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**Kendra:** When I first came into the field, we were doing partner notification and stuff with people with HIV. There's a few, at least, people in Richmond who started back when I did, which was 1989. So it was a very different perception. And it might be interesting to talk to...

**LB:** Absolutely.

**KW:** ...some of those people together.

**LB:** I would love to because... I don't know if you know Bob Higginson?

**KW:** Mhm.

**LB:** Of course you do because everyone knows everyone in this field, right?

**KW:** Right! Just about.

**LB:** Yeah. He was talking to me about some of those moments, but again I think if we could get a critical mass together, it would be amazing.

**KW:** Yeah. 'Cause the difference in telling someone they were positive back in the late 80s, early 90s, versus telling someone they're positive now... It's a huge difference, just how that news is delivered and what the expectation is.

**LB:** Yeah. Thinking about who becomes HIV positive...it sounds like that's also changed enormously over time.

**KW:** Yes, yes. Yeah, just going from a lot of men who have sex with men. We still see that, but it used to be more in the white community and now it's much more heavily spread in the African American community.

**LB:** And that's something I really wanna talk to you about, but I'd love to start off by just having you state your name and the date.

**KW:** Yep. My name is Kendra Weindling and today is July 3<sup>rd</sup>, 2018.

**LB:** Perfect. And now tell me something about how you grew up, where you grew up...just take me back to the very beginning.

**KW:** Yep. I grew up in Albuquerque, New Mexico, actually.

**LB:**  
Oh!

What a beautiful town.

**KW:** Yeah. And I went to school, to college, at the University of New Mexico, studied sociology. I heard about AIDS in one class that I took and that was “Deviant Behavior.”

00:02:32

**LB:** Wow.

**KW:** Yeah.

**LB:** When was that?

**KW:** That was in the early 80s. I probably took that class in 1983. Like I said, the name of the class was “Deviant Behavior,” and we heard about this infection that was spreading among men who have sex with men, which was, at the time, classified clearly as, “Deviant Behavior.”

**LB:** Which is mind-blowing.

**KW:** Yes. It’s mind-blowing.

**LB:** Do you remember what they called that disease?

**KW:** I think...I’m trying to remember if it was called AIDS then or came to be known as AIDS very shortly after that. But really what we were hearing about was this infection that was prominent in men who have sex with men that was destroying their immune system and they were dying. There was discussion in the class about—was that kind of karma, payback? If you weren’t engaging in this deviant behavior, you didn’t need to worry about getting this infection, whatever... Like I said, I don’t really remember what we were calling it back then.

**LB:** But you certainly remember the kind of discourse around AIDS in those early days.

**KW:** Yes, yes.

**LB:** Well, tell me what else you remember?

**KW:** Basically, in the community that I grew up in and even at the university, it was considered something that none of us needed to worry about, nobody that I knew. Now, as it turns out, a group of guys in a fraternity that I was very...I had a lot of friends in that fraternity...and as it turns out, many years later, many of them died of AIDS.

**LB:** Wow.

AIDS-related illnesses. Because many of the guys in the fraternity were gay, and so we learned later that they had died of AIDS.

**LB:** And were they out of the closet at that point?

**KW:** No, not at all. Not at all. I mean, there were rumors....but no. They took girls on dates and, you know, all of that. But... Yeah... So... It was just all rumor and then later we heard that it wasn't actually a rumor and that many of them had died of AIDS.

**LB:** Wow. So clearly Albuquerque's changed a lot from that time.

00:05:10

**KW:** A lot.

**LB:** Tell me about the atmosphere that you grew up in.

**KW:** It was very middle class. There wasn't much... Like when I was growing up I never even heard about the concept of homosexuality. It was just not something that we talked about. I didn't know anybody that I knew was gay. Obviously I did know people who were gay, but nobody was out so you just didn't know. And, interestingly, as it turns out, my sister is gay. Of course, now the community is so different, you know? And maybe there always some part of the community where it was okay and recognized and everything and I just didn't know about it. But now, of course, Albuquerque is pretty progressive. There's a pretty big gay community in Albuquerque and it's pretty widely accepted. It's not real conservative now.

**LB:** It's interesting. Were you from a very religious background?

**KW:** No. No, not at all. So...

**LB:** But it was just a very different time.

**KW:** Yeah, and I wouldn't say that my parents were necessarily real conservative. It just wasn't out in the open. It just wasn't discussed. Obviously my parents have had to, you know, come to terms with my sister being gay and that wasn't a problem for them when she came out.

**LB:** That's interesting.

**KW:** Yeah, I mean, they were very much like, "We just want you to be happy. What do you need from us?" So it wasn't necessarily that I grew up in a real conservative family—it was just not openly discussed.

**LB:** So take me from the moment that you're in that class studying deviants...

Mhm.

**LB:** ...to how you got involved in HIV prevention.

**KW:** So when I finished my degree I was applying for jobs. One of the jobs I applied for was as a public health advisor with Centers for Disease Control. To be quite honest this was back in the days before the internet, so you didn't read a big job description. It was at a career fair that I picked up the application. They were closing down the career fair so the people manning the table, the booth, were already packing up and weren't standing there when I walked by. But I thought, "Oh! Public health advisor, that sounds interesting." So I took an application, filled it out, mailed it in, got an interview, ended up getting hired. I really didn't know what I was applying for until the interview. And in the interview they explained that I would be doing partner notification, contact tracing, for people with STDs. No mention of HIV and AIDS at that time in the interview. And even then I was like, "I'm just really not sure I can do that job."

00:08:29

**LB:** Had you been applying to a whole range of different jobs or did you know that you wanted to go into public health?

**KW:** I knew that I was interested in the health care field so that's why I was drawn to that particular one. But really any of the social services held an interest for me. You know, you graduate with a degree in sociology and you're kind of like, "What do I do with this?" Right? And so I didn't have a firm idea of what I wanted, but I was very interested in health care, which is why I picked up the public health advisor. I picked up other applications too. But I did walk out of the job interview going, "They'll never hire me. There's no way I can do that job. I can't go out knocking on doors talking to people about their sex lives." I was pretty shy, which is hard to believe now. It was interesting because I told my friends what the job was after the interview and all my friends said the same thing: "You could never do that job." And there was a little part of me that was like, "Wait a minute! Who are you to say I couldn't do that job?"—even though I said the same thing.

And so when I got the job offer I took it. It required that I move to Chicago for training. So I went to Chicago. I did my training. And at the time, HIV was still very separate from STDs. They were two completely separate entities at the health department. The only HIV testing when I first started was anonymous. And so if somebody didn't return for their test results, we had no way of going out and notifying them. So the reality was...even when they started training the disease intervention specialists, which is what we were called... When we started with CDC that was the job we had. They started training us to notify people of positive results and talk about partner notification, but it was very rare that we did it because so many people didn't return for

results and we had no way to find them. So I had a little bit of experience with it at the very beginning but very little because, like I said, most people didn't return. Then I took some time off from the field and stayed home and raised kids. When I came back to the field it was a very different world.

**LB:** So you got in around 1983... 1984?

**KW:** That's when I first took the class. I graduated in 1989 and started at the CDC in 1989.

**LB:** Okay. And then you took time off for your kids and then when did you come back into the field?

**KW:** So I worked until about 1993...1994...and then I came back to the field in 2009.

**LB:** So it was very, very different.

**KW:** Very, very different. There was medication, you know, which... when I was leaving the field we had AZT, but it wasn't great. Can we take just a minute break?

**LB:** Yes of course.

**W1:** I just need to run and use the bathroom.

00:11:56

**LB:** Yes, of course. It's right here in the hall.

**KW:** Sorry, I'm very sorry.

**LB:** No, that's fine.

**KW:** Had a lot of coffee, a lot of water. This way?

**LB:** Yes. Down at the end of the hall.

**KW:** Thank you.

**Woman 1:** There is only 31 minutes left of recording on this. I'm planning on whipping out my iPhone at that point.

**LB:** Good, good, good.

**W1:** Just so you know if I take the microphone from her...

**LB:** I feel so slow today.

00:12:35 to 00:17:14 bathroom break for KW, LB & W1 chatting about coffee, tea, England, Yorkshire tea, weather, Civil Rights exhibition, VCU special collections etc.

**LB:** Where were we? So you were talking about exiting the field in '93?

00:19:17

**KW:** '93. And my last job in the field, before I took my time off, was as a Ryan White case manager for women... well, it was for an agency that served women with HIV. So if their male partner needed case management we would work with them as well. And a lot of their kids needed case management. It was so hard because one of the things that I did... This was also in Chicago still. One of the agencies that we worked closely with was an agency called Second Family. Basically we would help these women find a second family for their kids for when they passed away—because that was the norm. They were likely to die from AIDS-related illnesses. So we would work with this agency and there were many families that were willing to adopt the children. The mothers would have the opportunity to meet the families and basically pick a family for their kids. And then they would spend time with the family. When the mother would be in the hospital, the kids would go and stay with this family so they'd build a relationship so that when Mom passed away—the kids already knew the family that was going to adopt them, but it was so heartbreaking 'cause I can't even imagine having to pick a family for my children. Our daughter was... probably about six months old when I started working there. There were definitely nights that I would go home from work and I would pick up our daughter and I would sit down in the rocking chair and just hold her. My husband would be like, "Okay. One of those days." You know... lost a mom, lost a kid, horrible things, you know? And I just wouldn't put our daughter down and he would do everything else those nights. It was really hard.

**LB:** So were the kids also getting infected from birth?

**KW:** Some were. Some were not. For some of them, their moms got infected after they were born. Sometimes there were kids in the hospital for weeks on end and the moms were the ones needing the support. Other times it was the mom in the hospital and the kids needing the support.

**LB:** And the dads were...?

**KW:** Most of the people that I worked with at that agency did not have Dad involved in the family. There were a few that did, but most did not.

**LB:** And that was when AZT was available, but talk to me about the experience of using AZT back in those early-ish days.

**KW:**  
It  
was

obviously only so effective. It slowed things down but not enough, not like the medications we have now. It made people pretty sick and it was expensive. So it wasn't really necessarily something that was available to everybody. Although, you know, the people who were in extreme poverty could get it through Ryan White. It made them so ill that a number of my clients chose not to take it...because then they had no quality of life.

**LB:** Tell me about the Ryan White legislation, how that came about, and how that changed the field for you.

**KW:** The Ryan White legislation came about from Ryan White who was a young boy who was infected through a blood transfusion because of hemophilia. He experienced real severe discrimination. The neighbors wanted them to move and he couldn't go to school. No one would be near him. And then, of course, he did pass away from AIDS-related illnesses. Then his family advocated and they passed this legislation in his name to provide support for people who couldn't afford their HIV care. So it covers a lot of things. It covers case management. It covers medical care. They can get some dental care through it. It's not perfect, but it does help a lot. And so it did open up a lot of opportunities for people to get some help that they really needed.

**LB:** But there you were working with the most heart wrenching cases.

**KW:** Yeah. Like I said—it was so hard. I lasted in that job for right around a year. And then it was just too emotionally draining. Having kids of my own—I could not imagine what those women were going through. Yet I did, every day, see it...what they were going through. It wasn't just "What's going to happen to them when they die?" That was a big one.

But also just the financial need that they had because they couldn't work and the pride. They didn't wanna ask for help. So a lot of times as a case manager, I would get the phone call saying, "I'm being evicted." And it's like, "Okay. We got five days."

"No, I got the notice five days ago. They're here to move my stuff out."

00:23:14

But, you know, that pride. They didn't wanna have to ask for that help. You know, there again. There they are with their kids and their stuff is all on the sidewalk and, "What do I do know?" It was one of those jobs where you are constantly putting out fires and trying to support people emotionally through so many different things.

**LB:** What were some of the challenges that you came up with in that job? There was people not wanting to ask for help.

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**KW:**

There was still a lot of stigma. There's still stigma today, but it is very different from what it was in the earlier days when landlords didn't wanna rent to people if they knew they had HIV. They didn't have to disclose, but sometimes it would come out. There were still doctors who didn't feel comfortable treating. And so many of 'em lost their family when they told 'em because of the fear and the stigma. The family wouldn't wanna be around them. That was a problem with what was gonna happen to their kids because you know otherwise maybe they would've had family members. And some certainly did have family members who would take their kids, but a lot didn't.

**LB:** So it was a very, very isolating disease at that point.

**KW:** Very isolating. Yeah. They had each other. We had a support group and they had each other. It was a small agency so that was really nice. They all knew each other. And one of the things though that I really loved—we did a monthly food distribution. We had a food bank, a small food bank, so when somebody was in crisis we could give them a bag of groceries. But once a month we got about 3,000 lbs. of food donated and the van would pull up in front of the church that we were housed in and we would sort the food in the basement. So many of these women would come and help, because it was their way of giving back. It was just really moving to see women who were so sick and on oxygen, but they were determined to help. So on one hand they've got their oxygen tank and in another hand they've got whatever groceries they can carry in one hand...carrying it down into the basement. 'Cause we had to get all 3,000 lbs. of food down into the basement. We'd sort it into bags and then we'd carry all the bags back up. Those of us who could would be carrying six or eight grocery bags, but even the women on oxygen or whatever—they'd carry their one bag up and they'd come down and get another bag because they so wanted to give back. That was a really rewarding experience to see that. I loved food distribution day just because of that, because of the community that came together.

**LB:** It sounds amazing.

**KW:** It was. My husband would come and volunteer on that day and he just couldn't get over it either.

**LB:** When you think back to that time, what were some of the big watershed moments that you had? Things that just float to the surface of your memory when you think back.

00:26:43

**KW:** That is definitely one of them. And then helping the women come to the point that they could accept finding a family and meeting the family and helping them through that process—it's just something that will always strike me. And then also the early days of notifying partners...because that was such a scary thing for people to hear.

**LB:** How did you do it? How did you approach them?



**KW:**  
We

always did it in person. Even if we had a phone number we didn't call somebody because we didn't wanna give news like that over the phone. Once we identified that we were talking to the right person...we took a lot of precautions to make sure we were talking to the right person...and then we'd make sure we were speaking privately and we would just explain, "Your name has been given to us by someone who has HIV. They said that they were engaged in sexual activity with you so you're at risk. It would be good to get tested." A lot of people refused testing back then because they felt like there wasn't anything that could be done anyway and so they didn't want to know their status. They didn't wanna have to disclose to their sex partners. They didn't wanna have to tell their family. They didn't want all of that stuff. I wouldn't say it's easy now, but we have more tools now. That looks very different because now we can say, "We need to get you tested because, if you're positive, there's so much we can do to keep you healthy. So it's really important to know." But back then there just really wasn't much so a lot of people just chose not to get tested.

**LB:** That sounds like very difficult work to be doing.

**KW:** It was very difficult. The neighborhoods we were in weren't always the best. So there's the fear factor of just your own personal safety. There's the concern about how somebody might react when you tell them.

**LB:** And how did they react? What was the range?

**KW:** Wide range. There was definitely the shoot-the-messenger reaction of... not literally.... but get really angry, yell at us, cuss us out, tell us to, "Get off their property and never come back"... to just the: "I've kind of been expecting this," you know, that complacent...not complacent, I guess, but not surprised, resigned. "I figured this was coming," to the complete and utter shock and shut down "I don't even know how to react," and then denial. So we got all kinds of reactions.

**LB:** I bet. And so you're doing this really, really difficult work . You step back for sixteen years. So tell me a little bit about the interim, and then tell me about what you found when you got back and how you got back into it.

00:30:55

**KW:** During that interim I stayed home with my kids. I raised my son and daughter. For a lot of that time when they were really young, once I was out of the field, I kind of didn't give it a lot of thought anymore. I couldn't. I was emotionally drained. And I had my two kids—it's exhausting raising two kids. Anybody who says being a stay at home mom is easy does not know what they're talking about. And I was very engaged in that life, you know, of taking my kids to the park to play and that kind of stuff. But I did always just kind of... If I saw a news article, I'd read it. I wouldn't say I totally kept up with the changes as they were happening, but big changes, big breakthroughs, I did. Then I actually might never have come back to the field because I wasn't

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really... My husband was raising enough money and the kids were in school and I was volunteering and doing stuff. At the time we were living in Appleton, Wisconsin. They don't have a lot of morbidity there. I'm sure there's some, 'cause it's everywhere, but it wasn't like there were good volunteer opportunities like you get in a bigger city where you say, "I want to specifically volunteer with people with HIV...and you can find agencies that do that."

But then in 2008 my husband lost his job when the market crashed. His degree is finance, an MBA. That was a very tough field to get a job in back then. And so we started thinking about my experience and that is kind of a recession-proof field. I started applying for different, mostly, disease intervention specialist jobs to come back into the field—anything with STI and HIV.

**LB:** Were you doing a national search?

**KW:** Yes. That's how I ended up in Virginia. I got a job as the disease intervention specialist in Roanoke. And so moved the family to Virginia. I worked as the DIS in Roanoke for two years. And it was so very different than the first time because, first of all, they were totally integrated now. There wasn't this, "Oh yeah we do some anonymous testing and occasionally you'll be doing this, but mostly you're gonna do STD." Now it was equal. We did mostly syphilis and HIV. The gonorrhea morbidity is so high that there just really isn't time to run all the partners on that unfortunately. And then the other thing that was so interesting was the number of people who were co-infected, which wasn't as big an issue...may have been a big issue...when we were doing it before. But people didn't choose to test for HIV. And there wasn't this push to test. So again, most of that was anonymous. If they came in for syphilis testing, they got tested for syphilis/gonorrhea. They got treated. They were offered an HIV test. Most people declined and then went on their way.

Now, when I came back in 2009, it was so different because everybody was getting tested for both. The standard testing done in the clinic includes HIV testing.

**LB:** So it's syphilis, gonorrhea, HIV, chlamydia...

**KW:** ...chlamydia.

**LB:** What do you mean when you say that the morbidity for gonorrhea is so high that they don't bother to talk to partners?

**KW:** So when I was in the field in the late 80s and early 90s, we would actually interview people who had gonorrhea or syphilis and get the names of their partners and go out and notify them. The morbidity is so high—when I came back in 2009 and continues today—to where there just isn't enough man power to interview all of those cases of gonorrhea, and get partners, and do the partner notification for them.

**LB:** You mean that there's just so much out there?

00:34:50

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**KW:**  
Yes.**LB:** Wow.**KW:** That's not to say we don't care about the partners, but we counsel the patients to notify their own partners.**LB:** Okay.**KW:** And I will say, at the Richmond City Health District, if we have a patient who says, "There's no way I'm gonna tell my partners because I'm not comfortable doing that, but I'll give you their information." We will take it and notify them, but for the most part we rely on people to notify their own partners for gonorrhea and for chlamydia. And we focus on syphilis and HIV.**LB:** So you were down in Roanoke for a while doing that.**KW:** Mhm. And then a position opened up here at the central office at the health department as a program consultant. So I took that role. We moved to Richmond. I did that for about a year and then I had an opportunity to run the expanded HIV testing grant that we had for the State. So I was the expanded HIV testing coordinator. That was a very interesting job because the focus of that job was to expand access to testing for populations who are disproportionately impacted but expand it in a clinical setting. So rather than the outreach testing, that you may hear a lot about, of a health department going to bars... the health department, or a community-based organization, or places like Health Brigade going to bars and setting up testing events or just testing out in the community. So the expanded testing grant was specifically focused on clinical testing. The goal was to reach out to clinical providers who see people who are disproportionately affected—so you're federally qualified community health centers, emergency rooms, those kinds of places where people who don't have health insurance can easily go. We'd work with them to get them to incorporate routine HIV testing. I worked on that grant for three years. That was very interesting working with the emergency rooms and how to incorporate routine HIV testing.**LB:** What are some of the challenges you faced there? What are the challenges to having HIV testing come very routine for populations that are impacted disproportionately?

00:38:54

**KW:** Yeah. There's a lot of challenges. One is—doctors don't necessarily think that their patients are at risk. I don't know why. But they will say, "Oh I don't see people who would be at risk for that." So bringing in the data and showing what the morbidity is and explaining that there's an

estimation. At the time that I was doing it, it was close to 20% of infected people didn't know their status. That's dropped now. I think you'd have to double check my stats through VDH because I'm not as into that particular role so I don't know the stats, but I think it's down to 14 or

it's moving in the right direction. And so...convincing doctors of the need and then funding, because if patients don't have insurance—who's gonna pay for it? That's where my grant came in. We could come in and say, "Funding is not a problem. We'll pay for it." But then there is also the fear of: "What do we do if they're positive? We're not prepared to provide care." So helping them understand that we can do all that. We don't provide care at the health department, but we can help them link patients, if they don't have insurance, to Ryan White, and get funding for the medical care, and get them set up with a place that will accept the Ryan White funding so that they can get care. That was a big relief for the doctors, because a lot of them were like, "Who's gonna pay for it? I'm not equipped to provide that care and as a doctor I have an obligation, if I do a test, to make sure that they get the care they need." So getting through that.

And then at the emergency rooms it was unique because the emergency room doctors felt like: "Well we don't even see these patients again and we've got this, as a doctor, this obligation to follow up on a positive test." So again showing them how the health department would step in and do that.

**LB:** Interesting that there's that much resistance from the medical profession.

**KW:** Yes, yes.

**LB:** Now... one thing that I've been very curious about—have the challenges been particularly acute in Virginia because of the State's resistance to expanding Medicaid? Is that a factor or not?

**KW:** It probably is, but I'm not really at a great situation to talk about how because I don't really work with that piece of it. When I was in that expanded role, when I was doing the expanded testing grant, it was before ACA.

**LB:** Okay.

**KW:** And so there wasn't all the expanded...or Medicaid...and all of that.

**LB:** Right, right, right.

**KW:** I can tell you somebody who might be able to talk about that if you would like.

**LB:** Yes.

**KW:** Okay. Her name is Valencia McGee [00:40:43 name spelling unc.]. I'll give you her contact information.

**LB:** Excellent. That would be great.

00:41:35

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**KW:**

Yeah. So yeah, those were the biggest challenges at getting the testing in place was easing the minds of the providers that the follow-up would take place and they wouldn't need to worry about that liability of "I tested this person and now I can't help them." And then it was logistics—how to fit it into the flow of their particular clinic. 'Cause what works in one clinic isn't necessarily gonna work in every clinic. That was a case-by-case thing, you know. We would go and talk about their flow and give them ideas of what's worked other places. You just kind of had multiple different things by the time you've worked with a lot of different providers. And you can say, "Well, some places do it this way. Some places do it this way. What do you think will work best in your flow?"

**LB:** What kinds of solutions did you come up with to that problem of flow?

**KW:** Basically... *who* was gonna run the test. Because at the time it was a lot of rapid testing. Most places were doing rapid testing. So it was helping them see that either the lab tech, when the patient goes to have their blood drawn, could start that test. And the lab tech could be trained to read the test. Or for places where the patient goes into the exam room and lab and nurse and doctor all come to them—a lot of times the nurses did it. So and then providing the training so that the nurses and lab techs would feel comfortable running that test and interpreting that test. It's a very easy test to interpret. It's really pretty straightforward, but there's a lot of anxiety about "What if I interpret it wrong?" Once they see how the test runs that is easy to resolve, that anxiety, but there's more anxiety about "How do I tell somebody they're positive?" So we actually... There's a three-day training that they go to to learn how to do the counseling that goes with it.

**LB:** What are some of the things you tell health care providers who are in that position and apprehensive about it because they've never done it before?

**KW:** Just the same way you would deliver other diagnoses such as cancer, something else that a patient might have a bad reaction... you know, not a bad, you know, a scared, you know, whatever reaction to. And normalize it. Normalize testing. Normalize the result. This is not a death sentence. It's much like telling somebody they have chronic heart disease or diabetes or something. You're gonna now need to alter your life but there's a lot you can do. So helping them get the patient to understand that it's not a death sentence, because there was a time when it was. Not that we actually say to a patient, "This isn't a death sentence anymore." If they ask, certainly, but we don't even really go there. It's presented much more like any other chronic

disease: "You're positive. You're gonna need to take these steps. You can live a very healthy life." We have people with HIV now who are dying of other things that anybody else might die of—heart attack, cancer, not the cancers that people with HIV get, but, you know, liver cancer or whatever, diabetes, any of those things. Those are gonna be more of an issue for a lot of people assuming they choose to make the changes that they can make.

about that.

**KW:** The biggest thing is they have to be committed to going to see their doctor and taking their medication.

**LB:** How often do they need to see a doctor?

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**KW:** It'll change. It'll vary. It'll start out being probably you'll have a couple of appointments in the first month—one to get bloodwork, one to go back and talk about the blood work. The doctor will assess what kind of medication you need to be on, and get you started on that. You'll probably go back in one to three months, after you start your medication, 'cause they're gonna wanna check in with you see how you're doing on the medication and also do bloodwork and see if the medication's helping, if they need to adjust anything. Typically once people are established on a medication and doing well—they go twice a year, once every six months. So it's not that different than what somebody else with a chronic disease might need to do. But they need to be able to get their medication and take their medication the right way. And that's a challenge for a lot of people. We have a Ryan White case manager at Richmond City Health District who helps to resolve a lot of issues that keep people from going to their appointments, or keep people from taking their medication. Somebody who's homeless and doesn't have a place to store their medication. Somebody who lives with their parents and doesn't wanna store their medication in the medicine cabinet where they might see it. Those kinds of things can be barriers to care. And then simply getting to the medical appointment can be a barrier to care. So we help for all of that stuff.

**LB:** So after year three your grant finished up. What happened next?

**KW:** I then transitioned to be the supervisor at the Richmond City Health District. At Richmond City I supervised a team of disease intervention specialists. So they were the ones going out, doing the notification, and interviewing, and notifying partners, and doing all of that. And we have a PREP program there that I supervised. And the Ryan White case management program. So I supervised all of those programs. Richmond City was the first health department in the State to offer PREP. We're pretty proud of that. It's a pretty robust PREP program. We've got about eighty patients on PREP now. One of the things that I really love about what Richmond City does is that it's very integrated, the three programs—the Ryan White, the DIS, and the PREP. It usually starts with the DIS. They identify somebody who's positive they interview that person and get the partners, and the refer the person who's positive to our Ryan White case manager who will link them to care and help them to resolve any barriers they may encounter. They go out and notify and test the partners. If the partners are positive, they get the same service where they're interviewed. Partners are elicited and they're linked to care through our case manager. If partners are negative, we talk to them about PREP. And if they're interested, we would link them to our PREP coordinator.

**LB:** How many people should be taking PREP?

Anybody who is at increased risk. So that really varies and it can change during people's lifespan. So somebody who's in a relationship with somebody who is positive and they have happened to be negative—they should be on PREP. Somebody who has multiple sex partners should be on PREP. Somebody who engages in transactional sex should be on PREP. Some people may be on PREP even if they only have one partner and that partner is negative. But if that partner engages in risky behavior... they should be on PREP. So what we've seen is people cycling on and off. We'll have some people who know that they have multiple partners. They don't necessarily know the status of their partners. Get on PREP. Six months later they get into a monogamous relationship with somebody who is negative. They don't feel they need it anymore. They go off PREP. And we tell them, "Should your circumstances change, come back. You can come back on PREP. We don't like people to be on it if they don't need it. But if it's needed we don't anybody to feel like, "Oh I went on it and then I went off and now I'm embarrassed to go back." Come back. Get back on it. We want you to stay negative.

00:50:06

**LB:** And Kendra, I hope you will forgive all of these super basic questions. What we really want to do is be able to use these oral histories to educate people.

**KW:** Right.

**LB:** So what are the side effects of PREP if any? What are the barriers to people getting on PREP besides the medicine cabinet embarrassment?

**KW:** Right. So the barriers to PREP, specifically, are... 1. It's very expensive. And people don't necessarily know that right now they can get it free through Richmond City Health District or other places in the State. There are now other health departments in the State that are doing it, not all but a lot in Eastern. I think Petersburg is doing it. So there are places that people can access it all over the state. Another barrier is the need to be able to commit to taking one pill a day and the need to get tested every three months—that's quite a commitment for some people, to have to come to the health department. We would be fine with them doing it through their private doctor as long as we're able to get those results and see it. But a lot of people don't have insurance to pay to go to their private doctor. And, unfortunately, coming to the health department... we're a walk-in clinic. So it's not like you have an appointment and you're gonna be there for thirty minutes. So that can be a barrier. Picking up your meds, at first you have to come in every month and pick up your meds. Once you've finished three months of meds (and we can only give a month at a time, unfortunately so we can't give a 90-day supply) but once you've finished your first 90 days there's a possibility that we could get you on a mail delivery system so that at least you only have to come in every three months instead of every month because we can get your meds mailed to you. However there's a form that comes in that package that has to be filled out and mailed back on a self-addressed stamped envelope. For some people... they set that form aside...it gets lost...their meds never come. So there's all these little small things that, a lot of people that need to be on PREP, it doesn't fit well into their lives to have to go to the doctor every three months and have to remember to fill out this form and do all that. The medication itself is actually pretty tolerable. People sometimes complain of an upset stomach for the first few weeks or a month, but that resolves and it doesn't impact everybody.



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There's a lot of other medications that have much worse side effects. So it's not too intolerable. We don't find too many of our PREP patients complaining about that.

**LB:** Now how do you reach out to populations that seem difficult to reach but are very, very vulnerable like homeless people and sex workers?

00:54:36

**KW:** Mhm. They are a challenge to reach. We do a lot of outreach. We've got a lot of stuff on social media. In fact if you're following our Instagram and Facebook "Doing it RVA," you should follow that. Puttin' in a little plug for it. And share as much as you can. We do outreach in different populations. We put up fliers at local bars, particularly that MSM might frequent. We do our outreach through social media. We encourage our community partners to broadcast loudly that we have PREP available. So we get a lot of referrals from community partners. And it's been a lot of word of mouth on the street too. People tell their friends. We have a social network strategies coordinator also, at Richmond City, and that's been real helpful because basically the logic is—if I engage in a certain behavior, whatever that is, my social network probably engages in that behavior too. So having that coordinator... he reaches out to key leaders in different communities that might be at risk and motivates them to reach out within their social network.

**LB:** Interesting.

**KW:** Yeah. And then we have a coalition of community partners that meets every other month. We're meeting on July 19<sup>th</sup>. We meet on the third Thursday of the odd months from 2-3 at the Walgreens on Broad Street. If you would ever be interested in coming and seeing what that's all about, I'll pass your name on to the person who sends out the invites for that. So that's basically a coalition of anybody who might be interested in helping reduce morbidity and increase access. So we have the Walgreen Specialty Pharmacy, Richmond City Health District, people from the student wellness centers at VUU and VCU, Health Brigade, other community-based organizations like Nations Foundation and MAC. So we all come together and kind of talk about what can we do, what can we do as a big group. We share each other's events, spread the word about PREP, all of those kinds of things.

**LB:** Interesting, interesting. And now what kind of changes have you seen in the way the general public views HIV and AIDS? 'Cause you've had a long career now.

**KW:** Mhm. And you know it's interesting because I hear people talk about the stigma now and how awful it is and... There's still stigma—no doubt about it. I'm not saying that it's not bad. But in comparison it's not bad at all, compared to what it was. When I first started, people's families would disown them. I mean they were likely to die and they were likely to die a lonely death because their families were terrified of getting AIDS from them. They didn't understand. No matter... even when it was known how it was transmitted... there was still the fear. Now I think we've got a lot of work to do on stigma, but it's not nearly as bad as it was. You see a lot of places that just don't even see it as a reason to be concerned about interacting with people. And, of course, there's discrimination laws. I think HIV is now at that protected status where



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somebody can't fire you because you're HIV-positive. Now they can find other ways to do it. We all know that happens.

**LB:** What do you think are the biggest misconceptions that people have today about HIV and AIDS?

**KW:** There's definitely still a belief that it is only among gay men, which is crazy because that hasn't been the case for a very long time. It's spread in the heterosexual community. It's spread in the IV drug use community. So it's certainly not limited to men who have sex with men. But there's still that belief. And still just the...so many people just feel like: "Well, I couldn't get it because the people I have sex with are clean." So that there's still definitely a misconception—and this is true with all STDs and HIV—that "I can tell by looking at you if you're clean and if it's safe to have sex with you 'cause I would be able to tell if you weren't." So that's a biggie.

**LB:** Who are the groups that are most at risk now in Richmond?

**KW:** We're still seeing the most, the biggest, increases in African Americans. Young MSM of color are definitely identified as the highest risk. And IV drug use, still. People who engage in transactional sex as well.

00:59:09

**LB:** Yeah, that must be very difficult.

**KW:** It's very difficult because finding them, testing them, and getting partners is very challenging. Because a lot of times if they come in for testing, they don't know how to find their partners. They may be able to find a couple who are regular partners. But there's so many partners that they can't find. And when we test somebody who engages from the other side, like if it's somebody who engages from the "I receive money or favors or sex," they've got a lot of partners but they can't find any of them. If it's somebody who's paying for sex, they don't necessarily know how to find that person. So it goes both ways.

**LB:** So that's really tough.

**KW:** Mhm.

**LB:** If you could see federal, state, or city policies, related to HIV, change... what kind of changes, if you ran the world, would you like to see?

**KW:** Oh goodness. What kind of changes would I like to see... I mean anything that would help reduce stigma. Because I still feel like stigma is one of the biggest barriers to testing. People still are afraid to know. Another thing is, and this is changing, the criminalization laws. So many people have felt like we should criminalize anybody who's got HIV and doesn't tell their partner and has sex with them. But what that really does is discourage people from testing because if I think I might have HIV, but I don't know for sure, I'm not obligated to tell my sex partner because I don't know. And if I think I'd like to go get tested so I can get myself taken care of,

but I

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know I'm gonna continue to engage in sex and I don't want to go to jail, I might not go get tested. So I think that the criminalization laws... I think, you know, that there can be a place for them for people who... like sexual assault, that's very different. Or, you know, people who are molesting children, or you know there's that malicious intent. But you know I don't think we really see malicious intent as much as people think we do. I have not yet spoken to a single person whose attitude was, "Well, somebody gave this to me so I'm gonna give it to as many people as I can." I have had people say, "Somebody gave it to me. They must know they have it. I'm not gonna give you the names of my partners." That's a different discussion. But I haven't encountered people who are like, "But I don't care who I infect in the future."

**LB:** What kinds of criminalization laws do people have to worry about in Richmond and in Virginia?

**KW:** Well... you'd have to, again, double check me on this, but... I'm pretty sure it's still on the books that not disclosing your status and engaging in unprotected sex is a crime. But the burden of proof is very difficult, because if I go today and get tested, and I test positive, and I was last tested two years ago—how can I say one person gave it to me unless we test every single person? And even then what if I didn't tell you about somebody? There's a huge burden of proof. And then there's also the burden of proof of—did they or did they not disclose? Because some people do disclose and then the partner says, "That's okay. I'm not worried about it." And then when they get the infection, they might feel differently. So the burden of proof is huge. You rarely see prosecution unless it's sexual assault type of situations.

01:03:39

**LB:** Now... Richmond has a crazily high rate of HIV and other forms of STDs. I'm gonna ask you this question I ask everyone: Why do you think that is?

**KW:** Oh goodness. I wish I knew. I think it's a combination of a lot of things. Certainly you look at places like New York where they're much more progressive about funding and advertising and making things available than a more conservative State. And education. I think that we don't... it's hard to do enough education. And I think some of that, obviously, needs to fall on the parents, but there is something about the Southern culture where it's not really polite to talk about those kinds of things. You know, my poor kids got beat over the head with it, so... Syphilis might be conversation at the dinner table at my house, but... I think that parents need to become much more comfortable talking with their kids and not burying their heads in the sand. "My kids wouldn't have sex." I think we're seeing fewer and fewer young people having sex, but we're still seeing a lot of young people having sex. So while it's decreasing, it's still high. The last statistic I saw was 50% of school students had had sex by the time they graduated. For parents of high school kids to think it's not gonna happen... it is for 50% of 'em so you never know when that's gonna be your child so giving that education, making protection accessible to them, making them realize they can ask questions and, if parents aren't comfortable answering those questions or don't have the knowledge, making sure that they can point them to a resource. I cringe when kids get information from other kids 'cause it's not accurate information.

**LB:**  
How  
do

you think that educators in high school could do a better job of encouraging HIV prevention?

**KW:** Right?! Well...I think...I am a fan of not just abstinence-only education because I think that yes, ideally, abstinence would be what young people in high school choose, but that's not realistic. We know that's not realistic. I spent a lot of time in the high school when I was in Roanoke pulling kids out of class. We had clinic right there in the high school. It was a very productive time for me to sit there. That's where I ran Partners to Gonorrhea was in the high school. Because I felt two things. 1. I could access a lot of kids real quickly. I'd do 'em one at a time so they didn't see who else was there, but I could just, you know, boom, boom, boom, pull 'em out of class. I could cover a lot of bases within a short time period. I also felt like I could educate them before they developed bad habits. And maybe I could instill that good habit of using protection, and talking to their partners, and getting tested frequently, and all those things we recommend—while they were young. I could do it because I wasn't doing it from like in a classroom, this is in a school setting—I was in a medical setting. And they were already testing positive. So yeah I think education is a big thing.

**LB:** If you could say one thing to people in Richmond today about HIV and HIV prevention, what would it be?

01:08:01

**KW:** Get tested. Know your status, because if you don't know your status you're likely to spread the infection to other people and it's hurting your personal health. There's resources to get people into care. If you can't afford care, that's not a reason to not get tested. We can help with that. Yeah. I think that's the big thing: get tested. Know that it's okay to know your status and move forward in a positive direction.

**LB:** Is there anything that I didn't ask you that you would like to say?

**KW:** I don't think so. I think we covered it.

**LB:** Thank you so much, Kendra. That was great. Again please forgive the giant softballs, but we really want this to be a kind of educational booklet that we can pass out in clinics and places like that, you know, sort of the faces of HIV, HIV education, activism, positivity, and everything else.

**KW:** Yeah. Absolutely. It'd be nice if things changed.

**LB:** Wouldn't it now?

**KW:** I just, I don't understand. Especially the high schools. We had teachers who fought us having condoms in the clinic at the high school and giving out condoms to the kids 'cause they were like, "We don't want them to have sex and that encourages sex." Nooooo it does not.

**W1:** I didn't have condoms accessible in my high school anywhere.

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**KW:**  
It's

so crazy. Because having a condom does not make people have sex. Having a condom means they may have safer sex.

**LB:** I mean, my daughter graduated TJ a year ago and all they ever got were abstinence pep talks.

**KW:** Yep.

**LB:** It made me so angry.

**KW:** Yeah. Yeah. It's horrible. I actually, in Roanoke, had one mom...she found condoms in her daughter's backpack and she didn't want her daughter to have sex and so she brought her to me to talk with me and I said...

END TIME: 01:10:17