Interview with Positive Link Staff

Date: August 2nd, 2016

Interviewers: Patrick Shih, Fernando Maestre
Interviewees: Jill and Tamatha

[START]
Time: 2:10pm

Fernando: So well we introduced each other, what is your role in Positive Link?, so you said that you were..

Jill: So I am the boss. We have a prevention team, a services team and a housing team. And each of those teams has a team leader. So, I oversee all the direct staff, but I work most closely with the team leads in kind of setting strategic direction for each of the teams.

Patrick: So, how many teams?

Jill: Three teams.

Patrick: How big are the teams?

Jill: They vary a bit. Like Tammy's team is five. Mm five is almost an average, cuz we have 17 staff total. Five or six per team.

Fernando: Why do you have teams? Do you have to sort of separate because they're different?

Jill: Ehm, so we offer an entire continuum of hiv services. So we are out doing education and testing as well as kind of working with folks that are positive. We don't provide the medical care, but we provide all the wrap-around services other than medical care. And then we have kind of the housing component which is a pretty large part of what we do. Just trying to keep people stably housed. And those areas of expertise are very different and so we kind of have all of the things that are preventive that teams work together. So that teams typically, all the teams are working together in some fashion, but it is impossible for anyone to be an expert in all of those areas, in all of the intricate details that go on with it, so we have the three teams kind of focus predominantly on the programs that each of them works on, but then those programs also work together in wrapping around the client. So, that is the structure.

Fernando: okay, do they need to have any special educational background in order to be in each team?

Jill: We require a bachelor's degree for all of our positions. We have a few that require a master's degree. But, predominantly, just a Bachelor's degree. It's fairly broad in what they can be in. Predominantly, our prevention folks tend to have a Public Health degree. And, predominantly, our services and housing people have a social work, sociology, psychology. But that is definitely not across the board. We've got one of our longest staff members whose degree is in Education but she's been doing case management for 15 years. We look in those related fields. We tend to have more social work and public health academically-prepared folks, but I am not particularly more concerned with what their work experience is and the work style and they are looking to get out of their work.

Fernando: How many years has this place, Positive Link been in operation?

Jill: 25 years

Patrick: And then the person that you mentioned has worked here the longest, is that person 15 years?

Jill: no, we have 22 years, 21? Somewhere around there. Hang on a second. Yes, 22 years, she's our longest. She almost made it to the beginning.

Tammy: That's probably about right. Cuz I've been in the hospital 23, but here 16. And Julie

Jill: and Julie is a couple of years ahead of you. Yeah, so we don't a lot of turnover

Fernando: and how many of you are in all the teams?

Jill: 17. There's 17 staff in total.

Patrick: So you guys it would be very interested to hear from your perspective how this place has evolved over time too. The support for the community has grown over the years.

Jill: And, the disease has changed. We have to modify our services. Certainly, we are providing a much different service than we did 25 years ago before there were any meds. At that point, we were helping people die with dignity, be able to make their decisions about how they wanted their end-of-life care. We still do that now, but we don't do it with all of our clients. You know what I mean? The disease is not the same. It's definitely changed over time.

Fernando: So, your services would not be for medical treatment, they would be more for prevention?

Jill: We do prevention. We do diagnostic testing. We test for hiv, hepatitis c and syphilis. And then we do other programs. We have on our prevention team health education. So we do a lot of education stuff. Predominantly, testing and then we do risk reduction case management. And

we do substance use **hard** reduction counseling for folks that are positive and that actually runs out of our prevention team because it's a **hard** reduction model.

Tammy: And it might help for you to kind of brain around our services in terms of care coordination and services with clients is so when someone comes in we do an assessment and we look at no only their hiv status, but kind of where they are, their housing status, what their financial status is, their housing situation, do they have any support?, is there any legal issues, or other medical issues that's not related to hiv, is there any mental health concerns or substance use. We look at all of those things and the whole person and then kind of say okay what are your needs, and how can we help you get those met. So it is not just hiv focused, so someone comes in that doesn't have insurance and who just diagnosed and they don't have a doctor. Then that's where we start like doing an insurance application, what they are eligible for and then getting them linked up with a doctor. So while we don't do medical stuff, we help facilitate access to medical care and medication access. And understanding what is hiv and what is when they say your cd4 and viral load is this.. which are indicators of the progress of hiv disease. Then we help explain that and help them to understand what the process is that they are going to be going through in terms of their labs and their doctors appointments and medication and what that means, and that it is important to take them everyday about the same if you can. We deal with helping people facilitate family relationships and disclosing their status to a partner, or maintaining stable housing or maybe somebody who has been kicked out of their house because their mom is scared of them because they are hiv positive. So then we are going to work with them to help them access stable housing. Maybe they don't have any transportation, maybe they live in the outskirts of town and can't get to the bus so we might provide some transportation assistance, maybe they don't have food so we can uplink them up to resources for food assistance. Hmm, different things like that. So, it's kind of looking at the whole person and from there, figuring out what is our care plan. Like, what do we need to do and how do we need to prioritize those things.

Fernando: That's interesting. And do you use any specific type of technology while trying to cover all of these services?

Jill: Hmm, Google is your friend.. [laughs] You know, our care coordinator in Terre Haute sent me an email earlier and said, (she's fairly new), a client sent me this email and I don't really know that to think about this, do you? And he got a safelink phone from ***Indywise*** cuz he's in ***hipplus*** which is an Indiana medicaid program. But he hadn't gotten it out of the box and he's on a plan with his friend, but the cost is getting too prohibitive, he didn't know if he should use this phone and he didn't know anything about it. I know that if you're on..

Fernando: and why not a regular phone? Or email?

Jill: I'm sorry?

Fernando: cuz you're saying he was using a special phone?

Jill: He was using a phone that he's paying for. It's on a friend's plan, but the cost is getting prohibitive. So he applied for this safelink phone that's available for free through his insurance. But he didn't know anything about it and wasn't sure if he's getting anything and in order to provide adequate and effective services then we have to know our clients. This particular gentleman is very anxiety ridden, so any kind of change sends him over the edge. We are going to have multiple conversations about the same thing before he even starts to feel okay about it. So this is probably not the last time that we are going to have this talk about the phone. But I just googled ***Indywise*** state plus plan phone cuz that the handbook wasn't in there, it was just ridiculous, but in any event I sent her the link. It's a page that explains it. You have 500 minutes a month for the first 4 months and then goes down to 250, unlimited texting you can always call 911 and the ***Indiwise*** customer service even if you don't have minutes, which I didn't know.

Tammy: I didn't know that either. Oh, ***Indiwise*** is nice.

Jill: Yeah, or if you call and say hey I don't have minutes, but I'm in an emergency, can you call my care coordinator for me?

[laughs]

Patrick: so, generally, I'm curious about, you know, you say that people come through positive link to get a holistic assessment of the person at that stage. From the start of that engagement, how long do they stay through the program?

Jill: As long as the want.

Patrick: So that could potentially be..

Jill: Forever.

Patrick: So, that means that people that you continue to care, that population could be a growing number.

Jill: yes.

Patrick: And the, does the intensity or level of engagement change?

Jill: It usually does. We kind of look at whether they're high equity or low equity. So when people initially come to us whether they were just diagnosed, or whether they're accessing care for the first time. Or maybe after a lapsing care, they generally have a lot of needs. I would say typically people are not insured when they get to us, sometimes they are, but typically people are not insured. Typically, they have a lot of questions about their diagnosis. There's generally a lot of other things going on in their life. It could be hiv-related, could just as likely not be

hiv-related. There's a whole lot of needs when they first engage in care. Once we've been able to work with them for a while, and address the basic needs and get them stable and kind of work with whatever is going on medically, those needs decrease and so at that point is almost like a maintenance type of relationship where we're checking in with them once a month, like hey, everything is good? Do you have any questions? I think a lot of times what we find is that people don't reach out and ask for help. And so, once they're engaged with us, we're going to be calling them, and when they are stable we're gonna call them and be able to head off some of those things that over, you know, four, five, six months, become a crisis and if we catch them once a month or two because Tammy calls, you know, is there anything being going on? Well, I got this letter and I don't really know what it means. Well she can address whatever is on that letter right now versus waiting until it is a crisis six months down the road and they reach out to us cuz people don't want to have to ask for help, like I don't, you know, none of us want to, and so they can stay for us forever. We have clients that have been with us for 25 years.

Fernando: And the main type of technology that you use is the telephone to get in contact with them, or do you also use email?

Jill: We also email.

Tammy: Some we do text which..

Jill: which is a challenge..

Tammy: And it's a slippery slope because, you know, it's our personal cell phone numbers which we shouldn't put out there. We don't have work cell phones, but there are a handful of folks that that's is really, not the only way they will engage, but that's the best way. Like, I can call somebody over the course of 3 weeks and not get an answer, whether they don't have any minutes, they don't like to answer the phone. You know, it's just something that they feel like they can't manage answering the phone and doing what they are doing. But if I send them a text, they'll get back with me like that [snaps fingers]. So, and I have a gentleman I just started working with who had a lapse in care for about 4 or 5 years who lives out in a rural county. I met with him and his probation officer and she said he doesn't have service at his house. There's a spot in the yard over here that he can get service. She is like so texting really is best. And I knew that it was probably a bad idea, but if that's the only way that we can communicate, see he doesn't have email, so I texted him and said hey this is Tammy, this is my number. I already had a 3am "Hi Tammy". And I was like I knew this was a bad idea. But I haven't had any more since then. I guess I didn't engage. But that's the only way he is going to be able to communicate and he's got a traumatic brain injury, he was on a car accident, he's on probation and parole. He's about to lose his house. I mean there's all of these things that..

Jill: That all connect to him somehow, you know..

Tammy: Yeah, so clients use, or we use phone, email, sometimes Facebook if we can't reach somebody, we'll find them on Facebook and send them a private message. I mean, maybe we're not even friends with them on Facebook, but you can still send the message. Texting..

Patrick: So then, sounds like people that come through Positive Link usually these are kind of people who have fallen through the cracks, or like getting not enough support..

Fernando: yeah, what is the typical population?

Patrick: What I mean is that, are there cases in which that the population, they're more in a stable environment, that they're in a relatively good situation?

Tammy: Sometimes. There are some. Certainly, not the majority. But, there are some that come that really just wanna be sure they're doing what they're supposed to be doing. They're really on the right track and they have all the pieces and parts, they just kind of need that extra little ***impf***. Hm, but then some of those people as Jill was talking earlier about, clients who kind of get to the point where they are stable and they really are self-sufficient, they really maybe don't need us, but we're kind of a safety net so they want to stay enrolled in the services, because quite honestly we're different than other case management programs in that people come to our services and unless they move or they die, they stay. So, and given our staff that doesn't have a turnover, you develop long-term relationships.

Jill: We've worked with somebody for 20 years.

Tammy: I mean he's been involved in every part of their important milestones in their life, whether it's getting a job, getting married, having a baby, losing a job, losing a parent. You know, we end up being a constant.. [clears throat] and so, I don't know where I was going with this, I lost it, but anyway..

Patrick: How do they actually first find out about Positive Link? For example, if they didn't have access to Internet, or they don't have a phone, or they don't have a ***custom*** connection? Word of mouth?

Jill: Lots and lots of ways. Because we do testing, when we test someone and we are the one that is diagnosing them, we immediately link them into care. So when we give them their confirmatory test result, because that's scheduled cuz we have to send it off to the lab. We always have a care coordinator here when we're giving that confirmatory test result so that if they want to just go ahead and engage right then. If they don't want to we still need to agree to meet. Hey this is Tammy, I know you've have a lot today, but she's going to be calling you next week. Let's process things for a second. So we're able to like we are a referral source in some ways. The infectious disease doctor, Dr. ,,, we refers his patients to us. The hospital refers folks to us. Pretty much all of the social service providers in our region. We serve 23 counties. I would say almost we're it for hiv in south central Indiana and most other service providers are totally

willing to provide support in terms of case management, but they have no idea what to do about HIV so they all call us if they have someone who is positive. Word of mouth is tons. Tons of word of mouth.

Tammy: Yeah, and some do find us online. Other care sites in the state, if somebody is moving here, they will say, okay you are moving to Bedford, you need to call Positive Link. .. Health Departments..

{19:20}

Patrick: Is there a network, how many centers together to support all the entire southern Indiana?

Jill: So, for our programs it's us and our satellite in Terre Haut.. Oh my, well you're looking at us.. So we provide services basically from like Columbus to Terre Haut, and then most of our services go like from Martinsville down to Pegoli. We also provide our housing program, we do the hiv housing for Indianapolis and the ***donout*** counties to Marion. So we go all the way up to Anderson for some of our programs. The majority of them are pretty much more like Martinsville to Pegoli, and from Columbus to Terre Haut and then we have that northern region for our housing staff.

{19:50}

Patrick: Do they have to, I guess … to where they come from within this big area. Imagine if they get placed into the Indianapolis housing, do they just move there?

Jill: So, we have housing here as well so we have housing for all of our regions. Some people want to move from here to Indy, or from Indy to here. A lot of people looking to move to Terre Haut, but it happens I suppose. And then sometimes the housing that we have is here, and the person that needs it is in Indy and we are like this is what we've got.. You wanna move here? We have that for your ….. doesn't let us spend her money in whatever region in the state we feel like spending it in. So it's very geographically focused with **hud** funding. We kind of just triage that on a case by case scenario. And then we do have clients that live outside of those regions as well. I know you have a client up in ***New Poredge***, don't you? [referring to Tammy]

Tammy: This client moved to Georgia, but I did.

Jill: Oh yeah you did. And then outside of our region further down towards Evansville and further down.

Tammy: I have a client in Clark county, just right over the river from Louisville. Louisville basically. I have a client.

Jill: Do they choose to come here?

Patrick: Do you have like Skype or Facetime or something like that to talk to this client?

Tammy: He gets his meds delivered here so he comes here every quarter and then we talk via email otherwise. He wants to do that because of confidentiality reasons.

Fernando: And they have to come here to get the medication?

Tammy: I mean I have family in Louisville so if I happen to be going that way I would certainly offer to meet him, or meet him halfway even. I couldn't really justify driving 4 hour round trip for that purpose, but he..

Jill: Cuz I wouldn't approve it. [laughs]

Tammy: But he's one of those people you were asking about earlier. He came in into this program financially stable what he needed was support surrounding his hiv diagnoses. Period. He has a professional.. He has a phd, considered or equivalent to a phd, yes he has a phd, works in the medical arena. Doesn't need financial assistance, doesn't have mental health issues or substance use. He just needed support around his hiv diagnosis and confidentiality concerns and what this means for his life.

Patrick: Actually this is an interesting case, now that you mention it, did he actually choose Bloomington Positive link because is far away from where he actually lives.

Jill: in part..

Tammy: Well, in part yes. Primarily, he was working some here but his primary residence was in Jeffersonville. So he chose to come here because one: he was already here some anyway and it was far away from his home. And, but then he doesn't work here at all, but he wanted to stay here in services with us because it is far enough away that he trusts me, he knows he can have his meds shipped here, he doesn't have to worry about figuring out how he's going to get them through mail order at his building which creates a concern with what if somebody gets my package by mistake, what if they open it, what if they know what they are looking at, what if then my whole building knows, so that's all taken away by driving 4 hour drive round trip every 3 months to get his meds.

Jill: So we have a satellite office in Terre Haut, we have 3 full time staff over there. And then, we have a Columbus clinic. We rent a room in the Unitedway Building so we are in Columbus once or twice a month, then we're seeing people over there. Tammy goes south down to Bedford and Palili area we use a room in the hospital there where people can meet, or do home visit or meet in the library.

Patrick: Are most of these all walk-ins or pre scheduled?

Jill: Typically scheduled. I would say here we have a lot walk-ins because we're here. An not a lot of people are going to drive to ***Peyoli*** hope that their care coordinator is here. They are going to arrange that. But I'd say that majority of the time our stuff is scheduled, but we have some walk-ins here.

Patrick: When you talk about support, and earlier you talked about support about how you break the news to your partner? I'm curious in that person's case he's not telling to most people in his life, from your position is this just case dependant about how comfortable the person feels about disclosing that to

Jill and Tammy: Oh yeah,

Patrick: And also you talk about in his case that he has financial stability and housing and whatnot. What type support was he seeking for in this particular instance?

Tammy: I think just somebody to talk to. He's got a few friends that live out of state that he's confided in and he told his partner at the time and he didn't need any help with that. It was I think just wanting to have someone to bounce off of in terms of how he was feeling and what he thought about the medications and just asking general questions about hiv in and of itself. And confidentiality aspects and what my experience was in people who had been diagnosed and then you know disclosed to their partner and disclosed to people that they love whether it's their friend or family member or neighbours or whatnot. So just somebody that he knows that he can say oh hey I read this what do you think, or just send me an email and say did you hear about his new drug coming out, have you heard anything about it? Just those types of things.

Jill: but I think sometimes, and I don't know about this client in particular, but sometimes is just having somebody that knows that you are positive because if you haven't' disclosed and you don't plan to at this point and that you certainly don't need to, it is still nice to have that one person that knows, you have someone that you can talk about it. So I think a lot of times for folks that are in other ways fine and have the capacity to handle this on their own, they still want somebody that knows and somebody that they can talk to if they wanted to. So, you know, sometimes that's our role and it's not super time intensive on our part and we don't necessarily feel like we're doing a ton of work for them, but I've got one person that knows. We're the one person that they will talk to about it. So, for them, it's huge to have like this is that person that i'm able to talk to about it and I'm able to ask question to.

Fernando: And so do you think that that happens with the majority of them? They're finding this support only here, who else apart from Positive Link, do you think clients are seeking support from mainly?

Jill: Family, friends and partners.

Patrick: So for Positive Link a lot of these are one-to-one interactions? Because I think that these are private and sensitive issues, right? So, do you ever hold any kind of workshop or open forum style where people feel participating in?

Jill: So, interesting thing with that. We do have a support group. It's fairly small. They meet every other week and then we have kind of open home, we call them live and learns, but you know it's dinner and some kind of fun activity and some kind of education. And we've had … with people that come with that. We have 250 clients and if we had 15 at any of these it would be a huge number because when our clients are so diverse and hiv is the only thing that they have in common, ***it's really not allowed*** to have social support around. You know what I mean? You may have a 50 year old white gay male and a 20 year old African american female and a 35 year old latino. All in very different phases in their lives. Different socioeconomic, different religions, different everything, they don't actually find a lot of support from each other. Because they don't have anything in common other than having hiv which is something that.. Like for most of our clients one of the things that we really stress is that you are not your diagnosis. You know, so if we say you are not your diagnosis, but we're throwing them together with these room full of people, it would not gravitate towards it at all. Support each other doesn't work. And we actually just finished some research that we were doing that tangentially we looked at some client input about services and what they would like added or taken away. And one of the things is that they would like to have that client-to-client support level as well, but they genuinely don't really want to come to things because they don't have a lot in common with other clients. And so a lot of times is not so much that they want support here even though that's what they are identifying because we are a trusted place. But we are not actually what they are looking for, what they need is community, they need a peer group, they need to part of something which isn't necessarily going to happen here because our clients don't necessarily like each other just because they are all hiv positive. So, that's something that we are looking at right now is, you know, how we build that sense of community when clients are coming to us. We want to have more peer-to-peer interaction, but we really don't..

Tammy: A lot of people that, I think too historically, a lot of clients who say they want that and then we offer that and then they don't come.

Jill: yeah, I mean yeah..

Tammy: So it is kind of like okay.. We had all these women who wanted a women's support group, and then so we finally did it and it lasted about 5 weeks, and after that they were pretty much done. I had like one or two people that would consistently want to come and it's difficult to find a day of the week and a time of day that you could consistently do it, and like for us, it would just not work to spread it all over the place because it is just not functional. You have people who have kids, people who work or take classes, or they're just not going to get here by 11am. It just not happening, it needs to be at 4, but then you have people at 4 who have to get their kids off the bus..

Jill: Yeah, like people have lives, you know. The same reason I don't go to things even though I know it would cool and enriching for me. I don't go cuz I don't have time!

Tammy: The 2 events that we have annually that are very well attended are our summer social and our holiday party. And I think it's because it's purely social and there is definitely a lot of food. All the other things are centered around an educational topic of some sort, and that's where you get the 3 to 8 people typically.

Patrick: So then I guess they are really looking to, I guess, interact socially but not so frequently as like twice a year is fine..

Jill: And, like we are not event planners, like we are not party planners. We don't throw a party every month, like we aren't social. [laughs] We're kind of bound by if we do something that is social, there has to be an educational component. We need to be bettering health, we need to be promoting something because social services has to do something. You can't just party plan, you can … christmas, you can throw a BBQ in the summer, but it can't be like your main gig.. And so, and again I think that people have a lot going on in their lives. Last year we had an intern that was HIV positive, he's been several years ago, and we were doing, I don't know, like a client survey or something. Well, you know, these people want all of those events and we're like, well yeah, but no, no we need to put together a group and like 2 people came.. Like clients need these and they should come and they should.. And I was like, have you ever come to any of our events? cuz you've been a client here for 15 years! You know, and he was like well I have this going on and this going on.. And I'm like so does everybody else! You know, as far as being that social support piece, we are a little limited both because of what we are able to do and the fact that people are more than their diagnosis and when that's we are kind of promoting through a care coordination and you know, have a rich a fulfilling life, being hiv positive doesn't change that! When you do that and have a rich and fulfilling life, you are busy! And so you don't, you know, and then yes scheduling and all of that.. But yeah, it was interesting cuz kind of that perception of having these things for people to do.. But I think that particular case was really interesting, I remember sitting there and I'm like, finally I just said like have you ever come to an event? Well, no cuz I've got other things going on.. They all do!

Patrick: So it's interesting that part of it having a fulfilling life is that they get more entrenched in their, I guess, immediate peer support

Jill: and they have peer support which is great! You know, that's the goal! The goal is that people needs us less and we're able to kind of service that safety net. So if that's working then fantastic!

Patrick: So, one of the roles that Positive Link would play would be this trusted source that is confidential and safe that you can always come to ask for any kind of validation, questions or new drug information, or official sources because their friends might not have the official

knowledge whereas you would. And then you are much more familiar with the issues that they may have not potentially thought of.

Fernando: And also in these events there's an educational component generally..

Jill: Generally, I mean there are occasional things like knitting for stress reduction..but you know, we need our folks to have less stress and be less anxious, cuz we all need to have less stress and be less anxious!

Fernando: Okay, so that would be for example for an hiv positive person, sort of like how to cope.. You're showing them how to cope..

Jill: Sure. It's not like a class, I guess. We've done acupuncture. We've done pet therapy.. We try to make fun educational things, you know something engaging..

Tammy: We've done some ***healthy homes***, and yoga. We should get that woman come and do ***cherry*** yoga..

Jill: oh yeah..

Tammy: Or I could do cherry yoga..

Jill: But there's some type of educational component to it..

Fernando: And what about for hiv negative people? Do you have some sort of educational programs, or events like that for them?

Patrick: Like prevention?

Jill: So we don't have like an ongoing group of negative people that come to us because that clientele is massive! [laughs] Nobody pays for you to work with people that are hiv negative people in an ongoing basis [laughs]

Fernando: But for example, gay people, you know, like risk populations..

Jill: Like a big gay group we actually have one of those.. We do have CRCS! We do have risk reduction case management for people that are at higher risk of infection. And for 4 years we had an empowerment program which is just ***mnotem***, but it's a CDC program that was community building for young gay men, so it was targeted technically to 16 to 25, we targeted more 18 to 25 because you know under 18 there are all kind of things and stuff, they are minors.. Ah, but they really just did fun social events to build a community. And it was challenging because you had like these group of guys that were out at IU which is very different than I;m just coming out and I'm in ***Lenton***, or I'm not out but I'll drive an hour and a half to

Bloomington to go to this event in a place where I can be out and then I'll go home. So, everybody was kind of dealing with different things based on who they were. So we did have that for a while then it got ***defended*** to the state of Indiana. You underfund us long enough in Indiana you get an outbreak that's what we know. [laughs]Yeah so we have done some of that. And all of our education and testing is targeted to where our highest risk is which for us for our region is men who have sex with men, substance users and African american females because that's our **epi** data tell us is our highest risk groups and I mean certainly … the most of.

Fernando: So, if I'd be interested in Prep, I would have to come here, or is there any other place?

Jill: Yeah, it's a whole thing. Like we are going to talk about pep and prep. So, Bloomington is very limited is what we have in terms of access to prep. It is very very ***hedimous*** on where people can go. If you are student, actually you're fine. Just go to the Health center. If you are not a student, that's when it becomes … We don't have providers that do it.

Tammy: Which it still baffles me..

Jill: It's become my hobby. Like my hobby for 2016 and 2017 is getting prep into Bloomington.

Fernando: Oh yeah cuz I think that it's been a breakthrough, right?

Jill: Yeah, and it's been for a while!

Tammy: Yeah, we are a little behind..

Fernando: Yeah, cuz I've seen like in New York or larger cities obviously, they do have this in place..

Jill: yeah, yeah, the fail safe.. Like if you came to me and you're like hey I'm interested in prep. I kind of got my stuff together, I've got a car. I would be like you need to drive to lifecare in Indianapolis and get prep. I would call and get you all set up with an appointment and we're good. So it's become more of a challenge when people have more barriers because it's a little bit *hedimous* here and that's something that we are working on. Like fingers crossed, knock on wood, don't write on paper, but we're hoping to have an ongoing infectious disease clinic that would kind of have some walk-in stuff for post exposure, and some walk-in just like engagement for pre exposure prophylaxis here in Bloomington within the next year. Right now, it's fairly *hedimous*. We'd ask if you talked to primary care physician. We'd give you some names of some doctors if you don't have a primary care physician. You know, like, hey get this guy for your primary care. But it's very very *hedimous* on what people can get and typically it involves some driving to lifecare unfortunately. It's a totally annoying topic for me. So you can see, I'm like Uh! Because we should have it, like you shouldn't have to be a student in Bloomington in order to have it.

Fernando: For sure, another question that I have is about stigma. So, I think there's still a lot stigma surrounding hiv..

Jill: I also think that..

Fernando: And I have read that it's escalating again, that it was at some point going down, but it's again sort of going up again and I was wondering if you give people, I don't know, techniques or ways in which they can, you know, cope with that so they can feel better about themselves.

Jill: There are a few reasons I think that stigma is increasing locally. One, we had an hiv outbreak, like people had kind of forgotten that hiv was a thing. So that decreases the stigma if you just kind of forget it's around. And then our ***Vigo*** county region has been absolutely dreadful over on our western region because they have an hiv criminalization case right now and so it's been highly publicized, uhm so yeah people won't even walk by our table at health..

Tammy: And I kind of also think that..

Jill: and I think here you guys are seeing a little more..

Tammy: I think a big component of that and I was just talking to someone the other day.. Anyway I'm having a lightbulb moment, uhm I think because hiv has been around so long and like we got into this complacency and it's manageable, and you can take pills, and then all of a sudden you have this whole generation of people that really don't know anything about hiv. You go to an undergrad class on campus and give a talk about what we do and then we have clients that talk about their experiences about hiv and maybe they mention about Magic Johnson or Ryan Watt and these kids have no idea what you are talking about. They don't know, no clue. And so I think for somebody like me who I remember, you know, Ryan Watt being bullied in school and I remember his dead and how that... I mean that is what really led me to working in this field. Uhm, but then these college kids, they don't know..

Jill: It is just not talked about ..

Tammy: And so then it takes that fear quotient, you know, way up again because people don;'t know, the fear of the unknown and always with clients were starting to get back to this theme where the client goes to the dentist or the doctor and they'll go: well how did you get it? Even you have providers that I don't think they are very familiar with it, or that they have gotten into this complacent component too and they just immediately go to "how did you get it?" because they want to make sure they are not like you. They are not like you then if I'm not like you, I won't have it either, I don't have to worry.. So I think we are back there..

Jill: And I've seen more of people feeling like they have the right to know whether someone is positive or not. Like well I need to know that, I'm your dentist. Well, you don't actually..

Tammy: Are you going to have sex with them? **...**

Jill: Right? So my kids are 6 and 7, but when they were still in daycare. They were babies and I was getting them into daycare. One of the daycares had like are there any medical condition that we need to be know about? That's a perfectly fine question to have followed up by "is this child hiv positive?" and I was like: okay first of all, my kid is not going here and second of all you need to take this question off cuz you've already asked and if I wanted to share the medical condition, I would have answered that question. And there was a lot of pushback about like why would we need to know that, why? You know and so.. all of that.. I didn't see that kind of thing for a long time and people didn't feel like well everybody needs to know if you're positive because don't we need to do something different? Well no, you don't. But that hadn't happened for a while and then I feel that it does happen a lot more. And in part because people don't know so they don't the fact that you are not at risk! There is no risk!

Tammy: There is a huge lack of education. Even clients, people who are hiv positive would call and say "I just got offered this job and I just don't know how I'm going to tell them that I am positive but I don't really want to, but how do I do that? I'm like you don't have to tell them you are positive. You sure don't. Well I'm working in the kitchen, are they practicing universal precautions? Following **osha** rules? Then, you're good.

Fernando: yeah, this topic about stigma and victimization is interesting. I read something which was related to how gay people use Grindr on the phone to have sex with other men and they sort of have this negotiation of safe sex which is something that probably we didn't have before because it was kind of you wanted to meet a man and you went there and it was kind of weird to talk about those topics, you know, the heat of the moment and you're like I'm not talking about that..

Jill: Like we know why we are here.. [laughs]

Fernando: Exactly, but now that you have these applications, this technology, I can actually say okay I want this, this has to be in place in order for me to go to the next step..

Jill: And it's in your profile..

Fernando: And it's in your profile, exactly.

Tammy: But profiles are not always honest.

Jill: I mean they are not always honest. But asking me is always honest. I mean my profile would be just as honest as I would tell you. You know, either you are going to disclose or you are not. But we do outreach on Grindr and snapchat.

Fernando: And you do talk to them about how they can tackle stigma

Jill: Yes

Fernando: I was reading also this research that found that a lot of people who feel victimized they tend to have unsafe sex, unprotected anal sex, because they, I don't know if it's like something that has been proven or not, but they have a lot of internalized homophobia or a lot of stigma issues and they tend to sort of like do or engage in those unsafe sex practices. But I don't know whether that is something that you have noticed or encountered?

Tammy: I think that's possible. I just think it is just really individualized for each person. It is very difficult to kind of say yes for most or a subgroup. I think each client, you know, you could have 2 clients that have the most similar situations that you can get and then the 2 react completely differently. So I think that whole nature, nurture, all that stuff just come into play in how they respond to different things or the same things. Uhm, it's very individualized.

Fernando: Speaking of Grindr, do you think that it is helping, or is it becoming a problem in terms to trying to get people to practice safe sex?

Tammy: I don't know. I don't hear a lot about it..

Jill: I mean if you wanna cruise for sex, you are gonna cruise for sex whether you have an app or do it in the newspaper. You know.. [laughs]

Tammy: or hangout..

Jill: Or hangout at the ***cascades (arkades?)***.. So people have been cruising for sex long before there was Internet. So, it is a little easier because you can open and see all of your profile pictures. For an outreach perspective, it's much easier for us to do outreach when there is Grindr.

Fernando: Like an ad?

Jill: No, we have a profile. We just always have it when our open testing is going to be. So if someone is around us, they are going to see us cuz you know it is set up by how far away you are which is fascinating to just watch, cuz I'd be like somebody is 15 feet from me? I can see them! So it's just bizarre to me just how connected you are. But it is nice from an outreach perspective because you know our 2 primary populations that we work with are men to have sex with men and substance users. Those are the 2 biggest groups that we work with. And it is

really really easy to do outreach to the substance using community because there are places you can find them. Like you can go to treatment centers and find people that are seeking treatment for substances, you can go to jail and find people that aren't necessarily, you can go to homeless shelters. Like, there are defined places you can go that you are probably going to find a high proportion of people that are substance users. It is really hard.. I mean like we go to the Backdoor, we go to ***Zimbars*** so those are the 2 gay bars in our 14 county prevention region. You leave one of those 2 cities, there's not like here's where all the MSM are, and they're all here at this time on this day of the week where we do kind of have that for substance users. We can find them much easier and so, being able to use Grindr or you know, even Instagram and we do boosted Facebook post to targeted demographics makes it a lot easier because we can go to a location and just catch the people that are right around us. So when we boost a Facebook post, we don't boost it to the people that liked us cuz they are not going to really see our Facebook posts cuz that's how business on Facebook work. So if I'm going to be in Mitchell doing testing and we put that on our Facebook, when we boost that post, we are going to target it to I'm gonna say, a 15 mile radius around Mitchell, Indiana and you know, if we are trying to reach men to have sex with men, we are going to do everything stereotypically gay that we can because that's how we're gonna reach gay men and that's who we want to reach. But in a rural setting, we can't go find them. We have to figure out a way to get ourselves in front of them and you can do that very easily on social media because you're getting ads for all sort of things. So it's not weird. They don't have to like our page cuz they may not want to like our page. And then we have clients that like our page and comment on all sort of things. But there are other clients that would not like a Facebook page for Positive Link in a million years! You know, well you don't have to!

{51:45}

Fernando: Probably someone, they are worried that someone else is going to see that they liked it..

Jill: Exactly!, they are going to see that you liked that and that's in your likes, well why did you like them? Is it because.. Are you positive? Well maybe it's just because they care about hiv. You know? But when you do it as an ad on social media or you do it on Grindr, you are going to see me regardless. Like you didn't choose me, I came and found you. And so you can get around some of that stigma stuff, and you can get around to the marketing angle of how do you find this population that you are trying to find because social media makes it quite easy to do. Which is really nice for us.

Fernando: And you are using Facebook mainly?

Jill: We use Facebook primarily, yes. And then once we get there we use Grindr cuz then we can reach out to people and be like, you know, we are offering testing. If somebody clicks into our profile which is a squirrell cuz that's our mascot. His name is Gustav. So we'll dress him up for occasions and kind of make it fun, you know. So if someone clicks into that, then our profile

is about Positive Link and, you know, our little message thing is whatever our next open test site is. So, you get more information about the squirrel that's on Grindr then you just see our testing information. But yeah, social media actually makes it much much easier to reach people that are hard to reach, or maybe don't want to be reached in any traditional manner. But yeah, it's definitely quite your theme quite so much [referring to Tammy]

Fernando: I wanted to know a little bit more, just to finish, if you use any type of technology for you internally to manage, you know like, client records, or communication…

Jill: We have multiple databases. Every program that we have has its own, and none of them talk to each other. I mean they can't. Everybody knows that it's problem, but it's been so long that there's really nothing you can do.

Patrick: You mean that the databases are not capable to talk to each other, or are there legal reasons?

Jill: Both, yeah.

Tammy: Our databases are separate from the hospital.

Jill: yeah, we don't even share information with the hospital. So anybody that comes to us for any service whatsoever, there's zero record at IU health that they ever set foot on this property. So our stuff is all separate from that as well. But yeah, you know, we may have a program that is funded by CDC, so you are going to report up through CDC's processes, but we also have stuff from ***hod***, or ***hersa*** or from, you know, whoever, state department of health. Well, they each have their own stuff because they each fund a different piece of the puzzle, and none of those are allowed to talk to each other, and even if they were allowed, I don't know how you are integrating all that up and not screwing it up.

Patrick: So for example, if a person that got benefited by multiple programs..

Jill: Yes, they are in all of those then..

Patrick: Ok

Fernando: And the last question would be, if we were to design an application or technology and we had like a survey in order to ask questions in order to see if, you know, this application, this technology would actually work, do you think that we could somehow send that online survey to people that are coming to Positive Link?

Jill: Yeah, we probably could.

Patrick: You mentioned some research. Are these public accessible reports, articles that we can get?

Jill: It was done by a private foundation, so yeah..

Patrick: But are these published?

Jill: No, cuz they didn't find **pace to their capacity building project**. Cuz they decided to stop being a foundation instead. So yeah we weren't' able to complete everything in order to be able to publish. Cuz private foundations can do whatever they want and sometimes what they want is to stop being a private foundation..

Patrick: And in that case, then I guess they just took the data and left.

Jill: No I have it. I mean, I gave it to them, but I have it. Yeah..

Patrick: I was wondering, I guess do you have anything that from your knowledge that has been sort of documented about what you thought was pertinent and important for this community. Because it seems that you have been collecting this sort of informal knowledge through a variety of different ways, that things that you perhaps are very familiar with and then are document somewhere than you can share with us and we can.. Cuz I guess..

Tammy: I told you.. [referring to Jill]

Jill: [laughs]

Patrick: Another thing about the survey, I'd be curious to talk about, cuz you have 17 staff maybe if we can talk to, because you are in the prevention unit..

Tammy: I'm in services..

Patrick: and then there's housing and there's prevention. It would very helpful if we could talk to maybe a couple of staff within each of these to get their perspective.

Jill: sure.

Patrick: You mentioned that you have interns who might have experience.. And also whether to any of the future events that might come up that we might possibly come to.

Jill: Probably not on that just because form a confidentiality standpoint.

Patrick: So yeah okay, are there places where we might be able to, later on, leave our information so in case if they are interested in talking to us.

Jill: Yes, yes.

Fernando: Cuz you know, this is very new in HCI and for example I was reading this other project about how they created this application that helped with adherence to medications for hiv positive young people. And it worked. They worked together. So they designed the application with them so it was a participatory design and that was very interesting because they couldn't have been able to develop this app for a smartphone because they didn't understand what they were going through and this was for very young people. And so this application in a funny way reminded them, like they had a score system, you know, to incentivize them so that they can take the medication.

Jill: make it just not be medication adherence, like you know what I mean? Cuz yeah, from a development standpoint, it's going to be like do we need to ring an alarm every time? Like nobody wants that! Nobody wants that!

Fernando: Yeah, and actually they found out because they were like, okay do we send a message or something like that? And then they didn't want that. They realized about that cuz of them, and the colors and things like that, that they didn't want that to look like a medical thing..

Jill: Cuz insurance companies will do that for you. Like if you want that, you can get it from your insurance company. That's kinda cool!

Fernando: Exactly, so things like that. So we need to be in contact with people who are going through this whole thing..

Tammy: That's what I was thinking of, my client would do that. Play a game. I'm gonna make it a game..

Fernando: Thank you very much, you've been very very helpful. Thank you a lot.

Jill: Yeah, find out who you wanna talk to, I can get you with some other staff if you're..

Tammy: I can email you again and copy Jill so you can have their email.

Fernando: Sure, thanks!

[**END**]
Time: 3pm