

Interview with **Michael Chancley, Part 1**

In Part 1 of this series, Dr. Brian Wood interviews Michael Chancley from PrEP4All about the role stigma plays in preventing people from accessing HIV PrEP. The discussion explores patient perspectives around HIV PrEP, common misconceptions about the medications, and the role medical providers and organizations can play in helping to support and educate patients about the potential benefits of starting HIV PrEP

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Brian Wood: This is Brian Wood, from University of Washington for the National PrEP Curriculum. I am really honored today to be joined by Michael Chancley from PrEP4All to have a discussion about barriers to PrEP access. Michael, thank you so much for joining me.

Michael Chancley: Thank you, thank you.

Brian Wood: Michael, it's good to connect again. I've heard you talk a lot about PrEP access in other forums. There, obviously, are a lot of barriers and hurdles, a lot of things we could talk about. We'd like to focus today on stigma as a barrier. It certainly is a huge and important issue and really, the goal today is to raise awareness, help providers who are interested in PrEP to engage in conversations about sex and HIV risk and PrEP, hopefully, to help reduce barriers to help get PrEP to more people who would benefit from it. So, clearly, an important topic. We are not going to solve all of the structural and systemic issues, but really would like to help providers take a more stigma-informed approach and really raise awareness about this barrier. So I'm excited to learn from you and all of your experience. Maybe you could start by sharing how you got involved in this field, some of your professional and personal experience, if you are willing, and what really led you to this focus.

Michael Chancley: Well, just being a part of a community that is impacted by, not only being a part of a community that's impacted by HIV, but also seeing unintended pregnancies, other STIs. I have been volunteering, doing work in the sexual health field since high school and never thought about it as a career, but ended up just through volunteering and becoming a social worker. It was just like a natural match. I had already had all of this experience with volunteering with different local organizations, like assisting with outreach and things like that. So once I graduated in 2014 and became a social worker, that's also when I got into the HIV field full-time, which also just happened to be when the CDC released guidelines for PrEP. So it was like the new thing as I was entering the field and I was just really, really excited about it.

I became a PrEP user in 2015, and it was just interesting because I thought, oh, great, we're going to just end HIV and everybody is going to get on PrEP and great, my job is going to be done and then I can look at another career move. And that didn't... More than a decade later, it's not panning out the way that I was naïve enough to believe that it was going to pan out. I started seeing, one, just the lack of awareness that people had about PrEP, once people were aware of it, the mistrust they had of it, the misinformation that they were getting about it, and then even once people were sold and aware on it, just seeing the systemic barriers, whether it be coverage or lack of available providers. So it was one of those things that was just... I've just realized, oh, getting a community that's definitely strongly impacted by HIV, making sure that they are able to get on PrEP is going to be an uphill battle.

So I've had a opportunity to go out into communities and do outreach, be a part of social marketing campaigns, actually, coordinated a PrEP program that, literally, like we did all of the medication assistance, linked them to the provider, spread awareness throughout the community and the clinic and helped people navigate all of those barriers to getting on PrEP. And then I pivoted into doing national work with PrEP4All, where we are working to address those systemic barriers. So going from working with clients one-on-one to get them on PrEP to now bringing awareness to all of these things that are going on structurally and politically and mobilizing communities so that they can help make sure that people are able to access PrEP. A big part of that we've been doing is advocating for increases in the Ending the HIV Epidemic funding, as well as advocating for a federally funded national PrEP program.

Brian Wood: Thanks, Michael, for sharing all of that. You certainly have a wealth of experience you've involved from the beginning when PrEP was first approved. I remember that as well, and all the enthusiasm around PrEP, and then it really has not reached a lot of people who are interested in it or who may benefit from it, and so would certainly like to hear more about your experience helping individual clients, your experience on a national scale as well, and helping to advocate for PrEP. So you raised a couple of really important points there, lack of awareness, mistrust, misinformation. I'm wondering if we can dig into that a little bit more, and especially maybe we can start with the mistrust piece and stigma.

What I hear from a lot of patients I talk to is there's a lot of fear of judgment, of discrimination. There's a lot of difficulty both finding providers to talk to PrEP about or raising the conversations about sex, about HIV risk, about PrEP. So I'm wondering if I can ask your experience and how you help clients navigate that, how you educate other clients or providers. What does that look like for you, the mistrust and the stigma and the fear of discrimination in terms of just getting started talking about PrEP?

Michael Chancley: So it's interesting, I didn't get on PrEP until a few weeks after my 30th birthday, just working in the field. Like I said, I started advocating for PrEP in 2014. I didn't actually get on it until 2015, and I had never had a primary care provider since my pediatrician when I was a kid. And I just thought, generally, males, we are healthy. We don't engage in the health care system. So I think that was where I had to start, which was seeing young gay men coming into the clinic and they are going out in the community and doing outreach, and I have to put myself in their shoes. Like, you just started engaging the health care system for preventative health around HIV at 30 years old. And even that was not just inspired by age, but inspired by me seeing newly diagnosed clients on a weekly basis while engaging in this work.

So, I had to think, if you were not in this field and you were younger and you didn't have a primary care provider or insurance or resources, and someone, while you were trying to get an HIV test or out at a club and they were doing outreach, came up to you and said, "Hey, start taking this medication so you don't get HIV," would I have been sold? That was a question I had to ask myself, and I would not have been sold. I probably would not have wanted to get on PrEP at 21, 22, 23 years old because... So, I had to really think about my approach to having these discussions with clients and community members, sometimes listening to what their fears are. I would think about how sometimes a medical provider or a test counselor would approach me rather it be about sexual health, physical health, and nobody likes to have someone dictate what they should do, whether that be telling you, you have to use condoms, or you have to get on PrEP, or you have to engage in regular HIV testing.

So really meeting people where they are, what are your fears about this? I want to validate you in saying, hey, this isn't for you but would you mind talking to me about it? Why isn't it for you? So, you would get answers such as worried about what it would do to kidney and liver functioning because we saw all of those scary ads on social media and on a radio. Some people just not really coming to grips with where their risk is. I definitely know even talking about risk can be stigmatizing and subjective, but sometimes you have to just break it down for people. Sometimes you just have to really make people come to their own realization. So how many partners have you had recently? Or, if you have one partner, have you been consistently getting HIV test? Have you had any fears about HIV even when you are using condoms consistently?

You're here for some reason engaging me in this conversation, even though you're not completely sold on PrEP yet, so let's talk about why you're here, let's talk about why you even came and had this conversation with me, even though you may or may not think PrEP is for you. And so you would start... Sometimes people will start telling you that misinformation that they've heard or their own internalized stigma. I've heard people say, "I'm not promiscuous," or "I'm not a slut. I don't need that." So again, having those discussions, that was my original argument, like, oh, I use condoms all the time. And then having to have those real conversations like, oh, except for that time when... or it was

that one fun night out or that one road trip where met a cute guy. So had to really have those honest... thinking about how I had those honest conversations with myself, having people have those conversations with me, hey, if you are here and you're being treated for a second time for an STI, let's talk about that.

Again, not saying, oh, you got a STI, you should get on PrEP, but okay, let's think about how you acquired that STI and how that could have also been a HIV transmission. So again, just having those open honest conversations with people that are nonjudgmental, letting them come to their own realizations. A lot of the things we do in social work, motivational interviewing where we just ask those open-ended questions, even if you're not a social worker or a counselor, if you're talking to somebody about PrEP, asking those open-ended questions about what their fears are or why they're motivated to engage in a safe sex practice or risk reduction practice, such as getting tested rarely, or talking to their partners about safer sex practices. So just getting those conversations started.

And you know what? Somebody might walk out and say, I still don't think PrEP is for me, and I validate that, I'll give them more condoms, or if they don't want more condoms, I will give them a reminder, like, hey, come and get tested in three months, we can talk about this again. And so just, again, meeting people where they are. And I think once you start building that trust with people, people start opening up more and people start to trust that you, not only know what you're talking about, but you're not trying to force them into making a medical decision that they don't feel is right for them, that when they do feel like it's right for them, they can come and talk to you about it.

And I've definitely had clients who would come and get tested every three months, and at the three-month test it wasn't for them, at the six-month test it wasn't for them, but then a nine-month test, it's like, okay, so what steps do I have to take to see a provider in getting on PrEP? So just having those open, honest conversations. Same thing with communities, sometimes I would go to a venue and somebody may not be ready to get a HIV test or may not be ready to take condoms, but eventually, once they build that relationship with you, after seeing you there every other week or once a month, they start to... we'll pull you aside and start having those conversations with you, so.

Brian Wood: Thanks, Michael. That raises several things for me, one, the importance of engaging the conversation, being open and nonjudgmental, and continuing to talk and build trust over time. And in my experience, it can take time, I think... and I'm sharing my experience as a White cisgender male provider, I think sometimes trust is assumed and it really can't be assumed, it can't be presumed. It needs to be built. And I wonder if I can ask, does that resonate with you? Would you agree with that? I mean, that's my perspective as a provider, has been my experience that sometimes this takes time and no matter the conversation, whether it's about sex and HIV risk, whether it's about weight or substance use or anything that could be sensitive, that trust should not be presumed, and needs to be built and earned. Does that resonate with you? What's been your experience around that?

Michael Chancley: No, definitely. It definitely resonates with me. I think especially when seeing people come into clinic who they realize that we're from the same community. Sometimes I think we get to step into a professional environment. It's funny, I remember a story where someone, they were nervous about getting on PrEP and talking about their sexual, and they were like, "Well, how would you feel if you were a young gay person?" And then they paused and they were like, "Oh, you have on rainbow beads around your neck." And then that just opened up. I think it clicked for them, like, oh, wait, this is somebody who I can relate to. And that just opened up the flood of being able to discuss our sexual health. I told them, I was like, "There are things that I probably can't tell you while I'm on the clock." I would say, I'm on PrEP because I like to have fun too, leaving it at that.

But people feel comfortable, like, oh, okay, this isn't a salesperson talking to me. This is somebody

who is in community with me, who looks like me, who engages in the same things that I engage in. So I think that definitely helps a lot of times. Even when I would go out in the community and talk about HIV, I used to always like to partner with a coworker who did not look like me or who was not from the same community as me. So almost like, if a young lady comes up and they are interested in condoms or talking about safer sex practices, I can pivot to one of my coworkers, and if a young male comes up, they can relate to me. So almost bouncing off of each other's personalities and things like that versus going outreach with the coworker who we have a lot in common already.

Brian Wood: Sure.

Michael Chancley: And again, I think that is very important that when we go out and talk about PrEP, especially in marginalized communities, where people have historical reasons for having medical mistrust or just not trusting people coming into their community with an agenda, I think about even going out in the community and doing HIV testing and outreach and how eventually the community realizes, oh, they're giving us gift cards because that's a organization that needs numbers. So I always try to go deeper than that. Definitely going to, again, building those relationships, looking at those common things, things we have in common that could strengthen our relationship and building that trust. Making a medical decision to take a pill every day is not a easy decision. And just also recognizing that and having those conversations with people about how PrEP has benefited me as a PrEP user, I wouldn't convince you to get on... same way with even a COVID vaccine, I wouldn't convince you to make a medical decision that if warranted, I would not make that same decision for myself.

Brian Wood: Such important points. Thank you. It's a really good analogy, and what that's bringing to my mind, again, my lenses and experience as a provider is the need for providers to be intentional and really not make assumptions and help people understand that they're not going to be judged, they're not going to be discriminated against, they're not going to be judged or shamed or invalidated for raising this conversation. And it seems to me from what you're saying, Michael, there's a risk of the stigma and mistrust preventing even initiating the conversation. And so I'd like to ask you if there are examples of where you've seen providers do that well, just starting the conversation. You were getting at it a little bit with just talking about risk or if an STI is detected, talking about that and talking about HIV prevention options, but just thinking about the barrier of just starting the conversation, are there examples of where you think you've seen that done well, or what advice would you give about starting the conversation?

Michael Chancley: I can talk about my experience. I was doing PrEP outreach and education even before I made the decision to get on PrEP myself. I've always engaged in regular HIV testing since college, but never engaged in STI screenings, never engaged a medical provider. So it was actually took a nurse who worked at the clinic with us. He was maybe about eight or nine years older than me, but still a young person in the community who I felt like I could relate to. So it took those off-record conversations in the break room or popping in the office and just having conversations and like, hey, this is what's going on in our community. These are the rates. You should really consider PrEP. I know you're going out and talking to other people about it but have you thought about it? And so this wasn't a pharmaceutical rep or a provider who met me with their own preconceived notions about my sexual health or my community.

This was somebody who built the relationship with me. He was a medical provider. He was the one who first taught me about PrEP. And so I've tried, I think that one of the things I loved about the clinic that I worked in when I worked at the PrEP clinic in Decatur, Georgia, was we had diversity. We always

had people to, you know, you were, through the course, regardless of what demographic you fit in, I think through the course of seeing from a receptionist, to a test counselor, to a medical assistant, to the actual provider, to the pharmacy, at some point, you were going to cross paths with somebody who looked like you because we definitely had a lot of diversity within our workforce. So, we had someone who was Spanish speaking, someone who had experience being undocumented. We had a Black male medical provider, we had a Black woman medical provider.

We had older people who had been living with HIV for a long time who were test counselors, who were able to speak to their own experiences. Sometimes when you have that older person who comes into the office who may think, oh, I'm not worried about that, that's something young people get. So it was like, you were always... at some point, from walking in the clinic to walking out of the clinic, you were going to meet someone who was like you. And I think that's why... I think you have to start off again. That's why I say even when I go out and do outreach, I think having that diversity because you want to have somebody who has similar experiences to you who if you say, hey, I don't trust this medical system, well, let me tell you why I don't trust this medical system, and I still realize that this was something for me.

I think when you do that, it helps validate people, so they don't become defensive or feeling like they are being pushed to make a decision that they don't want to make. And again, that's what it took for me to get on PrEP. I don't know if that nurse would not have talked to me who, again, was a member of my community. I don't know if I would have been totally sold on PrEP at that time, so.

Brian Wood: I really appreciate you sharing that. And that's getting to me at the question of, what can clinics do? What can individual providers do, or public health departments, whatever it is, to really help people feel welcome, safe, like they belong and comfortable having these conversations? So diversity in the workforce, helping individuals to be able to connect with individuals who have similar life experience, providers and clinics who are interested in engaging individuals with PrEP and helping get PrEP to people who need it. What else comes to your mind? What else would you suggest?

This concludes Part 1 of my interview with Michael Chancley from PrEP4All on stigma as a barrier to HIV PrEP. Hear Michael's response to this question about helping people feel safe and welcome, as well as his perspective on other stigma-related challenges in Part 2.

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