

Into the Crip Universe: Crippling the Anthropocene

Season 1, Episode 1: We Love Like Barnacles

Guest: Patty Berne

Host: Rafi Ruffino Darrow

Content Warning: Medical eugenics, disabled death

[slow thumping electro music]

Rafi: Welcome to “Into the Crip Universe,” a production of *Sins Invalid*. I’m Rafi Ruffino Darrow. *Sins Invalid* is a disability justice based performance project led by disabled people of color and disabled queers. This season, we are discussing the present and future of climate chaos and its interactions with disabled communities. In this time some call the Anthropocene, which is the proposed name for the epoch we live in, one of human-generated change to our ecosystem, disabled people are both disproportionately affected and brilliantly thriving. Through interdependence and resistance we assert our claim to pleasure, access, and community. We are “Crippling the Anthropocene.”

Hi! This is Rafi, I’m an intern with *Sins Invalid*. And I just want to start off by saying how much I enjoyed this conversation that I had with Patty Berne. We dream about possible futures, talk about love and survival and barnacles, and disabled worth. Patty Berne co-founded *Sins Invalid* with Leroy Moore in 2006. They are widely recognized for their work to establish the framework and practice of disability justice. It was such an honor to talk with them, and to work with them as an intern.

Also this episode is going to be dealing with medical eugenics and disabled death for anyone for whom that may be a trigger. And I’m so excited that you’re going to listen to this.

[soft rush of air]

Rafi: Hi Patty!

Patty: Hi Rafi, thanks so much for inviting me!

Rafi: Yeah, thank *you!* Um, I thought first we could situate ourselves as people a little bit, like say who we are and how we identify so people know, especially for you, so that they know what amazing work you're doing. So, I already told you I'm Rafi, I'm a femme, trans, white, Jewish, multipli-disabled artist, and I use they/them pronouns. How about you?

Patty: I am a 53 year old, disabled, queer, Brown person of Haitian and Japanese ancestry, um, my mother is from Japan, my father from Haiti, and I am born and raised in San Francisco, California, living on Ohlone land, currently in the East Bay, and right now I am wearing femme-presenting clothes, a dress with floral patterns because it is so warm and beautiful outside, at least it's beautiful to me (*laughs*), uh, finding joys in all the ways that we can even though it is in fact the anthropocene.

Rafi: Okay, so, kind of the obvious first question I had is: why this podcast? Why did you want to do this, and why now?

Patty: Well, I was recently introduced to the world of podcasts by the brilliant Rafi Darrow (*laughs*), and I am really enjoying learning in a way that is not visually-based, um, just auditorily, and it seems that many other people are learning this way as well and forming community and you know, in some ways reimagining our social selves so to speak, I mean, I think it opens up our political imaginations, which is exactly as artists what we need to be doing in this moment, and that is why performance is so critical to, I think, communicate a different vision for, uh, disability embodiment, um, all of our collective embodiment as people. And right now, it's just, it's a mess! I mean, it's just a moment of fundamentally species-shifting mess. And, you know, really we should all be talking about climate chaos all of the time, and I think it's only because we live under a federal administration that is anti-science, and denying the truth of the changes in the world, and how so many of us are being affected by those changes, but we're not talking about it all the time! I think if I reentered the political world now, if I were to kind of start my work, it would have to be addressing the environmental global crisis that we're in.

(pause)

Rafi: In the section, we talked about the imagined near-dead status that disabled folks have in society: always thought of as close to death, and in other ways not worth their own lives. So we talked about that and how disabled experiences get tangled up with climate chaos and sometimes dangerous ways. We also talked about the powers of

representation and how without having figures of media and authority that look like you, it's hard to imagine yourself as a human that can survive in the world, and achieve adulthood. I remember how much this weighed on me as a child, this feeling that I couldn't and I wouldn't be an adult, that I wouldn't survive it... and it was just because I never saw anyone who looked like me around. Like, disabled adults didn't exist so, I must not either.

Patty: I started learning about climate chaos more formally through podcasts and books, but I think I always had a sense that in the event of you know, some sort of “natural disaster” as we’ve been taught to think about, uh, climate changes, um, I just assumed that I would be dead, you know? That there would be some major flood, or you know some sort of earthquake that I couldn’t protect myself from falling objects, um, but I just assumed that I was gonna be dead, that able-bodied people wouldn’t ally with me closely—

Rafi: Yeah.

Patty: —and a friend of mine was just, I mean, kinda rejected that possibility (*laughs*), um, and they were like “No! You know? It’s not okay! You know, besides me like as, you know, as your friend helping you politically, it’s not okay for people with disabilities to be just written off!” And I mean, just, of course I believe that emotionally, and that is part of disability justice, um, you know, ethos, and at the same time, I just hadn’t envisioned able-bodied/able-minded people really thinking about us. And—

Rafi: Yeah.

Patty: Yeah, (*laughs*) right? Because they demonstrate it all the time! But they don't! So, um, I really want to appreciate Micah Bazant, for, you know, articulating it to me in a very visceral way that that’s not acceptable for us to be written off, you know this was maybe, I don’t know, 10 years ago or so, and I’m just so grateful because it isn’t acceptable! I mean — it’s — we can see it now during the Covid pandemic the way that people with disabilities are so low on the, uh, you know, list of who to triage, that we’re not even invited to the hospitals! Like, there’s kind of an assumption that we should just stay home and die. And it’s damn near been articulated that way.

Rafi: Yeah.

Patty: It’s horrifying!

Rafi: Right. Both in the structure of the way that our society is put together, and then also through the media that gets made that doesn't really show us living at all, and like really only shows disabled people as children. I always found it hard to imagine myself as an adult, um, or imagine that I could, like, be alive as an adult, um, like you were just saying, like the idea of imagining yourself, um, alive as any sort of older person, feels kind of impossible, and I think some of that is because we don't see anyone who looks like us, um, around, that anyone is talking about or that is in media of any kind.

Patty: Mmhmm. I think in part because the assumption is that we're supposed to have withered away and, you know, that we're disposable! The way that nursing homes recently within the pandemic have been such hotspots, that there's just an assumption that you know—I remember I heard an interview recently that in Sweden, they essentially in an effort to get herd immunity, they sacrificed folks that were in nursing homes essentially. And I mean, I-I can't, I mean this is like, you, this is me, this is our friends, you know, we're a huge sector! And so to think that so many of us would just be bereft of support and aid, uh, is I mean, literally it's unthinkable. And yet we have to think about it. Because here we are. You know, within capitalism, within ableism, you know, within essentially an authoritarian or authoritarian-leaning government administration, experiencing the first kind of barrage of climate chaos. You know, the things that have happened already in the various hurricanes in the South, in Texas, in the way the pandemic has shown us who's prioritized. Um, I mean, it's here, it's not like in the future —

Rafi: Yup.

Patty: —it's here. And we can see who is, uh, invited into the echelons of safety, it's not the folks that who can afford private hospitals, you know? It's the folks that are in public hospitals that are left with less resources. Not only is it not acceptable, it pisses me off. Like again, this is *us*! And by us, I mean it's people with disabilities in particular, people with disabilities who are queer, gender nonconforming, disabled people of color, you know, folks that live on reservations, folks that are in lockup, folks that are not held by, you know, disability community as closely, or within a disability rights frame certainly. Um, yeah, no. (*laughs*) We have to visibilize what we're experiencing and will experience in much more kind of sharp detail, so that we can plan with other activists and organizers how we're going to survive climate chaos.

Rafi: Yeah, and so, what are some ways that individuals and activist groups can integrate disability justice into their climate chaos work?

Patty: Well, I think one of the first things that organizations and movements need to do is educate themselves around disabled peoples' lives (*laughs*) and who we are, you know? What we're living in currently, which is ableism, and a lot of folks on the "left" have not considered disability oppression as an institutional force.

Rafi: Yup!

Patty: And you know, they think that it's an "other" issue, as though organizing queer folks could somehow not address disability, or that organizing folks that are locked up somehow doesn't include people with disabilities. It is an like an affront to our senses — or certainly to my senses — that people that are, you know, supposedly on, um, the cutting edge of movements, are not understanding that disability oppression is essential part of the oppressions that we all experience in conjunction with (*pauses*) gender-based binary, heteronormative settler colonial oppression.

Rafi: Yep.

Patty: And, I think that educating folks about the difference between disability rights and disability justice is important, because people certainly *heard* about disability rights, but it's been maintained as an "other" issue, right? As a health issue.

Rafi: Right.

Patty: And you know, while education can do (*pauses*) some opening of minds, really what's going to open practices and hearts is including queer disabled folks in leadership, after folks have done some of their own works, you know? Like, after an organization has done some of its, uh, like anti-ableism excavating, then there's more space to invite, you know, disabled people of color into leadership or into, um, a guiding role in the organization. That's when organizations can invite, you know, gender-nonconforming folks with disabilities into their advisory circles, um, and, you know, that process has to start soon, (*laughs*) because the doomsday clock is ticking and it's literally seconds away from midnight. And I think, you know, when organizations become more aware, and moreover when we are engaged in the work more directly (*pauses*) that will necessarily shift the movements and necessarily shift the ways that we're practicing being in community with each other and holding each other in our visions of the future. Like, the future has to include folks with disabilities.

Rafi: Yeah. And what *is* your vision for a crip future in the anthropocene? What does that look like?

Patty: Well, there's the vision of the future, and then there's the process to get there.

Rafi: Yeah. *(laughs)*

Patty: And, um, you know, I-I am not arrogant enough to think that I can know much about the process of revolution, because we have not experienced that in *(pauses)* the US context. Like, on this continent — Turtle Island — we *(pauses)* Once, you know, there was a settler colonial regime set up, there have been movements that had revolutionary intent, but they've been undermined, and destroyed. I think revolutionary processes are complicated and messy and full of struggle and my imagining is that *(pauses)* it's going to be painful.

Rafi: Yeah.

Patty: As well as rewarding. But I want to stand with all of my crip kin in that process.

Rafi: Yeah, me too! *(both laugh)*

Patty: Yay, let's do it! *(laughs)* Rolling up our metaphorical sleeves *(laughs)* and get into it! And with our queer kin and, you know, our brown kin, and you know folks who have been colonized, and folks who have had borders placed on them artificially, and you know, this process I think can hold victories, but I think *is* going to be painful. But I can't imagine what that's going to look like in real terms. I *do* think that *(pauses)* I can see a future where *(pauses)* We're — I guess the only thing — term that I can think of at the moment, is I see a future where we are working with the will of the planet. Where we're not asking the planet to submit to us, but where we are working with and submitting to the forces of the land. And that's appropriate. And it's not a negative connotation, like "submission to." It's just means—I mean, this is our home! This is, we're a part of *(pauses)* so many processes. Like, we're a part of *it, them* so I can imagine, you know, for example, having personal care stations on every city corner.

Rafi: Mmm. Yeah.

Patty: You know? Um, filled with food that's locally grown, and offered by what the planet is willing to offer at that moment, um, and the people who, you know, are the historic stewards of the land, and I can see not using electricity at night if that puts too much drain on safe power sources, and instead using candles, or whatever we may need in the majority of, you know, residential homes. I can see an economy that is

based on people, and our needs, and sharing the abundance that's available to us. I mean, what's the need for currency?

Rafi: Yeah!

Patty: I mean like why not?! Why not have it be mutual aid, and, um sharing the abundance we have in our gardens, in our homes? I mean, what need do we have to, you know, have a home with six empty rooms and one person, one room? Right? Like, why not have everyone housed? Like, it just makes sense to me. I can see—And I can see these things because it already happens within communities, you know, between us, within crip communities, within queer communities. I already see the ways in which we develop systems of mutual aid that are so natural to us—why not extend those? Not just to people that we have known for 30 years, you know, but to people that are in our locale, where there's systems of accountability, where it's safe to do that. I mean, I-I can see (*pauses*) love being the primary means of interaction. You know? And I can see that — I can see us — like most of us gaining sustenance from the land, and our connections to the land. Getting our healing from each other and from the land, and having the medical industrial complex be converted into something which supports us rather than profits from us.

Rafi: Yes!

(*pause*)

Patty: I can see everyone acknowledging every body as beautiful. (*pauses*) I think it's as loving and validating, as easy in a way, as we are as little kids, before we get socialized into capitalist demands, and expectations of our bodies to conform. Before heteropatriarchy makes demands on our conformity. Just kind of being who we are and accepting that people are who *they* are. I just don't think it's gonna be easy to get there (*laughs*) so you know, that's why we're doing this performance, you know, uh, *We Love Like Barnacles*, is what I wanted to title it because we do, like we're—when I think about barnacles, I think about their staying power. You know, the staying power that love is and has, and how gnarly sometimes it can look to stay in relation, you know? (*laughs*) How like crusty and ride-or-die we have to be sometimes in order to keep that connection. Um, but that is what love looks like. Like, it's easy to love someone when they're at their most palatable (*both laugh*) and not at the moment of tension. But really, when it's time to take a risk and not be fearful, but take the risk to love, even when someone is being perceived as not lovable. I think that's where the revolutionary process, so to speak, steps up. So I'm thinking for example if I—if the California coast

went, and I was underwater, right? Like it's easy to like be in community and be down with me, when my home is cozy and you know people are coming over, and eating and petting the cat, you know, and there's wifi, you know, and it's all cozy, but when someone has to swim to my defense because there are people willing to inject morphine into me, so that in their eugenic viewpoint the people that are "worthy" of saving get resources, you know? And that's when I want someone to swim to my defense, and say "No, get your hands off her and let's make sure she's okay. Let's grab her wheelchair and her meds, and put all that on this raft and make sure she's carried safely onto this raft, and let's go to the whatever. Like the first aid station that's 20 miles away." You know, that's what revolutionary love can look like too. So, the show, I'm hoping, will demonstrate all of the contradictions that we're in, and hopefully help folks envision a path through it. So that we're better equipped to see what is possible as a species. And you know it might, I mean, real talk, it may well not work out, no matter what we do at this point, it's very possible that the damage has been done to the planet, and particularly given the way that the Amazon has been destroyed in the last few years, given so many things—given the way the ice of the globe has melted, you know, can't roll that back, (*laughs*), uh, but at least we can go down loving each other if we're going to end as species, we can end in community, and taking down as few other species as possible. I love the way that everything has been flourishing during the pandemic.

Rafi: Yes! Oh my god, the birds are just like having a ball! They are so happy.

Patty: Yeah. Everything is like "yay!"

Rafi: It's their world now.

Patty: Yeah! "Yay, the humans are less present!" (*pauses*) Yeah, I'm really grateful that you're doing this podcast, Rafi, because I think it takes a real width of heart, and a depth of heart to hold the truth of climate chaos. And be present to that grief, but also be present with our possibilities, (*pauses*) and with the love that we can have for each other, and *do* have for each other while this is all happening.

Rafi: I'm so glad to be in community with you.

Patty: You are so wonderful, you really are. (*laughs*)

Rafi: boop boop boop!

Patty: boop boop boop. (*laughs*)

Rafi: Um yeah, is there anything else you wanted to talk about, any questions that I should have asked you but I haven't?

Patty: Hmm. (*pauses*) I hope to see everyone, and be with everyone when our performance goes live on the computer. (*both laugh*) Such an interesting idea, um, new camera angles that we can get, when there is no audience in-house, and I hope that folks are with us on October 23rd, 24th, and 25th at 8:00 PM Pacific Time, and more information, I'm sure will be typed in somewhere in the podcast information.

Rafi: Yay!

Patty: Thank you Rafi!!

Rafi: Thank *you!*

[slow thumping electro music]

Letícia: Before we end this episode, we'd like to invite you to our upcoming performance *We Love Like Barnacles: Crip Lives In Climate Chaos* happening October 23 and October 24 at 7 PM Pacific Time, and October 25 at 3 PM and 6 PM Pacific Time.

For more information and to check out our show notes please visit our website at www.sinsinvalid.org! If you're listening to this episode after October 25th, you can find more information about our show recording there.

Don't forget to share, like, and subscribe. We hope to see you next time!

[soft echoing vocals]

Rafi: "Into the Crip Universe" is a production of *Sins Invalid*. Shani Banai is our sound engineer with concept also developed by Sofia Webster, Blair Webb, Lettie Robles-Tovar, and Patty Berne. Come visit us as sinsinvalid.org.

♪*At least I got my pain, got my babes, got my radio.
At least I got my pain, got my babes, got my radio.
At least I got my pain, got my babes, got my radio.
I feel like shit.*

I feel like shit.
I feel like shit.♪