

Into the Crip Universe: Crippling the Anthropocene

Season 1, Episode 2: Crip Resilience is Nature's Brilliance

Guest: Sofia Webster

Host: Rafi Ruffino Darrow

[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.”

This week I'm speaking with Sofia Webster who used to work with *Sin Invalid* and is now having a job at Crip Camp. This conversation surprised me. I've only recently come to identify as environmentally ill and hold everything that that means, and it seems like part of my own experience as an array of 25 disabilities stacked on top of each other in a trench coat comes from the toxic state of the air and water I grew up around in my beloved tiny city of Buffalo, New York which has been poisoned by environmental racism and classism and neglect. Thinking of what that's done to my city and its people feels painful and fresh but so important. I'm so grateful to Sofia for sharing with me and modeling her own process for dealing with these issues that spiderweb out into larger significance that I still don't know how to handle on my own.

[soft rush of air]

Rafi: Hi Sofia!

Sofia: Hi Rafi! I love that intro so much, I kind of cried a little bit.

Rafi: I'm so glad that you like it.

Sofia: I love it, and I love that we're exploring Crip brilliance in the anthropocene this season. It's so exciting to me.

Rafi: Yeah, just like the all of the lovely ways that we can do more than just survive are so exciting.

Sofia: They truly are, and I think that it's so exciting to, like you said, explore the ways in which we're thriving and living our best lives not just surviving and trying to go but day by day although that is a big piece of the crip experience right? is right okay how are we going to make it through this day. So I'm really excited to explore this with you, thanks for having me on.

Rafi: Thank you. Okay, so my first question is: what is your relationship to climate chaos?

Sofia: Oh, my gosh, what a great question! Okay, so my experience of disability is directly linked to the rise of climate chaos. I have Lyme disease which is an infectious disease caused by the bite of a tick. In my case, it was *Ixodes pacificus tick* which is a type of tick found in California. I was bitten in Sacramento County in 2008; Here we are in 2020 and I very much still have the disease and consider it my experience with disability and ticks really thrive in warm climates.

That's why we see a surge of Lyme disease and other tick-borne infections happen in springtime and in the summer, because that is the warmer seasons. However, um, with the rise of global warming winters these days are becoming more mild, and the amount of cases of Lyme disease are increasing as global warming causes milder winters. I think because of this there's going to be a lot more cases of Lyme and other tick-borne illnesses in humans and non-humans. Many animals can contract Lyme disease and other tick-borne infections; it's not just humans, uh, so I always think of people and non-humans with Lyme holding them in a special place in my heart because I know what it's like to be in a body, um, that has this infection, and I think that there's going to be a lot more cases in the upcoming decades. So because of the clear correlation between the rising amount of cases of Lyme disease and the rising global temperature, I identify as a person with an environmental illness. Because my illness would not be present had global warming not been a thing.

Rafi: Mmm, and so do you think that there's a particular place for a particular need for disabled people and especially environmentally related disabled people, um, in discussions of and reactions to climate chaos I would imagine so.

Sofia: Oh my gosh, of course, because it directly impacts us and so many people's experiences with disability is going to shift or has already shifted because of climate chaos, and I'm thinking of the annual wildfires in California and the ways they have historically impacted disabled people, especially disabled people who rely on electricity as an access need, or for people with environmental injury or illness. Our experiences with climate chaos in the context of these wildfires is that when these massive fires are burning it's not just burning these, um, natural things that the Earth produces like trees and leaf litter and things like that, but it's also burning up chemicals, and all sorts of things that are in people's houses at harmful volatile organic compounds or VOCs those are all being burned to which creates a really toxic air situation for everyone on the planet but especially impacts people with disabilities and people who have respiratory illnesses, people with multiple chemical sensitivity, which I also have. I have multiple chemical sensitivity, and so it just makes me think of— Oh, and there's also the flame retardants that they spray over affected areas after fires.

Rafi: Right.

Sofia: And it just makes me think of, you know, the— also the ways of how these big stakeholders as in, um, big chemical companies, the agri chemical businesses, and entities like PG&E - how they have historically, reacted to these fires and, you know, I'm thinking of in 2019 when PG&E shut off electricity access with very little and sometimes zero advance notice for people who are in affected fire areas which can cause people with disabilities to die. And it also makes me think of the phrase “Nothing about us without us,” which was actually coined by disabled South Africans during the Apartheid era to really show the importance of having those who will be impacted by a decision be the actual decision makers. So we are the ones who are going to be impacted by climate chaos, I mean actually everyone. Every being on the planets impacted by climate chaos, and it's also really important to continue to make sure there is space at these tables where these decisions are being made about how to react to climate chaos and how to strategize solutions. It's so important to have disabled people, especially people with environmental injury or illness in this decisions.

Rafi: And what do you dream about what that would look like? What does it look like to have disabled people and environmentally injured disabled people, um, being part of the solution to the current climate chaos?

Sofia: Ah, what a dream. *(laughs)*

Rafi: It's a big question.

Sofia: I love it though, and I think disabled people are really brilliant. I think we're really good at problem solving, and we're also *super* good at making sure that every voice is heard, and this has already been happening. It's already begun and disabled people have already made waves in dampening the effects of climate chaos.

Going back to your previous question about PG&E and the way that they reacted to disabled people possibly losing power, and possibly losing their lives and extension. I'm thinking of the organizers behind the movement #powertolive which is a group of fat and disabled people who have been trying to hold PG&E accountable for the ways they interacted with disabled people during these annual wildfires. I was so honored to be able to see — and it just made me feel very empowered to see the actions that those organizers did. They locked down the PG&E building, they had these beautiful art exhibits, and they are not going to get pushed around, and I think that's so beautiful and so important. And, it also — I mean, I also hold Patty Berne the co-founder of *Sins* and executive director, so in my heart when we have this conversation, and especially — there's this article that she wrote in collaboration with Vanessa Raditz for YES Magazine about how disabled people are such important players in strategizing solutions to climate chaos and so my dream is for disabled people of color to be seen as primary stakeholders in the outcome of the planet, because we are so impacted, and our words and our ideas are brilliant and they need to be heard.

Rafi: And how do you see the principles of Disability Justice being able to be used, um, in service of this work? What principle of Disability Justice do you think would be most helpful or important to keep in mind when discussing and tackling climate crisis work?

Sofia: What a great question! I mean, really all 10 of the Principles of Disability Justice are key, but the one that always sticks out to me, the one I always come back to is: centering those most impacted—

Rafi: Yeah.

Sofia: — And I just think it's incredibly important to be considering (pauses) all the pieces. All the pieces matter when it comes to climate chaos, when it comes to *every* issue really, but I think that it's important to know that disabled people are in every single community. We're everywhere. And I am thinking of people who are incarcerated, I'm thinking of Indigenous leaders, and undocumented people, disabled people who live in zones of high pollution like “Cancer Alley” in Louisiana, and the ways in which all of these communities are (pauses) experiencing the effects of systemic oppression, and what we've seen in systemic oppression is that the problems of these oppressions become magnified in times of crisis, and I think that is definitely the case with climate

chaos is I think that these communities are going to be the ones most impacted and are already being very impacted, and I think that it's incredibly important to make sure that we are listening to those who are being most impacted by systemic oppression.

Rafi: Thank you, um, this next question was one that *you* gave to me (*Sofia laughs*), but I thought it's really lovely, and I can't wait to hear what you're going to say, because it's not a question that I would have thought to ask: Um, so, what do you see as the relationship between land, toxicity, and healing?

Sofia: I could honestly talk about this for days! I think about it every day. It's like one of the great conundrums of my life I feel (*laughs*). Um, it's because the land is the way I originally became sick via Lyme disease, and this tick bite which I contracted while camping in 2008 when I was a teenager, and I've also noticed that land is the way in which I am also healing. It's an incredible source of healing for me. Um, I also experienced environmental injury in the form of toxic mold — mold toxicity. From 2015 to present, I lived in a moldy apartment when I was in college, and that was also, I mean, my experience with mold, I believe the root of it was unsafe capitalistic practices of construction, using cheap building materials to create student housing — I really think that is the root of it.

Um, but mold is also an organic compound. So, again, something that's organic that is causing me harm. And my experience with disability is completely tied to things that are organic, and it's complicated and (*pauses*) kind of confusing for me to try to tease apart when the land is a source of healing, and when it is a source of illness. I really feel like these overlapping systems of oppression are the root of why the land has so many illnesses attached to it — including climate chaos. And, I mean, one avenue of healing that I've explored really deeply is, it's called — well, it's more of a lifestyle change, than actually like a protocol of sorts if you're thinking of it as in like a chronic illness context.

So, what I have done is tried this lifestyle called extreme mold avoidance in which I go to a pristine environment — and when I say pristine, I mean from where there is very little chance where I will get exposed to mold — and see how my symptoms change. It's kind of a radical experiment of my body, and I really tune into what my body is telling me, symptoms that may come up, and see if it — if the symptoms change based on where I am. It's called the locations effect, and it is really interesting to me how my symptoms change based on where I am. So, when I'm in urban areas with higher pollution or higher chances of poorly constructed buildings, um, like the Bay Area where I currently live, I have so much more symptoms compared to when I'm in pristine environments.

And the place where I thrive the most is in Death Valley National Park in Inyo County in California which is another ironic thing, too, because this name Death Valley conjures up images of death and decay and kind of apocalyptic type of doom, but it's — that has not been my experience with it at all! It's been a place full of life, and where my body really is able to thrive, and kind of even relax a bit from being on such high alert. I noticed that when I'm in urban environments in my usual place where I live — the Bay Area — my body is on this high alert so often because I never know if today is going to be the day where I'm exposed to something that could really set me back like toxic mold, or a type of chemical that's going to set off my multiple chemical sensitivity. And so it's just so interesting to me that I do so very well — I mean my physical endurance just is through the roof when I'm in these desert climates and it's not my land. I mean even the Bay Area is not my land either. I am a settler on these lands, and I also am not able to visit my homeland.

Um, my dad is an immigrant from Ecuador. I used to live in Ecuador when I was a kid. I miss it very much, I would love to visit all of my family there, but it's very inaccessible to me, because of the amount of pollution there is. Um, most cars there use diesel, and smoking cigarettes is part of the culture. It's really difficult for me to imagine being able to feel safe there because of the amount of possible triggers for my illness, and so I hold that so often. Where I feel kind of pulled in all these different directions I want to go to where my family is in Ecuador and visit, and it doesn't feel accessible to me. The Bay Area and Northern California as a whole is definitely where my community and my loved ones are, but I'm also on this high alert all the time. I know that I feel really fantastic in the desert, and desert climates — especially in Death Valley. Um, but I don't know if I would really be able to survive there without community. Community I've noticed is really important to me, and I always tussle with the idea “While should I move there? Should I uproot my life here in the Bay Area?” I don't know what to do, and it's just something I've been in a thought loop about for, oh gosh, probably five years now. Yeah, and it's just (noise of exasperation) Well, it's just kind of complicated, and I've kind of compromised at this point. I visit the desert three times a year for two weeks at a time to get the health boost of being in that climate, and that boost carries me for the next two to three months while I live in urban climates in, um, the Bay Area, but it's quite difficult for me. It's something that my heart is torn about all the time.

Rafi: Yeah.

Sofia: Yeah, thank you for indulging me when — I mean I love talking about this so thank you for listening!

Rafi: No, yeah, and I asked. It was such an interesting question, um, I was thrilled to have you bring it up. Um, okay, now thinking more through these relationships between toxicity and land, and what healing looks like, and, um, you were a part of, um, in the Disability Justice primer you helped to write the, um, concept that was spoken about of environmentally and toxically injured folks as canaries in the coal mine, and I was wondering if you could explain what that idea was a little bit more.

Sofia: I would love to. So, that piece was written by Mordecai Cohen Ettinger of Health Justice Commons. I was a editor on the piece, I did not write it. I love, love the concept of canary in a coal mine and that refers to an old mining practice in which miners would bring down a cage canaries when they were going about their mining operations, and if the canary died, it was a sign that the mine was starting to fill with dangerous gases and that the miners needed to exit the mine as soon as possible. That's where the phrase comes from. A lot of people who have experiences with environmental injury and illness really res- um, that concept of canary in a coal mine really resonates with many people with environmental injury and illness, because in a lot of ways our bodies feel like these canaries, because we are tend to be more sensitive to pollutants in the air and dangerous chemicals and things of that nature compared to the rest of the population.

And my favorite line of Mordecai's in that piece is when he says, "This expansion and exploration of people and land has come at the cost of life itself, and so we the canaries are called forth to sing our urgent song of truth." I just really love that, because it— I mean, sometimes it feels really powerless to be in a position of being on such high alert with our nervous systems, and we never know when the next exposure is going to be, or if this is the one that sets us over the edge it can mean an exposure for me can set me back for weeks and it's so hard to be in a position where one doesn't have control over their environment. It's it like really sends my nervous system out of whack, and this line really resonates with me because it kind of flips that on its head, and tries to assert that canaries are actually very empowered beings because we have the power to know as oracles, of sort really, what the future is going to hold and how this is going to impact other people down the road. I mean, our bodies don't lie. Another point in the piece Mordecai says, the bodies of whales with their bellies full of plastic also don't lie. And that I find incredibly affirming. It was a joy to edit that piece with Mordecai.

We really tried to center that as much as possible while editing the Disability Justice primer. It's the second edition. It's called *Skin, Tooth, and Bone: The Basis of Movement is Our People*, and when going through the editing process of the pieces, we wanted to make sure the pieces were edited by other people of that community. So, I was a main editor on Mordecai's piece as another person with environmental injury and illness. In a similar way to how the section in the book about audism was entirely edited by Deaf and

Hard of Hearing folks without any interference from hearing people. We had a whole caucus of folks who were doing the editing on that piece ,on those pieces, and we just again going back to centering those most impacted — nothing about us without us — it's important that people who are impacted by issues are stakeholders in the way they're carried out.

Rafi: Word. So, what else did you — or maybe you can pick out a few that you felt most strongly about — what were a few things that you called for in the piece, or that Mordecai called for in the piece?

Sofia: Oh, boy. I love the idea of the moratorium AKA complete stoppage of new chemicals. I think that's really important, and it also brings up a sticky issue in our community is where is the line between, um, my role as a consumer under capitalism versus the, um, and the waves that I can cause with who I choose to patron with my money versus the role of these big companies themselves? You know, because I think that we can influence things based on our how the way we choose to engage under capitalism knowing that there is no ethical consumption under capitalism, but also understanding that we as people have the power to influence the way these companies do their business. Because if there is no demand there can be no supply, but we also don't want to let these big players off the hook. I think they have a lot to answer to, and so I think it's really interesting to me, the idea of introducing this moratorium on new chemicals, and it's always a delight for me to talk to Mordecai, because he has so much knowledge. I kind of (*laughs*) view him as like a walking encyclopedia of all of the knowledge of these terrible things that these gigantic corporations and forces have done to impact people. I really got a lot out of the Health Justice Commons popular education course *Understanding and Transforming the Medical Industrial Complex* — which I know you took too —

Rafi: Yeah.

Sofia: And it was horrifying and also empowering for me to understand the history of why my experience with the medical industrial complex AKA the MIC where that comes from, and how it was actually designed to oppress people. It makes so much sense! So, that to me is also really powerful and important is understanding the history of where these big players come from.

Rafi: Totally! So, how do you do all of that work, all of that good thought work, and leadership as a canary work, and all of the activism that you do while also caring for and loving for yourself in a world that is toxic for you in a number of ways? What does that look like?

Sofia: Oh, my gosh, Rafi! (*Rafi laughs*) Here you are asking the great questions! I love it. I love it. Woo. I have struggled with that for a lot of years. Trying to find a good balance between doing work for the movement, and doing work to make sure my body itself feels liberated, and as much as I can try to do both (*laughs*) it's very hard. Um, I think a big thing for me is feeling attached and connected to nature. That's big for me I used to — well, not used to — I have PTSD from my experience with Lyme disease. I have nightmares every week about ticks attacking me in various terrible ways.

Rafi: Yeah, yeah, yeah.

Sofia: I know, it's horrible. I hate it, and then (*laughs*) sometimes mold is a factor in my nightmares, too, where there will be ticks and mold in the same place. It's-it's not a fun time. So, and for a while when I first got diagnosed I held a lot of fear, um, for being out in nature out of fear of being exposed to Lyme disease, and that is knowing the way it affects my body. I am just so aware of the risk factors of being in nature, and I refused to go camping, or be in nature for a really long time after I was bitten by the tick and contracted Lyme. Now I've kind of reached the point where, um, I love being in nature, and I think there's ways that I can do it that are (*sighs*) more conducive to my access needs, and the situations of my body.

So, for one, there's not too many ticks in desert climates (*laughs*) which is another reason why the desert is so appealing to me is because that fear of being bitten and reinfected with the Lyme disease bacteria, *borrelia burgdorferi*, that is just a non-issue in the desert. It's great, and I think there's also ways to go about it where I seek out nature places in which there's a paved trail. So ticks tend to live in leaf litter, and tall grasses, on logs, and on boulders, and things of that nature, if I stay on a path that is paved or it's like a clear designated trail then I think my chances of contracting Lyme are lower and, it's also very fulfilling to me to be able to impart wisdom that I've learned through my experience onto others to hopefully ease their burden as well.

Rafi: Yeah.

Sofia: So, for a long time I was the facilitator of the Sacramento Lyme disease support group. Which I loved doing, because when I was first diagnosed with Lyme I used to go to the support group as a participant and voraciously take notes on different things that people were doing, their experiences with various doctors, and the newest research in Lyme disease, etcetera, things that people were trying out, and it was- I was like a sponge absorbing all this information. And *now* I am the one who is imparting that

wisdom onto others who are in the same boat, and that is really fulfilling to me. And, uh—

Rafi: Yeah.

Sofia: — so spreading the knowledge of what I know to ease the suffering on others is, uh, I find very personally satisfying, but there's also a lot of ableism that I notice in these chronic illness communities. I wish that everyone was tapped into the 10 Principles of Disability Justice, and realize that disability is not something to be afraid of. When I first got my first wheelchair, it was one of the happiest days of my whole life, because so suddenly so many new opportunities were available to me I felt *incredibly* liberating, but there's still so many voices in the chronic illness community that view disability as a bad thing. Capital B, capital T: *Bad Thing*.

Rafi: Right.

Sofia: And, um, it's not, I would love to be able to understand or get— I would love for the chronic illness community to understand that being disabled is okay, and it's not something to be afraid of. So, I think there's a lot of, um, internalized ableism in that sphere of organizing, and that is really kind of an impetus of my shift in focus to Disability Justice — away from chronic illness organizing around specific disease advocacy — is because I think that Disability Justice serves everybody not just one for a specific disease, and it really transcends disability itself. Anyone who has a marginalized body can benefit from having Disability Justice in their lives, and I also know that there's a tremendous risk for burnout and being so involved in these movements especially ones that are so close to our bodily experiences. So I try to be mindful of that, and just take time for myself. I watch a lot of Netflix, I like sci-fi *a lot*. I'm big into Star Trek. (*laughs*) Um, big into Star Trek. I like, um, The Great British Bake Off (*both laugh*) like these wholesome reality TV shows where it's like very low risk (*laughs*) I like those. And I love listening to podcasts, that's another fun thing for me to do, and, yeah, I try to balance the two, but I find that they just bleed into each other so much is my experience with my body, and my experience doing disability organizing, and trying to be a steward for Disability Justice, they really bleed into each other.

Rafi: Totally, that makes a lot of sense! Wow, well, thank you so much.

Sofia: Thank *you*!

Rafi: Yeah, the only thing I have left is just ask: is there anything else that you'd like to add? Is there anything that we missed?

Sofia: Oh, well I would love to visit, um, well I mean one thing that you brought up to me was the opportunity to talk about a special item that I have—

Rafi: Yeah.

Sofia: — that I feel is related to this topic, (*laughs*) and, um, okay, I really love quail, the bird. I think they're so *cute*, and they are— they scurry (*laughs*) they have, the California quail is the state bird of California, and on their heads they have a little plume that's made out of six feathers, and I first fell in love with quail, well, I mean I growing up in California I've seen them my whole life, but I really kind of got fixated on them (*laughs*) when I was camping in Pinnacles National Park about 3 years ago, and there was this whole group of them who were digging through the leaf litter under this big oak tree, and they use their feet to dig through leaf litter, then they use their beak to peck, um, to find little bits and goodies beneath the top layer of leaf, and they just make the cutest noise. They scurry when they walk around, um, I love when they're like in the middle of the road, and there's a big car coming, and they just are like, “Do-do-do-do-do. Well, I guess I'll move now.” It's like they're just moving at their own pace, and I think that they're very cute and cute, and I have this little plush quail, because I like them so much. (*laughs*)

Rafi: Oh baby.

Sofia: I know! It's in my room, because where I am in Fremont I don't see too many quail.

Rafi: No.

Sofia: But, anyway, my pet quail — who is plushie and not real — is named Quincy. Quincy the quail (*laughs*) which I think is a perfect name for a quail. (*laughs*) When I'm having like kind of a rough day at least I got my quail friend with me, I also have a quail poster in my room. I just love them. (*Rafi laughs*) I think they're incredibly cute and sweet and, yeah, just just good guys.

Rafi: I love how good neurodivergent brains are at finding joy, and the like repetition of small things that they've liked taken upon themselves to care about more than any amount of reason really.

Sofia: Wow, you totally get it. That's exactly what it is.

Rafi: Thank you for talking with me, Sofia!

Sofia: Thanks so much for listening to me, Rafi! You ask the most incredible questions, and this is my favorite thing to talk about, so it's fun for me, too. Thank you so much for the opportunity!

[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.♪