Podcast Intro:

Welcome to Coming Together For Sexual Health. This season, we're bringing together voices from across the country to talk about healthcare in rural America.

We're powered by nationally recognized experts in sexual health from the University of California San Francisco and the California Prevention Training Center. All views expressed are those of the person speaking and not of the CAPTC or their employer. Subscribe to get our latest episodes, share with your friends, and leave us a 5-star review to help more people find us. Thank you for coming together for sexual health.

Episode introduction:

Hello, and welcome. I'm Duran Rutledge, and I'll be your host for today's conversation.

As a Capacity Building Specialist with the California Prevention Training Center, I have spent the past 15 years providing training and technical assistance to health departments and community-based organizations across the country. And one thing that continues to fascinate me is hearing the stories of how people find their way into the work of HIV prevention and care—and, perhaps more importantly, why they choose to stay.

For some people, it may begin as a job or an unexpected career opportunity.

For others, the connection is deeply personal.

They may be living with HIV, have lost someone they love, or have seen firsthand how HIV affects their community.

Others are drawn to the work by a desire to use their voice, experience, and influence to support communities whose lives and experiences may be different from their own

That brings us to the focus of today's conversation: **What does it really mean to be an ally?**

Today, we'll explore what allyship looks like in practice—not just as an identity or a label, but as an ongoing commitment to listening, learning, building trust, using your voice, and recognizing when it's your role to step forward—and when it's your role to step back.

So, let's talk about it.

The idea for this episode began a few months ago during a virtual community of practice that my colleagues and I were presenting on structural interventions, to support HIV prevention and care.

I was leading the discussion on the importance of community engagement and why the people most affected by our programs must not only have a seat at the table, they must also have an equal opportunity to decide what's on the menu.

During that conversation, one participant offered a moment of honesty that stayed with me. She said, ***"I am a white cisgender lesbian who is not gonna have any idea what it's like to be black or brown and be a man who has sex with other men or the barriers that are gonna keep me from accessing PrEP. "***

That participant was Amy Nelson, a healthcare professional in New Hampshire who is passionate about improving the health outcomes in her community. Her words opened the door to a deeper conversation about humility, listening, and what it truly means to be an ally.

I hope you enjoy listening to this episode as much as I enjoyed conducting it.

-----Short Transition Music-----

sexual health has always been there. Plus now you have this is pre um HIPPA. So my mom was an ICU nurse specifically. Oh wow. And when I was in junior high, And so she made me volunteer at the hospital. And I can remember the end of one of my days walking in and you know, most ICUs will have little glass sliding doors. Mhm. And if somebody's there for a long period of time, family and friends will put up pictures, photos on the outside, or at least they used to. this would have been 87ish, I can remember walking in and seeing all these very vibrant and youthful pictures, but the person in the bed who I could only see from about waist to midchest down was emaciated. And in my brain, the only thing I could correlate that to was uh concentration camp. That was the look. That was what I had seen. any example of that looking like? And so I asked her, I said, because I couldn't I couldn't make the them match or coincide. The the person that was in the bed didn't coincide with anybody in the pictures on the outside. And so I asked I said, "Mom, what's wrong with this this person?" And she said, "He has AIDS." And I knew what it was. I already knew what it was. I said, "Oh, okay. And immediately I knew I wrote my first paper on HIV my senior year in high school. No, my sophomore year in high school, 1988 when it was still grid and art. So, and then when I was in grad school, was it Yeah, grad school, I volunteered to draw labs for one of our testing and treatment uh free clinics in Oklahoma City. So, it's always been there. I've never been afraid. I So, I was a phabotamist um in undergrad and grad school and even up to six years after I graduated college. Um and I was never afraid. Um you know, working in hospital, I didn't work just in hospitals, but when I worked in hospitals, you know, when HIPPA came along, you were no longer supposed to be talking about that. you weren't supposed to know, but of course people did. And then they would himhaw about who's going to draw it, and I would be like, "Give me that. Get the hell out of my way. Quit talking about this crap. They're a person." Um, one of my childhood friends, uh, her father was diagnosed and she was petrified to tell me. And I said, "Of all people, you know me, you know." you know, I was like, "Never." And I actually saw him in the hospital and drew his blood. I, you know, I didn't bat an eye. Um, so HIV's always been one of my loves and sexual health and STI and all of that, but the cultural

piece. Um, so my spouse is 12 years my senior. Um, she is white. I have been married to a man. She has never I've I would say I've grown a lot in in our relationship. We've been together was 24 years last month. I know, right? Amazing. It's amazing.

you were talking about, you know,

that kind of closing out around um how you got into doing the work, your good friend whose dad um had HIV and she was um cautious and fearful of telling you. to see people at their most vulnerable, especially living with HIV during that time frame before there were really effective treatments. It was really waiting for someone who's symptomatic to basically to pass, right? We didn't have anything that you know brought people back from you know advanced HIV what we call it now advanced HIV but you know AIDS back then. So where did that strength where did that that self strength do you think came from?

You know my mom was a very strong independent person. I was raised to be strong and independent. but I think I I I think some of that is just my personality. I will say the older I get, the less tolerance I have for nonsense. Um, but I am very vocal I think part of that's innate and that's my nature. r And I think it's knowing what's important. And I think leaving this world a better place than I came into it in the other thing, too, is don't mess with my partnerships. Don't mess with my relationships, in particularly my networking ones, because all I have is my name. I came into the world with this name and I will leave the world with this name and I don't need anybody else messing it up. I'm going to make mistakes along the way. Don't mess it up for me. but the cultural pieces, so growing up in Oklahoma, Oklahoma's pretty diverse. Um, you know, we have a large number of tribal entities. We have several large ones that provide their own health care. Um, I have close friends and colleagues who are tribal. My my spouse, she is also native, um, part native. And um it's and then we have um we have a historically black college in Oklahoma, Langston University. We have historically black towns. And so some of that I got really exposed to when I started in public health. And

my first semester of grad school. Um Kenneth Mroy is uh the professor's name and he is since deceased. He create he helped um create the ecological model. so he said, "Let's talk about when we're trying to get people to change behavior." And looking at it and saying, he said, "Let's just take nutrition because it's such a big topic obviously." He said, "You go to somebody in a community of color." He said, "In particularly, let's say a black community, you tell them they need to do X, Y, and Z to improve their health. He said, "You're not talking about the food they consume. You're talking about their culture, their identity." Yes. Their You're You're messing with their lives and I said, "Holy crap. Holy crap. This makes so much more sense than right or wrong, black or white. there is so much gray in between. And so that I would say is definitely the primary turning point All I know is the shoes that I've walked in.And it it's and then another thing that stands out in my head is um a former coworker who she said to me when we talked and she said Amy when you walk in a room people don't know that you're gay. She said, "When I walk in a room, they know I'm black." And I said, "Whoa."

so it's just it's paying attention.

Amazing. rr how are the community based organizations how do they support the work that you all do?

We have four. They call them ASOS still here. all four of those ASOS. So they're Ryan White contractors. Okay. Um and they're very um proactive and very much in the middle of when so for instance um this situation that I was talking about, you know, the unhoused community. two of them were very active in one of them has housing vouchers, you know, trying to get somebody to be housed for a little bit, trying they're also one of them, the ASOS is also a syringe service program. , the local health departments very active. They provide uh direct observed therapy for the TB patients that are in their um receiving treatment that are in their jurisdictional areas. Um it is it is very a very collegial work environment. um one town is a little more conservative than the other, so there are some barriers there, but overall, no, they're very integral and very much a part of what we're doing. One of our health departments, NSHA specifically, um is doing uh prep. They're doing PEP and they're doing PEP and they're willing to expand services to cover outside of their jurisdictional area. Um now, of course, they've asked the appropriate question is can we get more money to support that? Well, when we write for our new STI NOFO, maybe that's something we can ask for more money to support this the growth.

 with all of the biomed interventions that they're offering and hoping to get more money to provide more? What's been the community's uptake with the interventions?

So, you know, I love that question because here's my question. How do you measure that?

so I've been asking our excuse me, our HIV project officer this question for a while and finally she brought and I can't even remember the physician's name to one of our meetings. She's a physician and a researcher and she was talking about, you know, prep and getting people to to jump on board to prescribe and this that and the other. And um our program manager for the DISIS said, you know, this is all great, but this is what we have. You're talking about this. What can we do to to do this? And and I'm glad she said that because in my brain, you know, I think of data and I think surveillance data and big data.

So so out of that meeting with our project officer and the physician,you know, came the light bulb moment of oh my gosh, we can create our own data. And it's not that you're creating it, you're just creating it from a different format and a different way of gathering it. So as the prevent co-chair for the uh IHP workg group, we came up with steps that we want to do. We're going to identify the top prescribers of prep in the state. We're going to ask them to join a meeting and then identify the frequency that we want to create data. you know, do a baseline because that's been my biggest question is how do we find a baseline? as long as they participate in this, then we will create a spreadsheet or a list of these providers and push it

out through the HIV planning group and promote them as the prep providers in the state. If you want to be on that list, then you got to come to the table. And

I love the question. It's like well what is the baseline? How do you establish that baseline? I also think it's it's amazing just the kind of thinking outside of the box in the sense of bringing people to the table to kind of figure out well what is it that we want to measure? How do we want to measure? .

Here's the problem here in New Hampshire. And this was a problem for me in Oklahoma. white, cisgender, lesbian. you know, how do you get your foot in the door? here in New Hampshire, it's like 89 to 92% white. and if you look at our our number of HIV cases, a large number of them in particularly in the black community are non-native to the United States. So they're immigrants. Okay. So you're adding then another layer on that of of cultural like non-American culture and how where are the gatekeepers when you traditionally talk about African-American communities church community centers Oklahoma black rodeo uh you know the historically black towns those are where you're going to find your gatekeepers here what where do I find those folks

and then how do I get to them to say come Mhm. come to our table and why it's important that you are part of our table. A and you know we still HIV is still so freaking taboo. That's a whole we still can't get over that hump of don't want to talk about that. Why everybody having sex? Yeah, let's talk about it like salt and pepper. Let's talk about sex.

I love this aspect of the conversation because I think oftent times it's been my experience and I've worked in the field of you know HIV care prevention. Um I used to work for the the uh Alama County Public Health Department and I was a grants administrator. We funded organizations provide services. Now on this side of the fence, you know, uh I provide training, technical assistance. U been doing that for going on 15 years now. But I think oftentimes in my experience what I have witnessed is that depending upon the jurisdiction and depending upon you know the scale of the health department the amount of money that's coming in that the the the rate of HIV infections within um an area that there there are folks who are represented in kind of like the frontline staff. But what I also find too on the flip side of the coin, the heads up side of the coin is that a good high percentage are not people of color um that are really kind of making those kind of higher decisions and making sure that the the people that are providing those services um are anchored somehow in the communities that are most impacted by the rates of HIV. So to me it's like when you your awareness of that uh you know I hope that you know if that is a gap in in services or if that's a blind spot for some of the higherups that there's an opportunity to really kind of bring representation from the community with those voices because I think when anytime we ask questions about Why isn't

or why aren't people at the the table? You know, it's just like, you know, is this a table that I feel comfortable and safe sitting at? Is this a table that, you know, I'm invited to sit there because I'm X Y and Z a part of I fit a demographic or if this is a table where not only am I allowed to sit, but I'm also allowed to eat. And yeah, and I think that's really important.

Amy, I'm going to ask you some things. What does it mean from your perspective um to be an ally?

You fight for those who can't.

Okay. I

do have empathy and you have to fight for what's not right. if we want to talk about the abortion issue. My partner never been with a man never you know having children was never part of her scope. And when I got so riled up about it, she's like, "What? Why are you so wh why this doesn't affect you?" And I said, "Oh, wait a minute. Wait a minute. It affects my gender, affects how I identify as a female. And just because that time is long gone, that opportunity is long gone for me. And I chose not to do that. It was a choice. And I said, "People fought for that right for me. Why wouldn't I fight for that right for somebody else?"

Absolutely. Absolutely.

But I do think that one of the the key things in the work that we do, it's like you can't do the work and at some point not be impacted. You can't look at someone who is like newly diagnosed and go like, "Oh, you'll be fine. I just need to connect you to HIV care and that's fine." It's like, no, you may need to sit with somebody and let them cry. Let them cry for a life that they were anticipating would be different. Let them cry because maybe now they are aware of why they've been feeling bad and you're reassuring them that there's something that they can do to improve their health. oftentimes too it's like when people are impacted by HIV sometimes we forget that there might have been circumstances that put them in a position that they may not have been old enough to understand vulnerable at that moment that they didn't have enough autonomy over the moment or the situation to say no or to protect themselves. Like we never know and sometimes I hear that judgment from other providers, you know, it's, you know, you could have done this or you should have done this. Why didn't you wear a condom? Well, if a condom wasn't a choice or a condom wasn't available or if I make more money, I don't use a condom or, you know, I trusted and believed that the person was, you know, negative where whatever they said to me or just I was in love or any of those things.

we had folks that were very open and very comfortable, but there are some judgy folks and I used and in Oklahoma I was the HIV prevention program manager and so I was over the CTR piece that we did for with our community based organizations and the testing and everything. And when I started, CDC was starting to move away from the individual behavior modifications, you know, and doing the hardcore risk reduction piece. Um they were starting

to do more of the social networking strategy, the SNS and things like that. And so we completely redid our CTR and we would talk about I would talk about checking it at the door. This is not about you. This is about the person that you're is in front of you. You put that crap that you carry with you at the door. I'm not here to teach you to change your mind. I don't care if you don't change your mind. But you don't bring that judgment in when you're providing care for somebody

So, you just have to you just have to look at it differently. I got to leave this place in a better place than I found it in. and right now it's a hot mess.

Is it a hot mess in the sense of um lack of funding?

Is it a hot mess in the sense of just um not enough people doing the work?

what constitutes as a hot mess

so for me a hot mess is you know the you've got the political climate you've got the backtracking that we're we're undoing. Oh my god. Undoing. Yep. So many positive things. Yep. Yep. We're having to fight for things that we should have never had to fight for again. Ever.

To me, it looks like um I imagine like a like a grandmama quilt. grandmother quilt and all the little patches that you know a somebody sewn together to make it into this beautiful patchwork quilt. And all of a sudden there's one thread that somebody is pulling and that one thread kind of connects all those patches together. And as they keep pulling individual patches that represents something that we fought for or a step that we've advanced, you know, just kind of drops off into the pile. Then it's just this pile of just, you know, unconnectedness.

Yeah. And and I think getting folks who are not in our world, you're in my world to understand what the potential ramifications are. when we started talking here about how do we protect

our folks here in New Hampshire, how do we do that? s it takes all of us. Mhm. It truly takes a village. Whatever that village looks like, and if I can do something to make life easier and it's within my control, I'm going to do it. you have to

Amy on that note This has been wonderful in talking with you, hearing your perspective, hearing the generosity in your spirit, hearing your story, learning about you and your partner and just some of the trials and realistic tribulations and concerns because you know cuz we are in a hot mess and I never know if it's going to get hotter or if somebody's actually going to take that dial on the stove and turn it down or turn it off. But I'm so glad that there are individuals such as yourself. Once again, I will give great praise to you, Miss Amy, because um you definitely are somebody who stood out. You're definitely somebody that is aware of, you know, at least what's happening in and around your community, around the health

department, around the the folks who are being impacted by HIV. And you are an amazing person, and I thank you for sharing this time with me.

Outro:

Thanks for joining us. If you enjoyed today's conversation, please follow the show and leave us a rating wherever you listen to podcasts. It's a simple way to help more people discover these important conversations.

We also invite you to share this episode with a friend or colleague and use it to start your own conversation about sexual health. You'll find the resources mentioned in today's episode, along with a full transcript, in the show notes.

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This podcast is produced by Duran Rutledge and Catalina Macdonald, with our coproducer and editor, Isaiah Ashburn.

Coming Together for Sexual Health is brought to you by the California Prevention Training Center at the University of California, San Francisco.

Until next time, thank you for listening, for sharing, and for coming together for sexual health.