Transcript of Interview with Erin Waters By Kit Heintzman

Interviewee: Erin Waters
Interviewer: Kit Heintzman
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Location (Interviewee): Portland, Oregon
Location (Interviewer):
Transcriber: Angelica S Ramos

Some of the things we spoke about include:
Outliving the life expectancy for Black trans women. Having worked in corporate non-profits; currently working at a smaller non-profit. Being at the Meaningful Care conference in Portland Oregon in March; attendants getting messages to go home. Living with roommates at the beginning of the pandemic; different safety standards; moving into a rural tiny house with a partner. Pods and pod mapping. The medicalization of trans people; wait times to see a trans competent medical provider. Helping trans service-users navigate the health care system pre- and mid- pandemic; gender affirming surgery cut off. Knowing that those who are consistently disproportionately overrepresented with disabilities and lower life expectancies will be hit hardest by the pandemic. Generational trauma from medical violence; Tuskegee wasn't that long ago; Black women's maternal mortality. Medical racism; environmental racism. Negative medical experiences; relying on one's communities for healthcare. Affirming the experiences of those with medical aversion while advocating for vaccination. Advocating for marginalized workers. Medical literacy as a privilege; knowing how to self advocate as a privilege; medical bureaucracy. Directing vaccines to vulnerable populations; vulnerability defined by structure and prejudice; seeing vulnerable populations through the positionalities most likely to suffer from medical prejudice: Black trans women. When healthcare services try to help "the most people" the system supports white people. For profit healthcare. Focus groups bringing in marginalized people and only implementing the cheapest policies/those with best optics. Actuarial tables are death panels. Oregon's Medicaid. Teaching doctors about trans issues during medical visits. Emergency rooms costs on the infrastructure in contrast to preventative and equitable medical care for trans people. Whiteness and laser hair removal surgery. Not everyone can take the chance that they'll get COVID. The inappropriateness of messaging around associations between monkeypox and gay men. The social/cultural imperative that Black men make themselves small and unthreatening. Advocacy means going into a room and having no idea if you'll be able to change anyone's mind. Flattening various lived experiences into the term BIPOC. Implicit and explicit biases. Health is knowing yourself even when other systems tell you that you are sick; racism, transphobia, homophobia, ableism are sicknesses, not their targets. The difference between being uncomfortable and being unsafe. Knowing that there are whole parts of cities and states where Black people can't go and be safe. The threat of one's very existence scaring others so much they might be murdered. Trans people as the boogie men in legislative policy. Reform vs revolution; by any means necessary, by every means available // by every means necessary = by any means available. American exceptionalism and individualism. Therapy losing stigma; still inaccessible. Maintaining rigorous COVID safety precautions after others believe the pandemic is over. People are still dying of COVID.

Kit Heintzman 00:00
Hello, would you please state your name, the date, the time and your location?

Erin Waters 00:05
My name is Erin Waters. The date is October 20 of 2022. The time is 6:19pm. So I spent most of my time of the pandemic in Portland, Oregon, USA.

Kit Heintzman 00:20
And do you consent to having this interview recorded, digitally uploaded and publicly released under a Creative Commons license attribution noncommercial sharealike?

Erin Waters 00:27
I do.

Kit Heintzman 00:38
Thank you so much for being here. Could you just start by introducing yourself to anyone who might find themselves listening? What would you want them to know about you?

Erin Waters 00:39
Sure. So I'm Erin she/her pronouns, black transgender woman, I'm almost 40. So I've made it past the statistics of us only making it to about 35 or so I'm gainfully employed, still have access to family and partners. So kind of breaking a bunch of the the assumptions and the narrative that is written for black transgender women at this period of time, in our history, spent many years working in community health. So I started off my healthcare career working in a free clinic that did a lot of work with folks who were active users, undocumented, seniors, focused on Medicaid, Medicare, and then a lot of the trans and gender nonconforming community as well. From there, I started working for large scale healthcare. And so I work for some larger corporate kind of nonprofits, helping build their understanding of how to provide transgender and gender affirming health care, as well as some work around general like diversity and inclusion type of stuff. And then now I currently work for a small organization support a specifically supporting trans and queer identities in the greater Portland area.

Kit Heintzman 01:57
Would you tell me a story about your life during the pandemic?

Erin Waters 02:02
So the pandemic really threw me for a loop. The job I was working was definitely one in which I was expected to be in a building for most of my time, I had had was doing less of a direct community health work because I had a job that and was then coded to be working our human resources department, specifically around [inaudible] and inclusion were because of, I was able to build the training that I was able to offer. And I remember being at our conference, the meaningful care conference held near the airport in Portland, and we were all checking our phones all day, when was our company going to tell us to go home that something was happening, there was an illness that was raging across the world, we needed to go home and protect ourselves. And so we were all just and throughout the day, different people in different companies had different notifications at different times. So by the end, we were some of the last ones around four o'clock. So I immediately went into not panic mode, but damage control mode, because my community already struggles with accessing health care. While we made some really great strides in the last five to seven years, particularly on the west coast, the United States, and in the state of Oregon, in particular, it doesn't change the fact that there are a small number of providers. Our surgeries can take

us up for months and months at a time. And we were already struggling to get access to these things, a bunch of other cis people trying to access care. So I immediately started making phone calls, who had surgery that was lined up, how can we get them redirected? Are they going to have to cancel trying to get information out to let folks know that this does not mean you won't access health care. Who can we switch from in person appointments to telehealth? And how are we going to continue to provide education and training around di concepts how we're going to continue to educate people? And while just switching to zoom seems like an easy answer. It definitely wasn't. So I was sitting at the Nexus I was I was a puzzle piece of some immediate conversations around how we can protect one of our most vulnerable populations, and at the same time, continue to move forward knowing that if there's a pandemic, and it's hitting this country, the people who are going to deal with the most, the least benefits the people who are going to have the worst health care outcomes are going to be minorities marginalize, marginalized folks who were already struggling to begin with. And so we were trying to figure out how we were going to mitigate that because I can't take off my hat with being a black person than just focusing on trans thing just like can't do reverse. So how is how are we going to blend this need and try to anticipate what was really necessary in terms of these communities who are already healthcare system and Healthcare reverse already backs reverse. We've got things like the Tuskegee experiments which are refresh in some of the minds of our great aunts, great uncles and grandparents, how they, black women, and black birth givers just die more often, as do the children they produce, and labor and delivery faces. How was all of this going to be affected by this massive pandemic, because we knew nurses weren't going to be able to just go home, they were going to have to show up to work, same for doctors, so how were we going to be able to make adjustments. How could we start working people or getting people to work from home, I actually had to go to bat for a group of individuals, a group of black women who all have white peers had just been given this carte blanche to work from home, you've already got the technology we'll re route your phones, and the six black women in their department, we're doing the same job. But on a slightly different code we're being told they have to come in every single day. So we immediately started to see the similar same discrepancies, the same old same old issues that we do as we work with marginalized communities. So it really just became our main priority to figure out how to be connect with these communities, how to provide education, and then how do we continue to keep the healthcare system moving, because trans folks in particular live, many of us live in medicalized existence to get access to access to hormones, some of the hormones are scheduled one, so that skip one can't wear more than a round of a time per month. So how are you going to go into a pharmacy where we're already dealing with pharmacists who may want to fulfill that prescription? It was really challenging, it was really kind of interesting for me, to see how quickly I had to become an advocate how quickly I had to become a problem solver. And then how continually we had to really, really push the folks around us to put their money where their mouth is, if you understand that black, Trans and Queer People that black and brown folks, melanated folks in general, that seniors are going to struggle to get access to this vaccine, what are we going to do to try and expedite access to the resource, and at the same time, challenge that healthcare version in ways that are affirming because we can't just say, well, it's different this time, you know, we can try that all the Tuskegee experiments happen. Black folks who are struggling, but like this on this one thing, it's different. Come trust us on this. And so became this really interesting, and really complex battle, really, against misinformation and guest hesitancy. Our nation make decisions like, well, if you're in an urban center, well, the political group in charge was not really supportive of a lot of urban spaces. And so we knew that in those spaces, we have higher representation of black and brown folks, we're going to deal with that. Watching these protests demand to open, open, open, open, really coinciding with hard numbers coming out demonstrating that black folks and indigenous folks and Pacific Islanders in particular, we're all really struggling with surviving COVID. So I really just found myself kind of trying to find ways to get to as many different tables as possible, to try and remind as many people as possible, put your money, where the mouth where your mouth is,

if we understand that there are certain communities who are over represented with certain negative health care outcomes, how can you get ahead of the curve?

Kit Heintzman 08:34
I'm wondering if you could share a bit more about what in the in the example you gave, of the six black women who are being told to come back to work while their white peers were allowed to stay home, what did that advocacy look like for you? What were you like, how does how does one change that?

Erin Waters 08:54
Yeah. So it came down to making sure we understood who their union reps were, they didn't have the strongest union steward at the time who was looking out for them. It was figuring out who in my company could speak to them, because like different folks and admin, you know, we have rep to who spoke to union folks and figure out who those folks were advocating with my boss as well. And continually creating paper, paper trails, documentation. Well, why did these folks get to go home? And why are these folks who were doing the exact same jobs, slightly different job code, not able to go home, and it really came down to tenacity, perseverance, and maybe had a little bit of a jerk about it. I mean, I really had to lay flat. You are engaging in discrimination. This feels racist. This feels a discriminatory based on race. Why are you letting this happen? And asking that question over and over without being afraid conflict because it wasn't that I was calling an individual racist. I was saying the system was doing something racist. You have these women coded in a slightly different way. Pay them a little bit less I would initially presumed but it really They just had to how they came into into the department because it was merged. And so can we change that job to where we can't change jobs. How do we get them access to resources? Because then it became, well, we don't have the right phone for them, we don't have the right laptop for them. So how do we get it and calling IT, do you have six laptops? Do you have six phones that you can share out? And I understand that a lot of people are probably asking for these things in their departments. But we're talking about folks who were specifically doing some work around health, nutrition, and labor delivery. So they were doing some glue that holds the pieces together kind of work related to that. And so why why aren't those folks going to be prioritized? Are we not going to continue to try and prioritize the folks who need to have a baby are going to have to come in no matter what, when we have that racial concordance, we know that those health care outcomes are better. So it was really pulling every single piece of data and information out of pocket, it was really calling out that this is racist, what you're doing is racist. And while the system might just be functioning, as you expect it to, you need to be looking at the human element. Because it wasn't just an appeal to emotion, it was an appeal to a lot of practice. We've got people who are more likely to have to struggle with surviving covid, and they're having to come to work every day. And we've already done this with other folks. So it was really just pointing out and not being afraid of conflict around dealing with conversation. Well, I had someone say, Well, I'm not racist, and I can't really change the system. But you're allowing something that is racist to happen. That's, that's what's happening right now. And it took a whole lot of work. Similarly, when the time came, we, in the Portland area had our major health care systems kind of drive everyone to our mission center, so that we can work with as many people as possible, happening as if you volunteered, at the end of the night, there were a couple dozen extra vaccines that were available. And as time went on, and people were getting their vaccines, they would have more and more. And what we learned was that we had black folks and brown folks who were able to get one vaccine somewhere out in community but could not get it anywhere else. Were queer people who are immunocompromised, who weren't bumped up the list high enough, because while they were, you know, compromised, they weren't in the right age bracket and had specifically outlined comorbidities that we said were necessary for someone to have in order to get them to jump to the front of the line. And so myself and a group of

other folks were asked to build this table. And when we talked about, well, how can we give training? How can we give some iterations for folks to make sure that they can provide the best care possible to folks who may not necessarily align with their racial or cultural identities, and we ended up having to get really aggressive with if someone from a marginalized community that we know is struggling with health care outcomes, makes it through this space, for whatever we need to have, we need to get the system to bend over backwards in order to serve that, because we might not catch that person otherwise. And rather quickly, we ended up in that same situation we had to advocate with, with senior leaders, we had to advocate with DEI leads, and you know, equity inclusion, leaders and tables and councils that these different health systems had, we had supervisory to top of the chain who really needed to be pulled in. I mean, it wasn't just called it had to be pulled in and really made to understand some of the decisions that we were making were really, really, really, really important. Because someone who had already managed to get past some level of health care whether it's to get their first shot, or to go to this big building that was confusing people with tons of noise, tons of issues, especially folks that assess sensory auditory processing, you know, concerns for, you know, disabilities related to that we'll have a hard time. So how could we fast track them. And it again, not being a conflict, y'all are doing things right now that are ultimately racist, the people that you're turning away are not the middle class white folks that Portland is a bubble was really centered around. These folks are getting access to this because they know how to navigate their healthcare system. Because they already have a doctor who you know, that they can push to get access to these things. They know they can just show up, these other folks aren't. So again, demonstrating with as much data as possible to identify the harm with the information practices that are occurring on the ground, and then being that advocate calling out challenging folks not taking no for an answer. There was definitely a lot of words, just system. It's just how things are this job code is way will these folks have been have gotten access to your doctors, we can change the system, we can break it down. And ultimately we were able to start getting some of those excess vaccines directed to folks who are just showing up for marginalized and Why are communities because of volunteers? We were having repeats private people from health systems who already had this vaccine. So how can we spread that resource out to get access to people who otherwise weren't going to get in?

Kit Heintzman 15:14
Thinking about the pre pandemic period, would you say something about your own experiences with health and healthcare infrastructure and what that's meant for you in terms of medical literacy and learning about self advocacy?

Erin Waters 15:30
Oh, yeah, the healthcare system sucked. It still struggles in some. So as a trans person, and who someone who's black and a woman really being hit all of these different levels. And part of the reason I got into healthcare is because I realized I needed to be a part of the system that I was trying to access, I was fortunate enough to go to a presentation being held at one of the local universities. And it was just a symposium talking about trans health and a couple of other like, specific like disabilities. And the two folks spoke on behalf of the trans community and tried to access transparent what was wrong and what needed to happen. We're so passionate, if one of them was really like ready to just get into a punch fight for trans rights. And I remember just being moved by that in the moment, because they were saying in so many words, the system is built to exclude us, and it doesn't want to hear from us. And so we are doing the effective equivalent of standing on the front stairs, throwing bricks at the front door, until somebody opens and listen to us. Once that person listens us we hang we will stick our foot in the door and pull it open until somebody starts listening to us because we're screaming at the top of our voice. And once I once I got into healthcare, I wanted to do it in a place where I knew people were already struggling with health

literacy, people were already struggling with access. So I went to work [inaudible]. Immediately, it was very clear that the system is is not only labyrinthine, and circuitous and confusing. It was set up for people to fail. And free clinics struggle with the same things that for profit spaces do, which is there's a bottom line. And that bottom line is how do we keep the clinic doors open. And because so many nonprofits have to follow the cycles of grants, and they get grants from taxes paid by, you know, these businesses, that they have a tendency to follow some of these structures. So they build the systems to be as supportive as possible, as many people as possible. And we have to understand that from from the moment of the moment, we start thinking like that, we've decided we're going to support white middle class folks, white working class folks who are we're above the poverty line, even it's not much we're right around the poverty line. And it's that's very, very final default, we're supporting white people, because that's the largest number of people, we're going to help the largest number of people. And becoming very, very aware of if you speak English as an additional language, not necessarily a first or second language, if you are actively using if you're a sex worker, if you are trans gender nonconforming or queer in some way. Gay Straight lesbian, you know, under the umbrella system is was built insurance was built tell, you know, and if insurance was built to tell you no, these nonprofit systems and these clinics that have to emulate these other systems, because that's the way that they are credited, credited. They're seen as credible, they they're doing things in ways that make sense to us, because we're so used to dealing with a capitalist version of these things that the free clinic ends up having to emulate and model a bunch of that which which sucks. And so it's their job to say no. And it's no, because this isn't included under Medicaid, this is included under Medicare, or you don't have insurance. And the state of Oregon is actually really good around getting people access to state Medicaid. So we can get people to sign up and almost get the same service. And even still, with all of that with embedded community health workers, navigators, people were still struggling to understand well, how do I call the doctor What day do I call them and figure this out? How do I how do I take my meds? Because the doctor says take twice a day, and I know it take two pills a day. And I know I'm gonna forget, I'm just going to move them and there's medications and you can't do that. It's how do I know that going in to see a doctor there, they're going to treat my abscess that have been injected into and they're not going to treat me bad. But how can I talk about a sex worker who's here for a completely unrelated issue? It has nothing to do with like an assumed STI or anything along those lines. I'm having a foot problem and I'm on my feet all day. So helping these folks understand how to navigate the system was critical because there were high volume users and the high volume users also become primary er critical usage. First, the most expensive patient is the one who shows up at the ER for the first time, as opposed to go in and see a doctor or provider. But if you're dealing with the sphere, you're dealing with a subversion. If. And if you're already struggling with these things, and the system is set up to tell you no, well, then by the time we hit the pandemic, it was wash for some people. Trying to help folks before the pandemic was somewhat easier because well, people still believed in a lot of freedom of movement. I could call someone in a different location, there were a couple of free clinic spaces in town, where where do you usually sleep out? If you're living out where you're currently houseless or housing insecure? Hey, what's the thing that's going to be closest to you, if you're put on miss a Medicaid, you're assigned to a certain provider, Well, that isn't going to work for you. Let me show you how you can call and get yourself reassigned. Better yet, let me stay on the phone with you and help you get across the bridge. And then we're talking about trans folks who did not have any legal access or any legal guarantees when it came to health care. We were categorically excluded. Medicaid, Medicare, private insurance plans. And so free clinics are some of the only places some of us can access care. And that care look like once a month they did a clinic. And so if you didn't, if you didn't get a call at the right time, you'd have to wait two or three months to see a provider because only one day, did they have 10 or 11 slots to see transfers, or twice a month, from 6pm to 8pm. They see a handful of transfer. How do you even feel well, what days? How do I get scheduled? How do you make sure you don't forget your own schedule? What if you are having a medication

issue need to get your prescription renewed, you're not going to see a doctor for two months? No, all of this was the construct of people who could access the care or in some way, shape or form. So even pre pandemic healthcare in the United States was really struggling in my opinion, we're not doing enough to challenge healthcare burden, they were definitely not doing enough to really focus on how we support marginalized communities. And we're not still not doing enough to challenge the utilization management department. That's the department's usually making the yes or no, when you put in a referral for something. They're saying no, it's their job to say no, it's their job to identify. Well, this was worded incorrectly. We'll say we cover trans healthcare, we call it w path, the World Professional Association for Transgender Health. Okay, you say we covered that where we thought of that. But when I was trying to access facial gender affirming surgeries, or even breast augmentation, for the first few years I was there, the answer was no. And that was really, really complicated. How do we argue from the ground up if we can't argue with the private system, privatized, privatized private nonprofits, large scale, profits and function like private institutions? What can we do to challenge the state. And so there were a lot of people, names that come before mine in terms of challenging the state and how long they were in that fight, to try and get our Secretary of State of insurance to say, well, trans people have to be covered, whatever you're offering for cis people, is has to be covered for trans people. So we had a baseline, that's something underneath now we have to argue with the state to make sure that these particular things are not covered underneath. Okay, we've done some of these systems over here are not actually following the law. So how do we get the state of insurance stuff that we're something on there's Bureau, Bureau of Consumer Services, consumer and business services? How do we basically Yes, and Oregon, we get them to, you know, put some pressure on these folks? How do we get them to care? And the biggest challenge before the pandemic was how do we get people to care? How do we get them to care about our small communities, how to get them to care about our needs, in terms of health literacy, when they don't even care much about health literacy of other people? Do you under this umbrella of people who are persona non grata? And if you do, you're on your own, you're, well, maybe you can find a case manager who's overworked and overburdened, maybe you can find a CAC which is type drug counselor, and you can get to get them to help you, was always find somebody to help you. As opposed to this is how you can find help. Here's where you can go to find help. And so I have personally tried just trying to do a lot of work around supporting community health workers, and traditional community health workers. We have peer mentors, labor delivery mentors, we have peer specialists, folks coming out of or dealing with substance use. So what were the ways that we could really implement these people and place them strategically and effectively, to help counter some of the lack of care literacy that was present? My initial job at a large healthcare system was as a community health worker, that was my job title. And so my job was to talk with the treasurer.

Erin Waters 24:57
I was the trans community health worker for system 10s and 10s of 1000s people in it We actually have hundreds of 1000s of patients and 10s of 1000s of employees. So it was my job to play go between why this trans person is struggling with accessing health care, or figuring out, you know, what surgeries, or how do they get hormones? How do they get scheduled? Okay, that's part of my job. Literally calling a surgeon. Do you know anything about trans folks, you're doing ex surgery that has nothing to do with their trans identity, but this person is used as a them pronouns, this non binary, have you worked with someone like that for your protocols? Are you talking to preop? Are you talking to [inaudible], this happening in that situation? So trying to trying to find the ways that the city health workers to bridge that gap was was critical. And then we also had to, Well, are you struggling to find employment? Are you struggling to find food? You don't have vision covered? Okay, where can we have access to glasses? You don't have a dental card? Okay, where can we find you access to basic dental services. So just all

the food and housing and the trans community specifically, it wasn't as simple as well, let me send you over to this faith based institution, whether it's church or synagogue, or what have you. I can't do that. Because they may not be supportive of trans and queer people, you need a job and you're struggling getting employment, you're you need somewhere to live, you're struggling accessing housing, because whenever you show up this apartment that was available for you that you're trying to show up and fill out the final paperwork for well, there's an ID issue because your presentation doesn't match your ID anymore. And now that apartment is no longer available. So even before the pandemic trying to manage the social determinants of health was super challenging. It was not something that really any healthcare organism organization, aside from organizations specifically devoted to that work and some community based free thinks we're trying to do because they knew that trying to get ahead of these challenges was what kept people out of the emergency room most expensive option was critical, the most dire acute. And so I got to see what it was like for the average patient to have to work it out. Patients who would come to me with high levels of health literacy who still didn't understand how to get to the right doctor, how do I find a doctor that can work with my oncology, cancer related stuff, and my trans stuff? How can I as a as a trans man, as a, as a mask, identify a trans person wants to get pregnant? How can I talk to the labor delivery by respecting the identity of myself and my child? Because do you have another option, or pink or blue wristbands on my kid. So all of these of these challenges were present. And they were compounded by just being not a middle class, straight whites, cis person, because that's who all of our healthcare is geared for. The studies are geared around, it's how, who most of the form of pharmacology is based around. And so all of these other folks were struggling beforehand, and then the pandemic came in and hit like a train truck, and people didn't lose access to care. Some of it was by choice. They chose not to access because, well, I want to sit back. So people go in there, that's where they're supposed to go. And I don't want to clog up other resources, our community already struggles with submitting complaints. So before the pandemic, if you have had a problem where I submitted a claim, and I framed it, they put noncompliant in my chart, that changes the way doctors are going to treat me. I don't want to lose access to health care, because I was working with trans folks have a variety of different ages, particularly the older ones who have been kicked out of healthcare, for just saying well I’m trans and trying to access something maybe related to that. Maybe not related to that. I think I'm having an appendix issue. I think I have a severe cold and the transfer arm syndrome or Come on, oh, you're trans? Well, XYZ questions that don't have anything to do with this visit. By the way, we're not going to prescribe hormones anyway. Now, I'm struggling with folks who have disabilities wondering which appointment is going to be where I lose my medical autonomy. Because I already have to walk this fine line between high needs in terms of healthcare access, and the challenge of people thinking I can't do it for myself and the trans community struggles with that as well. The requirements for these mental health players from multiple providers, having to import all of your pain and history and being able to do it in a way that says I am dysphoric enough that I need access to surgery and medical interventions. But I have not heard that but I'm still able to make sound medical decisions for myself. It was already a mess. It was already this weird labyrinthine thing that everyone had to try and navigate. And the pandemic didn't really help with that. There were folks who were inclined to use telehealth their options phone calls videos, it's they were fine, but the trans folks trying to access certain sort of paniced because their surgeries got pushed back. And in some cases, folks that have already been waiting for two or three years, even before the pandemic, folks were waiting two or three years to access certain surgeries. And so while we were hoping providers would appear, it's very specific work. And so those things, even post pandemic have not necessarily been resolved. If you want to access facial hair removal, some health insurance companies will cover some won't. Electrolysis doesn't work for your skin type, because maybe you have melanin and your hair is curled. And most providers have never worked with someone like that, or the electrical current literally damages and scarring your skin. Well laser is covered, if it is that one provider who covered it, and you have to wait months to get in.

Similarly, if you want nurse to prescribe you to give you a shot of lidocaine so that you can tolerate the pain, because otherwise, it's a topical, you got to pay for out of pocket. You know, all of these things were constants and continual strokes, for those even for the pandemic. And so trying to trying to kind of qualify were worth things better or worse, it was really just a matter of things being different things were getting better because of the advocacy of folks who were to do this work. And we're really fighting hard as warriors on the front line to try and make change. And then get into the pandemic was it was just different. It's just a different type of complicated thing to have to maneuver. Because now folks are, they're still trying to figure out how to access house, housing, they're still trying to figure out how to access employment. But they're trying to do that with a pandemic in the background. So it wasn't, it wasn't necessarily easier or harder. It was just different. It was challenging beforehand. And it was challenging act through and still challenging. Now, that's hard to people feeling that we're post pandemic in October of 2022. When a lot of people in my community are immunocompromised, a lot of folks in my community cannot afford to get sick because they have surgeries coming up. They cannot afford to have COVID Knock a surgery that they've waited for for two years out. And so they struggle with socialization and feeling isolated because those who otherwise would try and go out. Because now they might get sick at a critical time. And they're watching all of these folks around us, who two years ago, I say inside, take care of yourself. We're all in this together. I'm tired, I have a vaccine, I've got some boosters, I want to go back out in have my life. And so now they're out in all of these different spaces unmasked tight knit quarters, unmasked for extended periods of time with a variety of people. And so the same communities were already isolated. Folks with a communal compromise folks, folks with disabilities, folks in the trans and queer community who couldn't afford to get sick. They're still struggling with isolation.

Kit Heintzman 32:48
If there was a period in your life where you had health care aversion, what did that journey look like getting you to medical advocacy?

Erin Waters 32:59
So I feel like my medical aversion started in my teens. I had my tonsils out in my late teens. And I was I was older. And so that was a terrible experience. The first thing that my doctor prescribed for me was not strong enough, would not believe me would not believe my black mother. But when my white stepfather called called the doctor and got us an appointment and took me in and advocated. I had some stronger by the end of the day. So I was the way I was raised, I was taught to see moments in which race might be a factor because while my stepdad was white, and my mother was black, both of her children, my sister and I were dark skinned. And so we knew we were going to be treated differently. And a very white portion of America on the East Coast, a place that had gotten rid of restrictive covenants not long enough ago. Neighbors didn't really like us Elks Lodge wasn't really interested like they had, they had come to our house and tried to [inaudible]. So trying to to wrap my head around what health care meant was complicated. And then by the time I was old enough to have access to somebody on health care, I was poor. So I was living under the poverty line. I was trying to struggle with Medicaid, Medicare, I mostly just didn't have insurance. And so I dealt with a health care issue in my foot. And it's common issue. There's pretty common stuff to pain management is one of the things have to happen as a result of it. And the sports medicine doctor that I went to wouldn't help me he I mean, my foot was in really bad shape and he's like take ibuprofen and don't walk and I kept asking like I looked online I know other people this issue pain management as a consistent thing is I get this because I don't have insurance you think I can’t pay for the meds or any and he had a million excuses under the sun. But by this point, I moved to a rural place south And it wasn't okay. Beyond that I've struggled with knee issues, [inaudible]. So getting into moving to the Pacific

Northwest Portland, I bounced around healthcare systems from job to job to job and never had good experiences. It was always being dismissed being overlooked. I dealt with a significant issue on the side of my knee, and general knee issues and pain management wasn't an option. It wasn't like I was I was asking them for our products. I don't really want that. Instead, I was trying to go to, is there a PT? Is there OT? Is there like nerve stuff? Is there anything to do? And I was consistently told no. And the worst experience was I had a doctor, my knee was swollen, it looked like there was a softball in there. And she sent me to get some X rays. And she said it just swollen, it doesn't really look like there's anything in particular that's wrong. So go home. But in order to do the assessment, she had twisted my leg, and knee and all these different positions in different ways. So my knee had actually swollen up more and I was no longer able to walk. So it's like, well, can you prescribe me something so I can get home? Because I'm lost. I didn't have a car. And she made me wait for 45 minutes in the lobby, only to eventually tell me no, wasn't prescribing anything. I could go across the street, go to CVS, get some ibuprofen and make my way home. And it was at that point, I lost absolutely any shred of faith, hope or interest in healthcare. I just existed without insurance. And I was poor. So it wasn't like my job technically had some I wasn't signing in or signing up for why did I want that to come off of my paycheck, if I wasn't going to be able to actually access care. I didn't, I didn't go back until I decided to move forward to transition. Someone had given me access to hormones. I was really fortunate to be around a Latina trans femme, who had also struggled with access to health care and access to providers who would respect her and all the parts of her identity. And so she gave me hormones under the table. And so that's how I started. But you know, obviously there wasn't a whole lot. And so I needed to get back into care. And so it was not until I had been I'd been making my own way for several months, I did a lot of work to try and find someone in community who could help me. And so I ended up traveling two hours by bus from where I lived in order to access a naturopath at one clinic, who I knew kind of had a good reputation for helping trans and queer people. And she was really helpful in the sense that she did get me moving forward. She did get me started. And I saw her for quite some time. But the moment healthcare forced me out of that situation got a different job, I could no longer see her that clinic was closing anyway, I tried a different portion of our healthcare system. And what needed was a note from a doctor so I could get my birth certificate change, because the state I was born required it. And so I scheduled an appointment and I said in so many words, I'm trans. I need someone who knows how to write a letter because there's specific verbiage. And I needed to change my birth certificate. And I needed to see a doctor who can do that. So the person on the phone search their system said, Yep, this is the person this is our specialist. This is this is someone who can help you. Well, the day before the appointment, I phone call it says the provider that I'm going to see has changed. And I panicked a little bit. Okay, well, y'all know why called like, you must have an knows what I need the provider for right? And the person that they switched it to. They were like, Oh, they probably know some stuff, most of our providers, some things. So I went into this new setting, afraid that I wasn't going to get my needs met. I get into the office and start talking to this person and come to find out what's this doctor who's claiming himself to be trans specialist who's present. Explain what I need. I explain why, he's confused. He is He is really confused because I know what state I know what needs to be in the wire. I have all my ducks in a row. So he's just surprised to see all this. Oh, he then decides before he writes this letter, I have to basically tell him my story. Like he's a therapist, I have to prove to him that I'm trans and have no consistent presentation of gendered congruence and gender dysphoria. So I have to prove to this doctor, this specialist that I'm trans enough to be worthy of this letter. Well, I start talking about my some of my history because I have to start talking about But other people community are struggling, why this is a problem. And what was supposed to be a 20 minute appointment turned into an hour and a half with a doctor in a typical system, which we usually only get 20 to 30 minutes most. And I basically taught this man the basics of trans healthcare. He was supposedly the specialist but did not know that W path was the standard. He was the trans specialist, but did not know what the standards of HRT were, in terms of how to get people started. So I had

to give him that information and where to find it. So I educated this human. And it put me off the health care, like put me right back off of health care again. And it was some months after that, in which I got to see those individuals talking about health care, trans health care, and making the decision to put myself on the front lines of that myself, between an already struggling community that is tired, that is just trying to get through their day and can't even just get on the bus go to work and come home without a million opportunities to be disrespected, dismissed, and potentially physically assaulted. And I needed to put myself between the problem and the people. And so that was, it was it was helpful to go work at the clinic that I did, because by the time I got there, they were integrating trans healthcare from just being an a once a month, every so often intermitting into in clinic into regular day to day, every provider should be able to do the basis, here's how we're gonna train them to do that. And so, I was I was, I felt fortunate that the way for me to get over my healthcare aversion was to get into it and get gritty with it. I was training and education around trans health, I was working the back end of health care systems, because health record systems are dirty, and messy and highly specific. But we needed the technical knowledge on how do you build this in such a way that I can even see trans and queer people, how do you build it in such a way to make sure the right flags come up, how you build it in such a way that providers can figure out what to search for when you need to order certain things, so that I can talk to other health systems with a higher level of competence. So getting past my health care aversion came with aggressively engaging with it intellectualizing and over intellectualizing it becoming a part of a system of education, becoming a part of this underbelly and its backbone, so that I could figure out how do we how do we get a patient in first thing in the morning, because we need one? How do I find someone like with how do we figure out track cancellations, so that I can call this person get them into the appointment right away before someone else sits, you know, sticks them in because transported to try and get access to her meds for a month? You know, so it was it was really about my aversion didn't dissipated, I don't think dissipate is the right word it, I was able to start dealing with it practically, when I got to a place where I could feel some level of control, and that control came from understanding came from saturating myself in the environment, I literally got a job in a clinic. I literally put myself in a position of how do I educate? How do I do this? What was it like what things are important? How do I work the back end? And how did this healthcare system work? How does the head provider work with the doctor of the day? How does the chief medicine cascade down because the all of that work with billing and admin, because the admin folks who need to be able to process that billing so that we can actually pay for some of these procedures, things we can't, how can we just make the decision to provide the care because that is our job. And it was getting into getting into was really getting into the ring, get some gloves on and just making my way through everything one thing at a time, is what helped me get through some of our healthcare aversion.

Kit Heintzman 43:40
How does that inform working with other vulnerable people who have a healthcare version, I'm thinking again, specifically, in the context of COVID-19?

Erin Waters 43:53
Um, I feel like giving us a strong sense of reality and what was actually going to happen. Being able to predict referrals are going to slow down. This is how we need to talk with surgeons. This is how we need to start accounting for marginalized people from the disability community, from the immunocompromised community, from our seniors and elder community, how how we can start breaking down this concept of bipoc. Because communities of colors is a useful enough term, but it doesn't speak to the issues that particular communities are really struggling with. The black community needs different things in the Pacific Islander community. And while they might be dealing with environmental issues, environmental change, and food apartheid, the ways it's

happening are different. So being able to talk to providers about how we can work with, you know, patients, so if we're trying to lower our diabetes score the A1C because that's one of the metrics that keeps you getting money from Medicaid and Medicare. How are we to talk with folks who are otherwise coming in to see us every so often, who don't really take phone calls, they're not going to pick up strange number. They don't really trust healthcare, and you give them all kinds of crap because healthcare hates fat people, and the body is larger. And so how do we reach out to this person? How do we work with someone who has been eating [inaudible] their whole life eating tortillas their whole life, you're telling him to stop eating the staple food. That's where he wants to see that's not effective. And so going into COVID-19, trying to anticipate how we help these marginalized communities with something I was uniquely placed for. But it didn't necessarily make it easy to have the conversation, because now everyone was in survival mode. And when people get into survival mode, they start to overlook things. Because now it's about survival. It's about how do I keep myself from getting sick? I have to come into work every day, we're just we have to reuse KN95s we're to reuse masks were having to try and get things from everywhere. We don't really know how this is this function yet for people negative pressure rooms, it's so bad. We don't have very many of those. What is the process for getting people who and how do we identify the hundreds of other patients separate. All of that was, it was just at first it was really gross. I mean, I do applaud healthcare for trying to deal with it. But at first, it was a complete mess. And nobody knew how were going to reach marginalized communities. Nobody knew. There were those of us sitting in these communities to try to explain to them that we can see the writing on the wall. We know what is coming. We know that if the health care that we have now is not serving certain populations, we know that COVID-19 safety processes protocols and how we start moving in safety, and it's going to negatively affect certain groups the most. And watching otherwise rational, empathetic, compassionate people start saying things like, well, we just can't do anything for then. I got really, really concerned because there's a story that I know about a patient in Katrina, back in Louisiana. And he was fat he was black. He was old, he was disabled. And so when the water level in the hospital was rising, and they were trying to decide which patients to take, they had to decide not to take him in favor of other patients, so they just left that man there, and others. And so knowing that, at the end of the day, healthcare will make the decision of who lives and who dies. This fear that people have a hole that we socialized medicine in United States, or moved to a more collective system will have death panels, who decides when people die that already exists. It already exists. It's actuarial tables that are reviewed by utilization management, budgeters and health care systems. Seeing in the same health care systems that there was, what is the cost of vaccine going to be? How do we prioritize people getting it and not taking into account, Okay, well, what about people who lack transportation? What about people with existing health care versus I can walk into this trying to overturn a beat and get past health care aversion? Like we walk in with good language with good modeling, good communication, good scripting. None of that was happening. While those of us who primarily worked marginalized communities knew that eventually, these administrators and people at the top we're just going to make the decision of who lives and who dies, who has enough comorbidities that they're not worth saving, which is something that happens in Sweden and the Netherlands, for people who were not a fan of lockdowns for which trying to say, well, these places aren't doing it. These places were doing fine. They weren't they were literally letting seniors their elders pass away, which is unconscionable. And some some of our communities, the lack of empathy that I knew was going to be endemic, was really, really challenging. And so having to walk into spaces telling people that they're not going to advocate for you. How do you advocate for yourself when you barely believe the system is trying to help you? How do you not seem more white adjacent, then community focused in those spaces? Because well, if you're trying to convince me to do this thing, the only people trying to convince me to do this thing are white people so what's your deal and COVID-19 mean, creating an even wider gap between healthcare outcomes and life expectancy for

certain marginalized people. Seeing numbers getting as low as like one in 1,000, one in 900, one in 700, some of these communities are dying.

Erin Waters 50:23
And we're still having a hard time getting [inaudible]. And instead of wanting to do work, healthcare systems wanted to have people like me to stand in front and automatically credential them this time, it isn't, that isn't true, this time, we aren't trying to kill you. We are in labor delivery. We are when it comes to cancer outcomes. We are when it comes to diabetes, and other is when we're trying to talk about body size, like we were killing you otherwise, but in this this space, this time, we don't mean it. But we're not going to do anything to outreach to your communities, aside from maybe going to a barber shop and handout leaflets about how you shouldn't be scared. There was definitely a lot of cynicism. But cynicism was not enough to make any of us stop, like none of us got into this because we were so cynical, we didn't, we weren't going to do anything, it was just seeing the writing on the wall. And that being the thing that motivated us, I understand that there's a wall in front of me and all you are giving me is a soup spoon to trying to get to the other side, well, I'm gonna use that spoon for all it's worth. And we'll find a way through. And if I get enough people with enough spoons, we'll get a little dent in this thing. And so that's that's really where it became critical for some of us to start getting ourselves on these COVID-19 panels and into some of these spaces. These coalition's these DEI committees. The State of Oregon made a decision around how they collect certain demographic information. And they were trying to figure out how to make it a standard across the board for everyone, because we weren't collecting certain information related to race, ethnicity, disability, and gender identity, sexual orientation. And so they made it a requirement. And so that became our job to make sure our systems were following suit. So we did need some top down approach, we needed positions of authority to say you have to collect all of this demographic information because I will start well, we know that these communities are being heard, we have to be able to track the information. COVID-19 has a ways to start with that. Well, the what readily became an issue was that they weren't recording publicly. The state was saying collect the information, these healthcare systems were not recording that information publicly because they were scared to they were afraid of the numbers that were that were coming out because they all knew that they were all failing, or marginalized and minority communities. They were reporting in some ways to general numbers, you know, certain things that they weren't trying to, they weren't trying to be completely transparent, which was so disappointing. I regularly asked, well, are we gonna put out a statement specifically to speak to the trans community because I was still connected to that community, saying you're not going to lose healthcare. This is what we expect in terms of how things are going to change. This is what we recommend, we would have telehealth, this is what we think is going to happen with surgery. This is what's being moved back. This is what's not that and here's why that didn't happen. It wasn't happening anywhere. And knowing that it was going to take time for them to fix their language around it. Kind of like another side guy sitting right now is monkeypox going across the world. And how instead of talking about as continually about extended contact, and that being the main and everyone needs to be mindful of it. They both it's something that's happening between homosexual men. And instead of just during the worker [inaudible], making sure that community is getting access to resources, we have talked about how it's happening to them. It's not an issue for everybody. It's most this community. And again, if we learn nothing from COVID, instead of saying this is something that's affecting everybody rather quickly became this is something that's primarily killing black, indigenous Pacificc Islander communities. Hispanic and Latin communities. So okay, well, now we'll talk about it 6, 8, 9 months in, and it's mostly just the sadness of it. Oh, it's sad that these communities are healthcare averse. And so a lot of white people in the position of why are these black people afraid of this? Who would want to kill them? Why would this be a negative? So no information or education around why the health care version existed was going around

either. So even trying to start kitchen table conversations between friends with co workers was not something that was happening [inaudible] COVID education, so to some to some of us, it felt have the balls completely dropped, people are stuck in survival mode, or making decisions about who's gonna live, they're trying to help the largest number of people fastest, which is by default in this free something that is white supremacist in nature includes white people as the default and [inaudible] because they are going to be the most help they're going to happen was access. And so how there was a lot of say, not a lot of do. And community specific culturally specific organizations really tried to come together really tried to build tables really try to get on these committees in these coalition's to push people, if someone from a marginalized community comes in and says they need access to this, this vaccine, give it to them, don't argue, get him in a system, what if they are in another system, we cannot don't care, don't double book them in the system twice, it doesn't matter, just get them the shots. That was really, really systematically changing for some people, because we're able to understand that we need to, in order to get equity, we have to think about specific asymmetries that got us here and the specific asymmetries that are going to balance that back out. Little by little. I know, I know black folks now who are never going to get a vaccine. They don't trust it. Not only do I trust the vaccine, the whole debacle and how things went, they're no longer getting flu shots, because they don't trust anything anymore. And the only healthcare education that was really coming out around why the health care exists, was in these marginalized communities, justifying the health care aversion, justifying the desire to not want to engage with any of these, these resources or these opportunities for health. They weren't going to the people who needed it most the people who had no idea why this would happen, those who dismiss these marginalized communities or diminish their experiences as this was so long ago, when there were there are women, now Indigenous women, and Hispanic and Latin women who are sterilized without their knowledge and against their will. So trying to watch the freight train of COVID-19 coming, seeing all these existing problems, and knowing that those gaps, were only going to get wider was really, really hard. And so a lot of smaller, culturally specific orgs individuals who had compounded deeply intersectional identities and practice around how to move with that how to make change speak to these systems really had to step up and then like, blow our way into some of these spaces, to make sure that that was really about harm reduction and damage mitigation. Harm Reduction isn't even the right word that's become a buzzword, right? It was about damage mitigation, more than anything, because the powers that be in the systems existed, we're not going to do the work, right. And we're just do the same things they always did while hoping for the best.

Kit Heintzman 58:04
Do you remember when you first heard about COVID-19?

Erin Waters 58:09
I do. Um, so a friend of mine, on the east coast, had a partner who was doing work in epidemiology. And he was telling me that his wife was freaking out about something. They just kept [inaudible]. And they weren't exactly sure what it was. But it was pretty noteworthy. It was respiratory influenced, or respiratory based, and they weren't sure about is gonna be like luminary network looking rough. And so in health care systems, we heard a little bit about this epidemic thing. We needed to be mindful, we weren't sure what was gonna happen. So I heard about it in the fall of 2019. And 2020. I mean, we I guess, by time we were wrapping up the holidays it was becoming more more spoken about health care systems. And by the time we were getting into like, January, February, and it was rough number we rising, we were all very, very aware of it. And what we didn't know was whether or not you know what that means for these corporate environments, where we're going to stay in office where we're going to go home. And like I said, there were people checking their work phones all day at this conference that we're going to get the go ahead and so to even go home, because of this pandemic, in a state

sweeping across the globe, and hearing about it, it made me nervous, because, you know, we always we always worry that the most marginalized will be the most effected. That's just it's just facts. and wondering, what were we going to do about it as a nation? What were we going to do about it as part of the healthcare system? And what are we going to do about it this individuals? Fortunately for me, the folks I was around seriously, we definitely remember that time where we were wiping down our groceries with bleach Wipes. So before things really kicked off, I was my living situation times with a couple of other people. And one of them had had a persistent cold. what he thought was persistent cold, he was immunocompromised. And so just something that was pretty common for him. But he said that it was different. This one just made him more tired. It was worse for him than he realized. And what he thought was a persistent cold and was causing a sort of consistent problem with his immune system. We think in retrospect, might have been COVID When we were testing for it or has access to at home tests or, or what have you. And so I think it was kind of totally exposed to it, I have not had a COVID that I know of, I testing, I'm still wearing masks. In fact, I travel today, family stuff and I was double masked in the airport from the moment I walked into the airport, the moment I walked out, I don't eat or consume anything during during that planning or anything because we need to take that seriously. And kind of from the beginning, seeing how my immune immunosuppressant you know compromised friends had to take it seriously and then seeing how the people around me because some of them are immunocompromised or have respiratory existence, territory issues, which can be super terrible. And so I initially heard about it as this kind of random thing of friends telling me out. I was kind of I think maybe exposed to it at one point and level a systematic kind of mostly because if I had it was completely asymptomatic as well as the other person living in the house. And then it was nothing but COVID. From the moment they sent us home, because well how long is this gonna last? Is this gonna be a week? It's gonna be two weeks, it's gonna be three weeks. Is this is this something that is how many people are going to be affected by this? Because you have one contagion, saying It's no worse than a cold and among worried about it, and then the healthcare system watching its its emergency rooms, and its ICU, and its hospital beds. Like literally like it was a fire sale, but every one of them up. So I know that I got a little bit of opportunity to hear about it early, but not, I would say coherent or cogent kind of way, because what was I going to do about it, you know, and what's being called COVID-19. At that time, it was I don't remember what it was referred to, as at first. But it was it was something was big, and it was coming. If we knew0

what was good for us, we would protect ourselves and we would have some masks ready to go, we would have had us to hand sanitizer ready to go. We would be prepared to kind of eat in some, we need to because this thing is going to come through it's going to be rough

Kit Heintzman 1:03:33
What was it like living with other people at the beginning of the pandemic?

Erin Waters 1:03:38
Oh my gosh. Um, so it was hard. I was living in a house with two other people a partner relationship that they had. I just moved out of another place across town, so it's close to work. And it, it honestly sucked the first because one of the folks in the house kept going into work. And they didn't have to the rest of their employees and staff had been told you you could work from home and their job was something to do from home. And they kept going to work because for them that was the space away from home away from their partner. They needed separate individual time. They were more productive when they went into the office and there was a low number of people there so they felt safer. But for me, I couldn't handle it. I just couldn't handle it. And so after like a week or so of that I had a nesting partner Well, there was not a nesting partner and not actually attended domestic partner with this person. Just Well hey, you want to come stay with me? On a small little farm outside of town.

They were living in a tiny house on property owned by some other queer folks. Um, and you know, it's sure, we're gonna be together for two to three weeks, either choose to be together for two or three weeks, or we're gonna be apart for two or three weeks and not see each other. And, you know, we made a decision while we just like, stick it out, because you know only be a couple of weeks, we can try that. It's like a super long weekend way. You know, it's kind of like a staycation. But we're actually working from home. And I am a very tall human, I'm over six feet tall. And I moved into a tiny house with another person. It was kind of wild. It was good in the sense that the only people on the property at the time or me, my partner, and the farm owners, there was another roommate who was not really there very often. And so for the first two or three months of the pandemic, I was low to no exposure, except for the people on the farm. And when we went out, we were definitely masked. We went shopping with gloves on my gloves [inaudible] in the house, and it was complicated, because a lot of their friends were on the fence about how seriously to take it. They had friends with a variety of different opinions on the subject, most of my friends my social circle, and we're just gonna talk to one another remotely try and wait for this to blow over. We had folks who were like, We don't believe this is a real thing, you should still come over to see us. And so after the three months or so when people were trying to get them to open up, it was complicated because we see who and our friends on our social groupds, we're going to take precautions necessary to protect us and who wasn't. And who was doing it from a place of you know, screw the system and who was doing it from place of understandable healthcare aversion. And who was doing it. And why, well I learned a lot more people with some of my circles were immunocompromised more than I knew they just didn't talk about it. Watching some of my friends who were living alone, isolated, and they didn't see anyone for a year, they saw not a single human soul in person for over a year. And doing my best to try and talk remotely. A lot of folks. A lot of folks that people hadn't heard from in years reached out people that I hadn't talked to in like a decade, almost a decade and longer had roots are you doing what's going on in your life are things cooling world you've gotten? So living with people and seeing how they move through the pandemic, because some of those folks over time, or other wear masks in the grocery store. They weren't necessarily doing in some there. They those friends aren't necessarily doing it with friends and friends. And so pod mapping, you build a pod and realizing how close that was to not sort of non monogamy where people were sexually active with one another. How do you talk about how do you build closer open, you know, kind of pods? And what does that look like? And how do you protect one another from malicious viruses. And so being around folks had some of the knowledge and skill being around folks who didn't have any of that knowledge and skill. And how frustrating it was to see some people closer to what's not taken seriously how disappointing it was. I know that two years in I'm still doing double thing. I am never going to go into the grocery store without a math and I haven't had a whole long time. What Why on earth do I want those things back and seeing how other people in our social circles through their social media? Well, I got a vaccine. So I'm okay. So they're going to big indoor gatherings, concerts, big indoor gatherings, weddings, big indoor gatherings, just general social events, dance parties, and they are masked for hours a smallish room with dozens to 100 plus people. It's psychologically challenging to see that we'll never forget the health care workers that I was around and listening to them just be burnt out. completely burnt out through from the beginning of the of the pandemic but we knew how bad this wasn't we knew we needed to ask keep socially distant from each other and people just weren't. And so the numbers kept rising, rising, rising, the obstinate people who are never gone and how those folks don't even realize that they're going to continue taking hospital beds not just now but they're Because we still don't know what long COVID does to people, there's kidney failure, trying to talk to people about that the death panels that I mentioned earlier, the Supreme Court in this country recently said, it is illegal for health insurance company deciding how many sessions of dialysis someone in end stage renal failure gets to have before the insurance can cut them off. kidney issues are a problem on COVID, respiratory issues or problems on COVID. So if you're having a kidney issue, you can't breathe, we're going to take up more

space in the hospital events. And people who are convinced that well, I've had a vaccine that means it is like a cold for me now, I'm not going to enter and the hospital is like, okay, but that doesn't mean you have other complications. And so seeing people who two years ago that someone was close to, some of them were really close friends, some of them were acquaintances, and things along those lines. mimic some of the rhetoric we heard the beginning of people who are not believers, is really challenging, and seeing how people that I live with how they've moved over time, what places are they less comfortable, still wear masks on what basis are they more comfortable, and how we as a collective, and a household have to have that discussion. And then seeing how people honor and fudge, and how we have to build trust with one another to feel safe enough to make those decisions. I did a little bit of traveling, see family, I'm in the home quarantine for a week, I have people who have done that they've gone off planes on right back to work, they've gotten off planes and on right back large black living situations or gone to concerts and things along those lines, they haven't taken that time. And so living with people, an up close view of hopefully folks who are similar to you, folks, by and large, are kind of similar to us, but not completely. And so you have to learn how to compromise, you'll learn how to keep your distance, the moments in which we'll I'd like to try this drink that you have because it's tasty. You made a fun cocktail or fun mocktail or something along those lines, or this thing you've cooked really tasty, we can't use the same spoon from Iraq or put the spoon in our mouth and back into a pot. And who feels that way who doesn't. And kind of feels that way. And who is better about that now and how we go to meetings in small spaces. And sometimes we're the only ones. It's really changed some of how we talk about trust.

Erin Waters 1:12:52
Because we have to trust one another, we have to be able to do that. And we have to continue to have a conversation around pod mapping and how we build pods of safety of networking, family and communication who have at least similar enough approaches to COVID and COVID-19. And how we're going to keep ourselves safe. Because I was very worried when other folks with multiple cancer survivor, I live with multiple folks over the age of 65, one over seventy. That was the target demographic for people who would struggle and you know, people who are also smokers, and, you know, so how are we gonna protect them, and how seriously it felt to me, and to protect them to find a way to protect these folks and make sure that I was taking this seriously because having those people around me and to this day I work with immunocompromised people, I still do a community health workers are very active in the community. And so how I can make sure that my my housemates and farm mates and how we're doing what's necessary, because one of the places I live on the farm, we're all kind of st page, folks who live in the city or place them out there not if they think they've been exposed, the quarantine put a mask on in the public spaces for a couple days. But maybe not. I can't go into that space. And my partner cant came from that space for some days, even though we have a room there. Seeing how some people have had to do things differently. If you're in an urban environment, you get stuck in an apartment, your access to outdoor resources, your access to outdoor socialization is different. Living a part of the world where it's cold if you don't have those outdoor heaters, it's cold and rainy in the Pacific Northwest. How are you supposed to be outside in January where it's cold and it's raining on you. There are ways of course, but they're challenging. And in that first year, not every patio was set up. Here's actually sold out. I remember people trying to make sure they can have some kind of option. And so living with people was good, and that it helped me keep a wider perspective and what felt good around collective engagement. We're on the same page learning compromise that people feel differently as time has gone on. And then keeping your perspective of some people have just had to move differently. Some people have access to different social resources. And if they take advantage of the resources, their risks are inherently higher, and how they've made their peace with that, because of the number of shots that they've had, how they've made their peace with that, because sometimes they mask, they made their peace of that,

because sometimes they'll hang out in their room for a couple of days to take a COVID test or two to see if they are actually exposed and what that means, and how if they've been exposed COVID. And then they get it. They're not as bothered. Oh I got COVID. For some people, I got it again. And how scary that feels to me to have to to have COVID.

Erin Waters 1:15:43
I've got all my shots, I do all the safety things. Because the part of the fear of living people's bring it home not wanting to be that ground zero, that initial vector has to happen so quickly. I had family members managed to avoid it, they had small children who could not quite get the shots yet. And they got it from their mom, who got it from somebody at church. And, you know, they had done everything they're supposed to, they're staying inside, they're trying to keep the kids healthy, and try to keep the kids safe because the kids were very young. So couldn't get the vaccines yet and couldn't really wear masks consistently or effectively. And just making sure that my engagement with the people that I work with, felt like it had the integrity that I was hoping for somebody taking it seriously around someone choosing to make this an important thing. And making it a real thing. And so that was that was good for me, like I said, Because I developed a bunch of different perspective, it really helped me understand compromise and how people have to move, while at the same time understanding what my values were, and how I was going to be moving through not just this, this pandemic, but a fundamental change shift and how we were going to be working with engaging with one another forever, because I'm one of those people who's picked up masks and hope to not take off I don't I don't see myself doing that. Myself encouraging people if you feel sick, if you're coughing, here's a mask, bro. Because if we can get to places a culture where if we feel sick, we can be masked, that's really what's going to protect them. Most people think we're sick, might be sick, might have been exposed, knows wear masks put a mask on face. But those of us who have to protect others still wearing masks. And even though we some less effective, still choosing to believe that we can make a difference in the lives of people in our immediate spheres, we can make ourselves safer and keep the folks around us you.

Kit Heintzman 1:17:47
Can you identify sort of earlier in life, where you learned to be so considerate and thoughtful of other people?

Erin Waters 1:18:01
I think it comes from it's that complicated. Because as a black person was initially perceived as male, you have to make yourself small, and you have to make yourself approachable, sometimes, most importantly, you have to make yourself non threatening. In addition, you know, being in a white neighborhood, how do I make myself seem quote un quote like one of the good ones, so that I wasn't treated as badly off the job. And seeing how people some of the people around me that I knew were quite selfish and self centered. And being raised by someone who really helped me understand that things aren't the same for everybody. And sometimes you have to be the change you see in the world. And sometimes that's still not going to be enough. And so at the end of the day, what you have is as much integrity as you can muster, because we're not perfect. And if you can lay your head down at night, and know that you've done something for somebody, whether it's with recognition or not different are different feelings around that I don't think we should never getting it can be demoralizing for some people always getting it go to some people's heads. But if you can lay your head down at night and you've done something for somebody that is meaningful. And that's really the plan like if this earth if this life is an entity of self actualization where we actually care about each other and have empathy. You have to model that as much as possible, while holding your boundaries around when it's not feasible, realistic or safe. And I think getting to understand how more often than not other people just feel unsafe. Other people feel under threat and then seeing

during They help people move into desperate survival mode. And not everyone still has the capacity to do something for somebody else. And understanding that everyone shows up in the work and a different way. Not everyone can be on the frontlines of protest, try that. And they're not everyone can be the frontline in a corporate space, or in the ivory tower academia, or staring at bureaucracies, and industrial nonprofit, I've done all that. That's how I can show up for work. Because I know that there's a person out there who needs access to this healthcare, who is ha another day job, they need to get through their day, and they need to do their work. And maybe their work is rocket science saving people. Maybe their work is teaching children, maybe their work is none of the above. And their job is to just try and survive today, every one of us who survives and thrives bidding in the eye of the people who really think that we are bad, or that we were mentally ill, you know, us thriving, is is revolutionary. And so anything that I can do to support that stuff off particularly feels good to me, it feels necessary, it feels realistic, and it feels critical. And if you know that, people are going to show the work in different ways, not everyone can show up in the same way. And sometimes you have to be the change in the world that you need to see in the world. And that on top of that, even after you do that, it may not be enough to really help this person who has been downtrodden, beaten, overlooked, and like just shy and dismembered by these systems are trying to engage with what can I do to make their existence a little less terrible for today, or tomorrow, helping build programs to support trans folks is one of the ways I do that, helping call out systems when they are being racist, and sexist, and homophobic and transphobic, and fat phobic and ageist and not caring at all about people with disability. And if they do, it's really, really ones. And that's like it, being able to carry that stuff. And knowing that if I'm in a space, I have this platform, who am I advocating for? You know, it can't just be me, it can't just be my identities. It can't just be self serving. Well, I can only speak from my experience. It doesn't mean I can't speak in favor of other people, I don't need to speak for them. I don't need to speak on their behalf all the time for someone to do that on their own. But I can speak in favor of these folks. I can be the the the thing that credentials them when they're not in a room with with these people, because in keeping their perspective has had real world results. I know the things that I've built know, the things that I've been a part of, I know the people that I've helped, there are people who are getting access to health care getting gender from healthcare today, because of the days that I cried, the days that I argued with people, the days that I had to find yet another way to go into the space explain people like us to people who don't understand us explains to people who don't respect us. So doing the work, while it is beneficial it is it is a little self serving, because you know I want access to healthcare to I need to know that if I'm going to a doctor's office that I have a leg to stand on, and that I'm not the first even if I'm the first patient and of course trans persons hearing about these things. And so all of this stuff blends together into the kind of person that I am where I'm just gonna get off the duff, and I'm gonna go do something. And being around immunocompromised people, folks with disabilities will change the way you move, it will change your life, because you will understand. The reason which the world was built to convenience, certain people. And that was done without even the remotest thought. The other people didn’t want to inconvenience. And so you got to get in or you got to get in and talk about it. You got to get in there and be that change. You got to be willing to rascal care with people who have lung cancer survivor survivors, most cancers. My mom had cancer. So I remember her immune system or her immunocompromised stuff and how we did it before. You know, being willing to bring my heart into the work, I think is one of the things that drives me because it's work. I talk about how it isn't just hard work. You don't just bang your heart up against the wall of the system, your bank or your head, not just your head and guess what your heart rang but your head and your heart, your head because you're trying to figure out this puzzle before your heart because it affects you, affects people around you, affects people you love affects people you don't know what that you care about. Because this is what we're supposed to do. If we're supposed to be on this planet long enough to figure out how to care for one another and share resources. We've got to have people who are doing it. You've got to have people to believe it's possible to radically change

the world, and are doing it all the time, in the words of Angela Davis, like doing it all the time. And that's hard. Eventually you learn how to age, the involvement, you can have how to hold the boundary so that you can be in it for the long haul. So that when you've already been doing it for years, and then we pandemic, you don't burn out, you don't take a backseat, you already have the network, you already have the social infrastructure, you already have a professional networking infrastructure, we try and make these changes happen, and then continuing to believe, in myself, you know, I don't know how far I can go in this room, I don't know who I'm going to get to change their mind or who I'm going to be able to get to move differently. But if I can get at least one person to leave this meeting, my things could be different with that I've made the change to to call my involvement worth it. And so I believe in the efficacy, you know, sometimes on we and disenfranchisement is real people would never jump into something or work, I feel like it's kind of a fundamental change. I'm standing on our, on the beach, from starfish into the ocean as the tide is going out. I know that. But it doesn't mean that maybe the tide wont come back in some day when it comes back with a whole different system, because reform isn't always necessary. Reform is baby steps, we can have a revolution. And if we do can do that, we have to have the people who see others around them and want to speak up in favor of those people, because they some of them have been disenfranchised and feel like they cant. Some of them have been systematically oppressed or they won't, they won't be able to get to that team. Being able to use my platform responsibly, is something that that weighs on me often. And I'm always trying to find not necessarily new ways, because I don't have to create new ones that have already been created. It's finding the people who've done the work. So I can find other ways to build different types of bridges, because that feels like I'm taking care of the people around me. That's probably some of what drew me to social work and community health work. I do I care about people that I care about every last one of us getting a chance to thrive. And those of us who are minorities, those of us who are marginalized, because women are not a minority population, they make up half the world, they are potentially marginalized, us thriving us being free.

Erin Waters 1:27:34
Is that is a revolution. It is us literally getting to have equal place in society where we matter, it's being hit by something like COVID-19, and it not being guarantee that we are not going suffer most. And that we're not going to be boiled down into a convenient acronym bipoc. Because what my communities, the black person is different than what the Pacific Islander community even though American Samoa and Guam have some similarities in terms of how a country has treated them. And what, like the big three Asian communities need, because that's different. And, you know, when we get there, we will get there. I don't want that to happen in my lifetime. But I also believe in planting trees that we will never sit under, because that is that is what our elders are supposed to do. They temper they temper youth with knowledge and wisdom of what has worked before what has been successful, and what hasn't. And the youth that we you're supposed to be keeping in mind have passion, and it is their job to come into what we have to say this still isn't good enough. And for us to find that balance intergenerational, where we can talk to one another so that we can continue to do things for each other. I feel like my work is around some of that helping people figure out how we can continue to support each other. Because I see each see ourselves in each other's shoes. That's that's one thing. But if we can see how our fight is bound up at another person's fight, and then we can see how there are people who aren't even at the table and how their is found on ours. That's how we get to a place where we're helping each other and remaining consistent in terms of believing and and supporting one another on as many on as many axes as possible.

Kit Heintzman 1:29:31
What does the word health mean to you?

Erin Waters 1:29:34
Oh my gosh. Health is a lack of fear. Health is knowledge and literacy. Health is to move to thrive. Health is so many things inside of it outside of an exam room. Health is a lack of racism and homophobia, health is wellness and being well happens on so many different faces, ourselves and our society and community and so many different axes of need, because health isn't just being in an exam and getting a prescription health is understanding what gets people to that exam, what keeps people from that exam so that they can have good health care outcomes, health is understanding that health care outcomes are affected by our behaviors, by health care decisions that people make, and that those decisions are actually a factor, how they communicate and how they communicate is a factor of their implicit and explicit biases, and how they communicate the ways they communicate people. So all of those things come into these individual decisions, individuals decisions, systematic decisions, because they've become systematic behaviors, and if unhealth is those systems, being healthy enough to understand that we don't serve certain communities, and instead, we're doing the best we can, and we're gonna tack them on at the end, understanding that there is no liberation. For some of us, it is only all of us, it's all us, or it's none of us. And that can't just heal a part of the population, part of the world part of the country health is the knowledge that I can get to an appointment, because I have transportation infrastructure, that if I need to make a dietary change, for whatever reason, I have access to food to be able to do that. That if I am trying to change some stress, that I have access to childcare and housing, I need surgery, I have access to housing to recover, because if you don't have housing, then you aren't able to get certain surgeries, they will simply tell you no. So you may have waited for two years and try to find someone who in your world who cared enough about you as a trans person supporting you getting surgery, so you go there house for a week or two to at least start recovering. No, it doesn't exist. So those people don't have [inaudible]. It's people understanding, it's it's people being healthy enough in their own minds to understand trans people aren't sick, we're not broken, where people aren't mentally unwell, we have just been able to break far enough from the system to see ourselves outside of the system to see ourselves well enough to be honest, that's health health is not allowing the system to use its power to dictate what health is for us. That power, a power dynamic that exists within a health system that can say you are only going to get a certain number of dialysis sessions, because that's all we're willing to pay for. Your health is something that number is a financial bottom line issue for us, at Trans and Queer People have existed since Mesopotamia and kingdom of Samaria we are we are in red records for longer than some of the people things the justifications that people use against us, they call us back our health is those people realizing are sick, that they do not understand that we are always been here. And so we will always be here. And health in our society is finding ways to engage with us to use in the middle where we compromise how we can both exist, survive and thrive. So health beyond physical, mental doctors and therapists, it's those social determinants of health and well being is who gets access to what education and why. It's how the supposedly canceled culture has gone up. But now we have to cancel books in the library up to an including canceling entire libraries. People have defunded libraries because they had a handful of books about trans queer people that weren't even in the kids section, or one counter I had to ask him specifically. That's what I see as as health is understanding and environmental racism is killing planet it's killing the lands, the indigenous lands at so many different people struggling to try and maintain after colonization. It's understanding that colonisation, and white supremacy and homophobia and transphobia, fat phobia and ableism are the sickness those of sickness, those that are sick in our culture, not the people trying to survive and it is hard to be trans person or queer person. It's hard to exist in a world that is transphobic and queer phobic. It's hard to exist in a world that is ableist. And so being able to see that where the actual sickness lies in our, in our culture, and our in our society, I think is what is health is able to see the sickness where it actually lies and changing the systems around us so that people have access to the system. Because there's this assumption that what's happening

is as we move towards more progressive values, and egalitarian values, what we're doing is we're trying to control outcomes control the healthcare outcomes, we're trying to control the social determinants, the outcomes, how people end up in life, that's not true. What's happening is we're trying to get on the front end, we're trying to control, access to access, not trying to control outcomes, we're trying to control access in the first place, who even gets to step up to the plate, who even gets into the doctor's office who even gets in there and knows that they can push back against the doctor without being afraid, who knows that you can actually appeal your denial? Who knows that and once they do that, they send it to this generalized medical board, that you can still you can, you can supposedly fight that you can go state, you can go beyond that there are ways to continue fighting, health is knowing that you are empowered, that you have access to these things that you can go into a room with a legislator, Senator, whoever you need to, and tell them that they're doing the way they're doing right now is incorrect. And that taking the one or two ideas from the focus group and implementing the cheapest one, and the fastest one, and the one that gets them the best PR, those, that's not enough, minimum 51%, you're gonna call a bunch of us together to talk about what your system is doing wrong and make us squirrel or system all of our pain out health in that moment is knowing your system is sick, and you taking the bare minimum of 51% of our suggestions, to make your system healthier, so that we can be healthy, because we are helping, and how we know ourselves and how we know what we eat. That is healthy. It's the other systems around us telling us that we're sick, that something is wrong with us that we're not okay. And all of these people co signing it. That's the part that is really unhealthy.

Kit Heintzman 1:37:06
What does the word safety mean to you?

Erin Waters 1:37:09
Oh, my gosh. Safety. Safety is knowledge that at the end of the day, you have somewhere to go where you are wanted and valued. That you know, you are wanted, not just that, you know, inside that you're wanted and value. And that it is because the world you live in, can see you as you are now with their with its biases against you, not with it's not with its respectability politics, or you not wait. It's you know, good, you know, really kinds of stereotypes put on you, at safety, to be seen, people have an understanding of you, your identity, and how you have to move through the world that they aren't colorblind, or culturally blind, or blind to your disabilities, because none of that is healthy. I don't want someone to invalidate or make all of what I've had to live through all of who I am, or how I have to move through the world, disappear. Because that's unsafe, you're going to treat me the way you treat the average person who matches your demographics and has the same average life experience. And you get to continue to impose your default as something that is normal. And it is not. It's not typical, and safe for me. Because that safety for you that psychological safety for you, by default creates a lack of safety for me, that’s part of why I dont talk about safe spaces in the work that I do need to go courageous spaces where we can be uncomfortable with each other. A courageous space is not as inherently an unsafe one, because safe one means one group. psychological safety given how things function now, it's more than likely going to be the most demographically dominant group or groups. Those identities are going to control the table. They're going to control what happens at the table. They're going to control what happens after the table. And that isn't safe. Everybody what for me to be safe I needed to the person at the other end of the table who has a completely different life experience than me feels courageous enough to step into a lack of safety around that they don't know what's going to happen to that, that space they have to that psychological that challenges and not being afraid of conflict is not the same as being unsafe. Being uncomfortable is not the same as being unsafe. That's why we need a courageous a space where we can find a little bit ability to be actually uncomfortable, not conceptually or

whatever, like actually uncomfortable where you hear about the racist, homophobic, sexist, misogynistic things that are that are happening. And I can feel safe saying that, and it's, it's a struggle because someone like me then also needs to come into the space with enough courage to know that that person needs to self actualize off of my pain, right? Because that's the opposite. They hear enough of my sad stories. And because, you know, logic is not about proving that health care for us is what makes us happy and access society that, you know, not being terrible fat bodies is what actually gets the concordance necessary to get people through the healthcare system was late, you know, that isn't as important. Those you know, that those things aren't as important to the people across the table, but I have to have courage to know that this person will be processing that in front of me, and processing that as a result of me My pain is going to be the thing that helps them self actualize. And that maybe it'll work this time, that can be difficult. And so we have to learn boundaries participating that situation is the knowledge that you're going to self actualize. Let me take these one, two ideas and use them incorrectly implement them incorrectly to failure, and then use that as justification not to do it in the future. But I don't feel safe enough to say so that I can hold a boundary, that I am not, not not going to let someone just slide on it. I feel safe enough to speak out. But know that I'm not going to have I'm not going to I'm going to be a little psychologically challenged. Because how many times have marginalized people that call a focus group 9,10, 11, time and they serve as cold, cold cuts, in some turkey sandwiches or a cold start to repeat that they got from a local grocery store. It's not real food, it's happening at two o'clock in the afternoon, Tuesday. You know, feeling that safety is the knowledge that I can go into the space real things are gonna be accomplished. And that courage is going to be exhibited on both sides until we get where we need to be. And then I have enough safety to say no, this is the second time you've called me not to do anything the first time now we're two years later, you're calling the same to try and address the same problem is still happening. Nope, I say no, I know hold that boundary and have enough safety to do that knowing I will be completely cut out of the conversation. Because I've done with this format, because this format isn't effective. Safety is the knowledge that I can go out on a bus or go out into any part of the country and not eat a green book. Because everywhere that I have moved to everywhere that I have lived, I have very helpful white people explain to me don't go to this part of state alone. And there are other parts of the state you just shouldn't go. Why because they're [inaudible] very just they're walking around at night alone, you may not survive. This was stuff I was hearing literally all through today. I was I was told which parts of the state that I may, I should not go to. I only told us when I visited places which parts of the city I shouldn't go to. And it's wild to see how white folks will say this about certain black parts of town. And how everybody else does this about chunks of the state. There may be certain cities or certain parts of certain cities where people cant go to, but their entire portions of states lack of focus and queer folks should not be going to. So safety is is an awareness that things around us are unsafe, how they are unsafe. And people being able to see that they are responsible for helping build that safety, our culture or government or neighbors have built safety for people with different demographic identities. They see themselves to see their stories. They see their power reflected, they see it being affected, they've got to help everyone else see that same safety so that they can be empowered enough to move forward with that same safety so that they can thrive.

Kit Heintzman 1:44:08
What does it feel like to hear someone tell you that there's a place you can't go to?

Kit Heintzman 1:44:18
Normal. Typical, likely, constant, upsetting, frustrating, disappointing. Real. That's there are parts of this country that I have no business going to, especially not as a trans person, person as a FEM as a advocate out outspoken, visible advocate. Realizing that even a green bookt may not be helpful for some of those parts Not realizing that

it's 2022, who could benefit from one, to be completely honest. And knowing that that isn't the case for white folks, you might go to a random place that you don't people there don't know you, they don't know anything about you, you are an outsider, you are an outside of the way somebody like me that's going to be an outsider, my mere existence is a threat to the bubble that some of these people have crafted for themselves. And they will engage in violence, social violence, of an erasure, legislation, social violence, or political violence of legislation and eraser, social erased social eraser from from all kinds of activities and public spaces. And literal, physical eraser, they will attack me, and they would be so angry, that I'm alive and visible, that they feel a need to take away my life. And it's frustrating, because sometimes you say that, and people will say, Oh, that's not true. We're we had a black president, what racism is so done, I really want to bring these helpful folks to these others, to talk about why you're telling me I can't go to the rural part of the state. Tell them tell them in so many words, why I can't go there. Explain to them that when I'm walking in certain neighborhoods, and towns and what I've lived, I'm gonna get the cops called on me, which is not safe. Because they don't, they might see a random white person walked in, they wouldn't be a little bit nervous, but they're gonna get that person to do something shady, they're not going to wait for that, for me, being told that there are places I can go is normal, there are places around the globe, that I cannot go. I don't talk about it very often. But I really liked visit some of the amazing bath houses around the world. They seem so cool. Some of them are old and pretty. And there's a unique vibe in those spaces, get to build community, and you know, get a clean shower. And I'm going to be able to go to some of those places, because it's not safe to go to those places, because legally, I'm not allowed. And when you bring up the legal thing, and people say, well, that's just what the people chose. So majority rules. Might is right. As long as most people hate a certain group, don't understand a certain group and want to limit movement, certainly, it's okay. Obviously, they don't like it when you turn that back on them in any of their demographic identities, social identities, but, you know, they, they want to say, well, you need to give people time. It sucks, because being told I can't go somewhere that I need to give people time to get over it means I'm not only am I not safe, there are people who are in those spaces who are just being left to die. They're being left to flounder, they're being left to struggle, they are being left behind. And it is because they don't share certain set demographics with other people around them. And those people feel its justified. And those people are so afraid, they are so deeply afraid of being minorities, without being able to talk about why they're afraid of being a minority, because they see how they treated people. They are afraid of being a minority in this country, or whatever country because once they are a minority, all they are able to really see is the behavior that they have put on minorities and they cannot conceive of a world in which those aren't atrocities are not pushed back on to them. And so it's revising again, that's sick, that is unhealthy. And they feel it because enough people have said so it's okay. And that if it's enforced by law enforcement, well, those people were just doing their jobs. And every 30 or 40 years or so we look back, and we go a little bit more Ooh, shouldnt have been doing that. And how people will look back 100 years on sale was different time people should function functioning differently, I hope we can let go that there's no reason that I wouldn't be able to get a new car, go in any state, any city, any area of America and not feel safe enough to get back in my car and go home. If I'm stuck out on the side of the road at two o'clock in the morning, that helped that I might receive some help with the very least I won't be harassed. None of that is true. As a trans person, I can't even travel across across country without the knowledge that there are states where I'm picked up by an ambulance. That ambulance driver does not have to help me they can say no, another ambulance driver or ambulance set of paramedics have to show up to come get the minutes are crucial if they Take me to a hospital that does not support people like me, then I have to leave that hospital and then be driven to another hospital minutes are critical. People like me have been allowed to die in the street, because a paramedic won't handle us won't touch us. And that's their legal right. It has been referred over and over and over again. So being told with their places I go is normal. It is typical for me, and it

sucks. And I don't like it and it feels terrible. But it is a regular, consistent part of my existence. And if I stood on a soapbox and rambled about it too hard, I would just be dismissed or shrug. That's just the way things are.

Kit Heintzman 1:50:53
What are some of your hopes for the long term future?

Erin Waters 1:51:00
My hopeful, long term future is that we don't have to let things get so bad that we only do that only the thing that humans do was react instead of proactively do that and just react. My hope is that, you know, we used to be able to back say things like, well, people are less homophobic, and by the numbers, they technically are, but they're legislating against us. They have a new boogeyman trans people are legislating against us. My hope is that 20, 30 years from now, our the generation behind mine, their children are able to see just how ridiculous, safe, unhealthy and how unnecessarily we moved. We tried to look back at the Spanish flu. And we saw that there were people who didn't want to wear masks, when they brought in seat belts, people didn't want to wear seat belts still don't want to wear seat belts. But now they are a much larger minority. And there is a majority who feel differently. And it isn't that I want majority to rule. It's I want people to be able to make a decision outside of a vacuum and outside of a bubble. And the more we do that, the more education people have, the more empathy people have, the more we don't just care about each other, the more we move in ways that are supportive of other people and their identities and people around us in their needs. If I had hoped for the future, it would be that those of us who are carrying the torch trying to set everything on fire, are able to hand that torch back to the folks behind us behind us. And they continue to set some stuff on fire. Because it's possible, we are capable of that. It's a world in which indigenous people are not just seen in terms of their the sadness of their plight, the land that has been stolen or lost the communities that have been broken, because they are still thriving, there are many that are still thriving. It would be that when we have a health care crisis, it isn't going to be a factor of knowing that x communities are going to struggle. And that if they are isn't going to be that, well, we're just gonna change all of our communication. So only focus on community and just, you know what everyone else at the end like we're going to be in this together. And we'll continue to think about being in these situations together. If there's a future for us, it is one in which we are not afraid of revolution. Reform is baby steps until system can tolerate a revolution in I. And I believe that by any means necessary, includes by every means available. And so more people were leaning on all of the different options we have not just a legislative option where you participated before yours and your 25 bucks the so you give a thumbs up and call it good. And then you get mad at people who are much more progressive who are giving mutual aid but don't really need to vote. Because they're doing the work in another way that folks in the mutual aid community are able to understand that some some folks will vote and some folks are only ever going to vote. But that we understand how we can mutually support one another and benefit each other and build the empathy necessary to get across some of the chasms that currently exists. And I don't necessarily mean the chasm between somebody like me, as somebody who thinks I'm an abomination, who's walking this earth. That's a boundary I get to hold. I don't it's not my job to convince that person to change the way they are. It's not my job to tell anybody how to think. But if there are people who are struggling and see how the system is failing them, they are able to look at me and see the system failing me and are able to draw a corollary they're able to draw from Well, they're able to see how our struggle is bound up with one another. And we are willing to work on this together, because that's that's the future. The future is the understanding that we we aren't an island. This American exceptionalism, deep individualism that is spreading across the globe is not the way forward. There are definitely downsides to collectivism, in the sense of it can become very rigid, you're not allowed to have a personal identity. But I think part of what we are doing with these lives that we have around us

is understanding the balance and compromise of where's our identity? Where's our empowerment? And where's our empathy and desire to be in this with other people, beyond people who share immediate demographic information beyond people who share immediate political opinions, there are political opinions that are harmful, in my opinion, no political opinion is ever gonna die, as evidenced by the fact that we study anti Semites and people who are aligned with Nazis, no entity, the that type of fascism was the death of millions of Jews. And they put African Americans into the camps and kick them out of the country. They killed queer people, they killed disabled folks like, they know what they're still people who latch onto that identity, and that social identity and social movement. So some of these things won't die, but they are harmful. And if folks can understand well, the Holocaust is often presented within within the view of the Jewish community and should be they suffer deeply. The Romani community can also be found in parts of the black community to German black community can be found at the National queer people, disabled folks, how we can make build bigger conversation because it's not for me at this point in my life of my schooling. And that isn't what I want to see happening moving forward in the future. It's about options. So people have more options, because we have more options, we can have more inclusivity, we can talk about the schwa and center, the Jewish community, who who dealt with a lot of death, and also talk about how that struggle was indicative of what other people were dealing with, and how other people found it. And how the Jews being cast out to so many different places, in terms of history is indicative of a lot of cultures being kicked out of different places and refugee status and how you have to build a cultural identity, beyond adversity, sometimes landless. And the strength that we can pull from some of those stories and some of those narratives indigenous community, still having some pieces of land, but given scrubland being lied to how we can see how our struggle, like there's no black liberation without indigenous sovereignty, there's no question of sovereignty without black liberation, because we're guests here. In many cases, most of our guests here black folks aren't. We were brought here against our will. But my freedom isn't going to happen unless people can also see how white supremacy and colonialism destroyed a bunch of indigenous stuff, but at the same time, did not destroy indigenous people. They are still here. Those peoples and communities and tribes and clans are still here. Black people are still here. We are not a narrative that has been built for us. They need more options and more opportunities and more people building together is what's going to create that bigger perspective to get those additional opportunities, build that bigger table and to hold the systems around us accountable and realistic ways.

Kit Heintzman 1:58:33
What are some of the things you do to take care of yourself?

Erin Waters 1:58:43
Oh my gosh, I read comic books, I play video games. I take walks without my phone. I look at some of the good news that's happening. You know where where are we being successful what laws are we're being changed. I listen to the stories positivity. I had someone tell me a story of positivity not that long ago. She works at a school. She was worried about being out at this school showed up in their progress pride flags everywhere. A lot of the young people in the school either identify as queer in some way or trans or non binary, all of the students are much more comfortable holding hands. And you know, just showing empathy and contact and being comfortable with one another. Those things lift me up. I like food. Like most people, I like to try new and different places. I revel in the fact that so yesterday morning, I was able to catch I had grits with eggs and salsa verde. And all of these things were a mix. You know, all these things come from different places. I get to do that I get to live in a place where I get to enjoy in so many different things, and so many different people, I get to go out to events and see my own people, I get to see them reflected in their art, I get to see other communities in other cultures, I get to see something beyond the standard DB defaulted whiteness in this country so that I can see myself. And therapy, I

really appreciate that more and more folks are talking about therapy, it is losing a lot of the stigma associated with it. Because therapy can be helpful. It is not currently accessible to everyone. There are definitely systems are not making that easy for folks to get get access to. But more folks are getting access to it. And hopefully as time goes on, and health systems are continually identified as failing on that one, you can do something different and they do. They find some differences, they find some opportunities to find joy. And finding joy is one of the things that bring me happiness for where do I find joy. And sometimes it's just thinking about being joyful. And, you know, wearing my blackness and my transness and my womaness and my queerness of the same time, and choosing not to be afraid in a particular moment, knowing that the fear is justified knowing that the fear is out there. And that taking my knocked my head on a swivel in terms of paying attention is something I'm not going to do but I can be joyful, I'm still here, I'm still breathing, I'm still successful, I'm still making changes, and other people are stepping into the room as well. That's that's really what brings me joy and helps me take care of myself. [inaudible] your team is so helpful for groceries and there's a meme going around in which a very bad then the orange rock fantastic four is just, he's making very sad face and the associated meme is my own looking at me have a full face routine. So just thinking about how I'm taking care of my body, and the things that I am doing to make me literally feel good. How am I doing? What am I doing with my gut health? What am I what am I consuming in terms of the media, in terms of art, in terms of literature, and all of those things be more more reflective of me and other people's identities, choosing not to just read a book that's full of white people, no black or brown people at all, and trying to grasp that experience unto myself. When I've done plenty of that there's plenty of art that I have seen that doesn't have any markings on it at all. And that's fine. I get to take care of myself by seeing self identity, my experience reflected the things that I'm taking part in the things that are supporting things that I'm consuming.

Kit Heintzman 2:03:00
I'd like you to imagine speaking to a historian of the future in the future, someone far enough away that they have no lived experience of this moment. What would you tell them cannot be forgotten about this pandemic?

Erin Waters 2:03:25
We are still at a time when you punish people up to an including deaths for being poor, for being black, brown being not white. We don't enter whiteness as being black, brown and indigenous being disabled for being that age old or too young get autonomy anymore. We can't forget about the pandemic was starkly. It reminded us again, that we exist in a time in which inequality is assumed to just be a thing we have to accept when we can feed the world dozens of times over when still are able to identify that chocolate tears are using slave labor, child labor, that domestic slave labor is a huge deal. There are children in the United States who are going to starve today while a billionaire goes to the moon, while law enforcement is still unable to see what is happening to themselves, law enforcement lost the largest number of their own staff to COVID. And that not changing some of how they move with empathy. Something that I think we can forget is that COVID-19 really brought out a lot of resilience and in people they learned to whether it's something tough. But what we want to do is focus on that resistance that people, that resilience focuses on the trial on the negative on depression. It's the resistance of people to continue to make sure we weren't an afterthought, to make sure we weren't just tacked on to the end. To make sure we weren't just let go. In all of this, that's really important because we live in a time in which those things are okay. People said a lot of stuff. And you'll read a lot of stuff about this time about how trans people are on the come up, and we're getting access to health care. But if you have time, go back a little farther, and see how Dr. Martin Luther King actually pulled in terms of support 1968 He was one of the most hated men America. And even now protesting in the streets. We agree with your mission, but not your methods. She wrote some letters from a

Birmingham Jail specifically talked about folks who think that way and say those things. Do you want to think about COVID-19 Think about the resistance that healthcare providers put up at marginalized people move through resistance to to believe that the health system could help some of us and more of us that we bring people across a divided bridge, that were those of us out there who weren't willing to forget us, but that it was us doing it, we had to think about us, the [inaudible] for us by us had to save ourselves. And that wasn't fair. If everybody is struggling, everybody should be coming up together. And that didn't happen. There was a lot of rhetoric. We were banging pots and pans outside of windows and doors, but we weren't paying nurses more. We weren't paying doctors more paying community health workers were getting people to the front lines of gaining access to the shock being left behind. We weren't paying those folks more, we weren't making it easier for them to do their job. We were literally watching people quit hemorrhaging staff, and they were just telling these people to try harder to work on it. They were saying they hope for change weren't actually doing it. They were saying they wanted things to be different. They wanted to help people and doing the bare minimum. The fact that we were able that many of us were able to live through this pandemic should never be overlooked. A lot of people came together, a lot of people are able to make change, a lot of people were able to survive. We lost like 1,000,003 million, 2 million people. Right now we're still losing 1,000s a day. And we've become so numb to it. Because of the way our society works, because we have our actuarial tables or death panels. Already, we've already made research, the majority has made a decision. About who can die? My hope is that if there's someone who has no lived experience of this, who [inaudible] digital records work backwards of years of the future. didn't learn a whole lot from the Spanish flu. We didn't learn a lot about homophobia from the 80s and 90s when we were letting people die from AIDS. We as a culture still in a place in which we are struggling to survive. And the moment we are reminded of that we trump people because that's what packs do. They want their outliers to come targets and leave them. My hope is that people in the future have realized that everyone's struggling is bound up each other. We could choose to make a different decision this time we didn't. So don't give us all the benefit of the doubt. Don't just let it slide. Say we did the best we could and understand that. But let it be yes. And yes, we did the best we could. And there were other things we could have done differently if we chose differently. Because the people who come after us need to learn from our mistakes. They need to learn from our successes. And whatever it is they have walked into. They need to be able to say this isn't good enough yet. We need to keep going. Because we can't let what happened in the past to hundreds and 1,000s and millions of people across the globe who didn't have access to resources. We can't let that happen again. We can't punish people for being poor. Or fat, or sick or old or not from a quote unquote, third world country, and I hope that term dies out global [inaudible] all that I hope things are different than. And I hope people understand that having access to options and opportunities is what makes change in our world.

Kit Heintzman 2:10:29
I want to thank you so much for the generosity of your time, and for the act of speaking truth to power. Those are all of the questions I know how to ask at the moment. So I just want to open some space. If there's anything you want to share that my questions haven't made room for. Please take some space and share some.

Erin Waters 2:10:55
I mean, the only questions I had or questions I can't get answers to have they finally put hot dogs and hot dog ones packages same size? Have we figured out that capitalism isn't the way or ice caps melt? There are people who care right now. And there are people who are trying there have always been people cared. And my hope is that there are more people who continue to care. So the only questions I have to report is how much do you care? What are you doing right now to make change? And whatever it is you're doing right now, what if for a split

second, you thought it was the bare minimum that you could be doing that there is another bridge, another group of people, another lost, stolen right. That you can build a bridge toward people get over under around and through? What are you doing right now to make a change? And what if you do something really, really radical tomorrow? reached out to somebody new, someone different someone new who's walking a similar path or parallel path like costumer? Who is that person, those people? What work you challenge yourself to do one additional question and pull up in yourself, which is going to be really hard for people kind of like me who do a lot everywhere. What if you thought about the work you did different and tried to build one relationship with the marginalized people? What if you had a whiteboard and you wrote on it the three or four groups who you still don't think that hard about or know enough about when I started this work, And honestly, I continue if I have a whiteboard near me, I write down each disability and body size because those are three I really needed to keep in mind because I am able bodied, I'm slim. And I'm not old enough to have society overlook me or try and take my autonomy or assume I'm [inaudible] in some way. And so I continue to what new bridge I build communities in what way can I think of or say something in favor of one of these communities? How can I talk about other indigenous community with different plight, that still struggling under white supremacy that I haven't talked about yet? Because I don't know enough. So what can we what can I do? How can I build a liberatory consciousness? Go from awareness to analysis, get some history, get some understanding, figure out accountability? How am I going to hold myself accountable in spaces, my things stakes? Am I going to mess up accountable, continue to work, and then get involved with the action so that I can be sustainable so that I'm not just jumping from awareness into incorrect action isn't helpful and unsustainable, or ultimately causes harm. Yeah, because I think I asked other people about that, because I asked myself, What am I doing? What am I doing today, but the bridge can I build? What bridge already exists, that I can get some other people across with me stable that because those are the things that matter. individual actions can snowball as long as we are able to look at systems and deal with systems and the people within systems that are perpetuating the system. Yeah, I think that's all I have to share.

Kit Heintzman 2:14:39
Thank you so much.