needed to change policy, and we needed to change it quick.

Dan LeDuc: These long, in-person lines were no longer plausible. Allowing patients to take home doses of methadone made it easier for many to receive care. It made people wonder whether this would be more effective in the long term.

Frances McGaffey: The Substance Abuse and Mental Health Services Administration, or SAMHSA, changed their rules temporarily to allow most people to get up to a month of methadone for at-home use. This was a game changer.

It was our opportunity to understand if these strict take-home schedules were actually necessary.

Drug researchers across the country sprung into action and there were a wealth of papers published on the impact of these temporary changes. And what does all of this data and evidence tell us?

We learned that people don't need to go every day to get their medication, and that it wasn't risky. The COVID-related flexibilities help methadone patients have a better quality of life.

Dan LeDuc: Then it was up to the team to figure out how to convince key audiences that these changes were working. Here's Erin.

Erin Davis: It's multifaceted. We had a lot of research showing increasing access to methadone really helped patients, but those were just numbers a lot of the time. And we know that facts alone don't change hearts and minds. So, we had to find the people who had both lived through the previous system and then also those who had benefited from these changes. We talked to a lot of health care providers who were seeing patients, and they were saying they're staying in treatment longer.

Frances McGaffey: One of the stories was about, you know, not missing Christmas morning with your kid because you had to go to the OTP to get your dose. We've really focused on telling that human-centered story so that people could understand the impact these changes had.

Dan LeDuc: Frances told us how this research and storytelling made a difference in advocating for those changes at the federal level.

Frances McGaffey: The story about what happened with methadone during the pandemic and after is one of those rare feel-good stories where data and evidence led the way.

And based on all of this, federal regulations have changed, making these flexibilities permanent.

Brandee Izquierdo: We've worked diligently with a lot of our stakeholders and our partners to make a larger impact. We're seeing that the science is saving lives. So why would we go back?

Dan LeDuc: Brandee and Frances told us about how the work continued at the state level. The team provided technical assistance to help states make evidence-based policy decisions. That includes analyzing data and developing plans tailored to their specific needs.

Brandee Izquierdo: We took a look to really figure out if there was consistency across federal and state regulations. And what we found was that there wasn't. So, we really revved up our research and our technical assistance in states.

Frances McGaffey: We looked line by line at how states regulate their opioid treatment programs. We then went to a few states showing them opportunities where they could change their rules to get people better care. A few of them have taken us up on this. Colorado removed restrictions, staffing requirements for their counselors, rules that made it harder to open new OTPs. California and Montana and Illinois have taken action to permanently change the way their states regulate methadone.

Dan LeDuc: And zooming in even more, clinics had an opportunity to reconsider some of their own rules.

Frances McGaffey: Clinics can determine their own treatment policies. So, there's a major need for quality improvement and cultural change within the OTPs to ensure that they're providing evidence-based, patient-centered care.

Dan LeDuc: As a result of these successes and lessons learned, the team at Pew is continuing and expanding work on substance use.

Frances McGaffey: We're trying to understand the ways that people actually use substances. We're increasingly finding stimulants in the systems of people who have fatal opioid overdoses.

Erin Davis: We are not just dealing with an opioid overdose crisis in this country. People who are using substances, there's often a larger issue underneath the surface, most likely trauma. We've got to get at those roots and figure that out, and that really ties into our prevention work.

Brandee Izquierdo: So how do we address this in its totality? We're working on lifesaving strategies and meeting people where they are.

Being a person in recovery, I started using at the age of 11. And we know statistically the average age of youth is around 14 years old. We know that if we can provide interventions for our youth population, that perhaps we can mitigate substance use disorder and start to figure out why people are falling in in the first place.

Dan LeDuc: Let's turn back to Jordan and her experience with trying to access treatment. She also said that more work needs to be done, especially in the way we view and talk about addiction.

Jordan Scott: The very incremental changes that came as a result of the COVID-19 pandemic is really just scratching the surface.

But the reality is, we could draft the most perfect piece of legislation regarding methadone and get it passed through Congress. We still have to shift the culture, and that's not easy.

But I don't want to be all doom and gloom. I remind myself to celebrate every single win because we're talking about systemic reform, and it's incremental.

Dan LeDuc: If there was a 20-year-old version of you who was unsure about seeking this treatment or was in that treatment and was ready to walk away from it because of some of these challenges, like you did, what would you tell them today?

Jordan Scott: I would tell a 20-year-old me, I should have moved to Philly, so I could have been closer to a clinic.

Dan LeDuc: It could have worked.

Jordan Scott: I know without a doubt that my life after that point would have been dramatically different, and nobody could convince me of that otherwise. And I know that—sorry. A lot of my friends would still be alive if they hadn't had to prove that they were worthy of accessing methadone.

Dan LeDuc: How important is prevention in this work, beyond the treatment?

Jordan Scott: I would say prevention is hugely important, but not in the way that we have traditionally defined prevention. So, when I talk about prevention, I'm looking at affordable housing, access to health care, access to education. I look at funding things like community centers again, and after-school programming.

For me, prevention is about focusing on the social determinants of health. Like, that's true prevention. How do we actually create and nurture healthy communities?

Dan LeDuc: Thanks so much for listening.

If you or someone you know needs help, please call or text the Suicide and Crisis Lifeline at 988 or visit 988lifeline.org and click on the chat button.

To locate treatment in the U.S. for mental and substance use disorders, visit FindTreatment.gov. This resource is confidential and anonymous.

We'll be back in January with more episodes.

And, in the meantime, if you have questions or feedback that you'd like to share, you can write to us at podcasts@pewtrusts.org.

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For The Pew Charitable Trusts, I’m Dan LeDuc, and this is “After the Fact.”