Crip Crap Podcast Transcripts

Season 2

Episode 23.5: Building a New Disabled South with Dom Kelly

Episode Description**:** Justin and Kennedy spend time with Dom Kelly, founder of New Disabled South, to discuss his work in the region. They touch on policy, disability rights and justice, sustainability in movement work, and more.

Justin: Hello everybody, and welcome to the Crip Crap Podcast, Episode 23.5.

Christea: (in song) That’s just some crip crap, don’t you know.

Justin: I am Justin Cooper.

Kennedy: I’m Kennedy Healy.

Justin: It is so good for you all to be here on this special episode. How are you feeling, Kennedy, today?

Kennedy: I’m doing okay. Like, I’m doing my first podcast episode from bed, so just wanna, like, shout out to all the crips listening from bed.

Justin: Yes, there you go. No matter where you listening to, listening from, no matter where you at, we are glad that you are here with us today. And we have a great guest for you all, Dom Kellett, Dom Kelly. Dom is the founder, president, and CEO of New Disabled South. Until November 2022, he served as the Georgia Fundraising Director and Senior Adviser for

Disability for Stacey Abrams' campaign for governor of Georgia. Previously, he was Senior Fundraising Manager and a Strategic Advisor for Disability at Fair Fight Action, the voting rights organization founded by Stacey Abrams, where he also created and led the organization's Disability Council, composed of prominent disability advocates and policy experts from across the country.

Dom is one of a set of triplets born with cerebral palsy and has been a disability advocate since he was four years old. Devoting his life to disability justice, progressive policy, and advocacy, Dom received a Master of Science in Nonprofit Leadership degree from the University of Pennsylvania School of Social Policy and Practice, where he also received the Excellence in Social Impact Award. Dom currently lives in Atlanta, Georgia with his wife Catie, their daughter Mahalia, and their dog, Vivi. And so, now we welcome Dom to our podcast. Hello, Dom!

Dom: Hey, thanks so much for having me.

Kennedy: Dom, how are you doing?

Justin: Yeah.

Dom: How am I doing? I'm doing pretty great today, actually. I'm not working from bed. I, I have a, an almost three-month-old daughter, and pretty much since she's been born, I haven't been able to work from bed because I, she often wants to be elsewhere, and she doesn't like to sleep. And so, my, like, you know, how I take care of myself as a crip has changed quite a bit since she's been born. But I dream of working out of bed. So, I'm, I'm, I'm with you in spirit, Kennedy. I, I wish I could. [chuckles]

Kennedy: The, I saw your daughter on social media. She is beautiful.

Dom: Thank you. Thank you.

Kennedy: What a time.

Dom: Oh, yeah.

Dom and Kennedy: [laugh]

Justin: And Dom, can you, can you describe yourself for listeners who aren't familiar with you?

Dom: Absolutely. So, I'll, I'll give a, I guess, a visual description for, like, access, and then I could tell you more about me. I'm a, a white man with curly brown hair. Right now, I'm wearing a gray New Disabled South shirt 'cause I try to rep my org as much as possible. And yeah, I've been, been, been working in this space for a while now, dreaming about how we build disabled power in the South and how we, how we fight back against the, the powers that be here.

And it's been like a journey of different twists and turns in my career to get to the place where I c-, you know, could actually launch my own thing and make it into something. But yeah, I pretty much just took a chance. And I've learned a lot from working in non-disability spaces and trying to, you know, force people in non-disability spaces to give a crap about disability. And, and so, it's been a, it's been a journey. But yeah, it's been exciting to get to this point now where I can, like, be my own boss and do my own thing and build something with cool people, and, and that's like, it's just been really exciting.

Kennedy: That's awesome. Yeah. So, for folks who aren't following, can you give an overview of what New Disabled South is?

Dom: Yeah, absolutely. So, New Disabled South is the first and only regional disability organization in the country. We are, we have a, also have a 501(c)(4) arm. New Disabled South is a 510(c)(3), and then our 501(c)(4) is called New Disabled South Rising. And between those two we are doing policy, advocacy, and some, like, beyond advocacy, just policy work at the state and local level. We are organizing, community organizing, both electoral organizing to get our community out to vote and be a part of our democracy, but also just in general community organizing, issue organizing, bringing our community together to have important conversations about the issues that impact us.

And, and then we're investing a bit in research. We need to have the data to back up a lot of the work we do, and unfortunately, we just don't have a lot of data. And so, we're trying to uncover that ourselves. And then we do our own, like, coalition building. So, we have what we call the Southern Disability Justice Coalition that has folks from across our 14 states coming together to share resources and information and strategize. And so, we can be thinking about these issues regionally instead of in silos. And, and so, yeah, the purpose of New Disabled South is really to build this opportunity to break out of silos.

It was really intended initially to be two things: a progressive policy think tank for disability in the South and a, a coalition of all of these folks from, disabled folks, from across our region. And it's kind of now expanded into doing that and more. And so, I like to kind of sum it up as, like, we're a, we're a progressive political home for disabled people in the South. And, you know, 'cause I think as a disabled person, I've, I've always, especially living here, I've always wanted a political home and have felt that, you know, our two major parties have forgotten about disabled people or just intentionally ignored disabled people at times. And it's been frustrating. And, and when you find a political home, when you find that home with your community, it can be really empowering, and, and it can…. So, that's the goal, is to build power, political power in our community.

Kennedy: Nice. Is the 501(c)(4), is that the policy branch?

Dom: Yeah. So, we, we do policy on both sides. With our (c)(4), we can do unlimited lobbying. We can't do that with our (c)(3). We have, like, limits for how much we can do and how much we can spend. With our (c)(4) we can do unlimited lobbying, but we can also do things like if we wanted to endorse candidates, or if we wanted to.... You know, there's, there's just, there's just more flexibility with our (c)(4) that we can do more politically. We can be, we can speak more.

We can speak partisan if we wanted to. We can, like, talk about things differently without fear of losing our tax status. So, the flexibility of having that, that vehicle is just, like, really critical for us. So, we, we operate them as two, as sort of two separate organizations, but we have a resource-sharing agreement between the two so we can, you know, our, like, staff work between the two. And so, we're all one New Disabled South, but we kind of run programs kind of separately and sort of operate them as two separate entities.

Kennedy: Oh, okay, cool. Yeah, I don't know a ton about policy, but that's good to know.

Justin: Yeah, that's really, that's really, that's really good to know. And with New, like, New Disabled South, you know, like, how, and like, when did it all begin? When did you decided to, like, focus on putting this organization together?

Dom: So, I started dreaming about it probably about three years ago. I, it took, like, different forms. I, at one point, wanted to do a campaign training program for progressives, disabled progressives, who wanted to run for office, and I thought that would be the focus in the South. So, then it was, you know, like I said, a policy think tank for disability policy in the South. And so, it's taken, like, different forms. I even was, like, thinking about doing like, like a donor community for disabled people, like building grassroots donor power. And so, I've had the general, like, idea for how do we, what's a Southern strategy look like? And that also came out of conversations with, like, friends in disability justice and disability rights spaces about where the gaps were. But really, I, I acted on it about a year and a half ago, over a year and a half ago. While I was working on Stacey's campaign, I, I, it kind of hit me that I wasn't gonna have a job after the campaign was over! And I'd been working on this, what is now Disabled, New Disabled South, this iteration of it and knew that this was all I really wanted to do but wasn't really sure how to launch my own thing and was talking to and working with my friend Maria Town. And I just kind of casually mentioned that, that I had, you know, my own thing that I wanted to do. And she was like, "Wait, you gotta tell me more about that." And I, and I did. And she really pushed me to, like, take some steps on it.
So, we incorporated, and after a few months of me, like, really thinking through what this would look like and how to take the next steps, I incorporated in May of 2022. And then once the campaign was over this past November, I was ready to go. I had funds already. Like, I just hadn't announced it publicly. I kept it pretty quiet. And, and so, yeah, I announced it in November. I brought on my co-founder and COO, Kehsi Iman Wilson, officially in December. And we, yeah, we, so we've been really in existence for like nine months officially. And so, we're, we're still a baby. We're, we're still new. [chuckles] And that's, that's also just like a pretty exciting space to be in because we have, like, so much, so much we, we can do and, you know, and we can, like, experiment with things in a, in a different way. And we're building an audience and building trust and a following. And that's, that's an exciting place to be.

Kennedy: Okay. It feels like it's been a way longer.

Dom: I know. [laughs]

Kennedy: [inaudible] so much. Like, I feel like I have seen so many different things on social media already. And yeah, it is, Crip Crap launched in December of ‘21. But it is exciting, like, how you can just, like, do what, [chuckles] do whatever works or, like, what you want. But yeah, so, in the first nine months, are there things you all have been working on so far that you’re most proud of or wanna highlight?

Dom: Yeah, there, there’s a lot. I mean, I think a big thing that we were able to work on and find success in, in Georgia was we were really fighting for, for Home and Community-Based Services funding. And in our state, we have a waiting list of 7,200 people who have intellectual and developmental disabilities waiting for Medicaid waivers that would give them care in their homes instead of institutions. And, and, you know, every year they fund 100 waivers, 200 waivers. But there, and there’s just no, like, there just hasn’t seemed to be an urgency or really care by the people in power to actually, like, allocate funds in a way that would help the situation. And, and I, I knew that that was gonna be a top issue for us because in the South, 75% of the people who are waiting for these waivers are in our region; 75% out of the whole country are in the South. And, and so, and I would say the majority of those—anecdotally, I don’t have the data yet, but we’re working on it—are probably Black and brown disabled folks.
And I knew that we had to, like, really push for this in a different way. So, we worked in coalition with, here in Georgia, some of the groups in the developmental disability space on just some, like, lobbying strategy and stuff. But we, we invested almost $100,000 this legislative session in paid media campaign to, paid and earned media, to get some attention in our state on this issue. So, we had TV ads in, in, TV and radio, in every major media market in the state. We had radio ads on rural and Black radio across our state. We, we had a, like, for almost $50,000 digital ad buy and where we got millions of views on YouTube.
And then we set up like a call center where people, where we called registered voters and asked them if they cared about the issue and then patched them through to the folks who make the decisions about the money. And the people who make those decisions were people that I went and had one-on-one conversations with who expressed that they cared but would say that they didn’t know where, how they would pay for it. And our state this year had a $6.6 billion surplus in our budget. That was like taxpayer money that just was sitting there. That was outside of our, like, rainy day fund. That was just money sitting there, and they would sit there and say, “We don’t know how we’re gonna pay for it.” So, our messaging with this campaign was, “Our state has the money. They just don’t wanna spend it.”
And, and we drove hundreds of calls and emails to those folks, those legislators, and worked in coalition with these other groups to really push this hard. And they wound up funding 1,000 waivers this legislative session in total, which was a lot more than they have ever done before. And, you know, we were hoping for them to do 2,500 waivers, but they did 1,000, and that was huge. Not nearly enough, doesn’t solve the problem, but I’m really proud of where we, where we pushed them to and this, the, like, starting point that this gave us now to, like, really do this work in a different way ‘cause no one had ever invested in that kind of media attention before until now. So, yeah, I think I’m most proud of that so far.

Kennedy: Yeah, that’s awesome. And that’s such an impact to the people who get the waivers.

Justin: Yes, for sure. For sure. That's really, that, that's really awesome. And so, Dom, like, what, like, what projects are, like, in the works now or, like, coming up with the New Disabled South?

Dom: We've got a lot. So, on the New Disabled South side, we are doing a plain language policy dashboard. So, basically, it's like a tool to use where you can go and look up legislation, bills that are active, and everything's presented in plain language, easy to understand. And it's both AI and human-powered, so like, it's a, it'll be an automatic plain language translation, but obviously, we need a human to be a part of that as well, because AI does not always get that kind of plain language translation correct. So, we're working through that right now, but that should be out, hope, ideally by the end of the month. And, and that's exciting. That's exciting for us as a project because we really want, we really think that people oftentimes have myths or, like, get pulled into myths and disinformation because things are presented in a way that's confusing, especially for the disabled community, but even just in general. I think sometimes people in power make things unin-, intentionally confusing because they want people to not understand the issues that impact us. So, like, we're trying to mitigate some of that. So, that's a project we're working on.

We are launching a big research initiative into the impact of policing on Black and brown disabled people in, in the rural South. So, we, we basically want to prove that, like, policing does not help disabled people—in fact, it harms disabled people, but particularly as it pertains to the South—and then make the case for funding things like non-police crisis intervention models and making the case to cities and states to, you know, give, you know, basically defund the police and fund things that actually keep disabled people safe. And so, we're working on that on the research side.

And then on the New Disabled South Rising side, the (c)(4), we are building out our organizing program for next year. We're gonna have, like, organizers out there getting people mobilized, registered to vote, get them organized around the issues ahead of the election.

And then we're also about to announce the fellows for our first fellowship cohort called the Spark Fellowship, and it's for state and local elected officials in the South to learn about disability justice and disability rights to help them have more of that framework in the work that they're doing. Because we know state and local policy impacts people's lives way more in most ways than even federal policy does. And, like, people think so much about the presidential election, which is of course really important, but, like, we don't think about how the people we elect locally or at the state level, like, people don't turn out to those elections enough. And, like, we know there are good progressive people, but we want them to understand disability and disability culture and, you know, what it means to have a disability justice framework in their, in their work, in their lives and, and hopefully see that start to translate into creating some more change for disabled folk. So, yeah, those are, those are a few things we're working on that I think is, I'm most excited about.

Kennedy: That's awesome. Wow. Yeah. I feel like a lot of people don't realize when it comes to care, which is where a lot of my work falls, that, like, it's literally state to state. Like, people move or don't move because different people are elected in different states. Policies around care are, like, always changing. But yeah, I think.... I feel like we could do, like, like, seven episodes with you on, like, we need to talk about parenting and care, you know—

Justin: [chuckles] Oh, yeah. Yes.

Kennedy: —and non-profits. Okay.

Justin: Yes.

Kennedy: But curious what, what...in terms of the larger disability rights and disability justice movement, where you see your work connecting to either or both, or like, how you see those two movements working together, if that makes sense.

Dom: Yeah, I love that question. I think we, we see ourselves fitting into both of those spaces. We know that disability rights is critical, especially given the systems that we live under right now in this moment, that we need, we need policy and legislation, we need law, and the basic legal protections. Like, that is critical. Do I wish that we didn't live under capitalism and wish that we didn't live under the system of government that we had? Oh, absolutely. Like, I'd tear it all down and, like, rebuild it if it was up to me. But that is not the, you know, where we are at. And so, I think disability rights is critical.

And disability rights has historically left out multiply-marginalized disabled folks, queer disabled folks, disabled BIPOC, you know, anyone at those intersections. And that's where disability justice comes in, and that's a critical part of our work, our values that myself and my co-founder, Kehsi Iman, put together. We, we wrote those values together based off of the disability justice principles developed by Sins Invalid and really thought about, like, how do we build an organization that is rooted in disability justice? Also knowing that we are students of movement and students of disability justice and that we are not going to always get it perfect, but that we want to always strive to do better and listen and learn.

And so, for us, those values, that that was reflected in those values and also, like, building a, an organization within the non-profit industrial complex that is so complicated. And under a capitalist society, like, how do we build an organization that is safe and healthy for disabled people to work? And for us, that meant, like, really thinking differently about our culture and our benefits and our salaries. That meant we, I wanted to have a four-day workweek. I did not want— And that didn't mean, like, that doesn't mean, like, you know, ten-hour days, four days a week. That means 32 hours a week with flexibility to work when and how and where our folks want to. We have our, we're an organization, like, that's critical 100% covered health insurance, like, things like that, that to me should be the norm but they're not. And we overwork people. It's why disabled folks are often left out of these kinds of job opportunities. And like, we just wanted to build a different organization. And so, like, while a lot of the work we do is disability justice work on the ground for our communities, it's also reflected internally in our culture.

And I am disappointed in so many disability orgs, especially mostly disability rights orgs, who don't have disability forward, like, internal culture. And it's reflected oftentimes in those orgs because you don't see as many disabled people working there. So, I think when I think about the movements working together, like, I could give you a million, like a million different ideas for how we can work together, like how those movements can work together on organizing and, you know, the actual, like, on-the-ground work. But I actually think it's really needed in our sector and in workplaces. Disability rights orgs need to think about the fact that multiply-marginalized disabled folks usually don't have opportunities to work in their workplaces, and it's because they burn people out. They pay people no money, and they don't give people the benefits they need to, like, survive. So, I hope that, like, my hope is we can help kind of foster that, like, learning and that change and growing.

Kennedy: That's great. Yeah, I feel like it's interesting, too, the, what you're saying about workplaces almost, like, replicates itself in the way that, like, you know, like you're talking about the money that went into the media campaign, and it's like, would people give you money to just give people care? And like, the way that different, I don't know, like, these, like, foundations or funders, like, I'm, I'm so interested in those conversations and, like, how that stuff works, like in terms of, I don't know, just like, yeah, the movements working together and, like, how, how, I don't know, how these things get decided, like, not even by you, but like, above, like, by funders and things.

Dom: It's...they're, they, they're tough conversations, honestly. I, I was in a room full of funders who, they were all funders who were committed to funding disability, and oftentimes, like, funders will give program project-based grants, but not like general operating funds, you know, every organization wants 'cause then you have flexibility with how to use it. But, like, my, my pitch to them was—and I've had this pitch one-on-one with funders before—like, yes, of course we want general operating money, but, like, this is, I have to tell them often that us hiring disabled people, us giving them good salaries with good benefits and having the kind of benefits that we have, like, that is mission critical. That's like actually part of our mission that that's not just like, that, that's not overhead. They, they think about it often as like, we don't wanna see too much overhead. And like, this, we're, we're hiring disabled folks. We're, we're, like, creating jobs, and we're helping. Like, giving good benefits is our way to help with that, like, liberation work that we ultimately wanna do. And like, I tell funders this all the time that, like, if they, if they really want to invest in disabled people, they will invest in, in their ability to live full lives. And that means, like, giving us money to hire people and do the work that needs to be done, so. And it goes over well, usually. I mean, there's some people who I think don't, don't get it. They don't see how. 'Cause you get s-, in the non-profit industry, you get so stuck in this, like, well, you can't have, you can't have high overhead, so people can't be paid enough because those, those people are strapped for cash. And, you know, you need to spend it more on the programs. And it's like, why? Why does it have to be that way? There's such a misconception about, about, you know, how that funding works. And so, anyway, that, it's one of my goals.

Kennedy: Awesome. Yeah. Yeah, I feel like I don't know if, like.... I'm trying to think what I'm trying to say. Like, do you feel like people are receptive to, like, disability justice initiatives or like? And I'm also thinking too, like, if there's ways we can partner. 'Cause that's kind of our intent with media, is to just, like, shift the framework, like, in, in people's minds all the time around disability. But yeah.

Dom: Yeah. I, I, I think that most, especially, like, if we're talking about funders, like, I think most don't understand disability justice.

Kennedy: Right.

Justin: Right.

Dom: If, if you say "disability rights," they're like, "Oh yeah, I understand, like, the ADA." Like, they have a very basic understanding of disability rights. Like, that they can conceptualize. They don't get disability justice. And, you know, I think some of the language might turn certain funders off. Like, when we talk about, you know, anti-capitalism, like, that probably freaks people out, right? Like, if, if we're gonna have disability justice, then we can't have philanthropy. Like, that's, that's the ultimate, like, outcome of disability justice. But like, in the interim, those of us who are doing the work have to have money to be able to do the work. So, I, I, I think it's a challenge. I think that, like, you talked about with media, like, narrative change is just as important.

Justin: That's right.

Dom: And I think that that's the work that all of us can do together is, like, how to, like, we need to get people to understand what, what disability justice looks like and, you know, talk about its history, talk about its principles, and, and get people on, on board with it. That, that, that's, that's the uphill climb, I think.

Kennedy: Yeah. For sure. I feel like, as, like, we've watched the conditions under which we "organize," quote-unquote, like, [laughing] just like, decline so rapidly in the past few years.
Justin: Yes. Mmhmm.

Kennedy: It's like, okay, we're able to keep those up. But like, is that also reason to just like, just do away with things? But yeah, no. It's, it's such, like, a tension.

Dom: Oh yeah.

Kennedy: But we can nerd about, nerd out about that, like, forever. But yeah.

Justin: Right. [laughs] So, like, like, Dom, you had mentioned, I think, and you had mentioned the mis-, misconception. Given the work that you do, you know, primarily in Southern states, like, you know, what misconceptions do you feel like people, you know, up North, especially, like, northern liberals and leftists have about organizing across the South.
Dom: Oh, so many. I mean, there's this, like, there's this, like, liberal thing that I see on Twitter all the time where people are like, you know, like, "Why do people even live in Texas? Boycott Texas." Like, they talk about that with Georgia. And, and I get it, like I, I.... Or they wanna, like, you know, basically Texas should secede from, you know, whatever. Like, I, I get where it comes from.

Justin: Mmhmm.

Dom: And we are also here. Like, it is not that easy for people to just up and leave where they live because we live in a state with a fascist government. Like, that's just not, it's— I think for, I see it all the time, and it, it pisses me off because people just don't think about it. Especially like, like, I'll, you know, be honest, like, I get, I have the privilege of, for multiple reasons, to be able to pick up and move, God forbid, if I need to with my family. It wouldn't be easy. It's not like I'm rich, but like, I could figure out how to scrape my money together. I'm, I'm a white dude. Like, I can figure out how to, how to move. But like, if, if we're talking about a multiply-marginalized disabled person, someone who may or may not rely on Medicaid, right, like, it, it is not that easy to just pick up and leave. And, and we, we also have a right to live where we wanna live. And so, I hate that when I see. It's mostly liberals, and it's mostly people from the North or maybe from California, both, both places I have lived, like, who, who say that. It's this idea that, like, the South is just, you know, it's a, it's a foregone conclusion that the South is, is, not, you know, we can't save the South, so why do people even live there? It's like some people don't have a choice. And I think that, that's frustrating.

And then, you know, in terms of organizing, I think this idea that, like, organizing is a lost cause in the South, because there are— I think the, the, the thought is that there are so many people on the right, like, why would, like, leftists, progressives, anyone who's not on the right organize? Because we're not gonna get the kind of change we wanna see. But that's not true. We live in very gerrymandered states. We live in states that, you know, are still people talk about Jim Crow and segregation like it's gone, but it's not. [chuckles] And we, people still live under that here. People still live under these systems of oppression. So, they have their, their ability to vote, you know, taken from them, it seems like, even more every year.

And so, like, it is not, these are not red states, so to speak. These are gerrymandered states. And the, the challenge with progressive organizers here in Georgia and across the South is that we have to work under those conditions. And we, we have to shift strategy and shift gears constantly to, to, you know, adapt to those changes and educate our people. And, and so, like, it's hard work, and, and it's frustrating when people in other parts of our country think, well, it's a lost cause. It's not a lost cause. It can't be a lost cause 'cause it's lifesaving work. And, and there are probably more of us than there are the people who support the Greg Abbotts and the Bryan Kemps. There are probably more of us than there are of them. It's, it's, we have to try to tear down these barriers they've put in place.

Justin: Exactly. And I think that's the, I think that's, like, the frustrating thing, like, I hear about as well is like, well, okay, well, people who live in Texas should, should move, or people in Florida should move, or people in Georgia should move. And it's like, it's very difficult for people with disability, disabilities to just up and leave.

Dom: Mmhmm.

Justin: And so, I think a lot of people don't really understand that. And, like, given in those states, as you mentioned, you know, you got people still fighting down there, and, like, they can't just up and leave. You know, they can't just do that. You know, you're, if you're there, you're going to fight for, you know, disability rights. You're gonna fight for disability justice. And so, I'm glad that you brought that point up.

Dom: Absolutely.

Kennedy: Totally. Yeah. I feel like people, when they assume that, like, the population, like, reflects an electoral map, it's erasing gerrymandering, but also erasing large groups of people.

Justin: Yes.

Kennedy: And I grew up in Nebraska. So, like, a little af-, right after I left, I was still a little jaded about it. Like, I get the, like, dismissal of, like, a grow-, like that environment. But yeah, it's, it's also people's homes, and like, like, having time away, like, now I, like, look back on, like, the positive things about living in a small community, or not that everywhere in the South is. But like, I don't know. Just like s-, like, it was a slower pace of life.

Dom: Yeah.

Kennedy: And definitely, like, lean back on some of that stuff during, like, the harder times lately of just, like, taking it easy and looking out for each other, like, your actual neighbors.

Dom: Yeah.

Kennedy: But we touched on this a little, switching back, is there other things you wanna say about, like, workplace cultures, maybe for listeners who hold power in any kind of workplace, about rest and sustainability?

Dom: Yeah, absolutely. I mean, I'll say it, in-, internally at NDS, we really try to, our, our, the way that I want to be as a, function as a leader in this organization and with my staff and colleagues, like, that is, it is critical for us to, like, function really democratically, little "d" democratically. Like, we, I, we have hierarchy and, and job titles, you know, because that's like how a typical workplace works. And there are some val-, there's some value to it. But we really value transparency. We value democratic thought. We, we really work to mostly not make decisions without making sure that everybody has a, a, an equal say and has the chance to express their opinions. There are some times where a decision has to be made on the fly between myself and Kehsi Iman or e.k. Hoffman, who is the assistant director of our (c)(4). But like, overall, we really try to bring decisions and ideas to our entire team. We, we have regular what we call, like, dreaming sessions where everyone just gets together, and we're just like, if, if we had unlimited money and time, like, what, what kind of cool shit could we do together? And everyone just, like, throws it out there, and then we, like, get to go back and look at it and be like, okay, actually, we can do this, or we can do this a little slightly differently than we thought.

So, like, I think that's really important to making a workplace more disability friendly and actually just in general a better place for workers because that, like, toxic power hoarding and information hoarding, I've been in workplaces where they've done that, and it, it's awful. It makes you feel like you're not a part of or you're not, you know, good enough to be at the table. And like, I just don't want a workplace like that. And so, I, we've been trying to intentionally create a place like that where everyone can feel like their ideas are heard. Even if someone has an idea and we don't go with it, or even if someone has an opinion about a decision and that's not the opinion that wins, like, everybody has the chance to, to, to express their, you know, honest feelings. And I think so far that's been really valuable to us building a sustainable organization.

And then, you know, in terms of, like, rest, sustainability, especially as folks who are working in movement, you know, it is hard living under capitalism and being in a workplace that isn't being more thoughtful about these things because sometimes you don't have a say. Sometimes you have to have a manager who, you know, is bugging you every five seconds for something and everything is urgent. And I understand. I understand that, like, this is, this is no-, like, what we are building at NDS is not something that everyone has. And so, I would say, like, find, finding those opportunities to rest, finding those opportunities to take time off, like, work cannot be everything. And I have to tell myself that all the time, especially when your work is tied to who you are as a human. Like, well, those of us who work in this space, it's, it can be, it can feel like everything is urgent all the time. And it's, it's just not. And I'm learning that now as a new dad, and like, you know, I'm learning that the longer I'm working in movement that, like, it's not sustainable if we, if we don't give ourselves rest.

I just bought the, the Rest Deck. It's like the founder of The Nap Ministry, Tricia Hersey, she put, made this Rest Deck where basically you pull a card, and it, like, gives you basic-, like some, like a reflection, something to meditate on about, like, you know, you deserve rest, you deserve to nap today. Like, it is amazing, and I bought one for everybody on our team and myself. And it's like I feel like everybody should go buy that and, and like, don't buy it from Amazon. Just like buy it from them direct, Nap Ministry directly, but it is a, it is a beautiful thing. So, that, that's some advice I have is go, go, go buy the Rest Deck. [chuckles]

Justin: Yes. Definitely need that. We need to, we need to make that a segment, Kennedy, focusing on rest.

Kennedy: Yes, absolutely. I love the Nap Ministry.

Dom: Oh yeah.

Justin: Yes. We, we, we love them so much. And so, last question before we end, is there anything else you want to add? Like, like, how can people get involved with the Disabled South, and where can they find you?

Dom: Yeah, I think I just wanna say that we are, we are trying to build a people-powered movement. We are trying to build community. We just did a, an event in Atlanta for, like, end of Disability Pride Month. It was just like a community conversation about the issues that face our city. And, and we wanna do that across the South. So, if you're interested in, like, hosting an event like that, like, we will set you up to do it. We'll send you the resources to do it. Maybe one of us can come out and be a part of it and help organize it. And, and if, if you're, if you're interested in that, you can, you can email community@NewDisabledSouth.org. But just generally, you can find us on NewDisabledSouth.org, on social media on all the platforms, including Twitter/X, which I really hate.

Kennedy and Justin: [laugh]

Dom: And I hate when it's become. And you know, but for now we're on there still and Instagram and Facebook. And I think we're on Threads, but we have, we haven't really used it. But yeah, NewDisabledSouth.org. You can find everything you wanna know, and we'd love for people to get involved in our work.

Kennedy: Amazing. Thank you so much, Dom!

Dom: Oh, thank you for having me. I've been so excited about this. I just love, like, I just love a good crip conversation.

Justin: Yes!

Dom: It's always, and I could just do this forever. [chuckles]

Justin: Yes. Yes, we could! And, like, and Dom, just like, thank you so much for just, you know, you know, you know, sharing about New Disabled South, and like, we really appreciate it.

Dom: Oh, absolutely. Thank you for having me.

Justin: And that, ladies and gentlemen, is the Crip Crap Podcast episode 23.5. Kennedy, where can everybody find us?

Kennedy: Crip Crap, we are, we are not on X.

Dom: Good.

Kennedy: 'Cause we didn't get on before stuff went down. But you can find us on Instagram @crip.crap.media, on Facebook, on LinkedIn under crip, both under Crip Crap and online at CripCrapMedia.com.

Justin: All right. All right. Thank you, Kennedy. And once again, thank you all so much for listening to our podcast, and we will see you on the next one. Take it easy.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet

But no cause for alarm
Stop a while to take my meds
Traveling real slow
That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don’t you know

Episode 23.4: Ableism and Trans Rights Past and Present with Joy Michael Ellison

Episode Description: Trans historian Joy Michael Ellison joins Justin and Kennedy to discuss the struggle for trans rights in the U.S. historically and now. They relate this movement to disability struggles through discussion of incarceration, psychiatry, sickness, access to public life, bodily autonomy, bathrooms, marriage, and more.

Justin: All right. Hello everybody, and welcome to the *Crip Crap Podcast* Episode 23.4!

Christea: (in song) That’s just some crip crap, don’t you know.

Justin: I am Justin Cooper.

Kennedy: I’m Kennedy Healey.

Justin: We are so glad for you to be a part of this podcast episode. How are you feeling, Kennedy?

Kennedy: Not too bad. Yeah, I...have energy today, and I’m really excited for this episode.

Justin: Yeah, same here, same here. Good energy, good energy. So, we’re going to go ahead and get started and introduce our guest.

Kennedy: Yes. We’re really excited to have our guest Joy on today. Joy Michael Ellison is a disabled transgender creator and time traveler. They are a scholar, a writer, and a lifelong activist. Joy is an assistant professor at University of Rhode Island, where they research transgender history in the Midwest and teach about disability justice, LGBT history, and transformative justice. They are also the author of *Sylvia and Marsha Start a Revolution*, a children’s picture book about the Stonewall Rebellion. Joy is interested in using stories, both fictional and true, to build community, document social movements, and imagine a liberated world. They believe that storytelling is integral to healing, transformation, resistance, and survival. Welcome, Joy!

Joy: Hey!!!! I'm so happy to be here with you.

Kennedy: Yay! I also wanna add to the bio that Joy was our first blog writer for Crip Crap.

Justin: Whoo!

Kennedy: So, if you get done with this episode, and you're like, "They're amazing. I need more," go to the blog, go all the way back to the first post, and it's a wonderful review of *Pose*.

Justin: Yes.

Joy: That's right! Yeah. I get to talk about Billy Porter with a cane, which is just, like, wonderful.

Kennedy: Yes.

Joy: What more could we want in life?

Kennedy: Absolutely. How are you doing?

Joy: I'm pretty good. So, I, I have a story for you. My favorite thing—well, one of my favorite things—in the whole world is watching birds and feeding birds, but I live in a fascist condo association here in Rhode Island that wants to ban bird feeding specifically because they have an anti-squirrel agenda because there are some ill-behaved squirrels. So, I've been trying to comply with their rules, but I discovered that the squirrels, the squirrels that come to my bird feeder with the hot bird seed that the squirrels can't eat, they still come sniffing around. And I've discovered that the squirrels that come are disabled. So, there's a little squirrel who has a limb difference that comes all the time! And there's another squirrel with a visual impairment who comes! So, now I'm just in disabled solidarity with the squirrels! [laughing delightedly] And I'm reorienting my bird feeding around the principles of mutual aid! And my condo association is just gonna have to deal with that. So, I'm great!

Justin: Yes. Yes.

Kennedy: That's incredible.

Joy: I love these guys. I love my squirrels.

Kennedy: This is the content we need. [giggles]

Justin: Yes, there we go. [laughs] And Joy, can you describe yourself for listeners who aren't familiar with you?

Joy: Sure! So, I am all of the things that Kennedy so helpfully said. I am also... I'm a very disabled person. I'm go by, through the Pokémon model of disability, like so many of us, where I have a fun physical disability, chronic pain condition, I've got some fun PTSD survival—survivor, hence, hence survival—experiences, and I am a Special Ed survivor. I feel like we need to start calling out the Special Ed experience specifically because it really is a distinct form of ableism.

Justin: Mm-hmm.

Joy: So, yeah, that's part of who I am. I'm a non-binary queer person. I've been using they pronouns for more than 11 years now, which I feel like needs to be said because we're in, we're in a very different moment, and it's a moment—than when I came out—and it's a moment that I find confusing. So, I've started to, to wanna tell people, "Look, I'm very old, and I just, I just need everyone to know that." And I am, I'm really, really interested in history, in research, in teaching, but also just in creativity and in finding different ways for us to connect with each other and to, to use our ability to imagine different outcomes and to share our experiences and stories in really beautiful ways. That's be-, that's becoming more and more important to me. So, I'm really interested in writing. I, of course, have the picture book out, *Sylvia and Marsha Start a Revolution*, and it is one of five picture books that will be forthcoming. But I can't tell you more about that yet. [sprightly chuckle] And I also do a lot of writing and commentary in many different places and remain involved in many different social movements. And I'm just always excited to talk with Crip Crap.

Kennedy: So, okay, yes. So much coming out.

Joy: [laughs]

Kennedy: We're gonna have like a squirrel solidarity front, books.

Justin: Books.

Kennedy: I think the gotta catch 'em all—

Justin: Pokémon.

Kennedy: Yeah. We can make some kinda app. Like, Twitter needs to be replaced anyway.

Justin: Right, right, right.

Kennedy: [laughs] We got options.

Justin: We got options. Options, yeah.

Kennedy: [laughs]

Joy: I love it. I love it.

Kennedy: So, that is wonderful. Anything else we should know about you? Like, the quirky things, like hobbies?

Joy: So, let's see. I will tell you this, that I am in the process of applying to a drag king academy. So, if I get in, I will be beginning my attempt to crip drag king, the drag king world.

Kennedy: Okay. I have names.

Justin: I have names. [joyful chuckle]

Joy: Oh, good! Yeah, because I need a name.

Kennedy: Okay. I don't know if you wanna go like, rural, but Johnny Smashed?

Joy: Oooh, that's good.

Kennedy: [inaudible; cross-talk] Johnny Smashed.

Justin: Yeah, [inaudible; cross-talk].

Kennedy: That's what I've been playing with.

Joy: Oh, I like this! I like that!

Kennedy: We'll talk. We'll talk.

Justin: Yes!

Kennedy: Okay. Okay.

Joy: Oh, that one's good!

Kennedy: Okay. I gotta say one more.

Joy: Okay.

Kennedy: This is not the topic of the pod—

Joy: [laughs]

Kennedy: Well, I mean....

Justin: It is now.

Joy: It kind of is!

Kennedy: 'Cause drag kings are, yeah, dire. Okay, so. Are y'all familiar with Bass Pro Shop?

Justin: Yes.

Joy: Yes!

Kennedy: Fishing store. Ass Pro Shop. [giggles]

Justin: You know what? Yes.

Kennedy: All my, like, rural queer ones that I came up with, with a rural queer care worker in the shower, and here we are. I like, late at night—

Joy: Yes.

Kennedy: —where my queer [inaudible; cross-talk].

Joy: I, I love it!

Kennedy: [laughs] Okay. We'll talk, we'll talk.

Justin: [laughing] Yes.

Joy: Excellent. Excellent.

Justin: [laughs] And so, and so, getting onto like, getting onto, to the podcast, Joy, can you, like, can you summarize, like, your, your academic and, like, other work in trans history sort of moving on from, you know, squirrel solidarity—

Joy: [laughs]

Justin: —Pokémon, drag kings, you know? [giggles]

Joy: Sure. Sure. It's all gonna connect. I promise you that even the squirrels are gonna connect. So, yeah, I am currently working on my first academic book, which is tentatively titled *Forgotten Feminists: Trans Movements in the Midwest from 1945 to 2000*. And I'm looking, I'm looking at specifically Midwestern trans movements, predominantly looking at trans women and especially trans Black women, but also looking at how race is operating more generally. And because I'm really, really interested in how our accounts of so many different forms of oppression, including ableism, would shift if we were really centering the contributions of Black trans women to our understandings of how sexual identity work. So, I am looking at this entire 50-year history, looking at everything from how drag has operated in the Midwest and how drag has been a lens through which mainstream culture understands trans femininity, and particularly a way in which trans Black femininity is commodified. And then also looking at how trans Black women have been critical parts of the female impersonation industry—and I look at it as an industry specifically—and have used their popularity to create really subversive spaces in which they could survive as a community.

I also look at some of the first formal trans organizing in the Midwest, which started in Chicago with an organization called the Transvestite/Transsexual Legal Committee. I look at the history of open support groups in the Midwest. So, these are groups oriented around cross-dressing that opened their membership to queer and trans people, so, so, people who wanted to include medicalized gender transition as a part of their identity and experiences. And how these folks become a really important part of creating the LGBT community, which before was really ex-, which was really or-, oriented around the G and the L, and the B was just like barely hanging on there and remains just barely hanging on. But they, particularly trans women who came to understand themselves as lesbians, became the, the bridge builders between very different communities: heterosexual cross-dressers and then queer communities specifically.

I also look at AIDS activism, particularly the AIDS activism of Black trans women who were incarcerated, which is one of many places where disability gets really engaged with in my research. And then I look at a group of people I lovingly call the trans witches, which were a group of Midwestern transsexual lesbian feminists in the 1990s who were interested in articulating trans responses to trans exclusionary lesbian feminist rhetoric through lesbian feminist lenses, including through witchcraft and spirituality.

So, that's, that is the milieu that I have been researching. I work with archival sources as well as oral history interviews, and I also have a public history blog called If We Knew Trans History, which you can find on my website, which is JMEllison.net, where I try to present my research for the public and also just try to talk about trans history and what it would mean if our social movements were actually informed by the struggles of trans people.

Kennedy: Amazing.

Justin: Amazing.

Joy: [delighted laugh] Thank you. I think it's amazing! I think it's just incredible to get to be a part of sharing the stories of people that have really become my heroes and who've really been just erased from our consciousness, even though they were such critical parts of so many movements that we're still involved in today, including disability justice work and including prison abolition work.

Kennedy: Totally. Yeah. And I feel like history is, like, so important right now for, like, hope.

Justin: Mm-hmm.

Kennedy: Like, people've been up against, like.... I mean, the current moment is obviously different, but, like, people've been up against so much, so many times before.

Justin: Right.

Kennedy: And yeah, with Crip Crap, we're, a lot of our listeners have interest in disability and not to, like, detract from, like, it's fine to just talk about one thing, but we're interested from, like, a solidarity perspective and in, like, finding disability in other movements—

Justin: Yes.

Kennedy: —where you see disability or, like, intersections with disability and ableism in your historical work.

Joy: Yeah, absolutely. Absolutely. I think it is a really critical thing to identify those intersections, in part because those are just our lives, right? Like, we are, like, I am a queer, nonbinary, disabled person. All of those things are always happening at once. And also, these systems are always happening at once and really feed on each other in fascinating ways and in ways that we need to understand if we're going to find ways to survive them and to liberate ourselves from them.

And, like, one, one way that disability justice really informs kind of my research on trans history is looking at the ways that, that prisons have oriented themselves around the idea of care. And, like I, I've been looking at how Black trans women in prisons are identifying prisons as a health risk and specifically as a HIV/AIDS risk factor, and then pointing out that every single time the prison system says, "We're going to care for you, we're going to protect you, we're going to provide healthcare for you," it is always done in a way that fundamentally undercuts the bodily control that trans people have over themselves and, and also undercuts their identities. So, there's this, there's this really clear, at least in my mind, overlap between ableism and where, like, cu-, care starts to operate a lot like cure.

Drawing on kind of Eli Claire's ideas about cure as a form of violence, care when it's used by a system like the prison system becomes another form of violence. And there's this really clear overlap in which what queer and what trans and disabled people—queer people as well—all have in common is that our ability to control our own bodies is systematically taken away from us by systems that feel they have the right to control who we are and that there is something wrong with us that needs to be corrected. And we also share a need to access healthcare and to navigate these systems in a way that gets us what we need while these systems are also systematically designed to disempower us, to control us, and to even kill us. And the way neither trans nor disabled people can be particularly precious about how we go about that, we just have to get what we need. And that goes doubly for those of us who have intersecting identities.

Kennedy: Totally. You also once were telling me about Sylvia and Marsha protesting outside of a psych ward?

Joy: Yeah. Yeah. So, this is, this is some of my favorite history. So, yeah, some of the, the most famous pictures that you've probably seen of Marsha, where she's holding a sign that says, "Power to the People" and a cigarette. She's got her fur coat, and she looks amazing. Target decided they needed this photo on a t-shirt, but they photoshopped out her cigarette 'cause it's Target.

Kennedy: And then put it in the back.

Joy: Anyway.

Justin: No, lord.

Joy: Yeah.

Kennedy: Yeah. And then just pulled it off the shelves.

Justin: Good lord.

Joy: Right. Right. You can only buy it online now.

All: [chuckling]

Joy: But. [laughs] Yeah. So, she's in front of Bellevue Psych Hospital. And this is a protest against this psych hospital, which was also being operated by New York University. So, it's a part of this academic medical industrial complex, which is important to map. And the reason why this protest was going on was because queer and trans people, particularly those of color, particularly those who were impoverished, and particularly those who were disabled were being systematically arrested and shoved into these psych wards, which were places of control that provided no cure, I mean, no treatment, no, no care whatsoever. Miss Major, another Black trans woman originally from Chicago—we'll claim her—she, she's talked about this and talked about how at that time, trans women living on the street were just constantly teaching each other how to get out of psych wards like Bellevue because the risk was so high. And Marsha had been repeatedly forcibly incarcerated in psych wards against her will and subjected to, for psychiatric treatment in the form of Thorazine, which is a serious, serious drug. And the reason why Marsha was constantly being targeted for this was because she was trans, she was Black, and she was also disabled. She, she has a great line where she says, "I may be crazy, but that don't make me wrong." Which just summarizes her disability politics beautifully.

And so, there was this huge movement to, to help people understand that the Bellevue Hospital was really a prison where people were being locked up against their will. But also, queer and trans young New Yorkers were saying really clearly, "We believe that we should be able to get the care we do want from institutions like heal-, like a hospital, and that those, those institutions should respect our identities should stop trying to cure us, and simply give us the resources that we do want. So, they're talking about free healthcare, free abortion, free psychiatric care on demand, on their own terms. And then also, and this is one of my favorite things, is they're, they're, they come up with this idea that they call oppression sickness. So, they're saying, you know, "These experiences of racism, of transphobia, of homophobia that we're going through every day are causing us mental health problems!!! They are, in fact, disabling, and we deserve care on our own terms." So, this is this incredibly powerful piece of disability history that we are not getting access to that I think we need in a desperate way and that we need to find and uncover more stories that show us what it means to understand the experiences we're having structurally and understand how they relate to multiple identities at once and multiple systems of oppression at once.

Kennedy: Totally. Wow. Yeah. It's like, runs old and deep.

Justin: Mm-hmm.

Joy: It really does!

Justin: Yeah, it, it, yeah, it truly does. And, you know, given what's, like, currently, like, happening, like, in, in our society in terms of, like, you know, things that are just, just happening in terms of, like, people's rights, you know, like, being, being taken away and just the constant fight that, you know, not just trans, you know, not just trans folks, but it's like people with disabilities, you know, you know, Black, Black, Black and brown folks and just the intersections that, you know, go around it.

And so, Joy, for like, for listeners who are, like, less familiar, can you give like an overview of the current bills that are just, like, attacking, like, trans rights across the nation today? Or just, you know, pointing people to, like, resources to find more information, you know, themselves?

Joy: Sure. So, we are in the midst of what I would call a backlash. And it is coordinated, it's strategic, and it is multi-pronged. So, across the country, Republicans are submitting a variety of bills that are attacking really the entire queer community, but through trans people specifically. And also targeting the entire, the entire community of oppressed people through going after the idea of critical race theory. And these things really, really intersect and cohere. They're very cohesive in the minds of our opponents, so they have to be cohesive in our minds as well. So, you're seeing a few different types of bills. We've got bills that are trying to prevent trans girls from being a part of sports. So, there are a variety of different spins on this idea, but they all come down to the idea that you need to be in the, you need to compete according to the gender you were assigned at birth. And this, Republicans are p-, are packaging this as being a form of women's liberation. But since when have they cared about women's liberation?

Justin: Right.

Joy: The, this is nothing more than a real way of controlling the, the bodies of trans people and the bodyminds of trans girls, and really saying that trans, trans children don't have the right to participate in society. And that becomes more clear as you look at some of the other bills that they are submitting in states across the country. There are also a lot of attacks on trans healthcare and specifically on the healthcare of trans children. So, you have proposals that criminalize providing trans kids with gender-affirming medical care, like hormone blockers, like mental health care that affirms their gender identity. And there's a range of proposals, as I said, but many of them criminalize healthcare providers for providing basic services that healthcare providers have for a very long time, somewhat begrudgingly, admitted are absolutely necessary! And that, we could talk more about kind of that history if you, if you like, because it's, it's important to ally with healthcare providers when we can. But it's also important for us to understand between ourselves that there's more going on there.

But that aside, the other category of bills that we're seeing are drag bans, which I find particularly interesting as a researcher. So, in Ohio, for example, there is a new bill that has been proposed that defines any person who ent-, who is an entertainer and performs as a gender that is not their gender assigned at birth, they define all of those people—which is just any trans person who performs anything. So, if I go to a poetry reading, and I read a poem, I, I have to, I'm under this bill. That's my understanding of this. That's what it appear-, it says—it defines all of those people as adult entertainers, so that, and as cabaret acts. So, that's the category that we put strippers and topless dancers in. And the idea here is that we're gonna restrict those folks from performing in all-ages venues.

So, this, this is all about, in the minds of Republicans, protecting children from seeing trans people and from seeing drag performers with this idea that drag performers are specifically grooming children for sexual abuse, which is just the old idea that they've been advancing for decades and decades and decades, that queer and trans people are pedophiles. And we know that's not true. We know that that is an absolute lie and that that has tremendous consequences for all queer and trans people, but especially for queer and trans families, for queer and trans parents.

So, this bill in Ohio is one of, I believe, over 14 currently like it. Although by the time this comes out, we'll see what's going on. And it really will have, if it's passed, it will have the effect of removing trans people from public life. Because it's written so broadly that if you attend a pride parade, you could be arrested because that could be construed as a performance. Drag Queen Story Hour could become a crime. But also, simply performing Shakespeare in drag would be a per-, a, a crime. Tyler Perry's entire career would be criminal.

So, what we really, we really need to think about this historically and to understand what this is gonna do because we've actually been exactly here before. Columbus, Ohio, was the first municipality in the United States to restrict cross-dressing in public and to say that it was illegal to appear in clothes that did not conform to your assigned birth gender. So, we've seen how that impacts people. And one of, one of the impacts that I think is particularly important to understand right now is that it, when, when people were arrested under these laws, the media always referred to them as "female impersonators." So, they understood them through the lens of drag, because drag has long been a mainstream, incredibly popular art form. Ronald Reagan appeared in a movie with drag queens that was produced by the U.S. Army, so I don't know how to say it gets more mainstream than that. I also just look forward to conservatives reckoning with those facts. Anyway!

What, what we can see is that when, when trans people are understood through the lens of drag, it undercuts our ability to articulate our identities as anything except a costume. It really undercuts our basic civil rights. And that what's at stake right now is just the right to be in public, which is something that disabled people have also dealt with historically and are continuing to deal with historically, in the present day. Like, when we looked at history, we could think about things like the Ugly Laws, which simply restricted people from, with disabilities, from being in public because they were ugly. According to basic bitches. Which is our new word for people who don't understand that they probably are disabled. Because more and more, I just think that able-bodiedness is to some degree a myth, [laughs] and that we probably need to talk more about that. Anyway.

And then today we could see this with COVID, too, where disabled people are being shoved back into our homes because people refuse to continue any sort of masking, any sort of accommodation for disabled people. So, we're, we're both returning to the old normal, and we're creating a, a new normal that is even worse. So, all of that is happening along with these critical race theory bans on books and on courses and a tax on higher education, which in Florida are really taking the, the form of laws that are having a massive chilly effect on higher education. And professors are terrified to simply teach courses that discuss oppression, privilege, and history. And we're, we're seeing people leave the state. And we're seeing these laws, though, spread across the nation. And there still is lots of time and opportunity to fight them, but it, the situation is dire. And we already had a dire situation! So, we have, we have a lot of work to do.

Kennedy: Yes.

Justin: Yes, we do. And, and to Joy's point regarding the, the Ugly Law, so Chicago was actually the last, the last city to repeal its Ugly Law in 1974, so.

Joy: Yeah.

Justin: So, yeah.

Joy: Wow.

Kennedy: Yeah. Interesting how everything's like, to talk about it with you in a historical context and then also connect all the things going on right now, and how these, like, policies, whether it's, you know, like, allowing police violence and murder or the pandemic or these bills regarding gender, like, we're just, like the, the way in the last few years that, like, disposability has been uber-normalized, not that it wasn't before, is, like, so disturbing.

I think, too, like, I saw just this morning an article, I believe in New Jersey, there was a mom and a son, and this son was a non-speaking autistic person who went into the restroom, the women's restroom with his mother and was kicked out of a movie theater. And people, so, people, this was on the Instagram of Crutches and Spice. Like, people are drawing these connections in how these bills are affecting everyone. And yeah, the bathroom is like a site of so many types of oppression and lack of access!

And you touched on it some, but is there other ways you see, like, historical context in what's going on right now or seeing connections between ableism and transphobia right now?

Joy: Yeah. Wow, that, that example is so powerful. It, it really, it really is. And it's, it's so maddening that we just can't all pee. We just like—

Justin: Yeah. Oh, God, yes.

Joy: [laughs] There is, yeah, I just wanna see more, more protests that are just about trans people and disabled people saying, "Where are we supposed to go?" Like, yeah. That's, that's one of my, my dreams because, because we have, we have that in common in a huge way. Yeah.

So, I think, I mean, historically, the other thing that really stands out to me is just how useful the idea of eugenics is and how much that is, that system is the thread that I see running through all of this. And you could see it really, really clearly in trans history where even some of the first sexologists that were trying to advocate for the civil rights of trans people were still doing it through the framework of eugenics and through these “deserving” and “undeserving” people. And specifically, like, looking, saying that, “Well, some, some trans people should, are okay to pass their genes along. And other trans people, well, they’re perverted, so they shouldn’t get married.” And like, so, yeah, shades of restrictions on Deaf people marrying each other and all sorts of, there are all, there’s, there’s a galaxy of parallels to trans people or to disabled people.

Also, we see this with, going back to what I was saying about healthcare providers. So, I’ve been looking at Minnesota, which was a center for trans healthcare because trans women fought to get decent healthcare. Because the first researchers to start providing surgery for trans women had the most eugenics framework for determining who could get that surgery imaginable. They were rating people based on their outcomes and whether or not they continued having trans friends after the surgery. That was a fail. Like, if you continue to be involved with the community, that was a fail because the goal of these surgeries was to cure being trans by eliminating trans identity altogether.

They also wouldn’t let you get married. Or they wouldn’t, they wouldn’t let you have surgery if you were married because that would make you gay. So, so, we can’t have that. So, there was just this range of, of, like, ableist rehabilitation-oriented rhetoric that’s encoded in who gets surgery at this time, including they wouldn’t, like, if you had a felony conviction, you weren’t gonna get surgery. If you were psychotic or a sociopath, you weren’t gonna get surgery. And their definition of sociopath is as flexible as, as any totally ableist definition of a psychiatric condition tends to be.

But what’s really remarkable and that I think can give us a lot of hope is that trans women in Minnesota managed to not only use this terrible system to get life-saving surgery that they desperately needed, but also, they successfully sued the state of Minnesota so that the state of Minnesota had to start paying for surgery, full stop. They, they won that, and it was a very precarious victory. But I think that’s the sort of thing that we need to look back at those sorts of victories right now and think about, like, what does it mean to wage a, a struggle that’s revolutionary in its hopes but is deeply local. What does it mean to, like, be engaging in local politics? Because the Republicans are geniuses at the local level, and we’re not. Chicago’s pretty good. I will say that. Like, Chicago’s learned how to do this. [laughs] So, once again, like, I’m, I’m just out here telling the world that the Midwest is deeply cool.

Kennedy: Yes. I feel like it’s like a bag, and once you open it and start taking things out, it’s like everything.

Justin: Mm-hmm.

Kennedy: Like, folks who are interested in, like, politics of bathrooms, I recommend checking out the Restroom Revolutionaries is a group in California who is doing, like, changing tables, tampons, like, gender and disability in, like, bathroom organizing on a campus. And I think they had a slogan, “Free to pee.” But yeah, like, everything you’re saying is making me think about, like, like, queer and trans folks being, like, historically listed as a diagnosis in the DSM and, like, yeah, let’s get rid of the DSM. But also, like, in the meantime, can you then get rights under the ADA through that? Like, can we share laws that way? Or, like, talking about marriage, like, and disabled people and marriage equality and services. And it just like, it’s, like, unfolding some kind of complex piece of origami or something. Yeah.

Justin: It’s that solidarity we need, need, need. We need, we need, we need, definitely need more of that. And so, Joy, so, what, what, what does, like, you know, speaking of solidarity, like, what does solidarity with trans pe-, with trans people look like right now?

Joy: That’s a wonderful question. And I think it starts by just asking that question. Because it’s so different than the way this is usually approached, which is, is to either say, “Oh, well, we just need to fix it for trans people,” which I understand. I understand that impulse. But you can’t fix something that you don’t understand. Or, or it’s like, “Oh, well, I just don’t wanna be rude.” This just becomes a matter of etiquette, which is very similar to my experiences of, of interacting with non-disabled people, right? It’s, it’s just like, “Oh, well, I just don’t wanna be rude,” which is not what is at stake. I’ll take rudeness in service of solidarity any day. But so, I think we, we start by a-, really asking that question and by trying to identify who is the most impacted and taking their leadership. And I wanna, I wanna name that that’s both very, very simple and also, very, very complicated.

And there’s a real, I think we really have to think about how targeted trans children are right now and how very young people are at the forefront of these movements. And so, we have to, and this is where, where again, there’s a, there is a real similarity between ageism and ableism. And I think the disability justice movement has some real skills to offer here. We really have to find a way to orient our movements around respecting the rights of children to make decisions about their bodies and also to respect their right to struggle, but to understand that testifying against a bill that is trying to remove you from public life is traumatizing and that we should not be thrusting our children to the front of the battlefield! We need to fight. We need to have a real conversation with each other about how we support each other and what solidarity looks like.

And it, like, I think, I think it really comes down to going back to Audre Lorde, as so many things do, to think about self-care as an act of political warfare and also to think about the looking at our differences in so many different ways, whether that’s sexual orientation, gender identity, age, ability, race, class, etc., etc., etc., and thinking about how we can use those as a dialectic, as a source of power and really find ways to protect each other. ‘Cause we’re, we’re not doing that in a really conscious way on a mass level yet. But this is where I see disabled people as having just a raft of skills because we have such different access needs. We are such a coalitional identity, such a heterogeneous identity, and sometimes our access needs come into conflict with each other. We know something about this that I think is desperately needed in the larger movement, and I, I hope that people start listening to us.

Kennedy: Totally. Yeah. I feel like...that, like, this question gets asked in so many different, like, contexts, and it’s like, do you interact with marginalized people, and like, how can you help them, [laughs] like?

Justin: Right. [chuckles]

Kennedy: It’s like you might have to start by, like, expanding your social circle, truly. Okay. This was so, yes, I’ve been trying to not, like, make a nightmare for our transcribers. So, that’s why I’m, like, interrupting guests less to hype them up. But I’m just over here nodding. But that’s all to say we, we also wanted to touch on your newest project with Leslie Feinberg’s photography. What, what’s going on there? I know some of the work around it previously, and how can people get involved in this?

Justin: Yes.

Joy: Yeah. Thank you for asking this question.

Kennedy: Mm-hmm.

Joy: I'm so excited. So, let's first of all, just have a moment for who Leslie Feinberg is.

Kennedy: Mm-hmm, mm-hmm.

Joy: Leslie Feinberg, who uses both she/her and zi/hir pronouns. Okay, Leslie Feinberg is one of my dearest heroes. Zi was a white Jewish lesbian-identified trans person who really embodied kind of a non-binary identity at a time when there, where there wasn't that language, and instead was using language like "genderqueer," but also just using the term "trans," like, at, like, identify as a lesbian transgender person. They were also a communist and deeply, deeply, deeply involved in anti-racist organizing, including rac-, the organizing to try to free CeCe McDonald, who was a Black trans woman who was incarcerated in Minnesota for defending herself in the middle of a racist, homophobic, and transphobic attack.

And, and Leslie Feinberg ha-, was also disabled, and that part of hir identity has been completely ignored by the scholarship and kind of the popular engagement with Leslie's work. And so, I've been looking at Leslie Feinberg's photography that Leslie made at the end of hir life when zi had Lyme disease and was at home and unable to leave the house and mostly had real struggle, it was very painful to look at bright lights. So, Leslie was kind of up and about in the evening and in the morning and was unable to write, which had been a major, major source of political organizing, just a major part of hir life, and was having difficulty talking. And what zi decided to do was to turn to photography. And zi said that zi wanted to make pictures, not take pictures.

So, this was this radical consent-based attitude towards photography, because, you know, as disabled people and trans people, we know that photography can be a real act of violence. Like, we are often subjected to non-consensual photography or photographed in ways that make us seem other. We're photographed in ways that make us prove our diagnoses, all sorts of disgusting, voyeuristic, frustrating photography modes. So, Leslie was like, I'm gonna make something else. I want to always show my pictures to other people and ask them, like, "We're gonna make the picture together. Is this photo okay?" And this is before selfies. This is like the early, early '90s. But as Leslie is stuck at home, Leslie can't ask for permission in the same way.

So, Leslie starts taking these absolutely beautiful, strange, breathtaking photos from hir window, and they, like, show windows as these, like...like, will show a picture of the window that really highlights the screen, and then will show, like, beautiful colors behind it. So, there's, like, this sense of being screened in, like, windows become permeable, which is really important for those of us who are at home just to show how we are connected to the outside world. The natural, the so-called natural world, the other-than-human world, was really important to find work. And photography was a way that zi was creating these connections.

And then Feinberg was also looking at social systems through photography and would take these really distanced shots that, where you couldn't see anyone's faces of, like, the, the senior citizens center across the street where disabled people and elders were chilling on the front porch. And that's, like, a really different picture of disabled people! And would also take pictures of evictions in a way that just highlights not the people who'd been evicted, but the system of eviction itself.

So, and then the long and short of it is Feinberg's photographs, which zi claimed as a part of the disability arts movement, are breathtaking and really, really, really important. And the way that zi talked, thought about disability and also how disability connected with gender is really, really important. So, I wrote an article about this that is a s-, like, a hoity-toity academic article looking at Leslie Feinberg's photography through Alison Kafer's idea of the political/relational model of disability, and I'm looking at, like, what would it mean to have a political/relational model of gender? Which I think could be really important for our movement. So, I'd written this article that I'm excited to share and to translate into more popular ways of engaging these ideas. And one of the ways I wanna do that is to invite people to make pictures and share them.

So, let's use Leslie Feinberg's techniques to make pictures of ourselves, each other, our world, and, and kind of document our experiences of gender, of ableism, of embodiment of the natural world, of these systems of oppression, and share them with each other. So, I hope that people will want to get involved with that, and I, I will say that I am both politically and, and spiritually bad at social media. So, I have not yet entirely figured out how we're gonna make this happen, but I think we'll come up with an Instagram hashtag. Maybe we can partner with Crip Crap and come up with some ways of getting this out. So, so, pay attention to this space, and we can come up with something that will work well. It's hard to know right now with Twitter being in flames! We're, we're kind of in between social media platforms, so we'll see what happens.

Kennedy: I'm already thinking of hashtags.

Justin: Yes.

Kennedy: This sounds great.

Justin: Yes.

Kennedy: So, I'm like, "Make don't take."

Joy: I love it. I love it.

Kennedy: Like, taking as like, taking something from someone.

Joy: Mm-hmm!

Kennedy: I would also say if folks are interested in photo, check out our last episode with Megan Doherty and our episode from last season with Marley Molkentin, a photo project we did together 'cause a lot of these themes are, like, in there too. So, yeah.

Joy: Oh, awesome. Maybe we need to do a joint blog post with all of those people, just talk about photography.

Kennedy: Yeah. We could easily put photos up too. Yeah. Justin's a photographer. It's, yeah.

Joy: Yes! Yes!

Justin: Yes, yes. I'm already thinking of, like, ways that we could, we could, that we could pull this off. Oh, yes, yes. I would really, definitely love to be involved in this.

Joy: I am so glad to hear that!

Justin: And so, so, Joy, like, before, before we go, is there anything else you want to add for our listeners to know?

Joy: Well, first and foremost, I want to say that Crip Crap is amazing, that you two are two of my favorite people, that I, that this is a pleasure and an honor to be with you. And as I said, I am bad at social media, but I do have a website. It is JMEllison.net. I am on Instagram. It's j_m_ellison at Instagram. And like, please be in touch. I love hearing from people. I am all, I am really trying to connect with folks more actively and find some ways to draw connections between all of these issues and draw connections between our tremendous creativity as disabled people and, and create some great art and some great community and some great sources of pleasure in our life because, my God, we really need it.

Kennedy: Absolutely.

Justin: Yes.

Kennedy: Yeah. It was—

Joy: And let's go feed disabled squirrels.

Justin: Yes.

Kennedy: [laughing] Yes! It was so lovely to have you on. And yeah, I hope we can keep partnering on a photo project or other things.

Joy: You know we will.

Justin: Yeah.

Kennedy: Yay!

Justin: So, thank you. Thank you so much. Thank you so much, Joy. And that is episode 23.4 of the *Crip Crap Podcast*. We are so thankful for you being a part of this. And how can, how can people reach out to us, Kennedy?

Kennedy: Yes! You can get in touch with us on CripCrapMedia.com, on Instagram, Facebook, LinkedIn. Our handle's either CripCrap or CripCrapMedia on all of those. You can look for our pink and black logo if you are sighted, and you can also email us, info@CripCrapMedia.com, and on our website you can subscribe to support more content, events, and other future projects.

Justin: Yes, that is correct. And so, thank you all so much once again for listening to the *Crip Crap Podcast*, and we will see you next time. Take care.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow

That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don’t you know

Episode 23.3: Portraits of Immunocompromised Resistance with Megan Doherty

Episode Description: Kennedy hosts guest Megan Doherty to discuss her virtual photo project, *Compromised*, which features immunocompromised subjects and their experiences during the ongoing COVID pandemic. They also discuss pandemic advocacy efforts, safer event support, and hopeful scientific interventions.

Kennedy: Hello everyone, and welcome to episode 23.3 of *Crip Crap: The Podcast*.

[folksy riff on acoustic guitar]

I’m Kennedy Healy. Unfortunately, Justin Cooper could not join us today. We’re very excited to still be talking with our guest, Megan Doherty, who is a Chicago-based photographer, a 2021 fellow with Disability Lead, and the current strategic advisor and project manager of Disability Lead. In her spare time, Megan enjoys practicing qigong. Welcome, Megan!

Megan: Hi! Thank you for having me.

Kennedy: Thank you for being on. How are you doing?

Megan: I’m good. I’m excited to be here.

Kennedy: Awesome. Can you describe yourself a little bit for listeners who don’t know you or your work?

Megan: Sure. I’m a writer, photographer, disability advocate, and a recovering academic.

Kennedy: Oh, I didn’t know that!

Megan: [laughs]

Kennedy: Anything in particular that you enjoy, like, writing about?

Megan: Well, for the past few years, I’ve been focusing on chronic illness, you know, medical research, disability.

Kennedy: Nice. And anything else you want listeners to know about you?

Megan: I'm also a rabbit person. I recently adopted another shelter bunny. So, if you like animals, I invite you to support the Red Door Animal Shelter located in Rogers Park.

Kennedy: Awesome! Is that where you got the bunny?

Megan: Yes.

Kennedy: Okay. That sounds like a lot of fun. How many bunnies do you have?

Megan: Oh, right now. But I've had rabbits in the past, and luckily, this is his afternoon siesta time, so he's not gonna be [laughing] distracting me while I'm talking with you.

Kennedy: [laughs] Are they loud?

Megan: They're really not loud, but they can be little mischief makers.

Kennedy: Okay. Gotcha. I always find out the funnest facts about our guests.

Megan: [chuckles]

Kennedy: That's exciting. Okay. More rabbit questions off of the podcast, but we've been talking about getting you on here to talk specifically about a photo project you've been doing. Does it have a title?

Megan: *Compromised*.

Kennedy: Okay, awesome. So, it's highlighting different immunocompromised subjects and just what the experience has been like during the pandemic.

Megan: Yeah, I'm disabled and immunocompromised myself, so I am doing remote portraits of immunocompromised people from all over the United States. And I'm also asking each of them to send me one sheet of paper, kind of like a letter, something written in their handwriting. It'll show the date that their portrait was taken. There'll be some, some data, some statistics about where we are in the pandemic right now, as well as their own personal thoughts and reflections about how they have personally been impacted by this. And their portrait will be paired with the letter.

Kennedy: Awesome. So, before we get too into the details of the project, what do you wish, like, everyone knew about the experience of immunocompromised people during COVID?

Megan: There's a lot that I would like for people to know.

Kennedy: Mm-hmm.

Megan: The way to sum it up is that this is a civil rights issue. Immunocompromised people have been de facto segregated out of public life. There's really no genuine access if there's no safe access. And right now, immunocompromised and other medically vulnerable people don't have safe access pretty much anywhere, not even our own doctors' offices right now. So, I think that it's really imperative for people to face the hard truth that this is eugenics. And by that, I mean state policies that are designed to maximize advantages for those perceived to be healthy at the expense of those considered quote-unquote "disgenic," a.k.a. people like me! [laughs] And, you know, a key example of this is ending universal masking, because all that really does is prioritize the comfort and convenience of people with health privilege at the expense of the health and lives of people like me. And not to mention, like I said a moment ago, it strips us of our right to fully participate in society.

Kennedy: Absolutely. Yeah. It's just been, like, watching the...the, like, wishy-washy of the mask policy, and yeah, I think the settings have become more and more dire in which we're no longer requiring masks. Yeah, it's very, very disturbing. Are there, like, any helpful coping mechanisms you've found or, like, would recommend for folks who've been isolated in the past three years, three-plus years?

Megan: I don't know if I can really recommend coping mechanisms to people. It's, it's certainly been a rollercoaster of emotions for me, and I've absolutely had moments of just pure despair. But the advocacy work that I've been doing at least helps me feel like I'm doing something, and it helps keep me from just being completely awash in nihilism and defeatism. At the end of the day, I just really need to be able to look in the mirror and know that I gave them hell. Like, when all is said and done, I can look back on this time, and even if everything that I'm doing right now ultimately fails, then at least I can say, you know what? I gave them hell all the way down.

Kennedy: Yeah. Yeah, I think...the, I think people have gotten somewhat nihilistic, which makes sense given all that's going on. But I do, yeah, I do think there's something to be said for, like, continuing to try. And all the people who, like, I feel like display hopelessness are actually still doing the work. So, like, I see that you're actually hopeful, though, you know? So, yeah, absolutely. I think, yeah, at least we can say we tried. But also, like, I still think there's, like, a lot of possibility for change and learning. And like, obviously not everyone took that, but, like, some people, I think had, like, big, different kinds of big, like, moments of realization because of COVID and, like, other social justice, environmental things that've been happening in our country. So, yeah, I love the idea of a photo project. I.... We did another episode. Me and a caregiver did a photo project about care during the pandemic, and I think it's been, it's like a really interesting way to communicate with folks. Was there, besides just like the overall what's going on in the world, was there, like, certain inspiration you found that sparked your project specifically?

Megan: Rage, to be honest.

Both: [laugh]

Megan: You know, a really twisted combination of rage and spite has motivated me throughout much of this. The only way that I can make visible those most at risk is to photograph them while we all shield ourselves from the safety of our own homes. And, and this is not just the only way I can actually do this without risking anybody's life, including my own, it also underscores the nature of the problem. People who view this project wouldn't be able to look at the photos and see how they were created without being forced to think about why they had to be created this way.

Kennedy: That leads right into my next question, which was how exactly did you go about photographing high-risk folks as someone who is high risk?

Megan: Well, a lot of failure, to be honest. I have this habit of repeatedly deciding to do things that I have absolutely no how to, no idea how to do when I start them. And given that I'm not remotely a tech person, this has been quite an adventure for me. So, it really took a few months at the beginning to get the first portraits off the ground, simply because I was cycling through various tech options and logistics and trying various methods and having them not work, explode in my face, etc. But I think, I think I've hit my stride now. I'm getting some stuff that I really like.

Kennedy: That's awesome. Okay. I don't know if I fully understood. So, can you explain again, like, how you shot the project remotely?

Megan: Yes. So, there are some apps where you can actually kind of take control of the camera on someone else's cell phone. So, that's a new one I'm trying. So, I can just, you know, have the app on my phone. They download the app, it's free, to their phone, and then I send them a little link to, like, a session. It's kind of like a video chat session. And I can see them and, you know, control the exposure, the, the focus of their camera. And then I basically, the hardest part is just art directing them, trying to explain, okay, "How do I want you to hold the camera? Where do I want you to stand? Angle it this way. No, your other this way. No, but, but actually, I mean, pivot it. Just hold it where it is, but, but pivot it. Don't," you know. So, that's been a bit of a trick figuring out how to use the right language to explain exactly how I want the image framed and where I want them in the frame. That's, that's been very challenging as well, almost as much as just the basic, you know, how do you get a pretty decent resolution image [chuckles] when I'm here in Chicago, and someone else may be in California or New York or wherever it is?

Kennedy: Do you think— Yeah, that actually reminds me a lot about, like, directing caregivers [laughing], like, in a very different way.

Megan: Mm-hmm!

Kennedy: But, like, as you as the artist.

Megan: Mm-hmm.

Kennedy: Yeah. It's interesting how, like, care appears in, like, remote, when you're trying to do things remotely. Do you think you're going to, like, just use the photos.... I mean, obviously, you'll edit them, but are you gonna do, like, any black and white or effects or [unclear; cross-talk]?

Megan: I'll do black and white. You know, I may do a little bit with color grading.

Kennedy: Okay, cool. And like, the, the print and such will depend on the venue?

Megan: I'm sorry. The what will depend on the venue?

Kennedy: Like, how or what you print them on.

Megan: Oh, yeah, yeah, yeah! So, if it's outside, there are a lot of different options.

Kennedy: Okay. Yeah.

Megan: You know, a lot of different. You'd have to take into account, you know, like, the elements. [inaudible; cross-talk] We don't want something that would be completely ruined.

Kennedy: Mm-hmm.

Megan: But yeah, there, there's a lot of creative ways to show work outside. I suppose my dream would be to be able to use light boxes.

Kennedy: Mm!

Megan: Because it would be a draw for people to see it in the evening as well. And also, conceptually, I think that's very interesting because we're pretty much stuck to largely being in community and socializing with people through screens.

Kennedy: Mm-hmm.

Megan: And so, you know, again, that's kind of gesturing to the only way we can participate in life right now is through a computer screen or a phone screen or what have you. So, having light boxes would, would really be reflective of that. It's kind of the only way we can interact with, with others in the rest of the world.

Kennedy: Yeah, that sounds really cool. I haven't thought about showing photography outside. And like, yeah, also, if anyone's listening [laughing] with an outdoor venue.

Megan: Yeah, right! If there are any. I imagine the whole light box idea would, would not be that inexpensive. So, if there are any rich art patrons out there, come slide into my DMs!!!

Kennedy: There you go. Okay. Cool. Yes. How do you envision, like, getting the project out there? Do you know yet?

Megan: No, not really. I'm still hard at work. It's not really ready for prime time. Perhaps in a few months, meaning by the end of the year. Depending on how much I can get done between now and then, I might start pitching it editorially. But at the end of the day, I really hope that it will ultimately be a project that can exist as, like, an outdoor public art exhibit.

Kennedy: Ooh, that'd be awesome. Yeah, 'cause there's obviously a risk to a gallery setting. Well, yeah, I love the outside idea.

Megan: Yeah. Yeah. I mean, it would be more accessible, so that perhaps people who are high risk will actually be able to see it.

Kennedy: Mm-hmm.

Megan: But doing it this way would also force a kind of quasi face-to-face, as it were, confrontation between the immunocompromised people who have been cut out of society and the people who are responsible for doing that to us.

Kennedy: Yeah, absolutely. Okay. I'm gonna, if I hear of any venues or anything, I'm gonna keep that in mind. So, how did you go about getting funding for the project?

Megan: Applying for grants. I got one from Getty Images and most recently from DCASE, the Chicago Department of Cultural Affairs.

Kennedy: That's awesome. And do you have an idea of the timeline of when it might be something people can view?

Megan: No, I don’t know. I imagine that the first time people will see it was when I can hopefully get a portion of it published editorially, but I don’t know exactly when that will be. And I would love to have the resources to continue working on it at least for another year or even two, because I kind of see this as one day being like a contribution to the historical record of, of art as activism. Art created during and about the COVID-19 pandemic that I hope will give future generations and future historians a glimpse into what it was like to be an at-risk person in a country that chose eugenics over their lives.

Kennedy: Absolutely. Yeah. And you mentioned, last time we spoke about it, but how many subjects do you have right now?

Megan: Right now, I just did my 13th.

Kennedy: Okay. That’s awesome. And are you still taking new folks?

Megan: Yes, 100%.

Kennedy: Okay.

Megan: So, yeah, I imagine that at least for another year I’ll be working on this. So, if anyone’s out there listening, and you’re immunocompromised, and you’re located in the U.S., I’d love for hear, I’d love to love to hear from you, or if you know someone else who is. Right now, I’m especially looking for participants who are people of color. And also, a lot more women have reached out to me than men, so I’d also like to get some more dudes part of the project.

Kennedy: Awesome. Okay. Do you have like a goal for the number of subjects?

Megan: At the end of the day, I would love to have at least 100.

Kennedy: Okay! So, you’ll be doing it for a while?

Megan: Yeah, for a minute. Yeah.

Kennedy: Okay. Cool. Are there any, have you gotten letters from those 13 folks?

Megan: Yeah. Almost all of them.

Kennedy: And is there any, like, threads or, like, things that stand out or, like, I don’t know. I don’t wanna, like, tell too much about the project before it’s out. But like, sort of like a trailer?

Megan: [laughs] A trailer. I mean, they’re all choosing to do it differently.

Kennedy: Mm-hmm.

Megan: Some people are writing a lot, like a sheet of computer paper, just filling the page with text. And some people are choosing to write a little, maybe just a few sentences. One person opted to draw something to express themselves. One person just kind of took words and phrases and just filled the page, filled that one sheet of paper with all the different words and phrases. And another person wrote down some quotes from, from other disabled people that best expresses how they feel.

Kennedy: That's awesome. That kind of reminds me of just like, yeah, like crip, like...the way that, like, brains don't work linearly or like.... I've heard, I've yet to read, but heard a lot about Alice's Wong, Alice Wong's new book as, like, very, like, piecing together, like, lots of different just like parts of life and drawings and different, like, practical tools and things. So, yeah. Excited to see it all come together. What do you hope the impact of the project will be?

Megan: Well, I think it mounts a pretty direct challenge to the political and social status quo, which has, you know, for a very long time now been downplaying the risk of the pandemic and is outright pretending it's over. I hope that the, that the finished work will kind of prompt people to rethink their acceptance of discrimination and/or deaths and may even mobilize some folks to participate in direct political action toward better public health policy. You know, a lot of this, I think, stems in large part because non-disabled people are really alienated from disability in general. They don't usually think about us, and they also have this subconscious fantasy of control over their own health. Like, they don't think that disability could happen to them at any time, and that health is often just a matter of luck or chance, you know? The idea of being able to control and have, perfectly gauge your risk and have personal responsibility over your health is just an illusion. This is, this is health privilege. It's easy to perfectly think you have control over all of this, but any, any sick crip will tell you that that is further from the truth.

And also, you know, something that I've been thinking about for a number of months and having conversations with other at-risk people is that it's actually not just non-disabled people who have health privilege. There are also other people within the disability community who have health privilege as well. And a lot of us feel like the wider disability community at large has also abandoned us in a way where we're always seeing on social media a big, you know, there's a disability organization, and they host an event, but there's no mask requirement. And really all that does is telegraph to us sick crips that we aren't actually welcome. Masking is an access need. It's an access need, just like having ASL, just like having captions, just like having ramps, etc. And all that does is tell us that our access needs don't matter and aren't worth fighting for pretty much because the disabled people who are healthy just kind of don't feel like doing it.

And I don't wanna, like, belabor this point too much, but it is, but I do think it's critically important. So, I'll just say that, you know, we see you. [laughs] Like, in general, like, the immunocompromised people are aware of, you know, people in the disability community, disability organizations that were very willing to give up on, on masking. And it's not okay. Like, disability identity is a political commitment, and that comes with certain responsibilities. And at this point, I truly believe that wearing masks in shared public spaces is not just the best way to keep people safe, it is also the strongest symbol, the strongest visual message, the strongest iconography we have of our shared commitment to ending the ableism and eugenics right now. At least that's the commitment that the sick crips have. We could just really use the rest of everyone's help!

Kennedy: Yeah, absolutely. I feel like it's been interesting 'cause I would say, like, I'm high risk, but not to the level of a immunocompromised person. And the, it's like disabled people know what happens when you become disabled. So, like, the caution was there for a while and is still for some people of just, like, not wanting to become more disabled. Not...I mean, because, like, it can be hard, like, to, like, in, from like a body sense, but also, because we know about, like, the systems and structures that then, like, throw disabled people under the bus. And we're seeing, like, this mass disabling event, and we're seeing COVID, like, causing people to become high risk. And like, it's just like really jarring to watch the ways that in the last year especially, just like, it's like.... Like, we have statistics. We have numbers. Like, we know it's not over. But so many people, I think, truly are convinced it is or are just too tired or, but like, we're so tired. But yeah.

Megan: Yeah. When people, you know, say, "Oh, well, do you expect us to wear a mask forever? You expect us to stay home forever?" I'm like, "Do you expect me to do these things forever?"

Kennedy: Right.

Megan: "Because I'm being forced to do these things forever because of you."

Kennedy: Right. Like, if we had all done that from the beginning or vaccinated the globe or etc., etc., etc. Yeah. Yeah. I feel like, I mean, Crip Crap remains committed to masking and, like, other precautions indoors. And I wonder is, is there certain action items that individuals listening or that you think, like, disability orgs could, like, partner around or anything you wanna shout out in that sense?

Megan: I mean, certainly there are some disability groups, disability organizations, you know, like Crip Crap that is continuing to say, "You know what? We can't get rid of masking. No, that's, that's not cool. "[chuckles] But there are, you know, there are, there are, there are others that are definitely not. So, you know, I would just say to anyone listening, you know, the best time to do the right thing was always day one, but the second-best time is always right now. So, if you're listening to this, and maybe you're thinking, you know, you maybe haven't been the best ally to immunocompromised people, whether you're disabled or not, it's not too late to fight with us and to fight for us.

Kennedy: Yeah, yeah. And just like, I think just like, mentioning your opinion. Like, I feel like people feel really confused or alone in their, like, continued precaution. So, definitely...if I see especially in the disability community, like, events not requiring masks, happy to, like, let folks know what I think of that.

Megan: Yeah. And certainly, I think, you know, I'm sure that there are some organizations that say, "Well, we can't require masks because, you know, Deaf and hard-of-hearing people have access, communications access needs, and maybe they rely on lip reading." Yes, that's true. But now we also have NIOSH-approved N95s that are clear masks, have these clear windows. So, whenever someone, you know, brings up that point, it just feels like an excuse because we do have protective masks that would allow for communications access for these people. So, I really don't see any good excuse to not do it other than the fact that people don't wanna.

Kennedy: Yeah. Well, and I think, like, people are afraid to, like, write access notes with nuance. Like, if you medically cannot wear a mask, then that's fine. But, like, if most people are masked, then, like, a room is a lot safer, so.

Megan: That's absolutely right. There are people who, because of their disability, may not be physically capable of wearing a mask, but that's not a reason to say we can't have a mask requirement. That is a reason why we should, because those people do not have the, the luxury of being able to choose to wear a mask to protect themselves. That's why we all have to band together to do it, to make that environment safer for them.

Kennedy: Absolutely.

Megan: And a lot more people are gonna be wearing masks if you make it a requirement.

Kennedy: Yeah. Yeah. Or like, I'll, you know, I don't personally, like, have a stock of the mask with windows. I could get some, but I also just, like, pull my mask down if I know someone, like, reads lips and then put it back. You know, like, there's just so many, like, ways to create collective access, and like, these times, like, are asking that of us in a way, in a new way. But like, we've always known how to do that, or like, we should always look to strive towards that. So, yeah. I don't know. Do you, do you get into, like, the nitty gritty science a lot of, like, pandemic?

Megan: With the people I'm photographing or just to keep up on it myself?

Kennedy: Just yourself?

Megan: Oh, yeah, I do. I do. Yeah.

Kennedy: Do you have, like, do you think about, like, the long term?

Megan: All the time.

Kennedy: What do you think?

Megan: I mean, that's what I have to tell myself, you know?

Kennedy: Yeah.

Megan: This is a horrible situation, but I gotta play the long game.

Kennedy: Yeah.

Megan: You know, I, I'm immunocompromised. I have a chronic illness called ME, Myalgic Encephalomyelitis. It's an energy impairment disease.

Kennedy: Mm-hmm.

Megan: You know, my body does not produce energy in a, in a healthy way, so I can't lose any more functionality than I already have.

Kennedy: Mm-hmm, mm-hmm.

Megan: So, that's, that's kind of the, that's it for me.

Kennedy: Mm-hmm.

Megan: So, I'm, I, I view the way I have adjusted my life as being the most reality based that I have probably ever been. And this, that this is the greatest investment in my health for the rest of my life that I could possibly make right now. I mean, I'm sure there are a lot of people who are doing yoga and drinking their green smoothies, but yet they're running around without masks.

Kennedy: Right.

Megan: I'm like, what are you doing? [laughs]

Kennedy: Yeah.

Megan: You know, you can only play Russian roulette so many times before you get shot with the bullet. So, you know, you can only get exposed to COVID so many times where that next infection just tips you over the edge to lifelong disability. And there ain't no green smoothie in the world that's gonna get you out of it.

Kennedy: Yeah. And I think, like, the effects of long COVID have been so, so, so, so downplayed. It's like a third of cases.

Megan: Yeah. I mean, I've seen—

Kennedy: [unclear; cross-talk] ...so high now.

Megan: It's a bare minimum of 10% of all infections lead to long COVID. And certainly, there are some studies that say it's closer to 25%. There are some that say it's closer to a third. I've even seen some say, you know, just in the study period where they were tracking people, after X number of months out of infection, half of the respondents said that they were still dealing with symptoms. But even if it's only 10%, that is an astronomical number of people.

Kennedy: Yeah.

Megan: I mean, and when you think about the odds, like, if there were a flight, and there were gonna be 100 people on the plane, and they told you even, even less than that, even just one person was gonna be thrown off the plane mid-flight, it's like, well, would you get on the plane? Probably not.

Kennedy: Yeah.

Megan: Why would you risk being that one person who gets thrown off the plane? But yet you're looking at a bare minimum of, of 10% becoming disabled by a COVID infection. And you're like, "Yeah, that's, that's fine. That's a reasonable risk to take. Let's go get brunch. Let's go to this party with and to this movie theater without wearing masks or what have you." It really doesn't make sense. It's not, it's not rational. Honestly, I think it's just a coping mechanism.

Kennedy: Yeah.

Megan: Because facing the, the true reality of how precarious your health is, is really horrific.

Kennedy: And I think everyone's become somewhat numb or dissociated unless people really do not care. But yeah, like, it's because it's, there's been an astronomical amount of death and we, like, one death was too many, like. It's just like I don't, I don't know how people...like, the lack of like.... Like, all the mourning I've seen has been from disability community and not, like, society at large. It just feels weird to, like, just, like, move on and act as if nothing has happened. Do you have.... Obviously, there's space to, like, continue to push for COVID precautions and mitigations. Is, do you, from all the research you've done, do you have an idea of, like, what you think the, like, a pandemic into endemic or, like, when, like, life might feel somewhat safe again, or is it really hard to tell?

Megan: I mean, I have no idea when it will truly be over. All pandemics end eventually. I don't know how much longer we'll still be dealing with what we're dealing with now. But I, I am hopeful because eventually, I don't know when, but eventually someone, I imagine, will invent a vaccine—maybe it'll be a nasal vaccine—that is really a good neutralizing or sterilizing vaccine, as in it will be the kind of blocking of transmission that we don't have right now with our current shots and that we so desperately need.

Kennedy: I didn't even know that was in the works. Is it in the works or just [inaudible; cross-talk]?

Megan: Yeah. There, there are, are there are folks trying to figure that out. It's not gonna happen tomorrow.

Kennedy: Yeah.

Megan: But I also don't think we're gonna have to wait a decade for it either.

Kennedy: Mm-hmm. That's cool. Yeah, science is pretty cool. Like, I feel like we've all kind of.... Well, I think we all know, a lot of people know a lot more about infectious disease than they did before, which is good if we can use it to [laughing] to keep each other safe.

Anything else you, like, do at home for fun?

Megan: I mean, I read a lot.

Kennedy: Okay.

Megan: I've certainly been bingeing a lot of, a lot of stuff, streaming stuff. You know, I've been steering, steering away from the more serious content just because I just I, I can't handle, my nervous system can't handle it. So, I'm watching a lot of comedies, romantic comedies. You know, I rewatched all the superhero movies. Yeah, I just need something to calm my nervous system down a bit.

Kennedy: Is there anything you're reading or watching that you'd recommend?

Megan: Well, right now I'm reading this book called *Cersei*. It's a—

Kennedy: Uh-huh.

Megan: Yeah, it's, you know, about the, the Greek goddess who was a powerful witch and kind of like a retelling, reimagining of her entire life, and it's great. And my favorite thing that I've watched is *Our Flag Means Death*.

Kennedy: [gasps] So good.

Megan: Yes! [giggling] I know! Soooo good.

Kennedy: That's awesome. Anything else?

Megan: Well, I can just say if there's anyone out there who, especially if you live in Illinois, I can plug a local grassroots advocacy group here in Chicago.

Kennedy: Yeah.

Megan: You know, we're, we're advocating for better COVID safety in both Chicago and around the state of Illinois more broadly. It's called Care not COVID Chicago, and you can find us on Twitter at @CareNotCOVIDChi. So, from there, you can go to our little Linktree and sign up for our mailing list, find out when our next meeting is. You know, we, we usually meet over Zoom, you know, roughly every other week, maybe every three weeks, and we'll talk about the advocacy initiatives that we're working on. So, come on by and find out how you can help.

Kennedy: Yeah. I feel like there's lots of, lots of grassroots orgs popping up. Chicago Mask Project if folks can't afford masks.

Megan: Yeah, and also, Clean Air Chicago, they donate HEPA filters for, you know, music and arts events to try and keep those safer.

Kennedy: Yes, absolutely. And you can just borrow them for free, right?

Megan: Yes, completely free.

Kennedy: Yeah. Yeah. So, yeah, definitely exciting to see folks pushing for change and making COVID precautions, like, financially accessible. And if folks wanna get involved in the project or just follow you in general, where can they find you?

Megan: I'm on Instagram @megan_e_doherty and also, Twitter, or X or whatever they're calling it these days, @MeghanEDoherty.

Kennedy: Awesome. Well, Megan, it was so good to have you on. We see you. We appreciate you. Really excited to see how the project comes out and to continue to partner on these issues.

Megan: It was wonderful to chat with you. Thanks so much.

Kennedy: Thank you to our listeners. Please check out CripCripMedia.com for our other content as well as our Instagram @crip.crap.media. And there is a new subscription on our website if folks wanna support more content like this and the other events and programing we do. And yeah, it was wonderful to talk with you, Megan, and we look forward to seeing everyone back here for the next episode.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That's just some crip crap, don't you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That's just some crip crap, don't you know

Episode 23.2: Access in Acting with Terri Lynne Hudson

Episode Description: Justin and Kennedy “sit down” with actress Terri Lynne Hudson to discuss accessibility, representation, and the state of the entertainment/theater industries for disabled talent.

Justin: Hello, hello, everyone. Welcome to the *Crip Crap Podcast* Episode 23.2!

Christea: [in song] That’s just some crip crap, don’t you know.

Justin: I’m Justin Cooper.

Kennedy: And I’m Kennedy Healy.

Justin: I hope you all are enjoying your summer and staying cool and staying safe out here. How are you, Kennedy?

Kennedy: Doing okay. Yeah. It’s Disability Pride Month.

Justin: Yes, it is. Yes, it is. Happy Disability Pride Month to everybody out there. And so, we’re gonna get, we’re gonna get started with this podcast by introducing our guest, Terri Hudson! Terry Lynne Hudson is a disabled, chronically ill, queer actor and multidisciplinary artist, and disability rights advocate living and working in Chicago. She has a B.A. in General Studies and the Humanities concentrating in theater, film, and dramatic literature from University of Chicago. She has studied at Second City, Vagabond School of the Arts, and Acting Studio Chicago. She has most recently performed as part of the Shift video installation led by Barak adé Soleil at the Museum of Contemporary Art in Chicago. And her voice can be found reading creepy short stories on Audible and on the Random Acts *Scary Stories Around the Fire Podcast*. Welcome, Terri. Hello!

Terri: Hello! I’m happy to be here.

Kennedy: How are you?

Terri: I’m doing good. I’m very happy to be here, happy to get to hang out with y’all today.

Kennedy: We’re happy to have you. We should also mention Terri has been the star of our film challenge productions—

Justin: Yes, that’s right! [laughs]

Kennedy: —along with Isabel, Alexis, and some other actors. So, yeah, it’s, it’s exciting to have you on the podcast.

Justin: Yes, yes. We’re so glad. And can you describe yourself for our listeners who aren’t familiar with you?

Terri: Sure. My name is Terri Lynne Hudson. I am a Black, disabled, chronically ill, queer artist, multi-disciplinary. I am primarily an actor. I have been doing audio narration and some multimedia projects and some interdisciplinary projects as well. And I live here in Chicago.

Kennedy: Awesome. Is there anything else you want folks to know about you, like, outside of your work, like a weird hobby or something?

Terri: I really love anything horror related. I eat, sleep, and breathe horror. I love scary stories of all sorts. I like crafting. I have a small jewelry business that I mostly kind of ignore. I have an Etsy shop, but I only put new things in it once every like five or six years. It's very sad.

All: [laugh]

Terri: And the amount of things I could have in my Etsy shop is not proportionate to the amount of things that are in the Etsy shop. It's not that I'm not crafting, it's that I'm not listing the things on Etsy. [laughs] Let's see, what else do I do? Aside from loving horror stuff, I love goth stuff, so I hang out with a lot of goth DJs on Twitch. And I am a new plant mom, so I have two plants I haven't killed yet, and I'm very, very proud of my alive plants. I love cooking. I love nerding out about food and food history and culture around food. And I...am running out of things to say about myself right now, so I'm gonna stop with that!

Kennedy: That's great. [chuckles]

Justin: Yeah. That, that's great. We might need to do like a food segment, you know, for future podcasts, Kennedy, you know?

Kennedy: Yes, I know. I was like, let's write a horror film. People who wanna manage your Etsy store, contact Terri.

All: [laugh]

Justin: So, Terri, like, can you tell us about your work as an actress and how you got started, like, doing it?

Terri: So, my start in acting really came around college. Prior to that, I had expressed interest, but there just wasn't any support for my interest. I went to a high school that didn't really have any arts. It was a math/science magnet high school, and just sort of nobody cared about plays or theater on an extracurricular level. And outside activities weren't really encouraged for me. It was always, "No, you just need to study more and focus on school." So, once I got to college, there was an informal theater program. There is now a formal theater major at University of Chicago, but there was not in the '90s. So, I attempted to get involved with that group, but it was hard to break into, really, even as just an unofficial student group.

So, I got involved with some community theater and was like, okay, well, maybe I'm, I'm not that bad, and I don't suck at this, and this can really be a thing for me. Because I was losing confidence with how hard it was for me to break into the student group. And then one summer I came home to Atlanta, Georgia, where I'm from, and there was an agent doing an open call, and I got my first agent. And that also gave me a confidence boost. And then I found a mentor my senior year of college who helped me write a one-woman show because I wasn't, still wasn't getting cast in things at school to do my bachelor's thesis about. And so, I did my bachelor's thesis was a one-woman show. And I just started, you know, pounding the pavement and auditioning like everybody else after that.

Kennedy: That's awesome. Is there.... Well, now I'm kind of curious, like, what are some of your, like, since then, some of your bigger projects or like things people could check out?

Terri: What can people check out? I haven't had a lot of stuff that's ended up like online. I'm in a movie that's on Amazon Prime. I'm only in it for about 30 seconds, but I'm really good. It's called *Frame Switch*.

Kennedy: Okay.

Terri: And so, if anyone has Amazon Prime, I believe it is still up. I don't know how much longer it's going to be up because I think it's gonna be redistributed. But the last time I checked, that was still on Amazon Prime.

Kennedy: Mm-hmm.

Terri: I am in a web series that's on YouTube called *Chapstick*. I'm in one episode of that. And I mostly am out there with my voice right now. I am a current and frequent contributor to the Random Acts *Scary Stories Around the Fire Podcast*. So, I will put scary stories in your ears. And I have two short stories that I've narrated that are on Audible, and hopefully, there's gonna be some full-length books coming up soon. I'm trying to get some things sorted out as far as doing full-length books as an audiobook narrator.

Kennedy: And have you done, like, theater things as well?

Terri: I've done a lot of theater. I have not been doing theater since the pandemic, really. I did a couple of streaming theater pieces in 2020 when people were doing that. I worked with Accidental Shakespeare's *Romeo and Juliet*, and I did *How Do We Navigate Space* with Strawdog Theater. I did a reading with ALTAR Theater, which is actually a company out of the Bay Area, and I did a reading of a screenplay with a company that was based out of New York. It was, ironically, 2020 was a really great year for my career because all of the ableism barriers that I have to fight when it comes to being physically on stage were just obliterated when everything was online. And the next thing I knew, all of these companies that I wasn't able to ever get on stage with physically were reaching out to me and just on offer, offering me roles to do these readings. It did help that my husband is an engineer, so we had audio/video set up I think a little bit earlier than some people did. So, I was just ready to go on a tech level. And once people knew that, I just started picking up all of this work from all over the place. And, you know, sadly, I'm happy that people are, you know, not in as much of a COVID crisis as we were three years ago. COVID's not over, but that level of crisis has definitely gone down. But since things have gone back to in-person, there has not been as much online work available. So, I haven't been working as much, as an immunocompromised person who is still avoiding indoor unmasked settings.

Justin: Yes. Yes. And so, I think as you mentioned, like, you know, you know, COVID is like, is, is not over. And, like, you and I had a chance to work together as part of this video installation for Shift with Barak adé Soleil. Can you, like, explain to the audience, like, your experience with that? And then, like, how did, like, COVID, like, change the ways you interacted with, like, the industry in, in general?

Terri: The experience with Shift was ultimately really, really great. It took some negotiation and some explaining, like, what my boundaries were and why my boundaries were why my boundaries, you know, why they were what they were. Sorry, I misspoke there. And Barak and I have known each other for a while, and we have been in creative space together before. We've collaborated before. So, we fortunately had a rapport before all of this, and we care very much about each other. And it was coming from a place of, you know, I really want to contribute to this project, and I want this project to succeed. But here are my boundaries about my health and safety. And Barak is like, "Well, I very clearly have this vision, but I also see you as an artist and a human being. And I'm hearing what you need in order to participate in this, and it's important to me that you participate in this. So, what can we do?" And we ironed it all out.

One of the few things I've done outside of my home was the videography for Shift, where Barak got a space, and everyone in the space was masked and vaccinated. And I appear in the videos for Shift completely masked because that was what was safest and best for me. And I was able to bring air filtration tools to the set, and everything was just really safe and really nurturing and supportive. And it was a really, really great environment, and I'm very happy that I did it. That was not the only question, though. There were some more questions in there! [laughs]

Justin: Nah, I was just, just listening to you, like, really explain, like, you know, what, what really, you know, had to take place in order for Shift, you know, you know, to work. And so, like, you know, we were able to, like, able to pull this off, which was just like a really amazing thing. And, like, Terri, like, being able to see, like, your, your, your portion, you know, of that video was just like really amazing. And like for me, I was, like, grateful to work with you, you know, on, on, on this project.

Terri: I was really happy to connect with you on the project. Like, we've just sort of been in each other's orbits for a while but hadn't been on the same project before. And I just do think that it was really beautiful that Barak was able to, like, reach out to community and pinpoint these different people with different perspectives and experiences, but yet with, you know, our undercurrents of all being, you know, Black disabled folks together and to assert our presences in the space of the MCA, even with one of us not physically being there. I think that that was really very, very cool, and I'm happy that I got to share it with you as well.

Justin: Aw, really, I'm, I'm just really, really grateful, you know, for that. So, like, I think one of the, another follow-up question that I kind of asked was, like, like, how did COVID, like, like, change, like, the ways you interacted with the industry in general?

Terri: Oh, so much! I mean, I basically don't leave my home unless it's medically necessary or unless I know that the entire experience of leaving my home has got a lot of COVID safety factored into it. So, I have not worked in-person other than that project and then one project in that little buffer area we had in like late May, early June 2021, where everyone had just been vaccinated. Everyone. But a lot of people had just been vaccinated, and we kind of thought everything was okay for a minute. I did another in-person photoshoot sort of thing then, but since then, I've only been working from home. So, that's been interesting. Like, I have an agent, and my agent just submits me for voiceover work now. And every once in a while, they reach out to me, and they're like, "Hey, we've been hearing from this theater and this theater, and they're wanting to know if you're returning to stage yet." And I'm like, "I can't. It's not, it's not prudent for me yet." I'm glad to know they're interested, but I can't do it. And it's just it's been interesting. I also got like an on hold for a TV series that I ended up not booking. And I'm honestly, it was bittersweet at the time, but now I'm grateful that I didn't book it because I think that the set was a super spreader [laughing] event at the time! So, I'm like, okay, I may not have, you know, a network TV credit, but I also still don't have COVID, and that is best for my body. So, I'm gonna make peace with that.

But yeah, since there has been about the past year of the big push of, you know, returning to normal, it's been hard, and I've been reevaluating my career and figuring out what else I can do as an artist while still staying safe. And I'm very happy that I lucked into the community that is the Random Acts, you know, podcast people. They do things other than podcasts, but I'm mostly involved in the podcast end. And they do a short horror fiction podcast, and I get to narrate for that. And it is my favorite thing. I love telling scary stories for Random Acts. And I have also gone through some audiobook narrator training and mentorship, and I have narrated two short stories for an independent author that are up on Audible. And I am working with a couple of different publishers now where I'm submitting auditions for different books that they have, and we're really just looking for the right marriage of narrator and work for me to start working on some audiobooks. And I do have a couple of other independent authors whose books are in my pipeline, and we're just still hashing out the details. So, it looks like I have gone from being an in-person actor to being a narrator, and I'm really fine with that.

I also have had a couple of wonderful opportunities to get involved in audio description and that sort of access-based voiceover work. I voice a sign language-using Deaf character in a documentary called *The Tuba Thieves* that premiered at Sundance. And that was an amazing experience that kind of landed in my lap, and I would really love to do more of that. It was a film that was centering the Deaf people, but they wanted it to be a multi-level access experience. So, they were thinking, well, how do we make this accessible to visually impaired people who are interested in this film? And so, that's why there is a voicing done for a character who is Deaf and using ASL. And that was just amazing. And I've been looking into doing some audio description. I've done a couple of smaller projects, but I'm looking into doing, like, TV and film audio description at some point as well.

Kennedy: That's awesome.

Justin: Nice.

Kennedy: Yeah, I feel like it's interesting how, like, access is layered in that way and is really getting, like, incorporated more in, like baked into productions. And too, with, like, the COVID stuff, like, for a while it felt like we, like a big chunk of people were, like, doing the things, and now it feels like something that's become a part of like a list of, like, creating access. Like, it's like disabled people are, like, leading the, like, how to like, I, I don't know if, like, generally people know about things like cleaning air and like....

Justin: Right.

Kennedy: Yeah. Like, it's, it's so, so, like, easy to us or, like, comes to us. And then, yeah, I feel like I'm doing a lot of educating these days on that kind of thing. But in terms of, like, with work or just life, what things have been helping you the most through COVID times?

Terri: Having a robust Internet connection.

Kennedy: [laughs]

Terri: And I do realize that there is an awful lot of privilege associated with that. We have really, really good Internet [laughing] where I live. And my husband is an engineer who works from home, so we have to have very reliable Internet. And a lot of people in our building are tech people who work from home. And so, my ability to participate in all of the online stuff that I've been participating in and to be reliable and professional about it has been largely dependent on our really super-good Internet. And also, the fact that I do once again have the privilege—I'm big about checking privilege, so I'm gonna be checking a whole bunch of privilege boxes as I lay this all out—is that I am married to a software engineer who is an AV nerd. So, the audio/visual equipment in this house, I jokingly refer to our condo as the CineSpace Annex because you could legit just shoot a TV show [laughing] in here! My husband has really been using my career as an excuse to buy toys, so we have stuff that, like, I'm like, "We could literally be shooting a TV show with this, like a, a broadcast-quality TV show. Do we really need this? Nobody else.... Okay, honey." [laughs] It's a lot! So, yeah, that's really been helpful for me in being able to work and stay connected. And also, socially. You know, my friends all live in this box.

Kennedy: Mm-hmm.

Terri: And it's really been helpful for me. And I connect with a lot of other disabled and chronically ill people, not just even all over the country, but all over the world, just online. And I've made a lot of really great community in a lot of different spaces because I'm able to do that. And, you know, big shoutout because of the strike right now to all of the actors and writers out there because who has not been binge watching things? You know, that doesn't happen in a vacuum. That's artists working really, really hard to get everybody's spirits up and provide some escapism and make people happy and make people think. And there've just been so many great shows and great movies coming out over the last few years, and people are out there outdoing themselves, and they should be compensated fairly for it.

Kennedy: Mm-hmm.

Justin: Mm-hmm.

Kennedy: Absolutely.

Justin: Yes, yes. And, you know, that's just a smooth transition to, like, you know, my, my next question. You know, given what's currently, like, happening with, you know, the writers' strike and a lot of things that are going on with, like, folks within the industry, like, going, going on strike, like, what were like, what, what, what do you feel, based off of your experience, like, what are, what do you feel like are the main barriers for disabled and other, like, marginalized actors in the, in the enter-, in the entertainment industry?

Terri: Oh, boy. Where do I start? My biggest fight here in Chicago has been, like, literal structural lack of access. Like, there are, I feel like prior to the pandemic, because they've been dropping like flies, so I wouldn't be, you know, wanting to be quoted for a count right now. But of the something like 250 storefront theaters in Chicago, a third, if that many, maybe even just a quarter of them were inaccessible spaces. And, you know, if you don't get to get into storefront shows and get seen and work your way up, you never become Equity. I'm 50 years old. I'm still not union. And it's not because I don't wanna be union, it's because I haven't had the opportunity to work my way up. I had my first Equity understudy cut short because of COVID. But that's the thing. That was my first Equity understudy. I would've gotten one Equity point from doing that show that I never got to do. So, there are people who know that I've been at this for a while, and they've seen me in things, and they're always really startled that I'm not union. And I'm like, I, I've never had the opportunity to accumulate the points.

Kennedy: Mm-hmm.

Terri: You know, I've, I've been called in by a couple of union theaters, but I haven't booked for whatever reason. I might not have been, you know, on the top of my game that day. But you never really know what fuels people's decisions, and it could be, you know, ableism, it could be lookism, it could be colorism, it could be sizeism. It could be so many things. You know, I'm a not just disabled woman, but I'm a short, curvy, brown-skinned Black woman who is also disabled. And all of those marginalizations just piled up into one person, just mean that I deal with an awful lot of barriers, and I'm not the only one out there. And we have to deal with that on every single thing that ever gets cast, ever. There are so many things where they don't look at intersections of identities.

So, we've had a big influx of disabled people on screens, and for the most part they've been white. And when they're not white, they are skinny and conventionally attractive. I've auditioned for two explicitly disabled TV roles, and both of them were cast with blonde white women. Like, I actually went and watched the shows afterwards to see who booked it, and both times it was blonde white women. And I think that one of them wasn't even calling for white women. It was specifically looking for POC, and yet they still cast a blonde white woman ultimately. And so, there's just so much to process there.

You know, it's like you're only allowed to have one marginalization at a time, maybe two, if you're conventionally attractive enough. And, you know, people think, okay, a disabled person goes in this box, and a Black person goes in this box, and a woman goes in this box. And what do you mean you're in more than one of those boxes? Okay, maybe we can put these two boxes together, and then that's the kind of character you are. Wait a minute. You're not coming across like that kind of character, so we don't know what to do with you. And it's just it's really complicated. There are so, people just think a lot in really rigid stereotypes. And I think that that's a big issue with the industry is people keep reusing these same tropes of the same types of people and not going out and looking for, like, new, interesting, authentic stories. And when you do get new, interesting, authentic stories, often it gets canceled really quickly.

Justin: Yep.

Terri: You know, I, I've seen some really great diversity on TV in the last couple of years in shows that have been canned, and I think that that's really sad. And it's similar on stage. You know, there are disabled actors that get work in Chicago, there are actors of color that get work in Chicago, but it ends up being like the same, you know, you can run off a list of the same, like, five, six, seven people who you see in everything all the time. And it's like, I love those people. They should get work. Other people need chances at work, too. And there's just there's still only so many shows and only so many stages, and there's still so many barriers into even getting to those stages because you have to work so much to get even a shot at an Equity show. It's not an automatic thing. I feel like people who aren't in the industry think that you just one day walk up and sign your name, and you join the union. It's like, no, you gotta get points. And those points have to come from somewhere, and they're not easy to get.

Justin: Right.

Kennedy: Can you explain the points a little bit more?

Terri: Not really, because I don't really understand them. [laughs]

Kennedy: Okay. [chuckles]

Terri: I will, I will throw this out there because this is the most that I've been made to understand them. I did have a mentor through this women's theater organization. I think it's called Statera. And my mentor was Equity, and she was trying to explain Equity to me. But this was in like 2018, so it's all real hazy, so I could be wrong. So, do not quote me on this. But basically, in order to get points, you have to get cast in a non-Equity role at an Equity theater. And that is dodgy to begin with because they have to give X amount of contracts to people who are already Equity, and then there's just like a couple of spots to fight over for non-Equity people to try to get a foot in the door.

Kennedy: Mm-hmm.

Terri: And, like, there's this whole culture of crashing Equity auditions, like hoping that they will see you. I've been fortunate enough that I've been invited to some Equity auditions, but I didn't book them. You know, people have seen me, they know who I am, and they ended up going with someone else. And that's not something I can do anything about. I just, you know, keep, you know, studying, being practiced, being ready to go, working on my audition game, and being ready to work when somebody wants to see me. But, you know, other than that, you've gotta be able to get seen, and it's hard to get seen. And then it's hard to get cast because there's just so few slots.

Justin: Right.

Kennedy: Uh-huh. Do you know how many points you have to get?

Terri: Nope. I just know more than the negative one that I have because COVID ate my points.

Kennedy: Okay. So, yeah. And then I also wanted to clarify: You're saying one third of theaters in Chicago are accessible?

Terri: On a good day.

Kennedy: Yeah.

Terri: Maybe.

Kennedy: Okay, oaky.

Terri: Yeah. A good maybe. And "accessible" in air quotes because, you know, as we all know, it's not a one-size-fits-all thing. There are places where I've worked with no problem as an ambulatory disabled person where my friend who uses a chair ended up taking a role that I couldn't take in the same space. And then she discovered she didn't have adequate dressing space and didn't have enough backstage space. And when she was asking me about access, like, it's a flexible space. So, it was more that I didn't know how it was gonna be set up. But, you know, all that I could say off the top of my head was, you know, the entry's flat, the bathroom has grab bars, and I'm pretty sure from just eyeballing it that all the doors are wide enough.

Kennedy: Mm-hmm.

Terri: But I wasn't able to give her the complete slate of information that she needed to know that she could work in that space, and neither was anybody else. Like, in my dreams, what I would like for there to be—and I applied for a grant to get help doing this, and I didn't get the grant—but what I would really like for there to be is a directory of all of these spaces, the performance spaces in Chicago, and what their access assets are.

Kennedy: Mm-hmm.

Terri: Because I think that a lot of companies get scared to say what they don't have, and they think they're gonna get targets painted on their heads or something. And I'm like, "Okay. Well, why don't we spin that and tell me what you do have?"

Kennedy: Mm-hmm.

Terri: Like, if you don't have an elevator, do you have grab bars in your bathroom? What are your door widths? We should know this. Is there a lip or a bump to get on your stage, or is it flat, you know, entry to the stage? Can you get a portable ramp? Are you willing to get a portable ramp if you are in an upstairs space, and you absolutely cannot accommodate someone in a chair or on crutches or what have you? Can you get an ASL interpreter? How about getting captioning equipment? What can you do, and what are you willing to do? And if we had like a directory of all of that so that disabled performers knew where we could go and where we could work, I guarantee you would see an awful lot more of us out there because we just don't know where we can work.

A prime example of this was when I first moved back up here in 2014 after a hiatus of living in Texas for 16 years, I signed up for an audition, and I got a slot. And I looked at the place on Google Maps, and there was a street-level entry with their name on the door. And I was like, okay, I'm good. And I show up to the place, and I open the door, and the auditions are up two flights of stairs.

Justin: Geez.

Terri: I had absolutely no warning that there were stairs. I had no way of knowing that this entity was not located on the first floor, and that should not ever happen to anyone. So, I was there, you know, 10 minutes before my audition, having to make the decision, do I drag my body up these two flights of stairs, or do I become that person who didn't show up at my first audition in, in a new city?

Kennedy: Mm-hmm.

Terri: And I made the decision to drag myself up those two flights of stairs. And I booked the role, which means I committed to dragging myself up two flights of stairs for six weeks. And it gets worse because after I did this, one of the people from that theater company actually called me up, asked me if I knew a leg amputee, and I was like, "I believe so, but why?" And they're like, "Well, we wanna do a show, and we're trying to be good and cast authentically, so we wanted to get a leg amputee." And I'm like, "Okay. Well, where are you having this show then?" And they're like, "Oh, in our space!" And I was like, "Okay, you want me to actually refer you a leg amputee to commit to six to eight weeks of dragging their body up two flights of stairs in a building with no elevator and—cherry on top—for free?"

Justin: Nah.

Terri: No!

Kennedy: Wow.

Terri: And I just wouldn't do it. And that also showed me that what I had done made them think that that was a reasonable thing to ask.

Kennedy: Mm-hmm.

Terri: So, ever since then, in solidarity with disabled community, I will not perform in inaccessible spaces. Like, I can technically move my body up a flight of stairs. It is difficult, it is painful, and it is not good for me. But is it physically possible? Yes. But if that's the message that it sends, that like, oh, if we're a cool enough company, disabled people will, you know, injure themselves in order to work here, and we don't have to try to accommodate anyone, I'm not gonna be responsible for putting that further out into the world.

Kennedy: Mm-hmm.

Terri: So, I just don't. My motto is, if a power chair can't get in there, neither can I.

Kennedy: Wow.

Justin: Wow.

Kennedy: Yeah, that is.... I mean, we've all been there, but it's just like the, what non-disabled people don't realize is, like…out of this world.

Terri: Really is. Yeah.

Kennedy: A guide sounds amazing. Shoutout, too, to Chicago Ramp Share. If folks in this city need portable ramps, it's a free grassroots group that can connect you to one.

And to your point about, like, needing authentic stories to be written, I think that's why it's so exciting, I mean, it shouldn't have to happen, but, like, to see the actors strike in solidarity with the writers. And I think just like more relationships there are needed to, like, like, why not write stories with, like, people in mind or like a certain intersection of multiple marginalized identities in mind? I think there's like this fear that the casting is gonna be too difficult. But, like, people are out there, like, looking.

Justin: Mm-hmm.

Kennedy: So, our next question is, I mean, we got the strikes, we have COVID, there's smog in the air.

Terri: [laughs]

Kennedy: What advice, nowadays, do you have for aspiring actors and performers, disabled or not?

Terri: Oh, my goodness. Advice? Do I have advice? I feel like I still need advice [laughs] at this point. But it's just [sigh] there's nothing else in the world like this work, you know? I've, I've been alive a while now, I've been an adult a while now, and there's just nothing else that I've ever wanted to do. So, it’s like if you’ve got that passion, if you’ve got that fire, find people that are gonna nurture it, find opportunities to use it. Because you’re just not gonna be happy doing anything else. And it’s gonna be hard. Unfortunately, it’s hard. Unfortunately, our society does not value arts the way that it should. And, you know, I know that people will push back against that, talking about, well, these singers are millionaires, and these movie stars are millionaires. And I’m like, that’s a tiny, tiny, tiny portion of the people who do that and who are good. And you just got to find people who are gonna nurture you and support you. And that is hard. You’ve gotta find your people because it’s really hard to do it alone without support, you know.

There are, there are some people who’ve managed to get, you know, their start doing stuff where they are completely writing and producing and creating everything themselves. And I mean, when you mention the working together, you know, with the actors and the writers supporting each other, we shouldn’t have to, you know? And people who are non-traditional in some way always get told, “Oh, go make your own stuff, and that’s how you’ll get famous.” And every once in a while, that works. But I made seven one-woman shows. [laughing] Nobody cares! And they weren’t that well, I won an award for one of them, but it was a minor award. And it’s just like, yeah, that did not get me famous. It’s not a guarantee.

And also, it’s just we are already the people with the most barriers. Why do we have to do more work? You know, nobody is telling, I don’t know, Reese Witherspoon, you know, “Why don’t you just go make your own stuff?” It’s like, okay, you’re an actor and you show up and you audition. And, you know, whenever people tell me that I need to be a content creator, I really push back against it. Because if I were a content creator, if that’s what I wanted to do, that’s what I would be doing.

Justin: Right.

Terri: But I’m like, I shouldn’t have to. I should be able to show up and audition and have a shot just like anybody else who shows up to audition. If you’re not telling every single person who walks into an audition room that they should go be a content creator, quit telling multiply marginalized people. Because we are human beings, we exist in the world, we have stories, we have relationships, we exist whether you want us to or not. And people love our stories! People absolutely love our stories. There’s still this mythology that Hollywood tells itself that things only make money if they are cast with, you know, conventionally attractive, abled white people. And it’s just not true. I mean, look at movies that have succeeded. Look at Jordan Peele’s entire career. Look at *Prey*. Look at all of this. Look at *Squid Game*. Look at all of the stuff that’s out there that’s different people, and people love it. I mean, I think that there are studies out there showing that diverse movies actually make more money, and diverse TV shows actually make more money! And we just need to up that diversity and keep telling those stories and get those writers in the rooms and get those actors in front of the camera because we’re out here, and we’re good, and we wanna work.

Kennedy: Yeah. It’s getting so boring, like, all the remakes.

Justin: Yes. Right?

Kennedy: We’ve seen this already. Like, let a marginalized person write something, for God’s sake.

Justin: [chuckles]

Terri: Let somebody write something because oh, my goodness. And it's just, it's a whole money thing. That's, I know people get really excited about the Disney remakes, and I, I am here for the Black *Little Mermaid*. I have to have that little bit of solidarity, but otherwise I have not seen any of the Disney live action remakes because I refuse to reward their bad behavior.

Kennedy: Mm-hmm.

Terri: Really, because the entire just rehashing of all of their animated stuff is to, like, not pay writers and not, like, buy new scripts.

Kennedy: Mm-hmm.

Terri: That's really what that is. It's gross. [laughs] So…. So, I'm just like, no, this is not good behavior, and I'm not gonna reward it with my money or attention. Just stop it.

Justin: Yes, exactly. Exactly. So, you know, continuing with the advice theme, do you have any advice for the entertainment industry itself?

Terri: Stop it! [belly laugh]

All: [laugh]

Terri: "It" being a big umbrella term for stop with the ableism. Stop with the sizeism. Stop with the colorism. Let diverse people in the room. Let diverse people in the writing room. Let diverse people direct. You won't regret it because people will spend money. They wanna see this. They wanna see it. I mean, look at, you know, what's sweeping the Emmys: *Abbott Elementary*.

Justin: Mm-hmm.

Kennedy: Yeah.

Terri: You know? *Bel Air*, unbelievably huge success. People want these stories. I'm still heartbroken that *Queer As Folk* reboot, even though it was a reboot, got canceled after one season because it was such a diverse reboot. It was so great. And then they canceled it. And we got our even more diverse, you know, reboot of *The L Word*, and then that got canceled.

Justin: Yep.

Terri: And I'm really sad because both of them had queer disabled people. And now there's two queer disabled people who aren't on tel-, aren't on my television anymore.

Kennedy: Yeah, I feel like, the, to your point earlier about, like, access in performance spaces, like, a lot of the emphasis is put on access for audiences, or, like, if you do find access info, it's about the audience.

Justin: Mm-hmm.

Kennedy: And, like, people can't even conceptualize disabled people behind the scenes, and then they're like, "Why are there no disabled people in the industry?" It's like, 'cause people are working 12-hour days. And like—

Justin: It's a lot!

Kennedy: Yeah. So, curious, like, if you have any more specific hopes for the industry around access, representation, or anything else.

Terri: It's, I mean, you're absolutely right. I have been in a couple of those theaters auditioning where they are bragging about how accessible they are for their audiences. And there is one theater who I'm not gonna drop a name on right now that has invited me to audition multiple times and expected me to climb stairs multiple times. And I keep telling them, "No, I can't, and someone has to come down here and make a space for me to audition. And you know me. As a matter of fact, you know me because your casting people came and saw me at an access audition," which, by the way, Chicago has done a number of. And it's not that they don't know that we're here, it's that they don't know what to do with us. Or they think they have to do something special with us.

Like, like, back in the day—and I also know that there are places that still do this—when I was in college, there would be all of this casting done for all the different shows, but then every year there would be the Black show. And I showed up at auditions for Shakespeare and for, you know, classic Americana theater. And there are times where someone almost out and out told me to come back and audition for the Black show. And I feel like there is a lot of that vibe out there with disabled people, you know. It's like, "Oh, well, we don't have any Deaf people in this show, but there's gonna be the Deaf show and you can come back and audition for that." But I have also seen shows challenge that and just cast a Deaf character. And the Deaf character's been amazing in a show that was not about their deafness. Because, you know, everything we do 24/7 is informed by our disabilities because we have disabled bodies, but it's not about our disabilities.

Justin: And so, like, going, like, going, going off of that, like, Terri, is there, like, anything else, like, you want to add?

Terri: Is there anything I want to add to that? I mean, I feel like that's kind of a lot already. I mean, we can, we have so many options, you know. We can tell stories with different bodies, which is a thing that people are doing to an extent. We can get different stories written. We can expand how we think about casting. I mean, there's no reason that ordinary people can't just be disabled. And I think that that's a problem that we run into that's stopping a lot of disabled people from, like, getting points and becoming union, whether you're talking about SAG or Equity is like, we often don't get considered for smaller parts or under-five parts because they're not specified disabled. And it's like, well, why couldn't that secretary or that nurse or that parent or that student, why couldn't they just be disabled? And then disabled people get to build résumés, and then we get to come back for more things. And hopefully that line of thinking expands to, okay, well, why couldn't this doctor be disabled? Why couldn't this senator be disabled? There are disabled people who are in all those roles in real life. Why couldn't this person be disabled?

Kennedy: Terri, we love you.

Justin: Yes.

Kennedy: Everything you said, I'm just like, yes. Thank you for coming on.

Justin: Yes.

Kennedy: We're curious where people can find you, socials or, like, projects or what's going on right now.

Terri: I am an old, and I am bad at social media. [laughs] So, I am on Facebook, but I'm not really anywhere else. I have an Instagram. I don't really understand Instagram. There are like 500 very bored people following me on Instagram because I have never posted anything! [laughs] But I am on Facebook. I do have a website that is about to get revamped and is going to link to what all I'm doing, where you can find all my audio work, where you can find what work I've still got that's up online. And it's just www.TerriLynneHudson.com. It is up now. It's just a bit out of date. But I do think that there's a spot on it where you can sign up for updates, and if not, we'll fix that in the next day or two. But yeah, it's just my first, middle, and last names. And I am also on IMDB if anybody wants to follow me on there and push my little star meter up or however that works!

Kennedy: Awesome.

Terri: And yeah, I think that is the extent of social media presence I have. I do not adapt well to new platforms. It's just kind of a lot.

Kennedy: No, that's great. And yeah, everyone, hire Terri.

Justin: Yes.

Kennedy: We hope we can collab forever.

Justin: Exactly.

Terri: Yep, forever! I love working with y'all, both of you.

Kennedy: Like we said, we're recording during Disability Pride, but this might not come out during the month! We're a little bogged down.

Terri: That's fine.

Kennedy: But we hope everyone had a good one.

Justin: Right.

Kennedy: We hope the strikes are over when this drops! And yeah, like, hope our listeners have a great rest of the summer.

Justin: Yes!

Kennedy: And thanks for tuning in.

Justin: Yes, please, please be, be, be, be cool. Stay, stay cool out here 'cause, like, the weather is just all over the place. So, just please—

Terri: Seriously.

Justin: Yes, yes. So, just please, please just stay cool. Make sure your pets, if you got pets, make sure they stay cool, and you all stay safe out here. Enjoy the rest of your summer. And this is the *Crip Crap Podcast* Episode 23.2! So, I'm glad that you all are joining us. You can, you know, follow us. Where can, where can, where can they find us, Kennedy?

Kennedy: So, we are on LinkedIn, Crip Crap; Facebook, Crip Crap; Instagram, crip.crap.media; CripCrapMedia.com. You can email us: info@CripCrapMedia.com. And we have a subscription now.

Justin: We do!

Kennedy: If folks want to help fund the pod, the blog, other projects, and events, we really appreciate a little bit of your monthly paycheck.

Justin: Yes.

Kennedy: Yeah. Thank you again, Terri.

Justin: Thank you, Terri.

Kennedy: Thank you, everyone.

Terri: Thank you for having me. This was so much fun, you guys.

Christea: [in song]
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That's just some crip crap, don't you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That's just some crip crap, don't you know

Episode 23.1: Wheelchair Bureaucracy and Daily Life

Episode Description: Justin and Kennedy are back and, given recent events, spend the first episode of Season 2 discussing and explaining the grueling process of obtaining and maintaining custom power wheelchairs as United States citizens with health insurance.

Christea: (in song) That's just some crip crap, don't you know.

Justin: Hello, everybody, and welcome to the *Crip Crap Podcast*! This is the first podcast recording of 2023. I am Justin Cooper.

Kennedy: I'm Kennedy Healey.

Justin: We are so glad for you to join us for this first episode of 2023. How are you feeling, Kennedy?!

Kennedy: Oh, I'm doing okay. It's February in Chicago...

Justin: Mm-hmm.

Kennedy: ...the Tuesday armpit of the year.

Justin: [delighted laugh]

Kennedy: It is sleeting...

Justin: Yes, it is.

Kennedy: ...currently.

Justin: Mm-hmm, mm-hmm.

Kennedy: Um...it's been a while.

Justin: Yes, it has.

Kennedy: Should we tell folks? How have you been, [laughing] Justin?

Justin: I am...I'm doing well. I'm doing pretty well. I've been, like, all, all over the place, just working on, you know, different projects and stuff and, you know, trying to, like, fully get back into work after being out for the last few months dealing with some wheelchair issues.

Kennedy: The topic of the day!

Justin: That's correct.

Kennedy: Wheelchair issues.

Justin: Yes, yes. And so, it has been just an interesting journey, to say the least, of the last few months and trying to deal with some wheelchair issues.

Kennedy: We are today's guests. [chuckles]

Justin: Yes, we are.

Kennedy: And we are here to talk about wheelchairs.

Justin: There you go. I’m glad to be here, Kennedy. Thank you for having me.

Kennedy: [laughs] Um, and I will say, too.... Yeah, we have other jobs, like, other work we do. We were both dealing with care-related things.

Justin: Yes. Oh, yes.

Kennedy: And, but the, the biggest trip-up in our little gap in programing was, uh, wheelchair issues, particularly for Justin. This is like a universal. Like, I’ve been there not for as long as this saga continued. But, um, yeah, we just thought we would get on and talk about that, like....

Justin: Ugh, Kennedy. Let me just, let me just say the last, like, like, couple of months have been so stressful for me in terms of, you know, my wheelchair issues. And I can share a little bit about, you know, what’s been happening. It’s back on November 17th my old wheelchair actually broke as I was traveling. I was transferring with, you know, you know, my mom was helping me, trying to get into my chair as we were transferring. And as that was happening, the seating post that kinda holds my, that kinda holds the seat of my chair in place actually snapped off. And so, as I’m transferring, I noticed something’s not right, but, like, I’m not gonna stop because I’m in the middle of doing this. And my chair just [ppbbbttt] kinda broke, and I was kind of leaning very bad to the left. And so, yeah.

Kennedy: Like, it’s like the piece that holds the seat to the base is just shot.

Justin: It’s just, it, like, completely snapped off. And so, I was just, like, in a really bad, bad place and really, in a bad situation because, um, to backtrack a bit, um, I was actually in the process of trying to get a new chair.

Kennedy: Mm-hmm.

Justin: And yeah, I’ve been, we’ll kinda get into that, that piece in a little bit. But, like, I was in the process of getting a new wheelchair. And so, I went through the process in the late summer of, you know, getting measured, you know, for this new chair. And that was gonna take some, obviously take some time to, like, arrive and you know.

Kennedy: We’re talking, okay. Like, we don’t know if this episode is for disabled people or not! Maybe you don’t use a wheelchair, you’re not around people in wheelchairs. But yeah, it’s a rant.

Justin: Yes!

Kennedy: And we’re gonna explain all the things, ‘cause sometimes we’re educational too. What would you say, like, your average time for getting a chair? Like, they say six months. That’s not even true.

Justin: It’s not true.

Kennedy: You know?!

Justin: No, it's not. It's not true. And the wild thing about it is, is that, you know, for people who use wheelchairs or scooters, normally the lifespan for the average wheelchair is five years, till you need, like, a new one.

Kennedy: Right. Supposedly.

Justin: Supposedly! Allegedly! But as, as with this process, it actually took close to ten years of getting, you know, from my getting my old, to getting, to getting, like, a new chair. And that process takes FOREVER.

Kennedy: Yeah.

Justin: And one of the things that's really demanding about the whole process is the time between you needing a new chair and trying to actually get a new chair.

Kennedy: 'Cause you had the old chair for ten years.

Justin: Right.

Kennedy: When did you start ordering the new chair? Do you know?

Justin: So, we started ordering the chair, like, back in late 2021.

Kennedy: Okay.

Justin: So, my, my doctor, my neurologist, you know, who, like, I had, like, been in conversation with, he's like, "Man, you need a new chair!" Right, right?

Kennedy: Mm-hmm.

Justin: Like, "You've been dealing with a lot of these issues on your current chair for so long that you can't keep doing this." And so, they placed the order for, you know, a new wheelchair. But, like, it took, like, forever to get that process going because you have to be in constant contact with your, not only with your doctor, but also with the wheelchair manufacturer where you get your wheelchair from.

Kennedy: Mm-hmm, mm-hmm.

Justin: And also dealing with insurance.

Kennedy: Mm-hmm!

Justin: And so, they're always busy playing phone tag with each other. And eventually, you have to kinda step in as a mediator…

Kennedy: Yes.

Justin: …to get everybody on the same page!

Kennedy: You have to lead. You have to lead the process, or it will not happen. I'm, I'm talking, there's like, five parties. There's the seating clinic.

Justin: Yes!

Kennedy: And then there's, like, a vendor, someone's manufacturing the chair, and then people are locally vending the chair. Those people don't get along.

Justin: No.

Kennedy: Like, no one, no one is happy. Everyone's pointing fingers at each other.

Justin: Right!

Kennedy: Saying that, like, "Fax machines don't work." It is 2023. Why is anything being faxed?

Justin: [delighted chuckle]

Kennedy: Why are we faxing?

Justin: Right! Right.

Kennedy: And this is like, we are people with insurance. Like, this is, like, best case scenario.

Justin: Mm-hmm!

Kennedy: Like, I have insurance through my dad's work. There's obviously varying levels of. But even for, like, the like, we're talking Blue Cross PPO, it's still a racket.

Justin: Yes.

Kennedy: Yeah.

Justin: Yes. It's all, it's all a racket. And we're, like, suffering the consequences of said racket.

Kennedy: Yeah.

Justin: And so, we're always having to go through this process. Even if it's just getting parts for your wheelchair, you still have to navigate through these channels of just incompetence and always finger pointing.

Kennedy: Mm-hmm.

Justin: And so, you have to work at making sure that you're, that you're getting the parts that you need or that you're getting a new wheelchair. And so, like, why am I doing all this work? If I'm doing all of this work for them, shouldn't I be getting paid?

Kennedy: Literally, like, there's no one employed by any of these people to, like, communicate with each other and follow up.

Justin: Right.

Kennedy: Like, they send the thing, and then it's just in the, like, bureaucracy, like, purgatory unless you go find out what is happening!

Justin: Exactly!

Kennedy: Yeah.

Justin: And so, once, like, once my neurologist was kind of like, "Yeah, you need a new chair. Let me give you the paperwork and get that, get that pres-, get that prescribed for you," then it's going through the wheelchair company. And that's like a journey within itself. And then it's like talking to, like, insurance. So, this process that started a year, almost a year ago, it took almost another, another at least six months to a year to get to the point where, okay, I need to be measured for a new chair. So, once it had, after I got, like, that process taken care, now you're playing the waiting game. And so, as you're playing that waiting game, I'm in my old chair, and with this old chair, if it, like, something had happened? If a part, like, broke off or if it didn't work, there was going to be a problem because I'm still in my old chair, and I'm waiting for this new chair to arrive.

Kennedy: When you say "old chair," we're talking about a chair where, like, the piece connecting the seat to the base is, like, loose.

Justin: Yeah.

Kennedy: Like, you could fully, like, spin around.

Justin: Spin around! [laughing]

Kennedy: I wish folks could see me right now. Like, I've had that happen to chairs, and I know what you're talking about. You can't go up or down a slope. You should not be sitting in it. It's not safe to be sitting in.

Justin: Right, right. But, like, as you're waiting for this new wheelchair, you're like, okay, I, I still kinda need this old chair, you know, and I still need to, like, navigate and do work that I, like, and do work that I do.

Kennedy: Yeah.

Justin: And so, I kinda still need to navigate in this old chair given that, okay, something bad could happen at any moment.

Kennedy: Yeah. Like, that's not, so, you're breaking bones, you're injured.

Justin: Right, right.

Kennedy: Yeah. Severely.

Justin: Right.

Kennedy: Potentially. Yeah.

Justin: And so, when that part broke, it was like, uh-oh. What do, what do I do?

Kennedy: Mm-hmm.

Justin: Because, like, my wheelchair, you know, I think for a lot of people who don't, you know, don't understand or the, what, what a wheelchair means to someone who, like, it's their livelihood.

Kennedy: Mm-hmm.

Justin: Like, I fully depend on my power chair, you know, not just to get around outside, but to get around in my house—

Kennedy: Mm-hmm!

Justin: —you know, to do the things that I need to do in order to be productive, in order to, you know, you know, see another day.

Kennedy: Yeah.

Justin: And, you know, when my, when that part broke off my chair, I knew I was in trouble because, okay, like, I notice my new chair is still coming, but now I'm in this position where I seriously need, I need help because, like....

Kennedy: Yeah.

Justin: I know, you know, if this old chair is broke, how am I gonna get around? How am I gonna navigate?

Kennedy: When it's set up, like, the insurance will not cover another chair until your chair is broken.

Justin: Exactly.

Kennedy: Which makes no sense! Like, this whole in-between part. You want us to be productive members of a capitalist society…

Justin: Right.

Kennedy: …we're gonna need wheelchairs, like.

Justin: Oh, yes! [chuckles]

Kennedy: Like.... And then the, the chairs, I want folks to understand, are, like, customized to our bodies.

Justin: Mm-hmm.

Kennedy: Like, every inch of you is measured...

Justin: Right.

Kennedy: ...so that you feel comfortable in this machine you're in all the time.

Justin: Mm-hmm.

Kennedy: So, like, when Justin's chair broke, I was like, "Oh, I have an old chair I could bring over." Justin is, like, two feet taller than me and, like, half my width. Like, it would just not work. Like....

Justin: It was funny 'cause, like, like, I was very appreciative of you, you know, asking about if I could, if you wanted me to use your, your old chair. And, um, even the wheelchair company, like, provided, like a, like a temporary chair.

Kennedy: Mm-hmm.

Justin: But the problem was that temporary chair did not fit to my specifications.

Kennedy: Yep.

Justin: As Kennedy mentioned, it fits to, like, someone else's specifications.

Kennedy: Yep.

Justin: And so, like, I'm, I'm 6' 3". So, I'm very, I'm a very tall person. And like, you know, doing all of those measurements is so important because not only am I tall, like, I have, I have long legs.

Kennedy: Mm-hmm!

Justin: So, but one of the main issues with my long legs is that, like, some of the features on different, different power chairs don't fit me. So, it has to be customized to, you know, to, to, you know, to fit me so I can be comfortable in this chair.

Kennedy: Mm-hmm.

Justin: And, you know, that process, you know, I think a lot, a lot of people don't understand that that process just is really draining.

Kennedy: Yeah.

Justin: And it really takes a lot out of you because, you know, you're now, you've been comfortable in this, in one particular chair, and now you're getting measured for something completely new. And now you have to be, you have to accommodate, you know, the issue that you had, you know, your old chair with this one. It, it's just, it's just a lot. It's, you know?

Kennedy: I mean, when I've sat in chairs that weren't made for me, I've had, like, bruises.

Justin: Right.

Kennedy: Like, it's that bad, like, it's…. With depending on, like, if someone can transfer out of a chair and if they're kind of a standard-size person, like, a lot of these rental chairs are just, like, standard.

Justin: Yes!

Kennedy: Like, your average person, like, your average like Hoveround, like, old person wheelchair.

Justin: Yes! [laughs] Right.

Kennedy: Um, for someone who's, who's not sitting in it all day, who doesn't need special features, like wheelchairs these days, they raise up, they recline, they tilt, meaning, like, the, the seat base reclines with the back, and the feet come out, like, all kinds of, um, things folks need to, like, stretch and move their bodies and yeah. It's just, yeah.

Justin: Yeah, and, you know, like, all of these features, you know, like, are very important to, like, our, our livelihoods and making sure that we're able to, you know, you know, to be productive. And, and so, yeah, just like going through that, you know, going through that process was a pain. Because, like, obviously, I needed this chair. I needed a new chair so that I can at least function. And, like, the past couple months have just been very brutal because it, you know, not having access to this new chair or even like my, my old chair being broke, it left me bedridden. So, I had to do a lot of work, you know, from, from, from my bed, which by the way, is not very comfortable for me because, like, you know, yes, I love my bed. Trust me. I love my bed. But I'm not meant to be in my bed almost for days or, or weeks, you know? And for me, it really caused a lotta issues physically because, like, I wound up, you know, having pressure sores on the, you know, on my tailbone. And so, I wasn't able to, like, 'cause, you know, because I wasn't able to, like, move around and navigate and tilt and recline in my chair so that I can take that pressure, you know, off my legs and off my back.

Kennedy: Mm-hmm.

Justin: And so, not have, not, not having, not having that was just such a pain. And it really caused, it really caused a lotta harm.

Kennedy: Mm-hmm!

Justin: And I think when, when it comes to issues like this, a lot of folks don't take those things into consideration.

Kennedy: Mm-hmm.

Justin: They just assume, okay, well, you can just get in your chair, and, you know, you can, you can, you could, you could just navigate and do all of these things. But there's, there's things that it, there's intricate things that go into, you know, how we, how we navigate, how we get in our chairs and how we, how we maneuver. And those are things that I think we don't really take into consideration when it comes to, you know, people who use, you know, wheelchairs and scooters, mobility devices, those type of things.

Kennedy: Like, the pressure sore is state violence, like.

Justin: Right.

Kennedy: That is medical violence. Like, the not having a chair, not having care. No one needs to have a pressure sore. They can be deadly.

Justin: Mm-hmm.

Kennedy: If they get serious, they can be, you can be hospitalized from pressure sores, and they literally do not need to exist.

Justin: Right.

Kennedy: Like, if we just had infrastructure. Like, it's just, like, so infuriating.

Justin: It can, it can be infuriating. You know, it could definitely be infuriating because I'm, you know, I'm thinking about, like, you know, issues that I've had, you know, in the past with, you know, with my, with my old wheelchair that required, you know, parts for it and having to wait, you know, weeks or months because, you know, things are moving slow that, you know, you know, people that are, like, in charge of making sure people have their wheelchairs are not doing the work that they're supposed to be doing.

Kennedy: Yes.

Justin: And that's, and that's something that has been a problem for many of us. I can just think, I'm just thinking of, like, horror stories that, you know, you know, people that I know, you know, friends who use, you know, wheelchairs about, you know, their issues with, like, trying to get parts or, you know, having to go out, you know, in like, the far, far suburbs to get their chair fixed because of how, of how serious the situation is.

Kennedy: Mm-hmm!

Justin: And we shouldn't have to put up with that, you know.

Kennedy: Yes.

Justin: As people who use, like, power wheelchairs, we shouldn't have to, you shouldn't have to go through that.

Kennedy: Yeah.

Justin: You know?

Kennedy: Yeah.

Justin: And I, I, I remember, so, [laughs] I remember.... So, I had a, I had a, I had a similar, I had a similar issue with the seating post before.

Kennedy: Mm-hmm.

Justin: So, about maybe about almost a year before, you know, this chair, actually the chair broke, um, I had a similar issue that required, you know, my mom having to take my chair out to the wheelchair company all the way out in the suburbs, far, far suburbs.

Kennedy: Mm-hmm. Mm-hmm!

Justin: You know, having to use her own money to get out there just so that they can, that they can fix it and having to navigate through that process. It's just, it's just bullshit.

Kennedy: Like, she got an accessible Uber just to take your chair.

Justin: Just to take my chair.

Kennedy: Yeah.

Justin: Just take my chair because of it was such an emergency of trying to get that, trying to get that fixed. And that's a problem. It's like a ma-, it's a major problem.

Kennedy: These issues are not treated like emergencies by doctors, by insurance, by the companies selling them and making them.

Justin: Right.

Kennedy: Like, point blank. It's, I feel like we should say, too, like, once you start ordering a new chair, you can't order parts for the old chair 'cause insurance is like, "We're done with that. That's not our problem." I'm like, "But you haven't delivered my new chair yet. Like, how am I supposed to function?"

Justin: Mm-hmm.

Kennedy: And so, like, the batteries, for example, are the first to go. If you do happen to get in a situation where you have.... Okay. So, right now, I have three wheelchairs, and it is only because in 2019, I was hit in a crosswalk.

Justin: Right.

Kennedy: And the insurance company of the driver that hit me bought me a chair. So, that one wasn't run through insurance.

Justin: Mm-hmm.

Kennedy: So, I started a process of ordering a chair a year ago. I have the new chair. It's broken. It's supposed to get fixed in a couple of days, but that took two months to, like, actually get the chair right.

Justin: Right.

Kennedy: But, like, so, the chair that I had here, so, me and Justin were waiting for our new chairs, like, at the exact same time.

Justin: [laughs]

Kennedy: And, like, are we gonna eat turkey together or not? Like, what is happening? And the...chair that I had here was the one that got hit. It's got a little crack in it, but it works.

Justin: Right, right.

Kennedy: And it had been sitting, uh, unused for so long that the batteries went out.

Justin: Mm-hmm.

Kennedy: So, your only solution at that point is to go to, like, an Interstate Batteries and, like, buy batteries out of pocket, which are pretty expensive, but they actually sell them for less than the freaking wheelchair companies. But I knew, like, the chair would've sucked for you anyway, you know? Like, we were like, "Should we do that?"

Justin: Right, right.

Kennedy: But it’s not even, like, what is comfort at that point? Like, I’ve been in that situation where I was, like, employed by a non-profit, and they were like, “Oh, well, you can work from home, right?” And it’s like, kind of.

Justin: Kind of....

Kennedy: Like, barely. Like, it’s, it’s your, it’s like, “Well, holds your arms up.” And like, everything. I was sitting, and I had no, I don’t have, like.... This is my old apartment. There was no, like, furniture for me ‘cause I’m always in my chair. So, we, like, went out to the public patio and got like a…

Justin: Public patio!

Kennedy: …like a lawn chair! And that’s what I was working from home in!

Justin: Right! I’m like, okay.

Kennedy: With, like, these little metal armrests, you know? It’s just not like. But yeah, people do not know. Yeah. All right. So, what eventually happened?

Justin: So. Okay. So, so, through this process, they did, like, the wheelchair company did, like, supply me with a temporary chair. But, like, after a couple of tr-, after a couple of tries trying to get into it, it just, I couldn’t navigate in my house.

Kennedy: Mm-hmm!

Justin: And I, like, I just threw my hands up ‘cause I was like, oh no.

Kennedy: Uh-huh!

Justin: I just, I just like, I can’t. I can’t keep doing this because, like, the way it was, the, the temporary chair was way too big for me.

Kennedy: Mm-hmm.

Justin: The joystick was like. And since I’m sitting in my, I’m currently sitting in my new chair, and the joystick was like this round, it was like this round joystick that, like, obviously I couldn’t grip.

Kennedy: Oh, my God.

Justin: I couldn’t do anything! And so—

Kennedy: Yes! It’s the details!

Justin: Yes! And so, like, as I’m.... You know, my, my place is, it’s a, it’s a nice, nice place, but it also, like, is pretty tight in certain spots.

Kennedy: Mm-hmm.

Justin: And so, just like, trying to, like, navigate around these tight spots in my house that, you know, I'm used to doing, I'm used to doing, I wasn't able to. And so, after a certain point, I just like, I was like, just fuck it. I'm not, like, I'm not doing this. I'm not, I'm not gonna just keep, keep using this chair, you know? And so, I had to at least get back to calling the wheelchair company and trying to at least figure out, um, "Hey, do you guys, like, have any idea when, a timetable, like, when my new chair is actually coming?" And, you know, not really hearing back from them, regarding it and having to, you know, call there every other day just to be like, "Hey, what's going on with this situation?"

Kennedy: Yes.

Justin: You know? "Like, you know that I'm, you know, I need my new chair. What's going on here?"

Kennedy: Mm-hmm!

Justin: "What's, what's happening with this process?"

Kennedy: Mm-hmm.

Justin: And so, I sat for a, a month. I wasn't, I sat, I sat at home for a month, you know, either bedridden or, like, really sitting in this old manual chair that I had for, like, 20 years. That's a whole, that's a whole nother, that's a whole nother story.

Kennedy: Yes!

Justin: But like, I'm sitting on this other old manual chair that's obviously, I'd outgrown, and it's not comfortable for me.

Kennedy: Mm-hmm.

Justin: And so, I spent almost over a month not being able to, like, really, like, move around in my house, which was like, really put me in a very bad place.

Kennedy: It was October to Christmas, wasn't it?

Justin: Yeah, it was something like, it was, like, it was November. So like, it was the week before Thanksgiving. 'Cause I was actually supposed to come hang out with you for Thanksgiving!

Kennedy: Right. Yes.

Justin: And like, once the chair broke, that kind of ruined, like, all the plans that I had.

Kennedy: Yeah.

Justin: And it just really put me in a, like, really in a bad place ‘cause I was just like, what am I supposed to, what am I supposed to do, like?

Kennedy: Yes!

Justin: Like, my job requires me, as a photographer, to work outside, and not being able to be outside was something that just really, you know, it just really put me in it. It made me depressed.

Kennedy: Yeah.

Justin: Because, like, I wasn’t able to do these things. And so, I was in the process for at least a month calling the wheelchair company, calling the insurance, seeing what’s up. And eventually, I did find out so that my, my new chair actually, so, my new chair actually arrived in, I think, a few days before Christmas.

Kennedy: Uh-huh.

Justin: And so, I was, like, finally able to, like, be in my new chair, which I’m currently in right now as we, as we speak.

Kennedy: Uh-huh!

Justin: It’s a nice little, nice little purple bad boy here. So, you know.

Kennedy: Yes!

Justin: You know, so, like, it is. I’m grateful that I’m in my new chair. But also, it makes me just think about the process that all of us have to go through…

Kennedy: Yes.

Justin: …in order for this to work.

Kennedy: Yeah. Well, I got my new chair on December 14th.

Justin: Mm-hmm. [laughs]

Kennedy: I was like, “How did I get mine before Justin?” ‘Cause I have this, like, this okay chair that the, the trucks who hit me in the crosswalk’s insurance bought. And I’m in it right now ‘cause the new chair’s broken. And like, um, that was 11 months it took to get that and get it wrong.

Justin: Jeez. Wrong.

Kennedy: And then on New Year’s Eve the motor broke.

Justin: Oh, my God.

Kennedy: And they replaced that before they ever got the parts. I kid you not, the guy who sold me the chair had a heart attack. I was like, “What are the odds of, like, all of this series of?” So like, the, the parts for comfort were supposed to come on Monday. But, like, I even remember texting you ‘cause I was like, “All right, I got a, I got a chair. Do you want this other chair? Like, the batteries work in this one.”

Justin: Right! [laughs]

Kennedy: ‘Cause I’d been driving it. Um, good thing you didn’t take it ‘cause I ended up needing it!

Justin: Oh, my God.

Kennedy: It is.... Yeah.

Justin: Please, please. And like, these are the things that, you know, we constantly have to go through it. And not even just for, as I mentioned earlier, not even just for a new chair, but just parts! So, like, if you need to, you know, get you, you know, get new batteries or new wheels, or it’s something that, like, you know, is important, is an important part of your chair is broken, like, what do you do? And I think a lot of folks just like, “Hey, you know, we’ll figure it out,” you know. Like, nah, we just, like, they’re gonna just figure it out.

Kennedy: Mm-hmm!

Justin: Because, like, this is my livelihood. This is my life.

Kennedy: Mm-hmm!

Justin: And for many of us, our wheelchairs are the only mode of, like, us navigating in spaces that are still, like, inaccessible to us, right?

Kennedy: Mm-hmm.

Justin: And then, so, yeah, it’s just like, you know, people don’t take those things into consideration when it comes to, like, our livelihoods.

Kennedy: Mm-hmm.

Justin: And it just goes, it just goes back to, you know, all these things of just like, you know, being in this, you know, having to deal with, having to deal with systems that are inaccessible for us…

Kennedy: Mm-hmm.

Justin: …and always having to go jump through hoops to, like, get the services and then get the parts and devices that we need.

Kennedy: Yeah. This is like a sliver of the pie of the violence if we're talking about care, housing, transportation, employment.

Justin: Right. Mm-hmm.

Kennedy: Like, all these barriers that disabled people face, and like, you cannot understate the mental health impacts of not having your basic needs met over, chronically, over and over and over.

Justin: Mm-hmm.

Kennedy: Like, and just, like, having motivation. The pandemic, and like, we know that, like, disabled people are gonna be, among other marginalized people, like, the highest impacted by climate change and, like, all these other things. And it's just like the whole thing's gotta crumble. [giggles]

Justin: It's gotta crumble. It's gotta go.

Kennedy: You know?

Justin: It's gotta go. Least, at least that, we could all, we could all agree that these systems that are currently in place, you know, just have to be abolished and be done with.

Kennedy: You know?

Justin: Right.

Kennedy: Like, and the part that kills me is that [big sigh] all of this, this systemic oppression that people don't understand gets applied to disabled people as, like, a character flaw.

Justin: Yeah.

Kennedy: Like, "Oh, you're lazy. You're not productive." We're overproducing all the time to just get, like, basic things! And like, you know, like, "You're not responding quickly enough. You're not alert enough. You're not," like, whatever it is. Like, disabled people are tired.

Justin: I'm trying.

Kennedy: Yeah.

Justin: I'm trying, Kennedy!

Kennedy: Yeah.

Justin: I, I really am. And it’s just like a lot of, a lot of the folks don’t under-, understand that, and we’re put under a lot of pressure to, you know, to conform and do all these things. It’s just like, “No.” I’m like, “I don’t wanna do this.”

Kennedy: Yeah.

Justin: Like, there are days now, you know, even with our, you know, being in my chair that’s like, there’s some days I just don’t wanna do anything. I’m just like, “No.”

Kennedy: Mm-hmm!

Justin: Even now that I have my new chair, I’m just like, “No, I’m gonna work on my, on my time.”

Kennedy: Yes.

Justin: And, you know, making sure that I’m taking care of myself.

Kennedy: Yes.

Justin: Because at the end of the day, that’s all that matters, is making sure that I’m still alive.

Kennedy: Yes.

Justin: You know, you know, these systems are often trying to kill us all the time!

Kennedy: Mm-hmm.

Justin: And we’re still, we’re still here.

Kennedy: Mm-hmm!

Justin: And like, we’re trying to live our lives. And, you know, just like.... And I think that’s why it’s just so important, I think, you know, for us to share these, these stories, because a lotta people really don’t understand these systems that are, that are meant to really hold disabled people down…

Kennedy: Yes.

Justin: …and keep them down.

Kennedy: Yes.

Justin: And not understanding that oh, these, these are problems.

Kennedy: Yeah.

Kennedy: Like, all of these issues are, are issues, you know, that disabled people have to go through every day and have to live with every day.

Kennedy: Yes.

Justin: And it's tiring.

Kennedy: People are resting from burnout. Like, yeah, we hope this'll contextualize, like, the speed of our content. Like, we're moving at our pace 'cause it would be a disservice to ourselves and our listeners to, like, pretend it's something else, to pretend that we were like able-bodied content creators, you know?

Justin: [delighted laugh]

Kennedy: That, like, pod-, that have a weekly podcast.

Justin: Weekly podcast! [laughs]

Kennedy: Maybe someday, like, it's also, we need more funding. We just launched a subscription that we hope people will check out.

Justin: Yes!

Kennedy: And if there's sponsors out there who are, like, ready to ride this wild timing roller coaster of our lives with us, please reach out.

Justin: Yes, please. Please, yes, yes.

Kennedy: You can email us: info@CripCrapMedia.com.

But yeah, I think like, um, like, durable medical equipment, I mean, it's all the things. Like, I think my biggest thing while you were going through that, like, my chair was whatever 'cause mine wasn't completely shot yet. But I have not had consistent care since October. So, just like that kind of staffing stuff, like, it kind of almost, like, flowed over. Like, "All right, that's a wrap on '22. We'll just pick it up next year!"

Justin: Yeah!

Kennedy: At some point, we're like, "That's it."

Justin: Right.

Kennedy: But, um, I think with, like, durable medical equipment, specifically like—which is what they call wheelchairs, lifts, certain medical supplies like shower chairs, these are like, this is like medical terminology for these companies that vend this stuff—um, there's lots of different folks in Chicago and everywhere. Every single one I've dealt with has been pretty bad, like, in different ways. Like, there was a decent place in Omaha that you could, like, go to, but, like, not everyone has.... You know, my parents had, I grew up in Omaha, Nebraska, and my parents had a van. So like, and like, you know, like, I would take off school, and my dad would take off work, and we'd like, go get shit repaired. You know, like, that's ridiculous!

Justin: Yeah!

Kennedy: Like, um, other places would come to your school, but then be, like, slower. Anyway, like, we're not gonna name names. We depend on these companies.

Justin: Right, yes.

Kennedy: But like, they all need to get it together, and they all, like, feed into each other. Like, if.... Like, the lifts somehow come a lot quicker. I get that the chairs are being custom made, but the insurance policies around it, like, you need to start the process sooner than.

Justin: Right.

Kennedy: Like, if we know the chair is looking a little ragged, let's get going.

Justin: Let's get going.

Kennedy: But like, if, if you think about, like, I uses CPAP, and like, that stuff is fine. Like, because more people, like, my parents both use CPAPs. It's not, like, so, so specific. It's something about wheelchairs specifically where, like, they're so hard to get, like, and the costs. I think that's why the insurance policies are bad. And 'cause insurance is just evil. But like, and like, health insurance shouldn't be a thing. People should just have what they need. But, um, like, we're talking $30, $40,000 for our wheelchairs.

Justin: Right.

Kennedy: Yeah.

Justin: Right, right.

Kennedy: Yeah.

Justin: And so, mine's was, I think, close to, I would say for the new one, it was close to around $40,000, you know?

Kennedy: Yeah. Yeah. Easy.

Justin: Just, just straight up. And, you know, that's like, that's just, that's like, really, like, frustrating when you see, like, the prices that go into, you know, you know, wheelchairs, like in the tens of thousands. And it's just, it's just astronomical. Like, being disabled is expensive as shit.

Kennedy: Mm-hmm!

Justin: You know? I think a lot, I think there's a lot of folks don't realize that, oh yeah, you could just easily get these parts or easily get, you know, these new chairs, and it's gonna be okay. The insurance is gonna figure it out, and everything is gonna work wonderfully!

Kennedy: Mm-hmm!

Justin: And it's just like, fuck that. It doesn't work like that. It's complete bullshit.

Kennedy: Well, and like, the, all these systems, like, feed into each other. Like, when you call about this stuff, it's as if you're calling to, like, report. Like, I've been treated nicer by, like, stores.

Justin: Yeah!

Kennedy: You know, 'cause you're, like, they actually see you as a customer. They don't have something to lord over you, like. And, you know, like, I'm like, maybe we oughta get on Yelp about it or, like, tag people on socials or, like, act like entitled customers at, like, HomeGoods stores because, like, like, the customer service, it's like they know that you need the thing. I mean, I'm sure they're tired. I'm sure their jobs are annoying.

Justin: Mm-hmm.

Kennedy: I'm sure they get a lot of negative energy directed, like, the people who answer these phones. But like, it's just like, like, it just doesn't feel like you're getting, like, a response. It's like when you call this date about a service, but like, we are, our insurance is paying them for a product! Like, can you be nice? Like, can you have empathy?

Justin: Yes.

Kennedy: Can you affirm what I'm going through? Can you act like there's urgency?

Justin: Right!

Kennedy: Like, I know you're getting, like, all these calls all day, but it's like you're dealing with, like, a hospital system, or, like, they're just like, whatever.

Justin: Yeah, you know, yeah.

Kennedy: Like, the tone is so. I'm like, do you guys think we have things to do? Or I don't even know.

Justin: "Oh, you need a new wheelchair. Mm, okay. That's cool. Bye."

Kennedy: Well, and it's really, like, life threatening. Like, in 2021, there was a woman named Engracia who was on a plane, and her chair was broken by the airline. Uh, and that really brought a lot. She had an exacerbated pressure sore and died because she didn't have her chair.

Justin: Uh-huh.

Kennedy: And it brought a lot of attention to the issue of airlines. Um ‘cause, like, we go through all this to get a chair. Then somebody wants to go on a trip, and it breaks. And you have to go through all of this again.

Justin: Mm-hmm.

Kennedy: And in that time.... And like, this could happen in the case of just not having a chair too. The airlines is a whole nother episode, like, a whole nother issue.

Justin: Oh, yes. Oh, yes.

Kennedy: But like, like, people are dying about this.

Justin: Mm-hmm. And I, I, and I don’t think people, like, get, like, the, the urgency that comes if, you know, your, your wheelchair is broken because you, you depend, you depend on it. And, and, you know, sometimes, you know, it’s frustrating having to wait for, you know, parts or, you know, you know, a new chair itself. But I think a lot of people don’t understand the urgency with it. And it’s such, you know, our wheelchairs are like, our, our wheelchairs are a part of us.

Kennedy: Mm-hmm.

Justin: And, you know, we can’t, we can’t do anything if our wheelchairs are broken. We can’t, you know, we can’t work if our wheelchairs are broken. We can’t go to school if our wheelchairs are broken. We can’t travel if, like, our wheelchairs are, are broken. Not by us! But just by other entities!

Kennedy: Yeah.

Justin: You know?

Kennedy: When she was traveling to advocate around care...

Justin: Yeah.

Kennedy: The, like I said, it was in 2021, but there was a lot of, like, petitions and a lot of, um, different advocacy around the airline stuff. Um, so, we definitely encourage folks to check that out. And condolences to her family, who’s raised a lot of hell about this. Rightly so. But yeah, people, yeah, do not know. Some people don’t care. The airlines sure as hell don’t care. Like, that kind of money for the repairs is just like pocket change to them.

Justin: Mm-hmm.

Kennedy: But it’s, like, so hard for folks to access through insurance.

Justin: Right.

Kennedy: Um, and sometimes they cover their mistakes and sometimes they don't. And we will definitely try and do a full episode on, on that.

Justin: Yes, 'cause that is, yeah, that is a topic that is definitely, that needs to be kind of fleshed out and, and discussed more because those are just like, this is the, like, what we're just talking about is really just the tip of the iceberg…

Kennedy: Mm-hmm!

Justin: …when it comes to, like, you know, like the issues that, you know, come from, you know, having our, our chairs, our chairs broken. And yeah, and that's something that definitely needs to be fleshed out a little bit more because we definitely have a lot to say about that too. [chuckles]

Kennedy: Mm-hmm! Totally. Yeah, it's. Yeah. All that to say is Happy New Year! [laughs]

Justin: Hey, Happy New Year. All right! Woohoo!

Kennedy: Happy Valentine's Day. Happy 22 Holidays.

Justin: [laughs]

Kennedy: We'll be back when we can.

Justin: Yes, Yes. Happy Black History Month too.

Kennedy: Yes!

Justin: All the, all, all the things, you know, yeah. Like, I appreciate you all, like, listening to our rant slash, you know…

Kennedy: Yes.

Justin: …discussion.

Kennedy: We missed, we missed you guys.

Justin: We have! We've missed y'all! We've just been, like, busy doing other things and, like, doing a lotta different, different projects, you know. And we doing big things in 2023, Kennedy. That's what we doing.

Kennedy: Yeah. We're excited to, to do more pod episodes and other stuff this year. We do have hope for the year but wanted to give everyone an update. I think we're still recovering from all the things.

Justin: [chuckles]

Kennedy: And yeah, just gonna sustainably move into this year, bring you all the content we can.

Justin: Yes, you know, we know that, you know, you all, you all have missed us. We've heard from, from y'all wondering when, like, the pod, the podcast is coming back. And so, you know, we're glad that you all are continuing to support us. Um, before we leave, Kennedy, how can people reach, uh, *Crip Crap*, and how can they subscribe?

Kennedy: Um, so, if you want to become a paid subscriber—we are gonna keep media free to those who need it to be free—but if you're able to support with a monthly amount of $2, $5, or $8, you can do that at CripCrapMedia.com/subscribe. Um, if folks have questions, access requests, you want to be a sponsor, our email is info@CripCrap.com. We have an Instagram: @crip.crap.media.

Justin: Mm-hmm!

Kennedy: We are now on Facebook.

Justin: What?!

Kennedy: Um, you can just look up Crip Crap, and, um, you can follow our LinkedIn page, if you're into that. [laughs]

Justin: We have a LinkedIn page! That is correct. We have a LinkedIn page, so please follow along with that, please.

Kennedy: Yes, absolutely. Um, yeah, we have lots of exciting folks coming up. Um, we're gonna be taking...uh, pitches for blog posts.

Justin: Mm-hmm.

Kennedy: The blog is specifically about, um, media representation of disability. So, if there's something you wanna write about or review, um, that info email, you can send us pitches there. Um, yeah.

Justin: Yeah. Yeah. So, I think we, I think we have all the, all the social media things, things down. So, you know, make sure to subscribe. And as Kennedy mentioned, you know, if you can't, if you can't subscribe for a paid subscription, that is totally fine. We're gonna keep giving you this content.

Kennedy: Mm-hmm.

Justin: We're gonna keep giving you this content, baby. So, don't worry. Don't worry about none of that.

Kennedy: [giggles]

Justin: We got, we get, we gotcha. So, we are gonna spirit. 2023 is going to be our year, and uh, be on the lookout for future episodes of the *Crip Crap Podcast*. And, um, with that, um, this is our first recording for 2023.

Kennedy: We did it.

Justin: And yes, we did it. We're going to do plenty more. And everybody, thank you so much for listening to this edition of the *Crip Crap Podcast*, and we will see you next time.

Kennedy: Yeah, thanks for coming along with us.

Justin: Yes.

Kennedy: Yay! 2023. Be resistant.

Justin: Resistant? There you go. Yeah, yeah, so, thank y'all so much, and we will see y'all next time.

Kennedy: Bye!

Justin: Bye.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That's just some crip crap, don't you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That's just some crip crap, don't you know

<u>Season 1</u>

Episode #1: Introduction to *Crip Crap: The Podcast*

Episode Description: In our inaugural episode, Justin and Kennedy introduce themselves, Crip Crap, and *Crip Crap: The Podcast*. They discuss creating in COVID, analyze the mid-pandemic moment, and confirm the need for disabled perspectives and accessibility in media and beyond.

Kennedy & Justin: Hello! (giggles)

Justin: Welcome to *Crip Crap: The Podcast*

Kennedy: The Podcast!

Justin: Oh my god!

Kennedy: We're podcasting!

Justin: We're doing it!

Kennedy: Justin, how are you?

Justin: I am very excited today, because we actually get to do our first episode. Our first podcast. Look at us!

Kennedy: Yes!

Justin: Doing big things.

Kennedy: Yeah.

Justin: Big things. How are you doing?

Kennedy: I'm doing good. This is exciting, um…

Justin: Are you ready for this?

Kennedy: I think so. Are you?

Justin: Yes, yes, I definitely am, am ready to get this thing started and you know introduce the world to Crip Crap.

Kennedy: Yes! I feel like we should let folks know this is a little intro.

Justin: Yes.

Kennedy: No guest this month.

Justin: No, no. Just a little, just a little try out here. You know, testing our voices and everything. You know, making sure that we deliver y'all a very good podcast.

Kennedy: Absolutely, and get to know us, get to know what we're doin'. Do you want to tell people about yourself?

Justin: Do I want to tell people about myself? I should. I should.

Kennedy: (laughs)

Justin: Just for for podcast purposes so people know like, know who they're, know who they're listening to. So um, I am Justin Cooper, uh I am, um, a disabled black man, um, who uses a power wheelchair. Uh, I am a filmmaker, a photographer, community organizer. What else do I do? I don't, I don't know.

Kennedy: Justin does a lot of stuff…

Justin: I do a lot of stuff. I do a lot of stuff. But mostly my area of expertise is filmmaking and photography. And I have been a filmmaker for close to wow, almost 10 years? It's been about 10 years.

Kennedy: Mm-hmm.

Justin: It's been about 10 years since, you know, I got started getting into like film and into telling the stories of people with disabilities. And I've been a photographer for about four years now. And so yeah, I've like been in a lot of places, I've done a lot of things in the disability community. And yeah, it's just, it's just I'm glad to be here, glad to be a part of this awesome thing (sirens in background) as you hear the fire truck go past, so just ignore that.

Kennedy: (chuckles)

Justin: And yeah but that's that's pretty much me in a nutshell so. Um, Kennedy?

Kennedy: Yeah, well so we should say we're recording in a home as of now.

Justin: Yes.

Kennedy: On a busy street. We might edit that out. We might not.

Justin: We might not.

Kennedy: There might be a cat. You know, like, it's COVID still.

Justin: Yeah, it's fine.

Kennedy: Like why, why are we always trying to pretend, you know? That like life isn't what it is. (both giggle) Yeah, in the spirit of cripness. We might not edit that out. Um.. yeah, my name is Kennedy Healy. I am a white, fat, queer, power chair user. And my background is in consulting and I am the founder of Crip Crap, trying to bring that into the media realm and also do more with writing and media making. So yeah, so I knew Justin as a producer and was like, "wanna start a podcast?" And here we are.

Justin: We are here. We are here, yes yes.

Kennedy: We don't know how we met, officially.

Justin: No, no, no. Just, somewhere.

Kennedy: In the community, (jokingly) in the movement?

Justin: Yeah, yeah. Pretty much. I think that's the story I think of all disabled crip folks you know "How did you meet?" "I don't know." Somewhere, but we we met and we developed a, you know, friendship that we've been friends for many years.

Kennedy: Mm-hmm.

Justin: And, you know, now we are building, you know, Crip Crap and we're presenting this podcast to you and, you know, we're gonna be, we're gonna be doing big things so, you know, this is who we are. Hey it doesn't matter how we met, but we met, so.

Kennedy: Yeah - here we are!

Justin: Here we are.

Kennedy: I would say we both do a lot of disability stuff.

Justin: Stuff, yes.

Kennedy: And, I think the goal with the podcast is to keep it in that realm but like have any other kind of intersection as topics within disability.

Justin: Mm-hmm.

Kennedy: Um.. we so, a little background on Crip Crap, we're a just starting media company that has this podcast, um we have a blog…

Justin: Yes.

Kennedy: ...that is going to be reviewing disability representation in media. And then we do offer consulting services to theater, arts, and media folks on disability, accessibility, representation, etc.

Justin: Right.

Kennedy: And we hope to grow from there but this is a big... this podcast is a big part of the beginning, which I think the whole concept for me came out of COVID.

Justin: Mm-hmm.

Kennedy: Being at home wanting to create things and just sort of the like way that the media was… this happens all the time to disabled people, but like everyone was talking about us like, "we have to protect the most vulnerable." Yeah, but no one was talking to us or not enough…

Justin: No.

Kennedy: ...and then like all these promises like all this lip service from politicians was not being carried out. Cause there's no, there were no, there weren't enough disabled people in leadership roles.

Justin: Right, right.

Kennedy: So, yeah we're here to not go back to normal but to make sure that folks are incorporating access in not only media, but everything in the future.

Justin: Right.

Kennedy: Um… the main audience for Crip Crap would be disabled folks, but it's not like a sepratist space like we invite other people…

Justin: We're inviting others to be a part of it…

Kennedy: Yeah to like learn about disability culture.

Justin: Right.

Kennedy: But it's not going to be catered to like educating…

Justin: No, that's not what we're trying to do.

Kennedy: Not the media, if you pay us to consult then of course.

Justin: Then, then we can do that - yes!

Kennedy: Of course.

Justin: Then we can educate. We'd be more than happy to educate.

Kennedy: Yes.

Justin: For the right price.

Kennedy: Mm-hmm.

Justin: So yeah, I think like, you know, one of the things that we wanted to really do with this podcast is we wanted to at least, you know, shoot for like monthly episodes, you know, mixing up between guests and like different topics that are like happening, you know, within the community and affecting, you know, media and, you know, where we live in the city of Chicago. And so I think one of the goals is that we want to, you know, shoot this monthly but, you know, we're all like working on crip time and, you know, for me, you know, crip things do happen, you know, even though you try to, you know, time and, you know, put things out there but, you know, crip things happen. Y'all all know. So, you know. Yeah. That's really the goal is to really come up with monthly, monthly episodes and, you know, focusing on like topics including like political, culture, cross-disability, you know, intersections with other identities, you know, care, sexuality, fashion, sports. But, you know, maybe maybe those last two we'll, you know, let people know depending on the guests that we have, you know, for for our pod but yeah this is, this is what we're what we're trying to do and, you know, put stuff out there, you know, for, you know, us fellow crips and for, you know, people with disabilities, you know, because there's not a lot of media representation out there, you know, in terms of dealing with people with disabilities and so, you know, so Crip Crap is going to be the thing and this podcast is going to be the shit, you know…

Kennedy: (giggles)

Justin: I didn't know if we could curse or not but, you know… it's gonna be the shit.

Kennedy: I think, yeah, I think we just made that rule (laughs)

Justin: (laughs)

Kennedy: Yes we can. Um… yeah and I think, yeah, we're based in Chicago, so I think a lot of stuff especially at first will come out of here, but um we won't like limit ourselves to that.

Justin: Oh, no no.

Kennedy: You know, Justin and I are both power chair users.

Justin: Mm-hmm.

Kennedy: We have genetic disabilities and we're excited to hear from folks with other types of disabilities as well.

Justin: Right.

Kennedy: Thinking about like the mad movement…

Justin: Mm-hmm. Mm-hmm.

Kennedy: ...sensory disabilities, neurodivergence.

Justin: Right. It's a lot… there are a variety of disabilities, you know, out there this is not set to one thing and so I think it's important for us, you know, when we're doing this pod is to really, you know, spread it out to, you know, all people with disabilities and having, you know, conversations that I feel like are very important, you know, in our community and, you know, and I think thats something thats very important to the both of us, right?
Kennedy: Yeah, for sure. And yeah, just thinking about, yeah, like the ways that not all disabilities are visible and if there's like folks out there listening who might be questioning disability like this space is for you, too.

Justin: Right.

Kennedy: Yeah.

Justin: It's an open space for everybody. This is what we gotta do, you know? Gotta have some fun but then we're also going to be talking about a lot of important topics that, you know, affect our community and, you know, yeah that's that's what we wanna do with Crip Crap.

Kennedy: Yeah and I think we're in like a really interesting moment…

Justin: Mm-hmm.

Kennedy: ...like being in the U.S. with access to vaccines, but like the pandemics not over.

Justin: Over, no it's not over. Uh uh.

Kennedy: Um... and but like we're able to connect a little more…

Justin: Right.

Kennedy: ...and I think we're all like trying to heal from the past year and like figure out what moving forward looks like.

Justin: Mm-hmm.

Kennedy: Did did like lockdown and stuff like affect your artmaking Justin?

Justin: Man, it it like it was a series of like ups and downs.

Kennedy: Mm-hmm.

Justin: You know, when, you know, when the pandemic started, I was like doing some, you know, disability organizing work…

Kennedy: Mm-hmm.

Justin: ...that got like immediately shut down…

Kennedy: Mm-hmm.

Justin: ...because of the pandemic, so there were months, you know, where I was like really depressed. You know, I didn't really want to do anything. And like really it just really brought me down. And then you know the summer of last year that's when like I started, you know, started focusing on my photography work and that like really, you know, started to, you know, boost my spirits up a bit and, you know, it really made me focus on more of my work as, as an artist and like trying to figure out where my next steps are going to be, you know, in what I was doing. And then fast forward to this year, and it just like there was these whole bunch of different opportunities for me to showcase my work, showcase my photography work, um I was in a couple of art galleries you know…

Kennedy: Nice

Justin: ...you know during like early spring and summer...

Kennedy: Mm-hmm.

Justin: …um I got actually sold a couple of my art pieces.

Kennedy: Mm-hmm.

Justin: So I was like yes that that that works for me, because I kinda you know kinda need that and um…

Kennedy: Yes!

Justin: Yeah and, you know, now it’s like really opened the doors for me to like interact with other disabled artists, you know, in Chicago. And not just in Chicago, across the country, too. And that's something that I never would have imagined like last year, especially because there was a lot of uncertainty like around everything and, you know, now it's just like wow like I’m actually an artist. And I’m like holy shit, I’m selling stuff in different galleries and it's just the work has just been, it's been an incredible journey. And I’m looking forward to like continuing that journey through, through this podcast. And through working on like expanding Crip Crap as a whole.

Kennedy: Mm-hmm. Yeah and you mentioned, were you referring to summer 2020 as the first summer?

Justin: Yeah so for summer of 2020 was really what really got me doing more of my photography work.

Kennedy: Mm-hmm.

Justin: And then that sort of, you know, coming into this year, you know, I was talking to a lot of folks about, you know, the work that I was doing, you know, during like 2020 and that really sparked a lot of conversations with folks when I would like showcase my work. Because I was talking in terms of, you know, with the photography work that I do, you know, accessibility is a huge issue.

Kennedy: Mm-hmm.

Justin: For, you know, for me getting around and so, you know, when I was like showcasing my work, you know, it looks like, it looks like ordinary photos…

Kennedy: Mm-hmm.

Justin: ...until I start telling the stories of how I got access to places that I wouldn’t have gotten access before…

Kennedy: Mm-hmm.

Justin: ...before the pandemic.

Kennedy: Mm-hmm.

Justin: And so you normally like for us, you know, wheelchair users out here, you know, people are all over the place and they’re kind of in the way and, you know, you’re like you’re trying to navigate through people and, you know, navigate through different streets and everything and so during the pandemic like people weren’t really outside.

Kennedy: Mm-hmm.

Justin: So it was just like, “oh okay, I can easily get to these places now that were like inaccessible to me.”

Kennedy: Yeah.

Justin: And so that's like that's what I’m really doing now photography wise is really, you know, showcasing like, you know, accessibility or like the lack thereof in different places because thats thats thats a constant issue and its been a constant issue since, you know, stuff has opened back up, you know, especially in the early spring and summer…

Kennedy: Mm-hmm.

Justin: ...where, you know, a lot of places of business, you know, especially bars and restaurants opened up a lot of their outdoor seating and so it made it difficult to navigate those spaces…

Kennedy: Mm-hmm.

Justin: ...because they were inaccessible. The photography work has just been amazing and I’m just like excited to see where it goes.

Kennedy: Yeah, yeah, I feel like, yeah, the way that the shutdown and then both like the opening of virtual spaces…

Justin: Yeah.

Kennedy: ...like created access.

Justin: Mm-hmm.

Kennedy: And I think there's kind of like this crip mourning of like the shift back to what people are calling normal.

Justin: Right.

Kennedy: Um, because normal meant inaccessible… yeah, planning transportation and things going late into the night and even like folks still not feeling comfortable like in unmasked indoor spaces…

Justin: Right. Exactly.

Kennedy: ...who are high risk.

Justin: Mm-hmm.

Kennedy: Um, even if COVID, you know, is way less likely to kill someone who is vaccinated, you know people fear...

Justin: Yeah.

Kennedy: ...hospital stays and things still, um especially with the rate of unvaccination.

Justin: Yeah.

Kennedy: Yeah.

Justin: And so yeah it's I think it's something that, you know, for us, you know, we’re always like trying to be careful as much as possible even when like people don’t really like think about us when it comes to like these issues…

Kennedy: Mm-hmm.

Justin: ...it's often like okay, we're often like put on the back burner or just not thought about at all. And so I yeah, I think like like COVID is like we're still in this, like as you mentioned like we’re still… we're not even close to like being like out of this. And so it's just interesting seeing like how people view accessibility.

Kennedy: Mm-hmm.

Justin: And how they view like okay, how do they view people with disabilities?

Kennedy: Mm-hmm.

Justin: Because it shows like, there's a like, to me there's a lack of empathy when it comes to like accessibility issues. And so people just assume that “okay, if we put this, if we put a ramp here, you know, we did it. We solved our accessibility”

Kennedy: Mm-hmm.

Justin: But it's like no, no you have not, and it's just that, you know, sometimes just seeing what I see outside it's like yeah there's still issues that need to be discussed when it comes to like dealing with accessibility in COVID.

Kennedy: Yeah, absolutely and like yeah just thinking cross disability, I think our, sometimes our access needs get put first cause like when people think disability they think wheelchair.

Justin: Yeah.

Kennedy: But there's like so many more layers.

Justin: Exactly. Yes.

Kennedy: Um. And I do think like the, like the disabled internet got so good in COVID, and like um disabled people on different social media platforms, and like the accessibility of virtual space like across state lines, so you did find and see the people who cared and like started to pick up on things.

Justin: Yeah. Mm-hmm.

Kennedy: Um but yeah obviously so much more work to do but I think that summer of 2020 was pivotal. The way like abolition…

Justin: Mm-hmm.

Kennedy: ...like police and prison abolition…

Justin: Mm-hmm.

Kennedy: ...and the focus on racial justice and police violence took off and how that like, that layered with COVID, not that like either of those things should have happened to make things happen, but I think conversations around labor…

Justin: Yeah.

Kennedy: …and care…

Justin: Still going to this day!

Kennedy: ...and like healthcare like everything just like snowballed um…

Justin: A lot of things are, a lot of things are changing, and you're just seeing the result like now of like how labor is like we're not going to be, continue to be mistreated, you know.

Kennedy: Mm-hmm.

Justin: You know, we're not going to be, you know, we're not going to continue to take you know dangerous working conditions and all, all of that sorts and, so yeah, there's there's a lot happening and there's this huge, there's a movement like happening with folks that are just like no were not going to... we've been working, even during COVID we've been working, you know, our asses off and we're not getting, you know, properly compensated or in danger you know every time we come to work we don’t know if were going to get injured or were going to get killed…

Kennedy: Mm-hmm.

Justin: ....because it's just poor poor management.

Kennedy: Mm-hmm.

Justin: And so now, you know, a lot of these things are continuing as we’re seeing now, you know, you, you’re seeing just this up, just this this uproar and people are just like no were not going to sit here and continue to take, you know, what you’re giving us.

Kennedy: Mm-hmm.

Justin: You know?

Kennedy: Yeah. And I think like with this podcast and this company like we want to talk about all the things just through a disability lens…

Justin: Mm-hmm.

Kennedy: ...cause that's like not the dominant lens…

Justin: Exactly.

Kennedy: ...that gets put onto things…

Justin: Right.

Kennedy: …so and just yeah like keeping that momentum because like so much violence had to happen to push everyone to this brink…

Justin: Right.

Kennedy: ...and it shouldn’t have to be that way.

Justin: It shouldn’t have to be that way, but here we are.

Kennedy: Mm-hmm.

Justin: And so we’re, you know, with this podcast we’re gonna, you know, really bring that to ya and bring different topics, you know, just to, you know, not only make you laugh, but just like make you think as, make you think as well.

Kennedy: Yeah.

Justin: And so yeah that, you know, our podcast is going to be, it's gonna be awesome!

Kennedy: Yeah we gotta do both…

Justin: (laughs)

Kennedy: ...cause like I feel like I stopped reading political things like extra things like I read the news and then that would like hit my capacity.

Justin: Right. Yeah. No.

Kennedy: Yeah (laughs) so we're gonna do it with joy!

Justin: Yes.

Kennedy: Thank y'all for listening.

Justin: Yeah and thank, thank y'all for listening to this like short little, short little uh podcast, you know, we we plan to, you know, go go go a little bit further in future future episodes but, you know, this is like our, you know, introduction to to to y'all and, you know, we want to continue to, you know, continue to give you, give you the good shit.

Kennedy: Exactly. Yes.

Justin: Give you that Crip Crap.

Kennedy: We um are... we would love to have sponsors…

Justin: Yes.

Kennedy: ...if folks wanna reach out about that.

Justin: We're always looking for looking for sponsors, you know, to support to support our podcast.

Kennedy: Absolutely. This is the first episode.

Justin: Yes.

Kennedy: But we hope to have more fun tricks up our sleeve.

Justin: Oh yes.

Kennedy: Sponsors. Maybe a song.

Justin: A song, yes! A song.

Kennedy: Um maybe some bits…

Justin: (chuckles)

Kennedy: ...maybe some video someday, um and if folks are interested in sponsoring…

Justin: Yeah.

Kennedy: ...the contact info for Crip Crap is on cripcrapmedia.com under the, the contact tab…

Justin: Mm-hmm.

Kennedy: ...is where you find that info…

Justin: Okay.

Kennedy: ...or if you want to know anything else from us or you have an access request or whatever it is.

Justin: Right.

Kennedy: Um, you can also follow us on Instagram @crip.crap.media

Justin: Oooo!

Kennedy: And, yeah, thank you all so much.

Justin: Follow us there! Do that, do that, you gotta do that, you know what they say, you gotta follow and make sure people know what we're doing and yeah, please do that.

Kennedy: Absolutely.

Justin: Mm-hmm.

Kennedy: We'll put up posts about new podcast episodes, blog posts, etc.

Justin: Right.

Kennedy: And we will talk to you all next month.

Justin: Yes we will. Alright.

Kennedy: Bye!

Justin: We did it!

Episode #2: Fashion as Worldbuilding with Sky Cubacub

Episode Description: Justin and Kennedy discuss recent events surrounding COVID and ableism. Then, they interview Sky Cubacub, founder of Rebirth Garments, about accessible, gender-affirming fashion as resistance.

Christea: *guitar instrumentals*

Justin: Hello. Hello, everybody. Oh my goodness, we made it to a second episode, Welcome to the Crip Crap podcast. I am Justin Cooper.

Kennedy: And I'm Kennedy Healy.

Justin: Yo, Kennedy, we did it. We we made a first episode! Look at this!

Kennedy: We are somehow still kicking.

Justin: (laughs)

Kennedy: Was that ableist?

Justin: No, no, I don't think so.

Kennedy: (giggles)

Justin: If it is, someone will will correct us on that. But we, we we we recorded the first episode and now we are at episode two. We are so happy that you are here listening to us on this episode. We got some important topics to talk about. We got an awesome guest that's really, really, really cool. And so, you know, first of all, we want to thank you for listening to the Crip Crap podcast. We're very thankful for you that you listened to the first episode and that you're here for episode two. We are very excited.

Kennedy: Very excited. It is. Things are rapidly changing in the news. So we just want to note that today is January 26, 2022 when this intro and the conversation with our guest was recorded. Our last episode was released when we launched on December 11th and immediately after things really shifted with COVID.

Justin: Oh yes.

Kennedy: So I feel like and that episode was recorded well before it was launched, so some people had mentioned that I sounded very optimistic.

Justin: (giggles)

Kennedy: So we'll be noting the dates a little more during this time.

Justin: Yeah. Well, I mean, we had we had every right to be optimistic, you know, given given COVID and given everything you know, we didn't know if we were going to make it to episode two. But guess what, we did. We're here. We're going to do this.

Kennedy: Here we are.

Justin: Right here we go. We believed in us, I believe in, you Kennedy, you know that.

Kennedy: Oh, you too Justin, fully. We took a little break in January to move everything virtually. Justin is on it with the virtual recording and sound and etc. and we'll have more tricks up our sleeve as we go.

Justin: Yes. That's right. And so, you know, today we wanted to talk to you a little bit about, you know, what's been what's been happening as of late, as Kennedy mentioned, you know, we were preparing to record our second episode and then, you know, Omicron came through and, you know, we had to go back to doing what we should have been doing, you know, staying inside and keeping your mask on and doing all the things. And, you know, now we're like, we're still doing this virtually. And Kennedy, like, how are you, how are you feeling, you know, during during this time, how have you been feeling?

Kennedy: Ooof, so much has happened since our last episode, I think Omicron has been pretty re-traumatizing for disability and other high risk communities. I think the whole pandemic I kind of oscillated like big ups and downs. My friend, early on, my friend Annie called it the Corona coaster.

Justin: Yes!

Kennedy: Like, yeah, feelings of like because you also have a lot of energy when you're like, stuck inside. But I think my highs are leveling out a little more this year. I do feel a little more prepared for lockdown this time around. I'm hanging in. What about you?

Justin: You know what this, this time well, this month in general has been just full of so many like, you know, ups and downs and, you know, it's just been me trying to find a balance in the things that I'm doing. So I'm actually scheduled since we're recording this on the 26th, I think, on February 4th. I'm actually showcasing an exhibit for Gallery 400 called through my lens, and it's gonna be showcased outside of the gallery that got these huge windows on the side of Gallery 400, where they'll be like showcasing my work. So if you're like walking by or rolling by in your wheelchair or just driving by, you can actually see that you can actually see like photos that I've taken during the pandemic, you know, on on on these huge windows. So like, I've been like working on that. I was supposed to be like traveling, heh, during this month and due to unforeseen circumstances that has that didn't happen. And so I've been just really staying, staying in and just focusing on focusing on my work and continuing to do that. So like, I'm really excited for this gallery and there's a couple of other projects that have, like, come up in the, you know, during this month that like, I am really thrilled to to be a part of. And so even like, you know, just thinking about everything you know, I, you know, even during this pandemic, it's been a struggle having not been able to be outside as much as I want to. But then also it's giving me so many opportunities and it just is just continuing into 2022. So like this month, it's just been it's been a lot of work and like, I'm excited for like everybody to like, check out, check out my my exhibit.

Kennedy: Yes, Justin, I'm so excited to see this and this is at Gallery 400 at UIC in Chicago?

Justin: Yes, that is that is correct. So it's opening, so it's official opening is Friday, February 4th and it goes to July 2nd. So it's about like five to six months. My work will be displayed out for everybody to see. So, you know, I'm very excited, very excited for the opportunity. And like as we get closer to the actual opening, there will be a few things that I will share. And of course, add to, you know, Crip Crap media so that y'all, that y'all can check it out.

Kennedy: Yeah, I did share something on the Instagram story, but we'll definitely get something more permanent up there so folks can find the details on our Instagram.

Justin: Yes. Exactly. And so, yeah, given with with everything that we've been dealing with, with with with COVID, we we might as well just like dive in to like big stories that kind of happened like earlier this month involving involving the CDC. CDC Director Rochelle, Dr. Rochelle Walensky, who back on January 7th made an appearance on Good Good Morning America, talking about COVID and talking about Omicron. And, you know, she was talking about, like a lot of people who had, like, that were that were dying, you know, you know, of COVID 19. And in the video, if you if you see, if you've seen it, she's sort of like cheerfully, you know, talking about like, you know, hey, like she was replying to like like those that have, we're dying of COVID 19. We're mostly people with pre-existing medical problems aka people with disabilities. The overwhelming number of deaths as she told it, over seventy five percent occurred in people who had at least four or more comorbidities. So really, you know, they these are people who were unwell to begin with. And yes, it's really encouraging news in the context of Omicron. And let's just say that the disability community was not thrilled with these comments because it was basically just like, Hey, you know, oh, this many folks are dying, so it's totally fine. You know, it's good we're doing this. We're going to continue to go through with this. Oh, hey, you know?

Kennedy: Yeah, disabled social media after that was wild. The comorbidities that she's referring to, you can look up what they consider. These are not... a lot... there's a lot of things on that list that are very common among Americans. And yeah, just to say that anyone's death is encouraging is so atrocious.

Justin: Yes.

Kennedy: Yeah,

Justin: It's very yeah, it was it was very atrocious, but like she she later apologized for her for her comments, but, you know, still just like just cheerfully like it, just saying it the way that she did just really turned off a lot of folks, you know, especially within the disability community, because oftentimes many people pretty much want us dead. And it's something that's me, you know, that we've like have struggled with for for for decades. And, you know, hearing someone you know who's like at the head was at the top of the CDC saying comments like this. It just really reaffirmed for a lot of a lot of us that, you know, yeah, people are purposely trying to kill us, especially, you know, especially during this. And it's just it was just, you know, listening to the comments and hearing that folks' responses to it, it was just frustrating, you know, just just hearing, just hearing those type of words, you know what I'm saying?

Kennedy: Yeah, absolutely. And I think that the conversation about disability and eugenics is ongoing and definitely COVID brought it up a lot more early on folks were talking about who's going to get the hospital bed when there aren't enough left and things along that line, rationing health care is like the shorter way to say that. And just to hear someone under an administration that a lot of people hoped would be better around COVID specifically. Very disheartening.

Justin: Yeah, this is very disheartening, very disheartening to hear that, but you know, for for me, like, you know, it was disheartening but not surprising because, you know, it's like pretty much really how a lot of people especially like able bodied people, you know, really feel like towards, you know, people with disabilities. And it's something that we have constantly that have struggled with and have constantly fought against. And they're sort of like, you know, it's sort of like, it's sort of brought out a lot of conversation within the community. And there was one article in general that really, really summarized, you know, how people with disabilities have, like are really feeling in the midst of all of this. And so on January 16th the great Mia and Mingus wrote an article about like about all of this, and you know, the title of it was "You Are Not Entitled To Our Deaths: COVID, Abled Supremacy & interdependence." And, you know, it was just really spot on about how, you know, how many of us kind of feel about abled bodied people and how they react to people with disabilities. And, you know, trying to like, you know, you know, just being tired of trying to, you know, find grace with people who are often like, not not for us and not really, you know, not really for, you know, people, you know, not really for disabled folks. And it's just really a culmination of a lot of things that's just really making, you know, our community very frustrated with how this has been, how this is, how, you know, COVID has really, you know, struck our community and how a lot of people really don't care. And it's not just with COVID, it's like it also like goes into like accessibility. And a lot of other different issues surrounding, you know, a lot of other disabled issues. And it's just it's just a it's just constant frustration, you know?

Kennedy: Yeah, absolutely. I think it's hard to know. Like what to say in these moments, and so many things have been said over and over in disability communities. And there's a lot of different resources out there, but this piece is really gut wrenching, puts a lot of, like you said, people's thoughts into words, and we did link it in our Instagram Story on Crip Crap that it's in one of the highlights now under COVID and also, if if, I know the Instagram Story isn't like the most accessible feature, so it's also on Mia's blog, Leaving Evidence. But yeah, I think Justin like talk about like me, talking about this winter being like retraumatizing from last winter, just like the whole pandemic. Um, really picking at like all those ways, disabled people are left behind their whole lives, whether it's like not being able to get to your friend's house for a sleepover as a child or like something as simple as that and then just like watching the world go out to nightclubs right now while we're trying to find masks so our PAs are protected, and so is is... Yeah, it's all the things.

Justin: You know, it's like, yeah, it's like we're just constantly, you know, fighting for survival every day, you know, making sure that we're like taking care of ourselves, but then also like making sure like our PAs and people who are like our caregivers and, you know, that are like really taking like really taking time, you know, to, you know, to to to to help us. And, you know, we want to make sure that they're healthy and that they're, you know, OK, you know, while they're out. And so it's been it's been it's been a struggle, you know, and I've seen it and I've heard it from other other friends who like, are struggling because, you know, hey, we want to make sure that we're still here, but also we want to make sure the people that are at our, you know, assisting us and taking care of us, you know, making sure that they're OK. And so, you know, I think this is another thing that I think a lot of able bodied folks don't really take into account. You know, the things, the steps that we have to take in order to make sure that we're safe in order to make sure that you know, we're we're we're living to see another day, you know?

Kennedy: Yeah, yeah. Like housing, transportation...

Justin: Right.

Kennedy: ...care...

Justin: Yes.

Kennedy: ...like health, like keeping up with your health care. Like all this was hard before COVID. And now it's just like compacted. Like the layers are like and in and out and up and down and the waves, the uncertainty like um, especially right now is is really hard to deal with, and I think like what I know for sure is that Crip community has saved my life like a thousand times over.

Justin: Yes.

Kennedy: And when you were talking about the work you've been doing lately, like it's so important to be making things where disabled people can see themselves right now because we can't see each other like in person, like the last person I'm going to like if I'm taking a calculated risk, the last people I'm going to do that with is other high risk people and yeah, I think just like making art that reflects the disabled experience is like the main thing I can bring myself to do right now. And so I've really been diving into that as a coping mechanism, and I also started making coloring pages, though that's been fun.

Justin: Yes, yes.

Kennedy: Yeah, but no, I think we really need disabled voices and marginalized voices right now, like...

Justin: Oh yes.

Kennedy: There's a point in the piece where Mia talks about the feeling of needing someone who doesn't need you, and I totally understand what she's saying. And I think her article also like in a personal sense, but I think her article also points to how systemically, if we keep going the way we're going as a society, we're not going to have when the world's going to end. Like climate change, COVID, the number of deaths is harrowing. Like, I don't, I worry the way this has been normalized that like, how are we going to get back to a society that doesn't normalize death, which is not that that didn't happen before COVID with other systems of oppression, but I think just the sheer numbness that everyone's taking on to get through, like...

Justin: Yeah.

Kennedy: ...we we got to build something different and like, we need new leaders to do that.

Justin: It's just it's just been baffling to me, the number of people that are like comfortable living with COVID, you know, and but from my perspective, it's like one I don't want to be living with COVID. No, I don't want I don't want to have COVID. I don't I don't want to have any of that. And I don't want any of my friends to have COVID. So I don't want to sit here and live and live with it and live with people dying. That's just not like, that's just, you know, what I do. And then that's not who I am. And so just seeing the number of people that have just been normalizing this, it's frightening. And it's very it's very scary because we shouldn't be normalizing death, you know, I mean, we understand it happens, you know, death happens every day, but we shouldn't be normalizing just OK well, this no number of people died today. And OK, you know, that's what's happening, what's happening next. But no, we, you know, we can't just keep continuing to live through this this cycle. And it's important for us to have disabled voices and marginalized voices, you know, put out there in the forefront because we're the ones that are, like, really dealing, you know, really dealing with this. And, you know, something has to change. And I've just noticed, like, you know, the work that I do like as an artist, the photography work that I was doing, you know, and I'm still doing, you know, focusing on like accessibility like during COVID, it's it's really shown me that, you know, I think there's a there's a lack of empathy, you know, towards people with disabilities. It's just people that don't want us around. And so we have to have our voices out there, you know, out there in the forefront, we need to have voices that are out there, you know, really changing this system because the system needs to fucking change. It really needs it really needs to change. And you know, the renaissance will come, you know, when more disabled, you know, marginalized voices are heard when we have more disabled and marginalized, you know, leaders really making this make making the decisions, you know, because let's face it, we're we're we're at a point where all of this, all of this shit is like just bad. Everything's bad...

Kennedy: Mmm hmm.

Justin: It's just bad. And it's like, we're like, you know, being, you know, the planet. You know this this country, the planet, everything is like being held on by like, by like duct tape. And, you know, if it falls apart, we're just we're all doomed and we have to make sure that, you know, there are more voices out there that are like, No, we're not going to let this happen. What can we do to change as a society and what can we do to make sure that people are living?

Kennedy: Yeah, absolutely. Like as much as. Whether it's gender, race, sexuality, disability, as much as, et cetera, like as much as people in who aren't in marginalized groups like think they don't need marginalized people like now more than ever like. Again, going back to the article like. Mia, is like we've been talking about this since before COVID. Like, can you just trust disabled people of color? Can you just, you know, take the lead and and give a crap about people's lives. But yeah, I find that I'm trying to like balance my grief with creation and joy. How has that been for you?

Justin: It's been you know what it's like it's been it's been difficult, you know, handling like, you know, trying to find that balance because I'm constantly I'm constantly like saddened, like at how you know how we are as a society. I'm constantly saddened at how we view, you know, certain groups in, you know, in our society. And, you know, for us, like constantly, you know, screaming and telling people about these issues. And yet, you know, nobody listens. And still, even during this time, nobody is like still listening. And it's just like, it's really frustration. So it's like, there's a sadness, there's a, I'm saddened. But then one of the things about, you know, during this pandemic is like, it's brought me so much joy, you know, and it's like giving me so many opportunities to showcase my work. It's given me an opportunity as an artist to, you know, to at least continue to do the work that I do that even at the beginning of this, I didn't know how this was all going to work. And so, you know, on one hand, you know, I'm constantly saddened, but on the other hand, I'm just like, wow, I've gotten so many opportunities. I've gotten so many chances to explore, you know, my work as an artist and how I can and how better I could be going forward in talking and showcasing like disability issues for people to see, you know, through, you know, through my lens or through, you know, the photos that I take. And so it's been it's been it's been a, you know, trying to balance that is just so difficult because, you know, you understand what we're we're we're still in this like there is like we're like, no matter what other folks say, like, we're still in this pandemic, we're still indoors. We're not, you know, back to normal as everybody is like trying to be and like, there is no there is no normal after this, you know, there's going to be a lot of different changes. But yeah, just balancing all of that. It's it's very it's very it's very difficult, you know?

Kennedy: Mm hmm. Yeah, I think, the, I think disabled people feel really invisible right now, and so it's especially important to like be a mirror to each other. And I think just like being out there and doing your thing and doing your work is absolutely. Um, I mean, like, always important, but like more important than ever and like is is going to have a big impact on people stuck at home feeling and all these feelings. I know like at first pre-vaccine, I was just totally in survival mode and pretty disconnected from my emotions, and now I try to take like some time every day, light a candle, often I play Brandi Carlile's cover of Hallelujah and just kind of like, give myself a second just to like feel things and then try to just keep moving forward.

Justin: Mm hmm.

Kennedy: But yeah, I think if there is like some kind of renaissance after this, it's going to be so crip and accessible and like, uhhh, I can't wait to just like hug everyone and do regular things.

Justin: I know, right? We we we need it like, we need that we we we need that renaissance. And you know, it's something that like, I feel like it's it's something that is much needed because, yeah, I mean, it's like I miss my friends I miss like hanging out with folks and going to different places, you know, just seeing folks. And you know, as much as I like spending time by myself like, I want to hang out with folks and do great things. And so yes, there's this renaissance must happen. It must happen. It must happen with people who are disabled, that we have more access, that things are more accessible. And they're not just not just like physical access, but just like access for all people who you know, hey, this is this is what we need, and it's something that I feel like we, you know, as as as Crip Crap, as you know, doing this podcast where we're helping, we're we're doing, we're doing our part.

Kennedy: Absolutely. We're going to we're going to make it happen if it doesn't so. Speaking of Renaissants, Shall I introduce our guest?

Justin: Yes, go right ahead, please.

Kennedy: So we're very excited today to introduce Sky Cubacub - they, them, xe, xem, xyr - is the non-binary, queer and disabled Filipinx creator of Rebirth Garments, a line of wearables for trans, queer and disabled people of all sizes and ages. They are also the lead editor of the Radical Visibility Zine, a full color cut and paste style zine that celebrates disabled queer life with an emphasis on joy. Sky was named 2018 Chicagoan of the year by the Chicago Tribune and is the 2019-20 Kennedy Center citizen artist and a Disability Futures Fellow. Rebirth Garments has been featured in Teen Vogue, Nylon, Playboy, The New York Times and many more. Find them on Instagram, Tik Tok and Twitter @rebirthgarments all lowercase along with Facebook at Rebirth Garments - two words with the R and the G in uppercase. All right. Hi, Sky.

Justin: Hey.

Sky: Hi.

Kennedy: Thank you for joining us as our first guest.

Justin: Yay!

Kennedy: And for our first virtual podcast recorded over Zoom. How are you doing?

Sky: I'm doing great. I've been recording videos the past couple of days for Radical Fit, my queer DIY fashion curriculum with the Chicago Public Library.

Kennedy: Awesome.

Justin: That's cool. That's cool. So Sky can you describe yourself for our Crip Crap listeners who aren't familiar with you or or your work?

Sky: Yeah, I'm Sky Cubacub, I run a clothing line called Rebirth Garments, and it's for queer and trans disabled folks of all sizes and ages. It's very brightly colored, lots of geometric pattern, lots of fun color blocking, all in stretchy spandex and meshes and holographic fabrics. And it's all made to measure to everybody's specific measurements. And both Kennedy and Justin have actually worn my stuff before Kennedy has modeled for me, and Justin was in a music video that I costumed.

Kennedy: Oh, I didn't know that. That's awesome. Yeah, we love Rebirth in terms of besides work. Like, is there anything else we should know about?

Sky: Oh, I guess I have been resting a lot the last two years. I I got mono right before the pandemic started and it basically made me have CFS. So I've just been a sleepy baby a lot. So that's kind of I'm leaning into it now. I'm just doing everything from bed, pretty much usually.

Kennedy: Oh, wow. Yeah, that seems like terrible timing, but also maybe worked out in a way.

Sky: Yeah, no, I think it was good timing.

Justin: Yeah.

Kennedy: If it had to happen.

Sky: Yeah.

Kennedy: Yeah.

Sky: Yeah. People were more understanding in some ways.

Kennedy: Totally. Yeah, it's funny how everyone needs access now.

Sky: Yeah.

Mmm hmm. For sure, that's that's it's very interesting how we all need this now. I would love to work from my bed. You know, I love it. You know, just hey, during this time, it's been really good and very, very relaxing. So I'm taking it, you know? So Sky, can you tell us a little bit more about Rebirth Garments and its history?

Sky: Yeah. I started Rebirth Garments in the Summer of 2014. I had been dreaming about it, though, since I was in high school. I, so I'm non-binary. I also identify as Xenogender, now that I have found out about this amazing word, which is kind of instead of being within like a spectrum of male to female, like thinking more about like more expansive gender that isn't based in those at all and is even more like like based in kind of like aliens, actually. So a lot of neurodivergent folks kind of vibe with that identity and including myself. So, yeah, when I was in high school, I really wanted gender affirming undergarments like chest binders and packing underwear, and I couldn't find anything that was accessible to me as a teen with no access to digital money because all of those types of garments were more so sold in sex toy shops, which have like an age limit of 18. So I thought about making these huge chest binders that were also not just like boring, white or black or a beige that they marketed as nude. That like just was more celebratory and fun and cute, and went with the clothing and style that I liked. So, yeah, I'd been thinking about that. And then when I was in college, I didn't really have time to make this clothing line, even though I really wanted to. But then I gained one of my other disabilities. When I was 21, my stomach kind of stopped working properly, so I had to take off a semester from school. And during that time, I also found out that I like couldn't really wear the pants that I had been wearing before. Like, I liked a lot of really tight skinny jeans that were kind of unforgiving, and I was like, oh, I just got to get rid of this and make really soft, stretchy, comfy clothes. So I was doing that for myself, and when I came back from my semester off, I decided to start this clothing line that was both gender affirming undergarments and also clothing for disabled folks. And originally, I thought they might be two separate clothing lines, but then I was like, there's got to be other people like me who identify as both queer or non-binary or trans and also are disabled. And luckily, I was right. And there's a huge, huge, amazing, super cute community that I love who all model for me and are friends and clients.

Kennedy: That's awesome, yeah, I feel like that's such an evolution, like when I was in high school, I didn't even know like about the kinds of things, like that the jobs I wanted were possible or existed, I feel like. But that's like, really great to like, see it grow from that. And definitely like, yay for new genders and I can totally see like the sort of influence of space in your work and colors.

Sky: Definitely.

Kennedy: That's awesome.

Justin: Yeah.

Kennedy: What kind of things are you working on currently?

Sky: So right now, I have been getting all of my employees Calla Bordie, Morgan Hill, and Kaleigh Moynihan, Kaleigh from Authentic Skid Mark. I've been getting them all into places where they can do orders pretty independently without my help at all. Caylee is about to move to San Francisco, so we're actually going to have a representative on the West Coast, which will be exciting. So she's working on copying all of my gazillions of paper patterns, which is a feat. But I think it'll be really great because then I can have folks on the West Coast like, come to her for fittings. And I know I will have some shows there, possibly this year. But you know, who knows with COVID? So yeah, I'm really excited to have them all kind of work on orders, and then I can focus on doing teaching, making videos, lecturing, doing podcasts and interviews like this, and also making sure that I can rest enough for my body because. When I started the clothing line, yeah, I didn't have this particular disability and, yeah, my disability was was the focus was different, like the focus was being able to have my own hours to work around my stomach and and it's different ideas of if it was going to work or not. And now it's more like I'm asleep 12 to 16 to 20 hours a day sometimes. So trying to rest enough and also but also be able to share my work as much as possible. So that's kind of why I've been focusing on teaching a lot because I really want other people to be able to do this type of work and feel empowered to make their own clothing and also make clothing for their friends and communities.

Kennedy: Yeah, that's awesome. Like, I feel like a lot of disabled people lean towards entrepreneurship for access.

Sky: Yeah.

Justin: Yeah.

Kennedy: I'm glad it's worked out as like your own ability statuses shifted. Did I also hear something about a children's show?

Justin: Yes.

Sky: Yes, that's the other thing that I'm like really excited about. So like the Chicago Public Library and our in our program radical fit, that's like geared towards teens. And I've always felt really good and comfortable making content and teaching teens. I think partially because even though I'm 30 right now, most people read me as a teen. And yeah, so it just makes it really easy for me to talk to them and get, you know, them the resources they need, but I haven't really tackled working with kids too much and I really want to because kids get very excited when they see me, but I just haven't had the focus of making stuff for them yet. So yeah, it'll be called Sky in the Rebirth Warriors, and I'm going to have a lot of collaborators, but definitely Colectivo Multipolar will be doing videography and being a wonderful photographer too for it. So it's really cute. And I already have a teaser video with the theme song by Afroshoujo, which actually is the same singer who sang your audio descriptive lyrics, Kennedy, in the RBC2 show.

Kennedy: Yeah.

Sky: And every episode will talk about like different kind of access, like issue or need or exciting disability like topic. So...

Kennedy: Cute.

Justin: That's awesome, that's like really that that's really cool. That's like, I'm excited for that. I definitely like right there and just excited about about about all of that. That's really awesome.

Sky: Yay, I'm glad. Yeah, I mean, y'all should come on the show, too. I want to just have, like everybody who's ever modeled for me, basically come on the show and say something that kids would be excited about or like, just, yeah, talk about yourselves and stuff like what you do for fun and for work. And just to show different futures.

Kennedy: Yeah.

Justin: Mmm hmmm. For sure. For sure. I think that would be, yeah, me, yeah, we're down. We're definitely down with that.

Sky: Cool. (giggles)

Justin: So like, I want to go back a bit. We talked a little bit about the pandemic and COVID, and we know how like, it's been devastating to like many communities, including people of color, disabled people and like people who do creative work. And so you talked about it a bit, but like, how has the pandemic like shifted like your work, your pace and outlook on on everything? And what, if anything, has has been getting you through?

Sky: Yeah, I mean, I feel like so many things have changed because the pandemic starting like really lined up with when I when I started feeling really sick with mono. Like yeah, in some ways it allowed me to take off a lot more time and to have the accessibility to do so many things online because everybody like, yeah, because abled folks were like needing that too. So I was like, phew, like, good thing I did that. Somehow I got at the same time. But like I mean, I've had anxiety and depression and panic disorder for my whole life, and then I've had like PTSD since I was twenty two or three? So, yeah, like obsessing over the news and stuff was really overwhelming and yeah, it would sometimes just make it like, yeah, it would just use up all my spoons for the day. So I had to be a little bit more strict about not consuming too much of that stuff because I think the work that I do is really important. And just like needing to have energy to do that so that I can help my community. I like thought that I was going to have to close Rebirth just a couple of months in because I ran out of money and I was like, well, I don't really know what I'm going to do. And then literally the day after I decided that I was probably going to close Rebirth, I got an email from the Disability Futures Fellowship saying that I got this $50,000 award and I was like, (laughs) oh, my goodness. Like, phew. Now I don't have to close it. And I actually was able to hire three employees who had all been, yeah, who had all been working at places that had, you know, cutbacks or or closed because of the pandemic, so I was able to hire three people who are awesome sewists who were out of jobs and like, you know, allow them all to work from home because they all had they all have the machines needed, or I had like a lot of portable machines that they could take. So we could all like distance very safely or just come into the studio and when they were alone. And then with that money, I also was able to shift my production into focusing on face mask making. So I like started making a ton of masks and masks with clear windows that are more accessible for Deaf and hard of hearing folks, but also for neurodivergent folks and kids and just any, any type of person who would benefit from seeing people's mouths and doing the different kinds of attachment styles. So I have like, I think, 11 different types of attachment styles because not that ear loops don't work for everybody. For me, I just have too many earrings and I was like, I can't deal with wearing ear loops cause they're in my ear so much, so I do like around the head ones, but I have like snaps and velcro and magnets and like hoody cord poles and things like that. So yeah, I totally was able to kind of save my business through that and then with the money from the fellowship, I was also able to make tons and tons of free face masks for for disabled folks, for queer and trans folks, for black and brown, folks, for houseless folks and for folks who were going to Black Lives Matter protests and other kinds of protests. So and I continue to make free ones for for anybody who needs.

Kennedy: That's awesome, and like what timing on the that grant? Like, so glad you got that and are still kicking and doing all that, which kind of leads into my next question, which is fashion or otherwise, how do you understand your work as part of a new world building that we so desperately need right now?

Sky: Yeah, I guess that's like what I think about all the time. That's that's what I've been thinking about since I was a child. Like, I would obsess over ideas of like like I would research like utopia or like utopian dress and things like that in high school and college. And just like write so many essays like about different types of like yeah either utopian dress or like future ideas of dress and things like that just so that I could kind of through that research, I kind of figured out what parts I liked and what what my idea of utopian dress would be. Because like, yeah, some folks, it's like having no choice and just having like just one outfit all the time and you don't have to think about it is like one idea or like everybody is wearing the same thing or, you know, stuff like that. But for me, it's like having unlimited choice and everything completely custom made and just getting to dress exactly however you want to and like having that option and that autonomy, just like making people, it would make people feel so good in their bodies and like, yeah, good physically and also emotionally, and be able to then be your best self because you don't because then yeah instead of the like, you don't have to worry about your clothing because it's the same thing every day or everybody's wearing the same thing, it's like you don't have to worry about your clothing because it you don't have to be like thinking about how uncomfortable it is or things like that. Like, you can just move and be how you want to be. So that's something that I think about a lot, and I wrote my manifesto "Radical Visibility: A Queer Crip Dress Reform Movement Manifesto" in 2015, and it's all kind of talking about another idea of that's like connected to my idea of utopian dress, but an idea where us as folks with marginalized identities, dressing just in a way that can't be ignored so that nobody can just like pass us on the street and not notice us, it's like. But again, it's like having the the choice to be able to do that or not, rather than being subjected to only wearing things that look like scrubs or like medical clothing.

Kennedy: Totally, yeah. Do you find that like when people encounter you or your clothes or like are in educational opportunities you're offering that like the fashion itself is like shifting and changing perspective?

Sky: I think so. I mean, I've had a lot of people following my work since I was pretty young. I mean, I've always dressed pretty excitingly and I my style is pretty much the same as it was when I was a freshman in high school, like when I finally figured out like, yeah, so I dressed kind of eclectically and in a lot of clothing that my grandma made or from thrift stores when I was a child. And then there was two years where I was like, I'm going to try to fit in and wear Juicy Couture and Coach purses and things like that. But I was so uncomfortable with my body and just like, I don't know what I'm doing. But then I I mean, yeah, then I met slash just saw my first girlfriend on my first day of high school, like just wearing like costumes to school and like a faux hawk and like those jelly bracelets and, you know, studded bracelets and stuff like that and I was like, oh my god, that is what I have been wanting to dress like forever. And I was like, ok, well, I guess what I mean amazingly, my high school had no dress code, which is so cool. And so, yeah, I would. I just started wearing costumes to school to and things like that, like, I wore cat ears for the whole time I was dating my first girlfriend. They were her cat ears. It was like a really gay cute thing. And then like, yeah, just got got to play around with like my makeup and like my just like my full expression of self and really found myself in my style then. So like, I mean, yeah, just just seeing my first girlfriend dressing the way she wanted inspired me to dress the way I wanted and then like, has completely changed my life. And there are so many instances of that, like my best friend from grade school, Frankie, who still is like usually the stage manager for all of my shows. Like she was so radically visibly like gender nonconforming as a child like and that just yeah, that made it so that I never like questioned other people's gender expressions or genders like I'm just like, oh, yeah, that's just how they are, which I think would be better. So yeah, I think I mean, I see so much power in clothing and expression, but also in just like yeah how people just, yeah, just how people live and are. So I just try to be my authentic self, and I think a lot of times that helps other people. And I've yeah, I've heard that from people like some people I've met were like, oh, I saw you 10 years ago on the train, like having like a weird sword fight wearing a cat costume like or like, yeah, people who are children who saw me and met me later and were like, oh my gosh, I saw you just walking on the street yeah 10 years ago or something, and it was so exciting and I got into fashion from that, like just so many instances of that. So that's also why I really wanted to do more focused teaching with the with the library and radical fit and also with the kids shows. So that like like if I can affect so many people just by being out in the world, but like then how many people could I help and effect if I'm like actually talking and talking about my work to them. Yeah, maybe through a screen, but like just a little bit like they're learning more about me. It's not just seeing me like a glancing walking down the street.

Kennedy: Totally, that's awesome.

Justin: Yeah, that's really that's really awesome. Sky is there anything else you want our listeners to know about you or anything else you want want to add?

Sky: Hmm. Yeah, I guess, like if anybody has anything that they want to learn how to make, maybe like tell the Chicago Public Library that you want me to make a specific video and then I can make a tutorial for it. So yeah, because I would be really down to make some more, yes, specific projects like right now I'm I just shot a video for how to make a chest binder, and right now I'm shooting a video on how to make like a parking belt and then I'll be making a tutorial on tucking undies next week. So like, yeah, but I would also love to do a bunch of like disability specific. I mean, everything that I do is through the lens of queerness and nonbinary ness and disability, but like getting to do some very specific videos on disability and like, quote unquote "adaptive clothing" would be really cool.

Kennedy: Yes. Is would like a vest be too complicated because I need all the vests, so I will call the library.

Justin: Yeah, we'll do that. Yeah, we'll be that and we'll tell our friends to call the library too, you know?

Sky: Yeah. I love vests. And yeah, I'm making vests. I have your vest over here, actually in my closet.

Justin: (giggles)

Kennedy: That's awesome. Ok, so in your bio there there was info about Instagram, TikTok and Twitter and Facebook. Is there any other things you want to shout out where people can find you or get involved in your work or buy your work?

Sky: Yeah, you can buy my work on Etsy if you go to Etsy.com/shop/rebirthgarments. There's also like a link in my bio on Instagram with all the links to everything. But yeah through Etsy, you can get clothing, zines, pins, patches, stickers. I just got a bunch of new holographic stickers and like "Access Bitch" stickers and things like that. So that'll be like, those are really cute. I also have more like ready to wear clothing. It's through one of those print on demand websites. I use Teespring, but you can get like just a queer crip symbol on a shirt or something if you want something quick. But I do have some fun prints on there, like especially of a bunch of my father's paintings that are like, really beautiful and rainbows and geometric, which are a huge inspiration to my work aesthetically. I also have a CBD line. It's called radically chill. You can get it at radicallychill.me. And yeah, I am an editor at this cute fashion and lit magazine called Just Femme and Dandy. And there's usually submissions open for for the the magazine. So we're about to have the second issue coming out, which is actually Rebirth themed, inspired by my clothing line. But yeah, there's going to be. They're supposed to be two issues a year. So yeah, just look out for that. If you're interested in fashion, I the section that I'm in charge of is called Cancel and Gretel, and it's about ethics and inclusion in fashion. But basically just I want to just hear from all of the queer crip folks and their takes on fashion. I'm also the Access Brat there. So I like do the making sure everybody writes image descriptions or making the images of descriptions and audio descriptions for the whole magazine. So you can see the first issue up and yeah, there's everything has image descriptions and then there's a video that I feel really good about that has a really good audio description. It was like there's a ton of different types of dancing. It's like voguing and tap dancing and like modern or lyrical and like some other stuff, and I was able to describe it all. (giggles) So go check that out.

Kennedy: That's awesome.

Justin: That's cool.

Kennedy: Wow, you're doing so many things. Thank you like for your range of work and...

Justin: Yes.

Kennedy: ...for coming on and for keeping us all like comfortably dressed all the time.

Sky: Yes. Thank you for having me. I love you all.

Kennedy: Yes, so much love.

Justin: Yes, all the love.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk

Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don't you know

Justin: Our theme song for the Crip Crap podcast was written by Christea Parent, a.k.a. Mo Less. Thank you.

Episode #3: Disability, Art, Therapy, and Community with Bri Beck

Episode Description: Justin and Kennedy interview Bri Beck about disability affirmative therapy, art, community healing, and mental health. We look at barriers to accessing therapy that affirms marginalized identities and dream up alternatives.

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Justin: Hello. Hello. Welcome to episode three of the Crip Crap Podcast. I am Justin Cooper.

Kennedy: I'm Kennedy Healy.

Justin: And today we have a very awesome guest, one of our good friends, Bri Beck. And so we're going to get right into this conversation here. So we'll do a little bio. Bri is an art therapist, an artist, works full time in private practice, part time for the Access Living Arts and Culture Project, doing arts and advocacy work throughout Chicago. She also hosts a free mental health support group via Zoom on Monday evening. So welcome Bri, to our podcast.

Bri: Thank you so much for having me, Justin, Kennedy.

Kennedy: We're so excited. I also have to shout out that Bri designed all of the Crip Crap branding.

Justin: Yes. (laughing)

Bri: (laughing)

Kennedy: If you think accessible design cannot be cute, then Bri is here to prove you wrong.

Bri: Thank you, thank you. Kennedy was a great collaborator. We had a lot of fun coming up with some of the graphics and the colors. That was very much your aesthetic as well.

Kennedy: It was a good time.

Justin: Good times.

Bri: A lot of fun and I'm happy to have made it to the podcast portion of this Crip Crap endeavor. So thanks for having me on today.

Justin: Yeah.

Kennedy: Absolutely.

Justin: We're so glad that you are here. But first of all, how are you doing?

Bri: You know. It's a rainy day here in Chicago, so I just I just dried off, you know, I came in like a drowned rat outside, but I'm okay. I'm okay. I'm, I'm happy.

Justin: Yeah.

Bri: I'm a little exhausted this week. You know, I think daylight savings has been tough on my circadian rhythm, like it has for for many of us. So I'm just, like, feeling I feel like I'm playing catch up a lot, just trying to, like, keep up. But I'm in a positive mood. I'm looking forward to, to being on this. This is my first podcast.

Kennedy: Yes.

Justin: Oooo, yes.

Bri: So it's a new yeah, it's a new day.

Justin: Well, we are glad that you're here. And yes, Daylight Savings Time has been kicking all of our asses during this week...

Bri: Yes, it really has. (laughing)

Justin: ...so we're just in catch up mode. So thankfully we are glad that you are here and spending time with us. So can you tell us a little bit about yourself and describe yourself for listeners who don't know you?

Bri: Sure. So I am a therapist, a licensed therapist. I studied art therapy, so technically an art therapist, but by day I am the therapist that sits in the chair and does a lot of space holding for clients of of all sorts. I'm currently working in a private practice setting and the group practice that I'm a part of sees clients that are female identified. That also includes non-binary folks, just essentially not cis men, just because the practice is meant to be more of a safer space for for female identified clients. Yes. So a lot of my clients are young people, anywhere from high schoolers to a lot of college age students, young adults, some older adults. So kind of runs the gamut. And I see people for all sorts of life transitions and things like anxiety, depression. And I also do see people that live with chronic pain, chronic illness, other forms of disability. And I'm hoping to continue to grow my therapeutic practice towards the disability specific community because there's not a lot of representation for therapists out there that are doing disability, affirmative work.

Justin: Mmmm. So when I'm not doing the whole therapist thing, I work with Access Living, which is a Center for Independent Living, I believe is the the name of the type of organization that Access Living is. And within that organization is the Arts and Culture Project. So I work with a colleague of mine named Sandy Yi, and she and I do some arts programming a lot virtually for now. And that also includes this mental health support group for folks in the disability community in Chicago. And since we're virtual beyond Chicago. So yeah. A lot of things I'm trying to figure out who I am and being both a therapist and artist simultaneously and what what that can look like all together.

Justin: Yes, yes, exactly. So it's like as an artist, can you tell us about your work?

Bri: Sure. So I started really infusing disability identity into my work pretty late ish in the game. So I'm only just 30 now.

Justin: (laughing)

Bri: So not like I, I have a lot of years left. But I've always been you know, I've always loved art. Even as a kid, I was the art kid in school and made that my my first love. And I never really started infusing disability into my work until I came to Chicago and went to grad school for art therapy. So I was in my mid twenties and started being exposed to disability arts and culture here in the city and realized that art for me was my own form of therapy and coming to terms with my own experiences and my identity. I started processing my experiences of navigating the medical system surgeries, dating experiences so my work ranges anything from sculptural to installations where so I'm a person with dwarfism and so I sometimes create alternate environments for the viewers to experience what it's like to be be in a body that navigates the world differently or sees it through a different perspective. So I'll hang my work lower on the wall, just make people question their surroundings and how they have access to it. So yeah, my work is pretty mixed media and but definitely speaks to the disability experience both on an internal level but also comments a lot on ableism in society at large outside of myself in my own experiences.

Justin: Right, right.

Kennedy: That's awesome. As a therapist, kind of jumping back to that, how do you see therapy relating to social justice and why? Like in that realm, is it not enough just to treat mental health symptoms that are related to oppression? But like how could the field or in what ways does the field further pathologize marginalized people? And how could the field like work against oppression more systemically?

Bri: Totally. Yeah. I mean, the mental health field absolutely exists within the medical model of disability as it stands.

Kennedy: Mhmm.

Justin: Oh yes, yes.

Bri: Like it does. So there's something something it's something I grapple with all the time, like being a part of a system that accepts insurance for diagnoses and can pathologize very human experiences, particularly living in the world that we do today, where it's very normal, um what's the word, expression of our lived experiences to have anxiety about the things going on...

Justin: Yes.

Bri: ...to be depressed or to be run down or exhausted, or of course, if you are marginalized in any way, multiply, marginalized, you're experiencing trauma at such high levels. And you know, so much of being a therapist is seen as how do you help someone get better or cure these symptoms or take them away? And you can't really look at the individual and the symptoms that they have without examining their outside world and their identities, their their traumas, their socioeconomic status, their their job, like what are the factors at play, their relationships, how they've been abused or not. So therapy, I was in grad school and I heard this this quote from a professor that essentially just said, "therapy is liberation." And I think about therapy as like helping individuals kind of liberate themselves and find their power and understand holding space for them to understand their lived experiences and make sense of them and feel validated and to be given tools to move forward and to integrate their experiences into purpose. But also, where am I even going with this? How that's just on a very individual level, but I feel like therapy can be don in the world like there can be therapeutic things to to heal...

Justin: Right, yes.

Kennedy: Mhmm.

Bri: ...so many of the things that are just collective traumas that we experience.

Kennedy: Yeah, like all the therapists I know right now are so tired...

Bri: (laughing)

Justin: (laughing)

Kennedy: ...like given the state of the world and like, how that's affected everyone's mental health. Like, I'm like, no one can do everything right. But I think even in the past few years, like since I saw my first therapist like after college and I've just seen a shift, knowing therapists and going to therapy and like in the world at large of like people actually thinking more about systems in therapy work.

Bri: Yeah. Yes.

Justin: Yes.

Kennedy: So that's good and yeah, I hope it continues.

Bri: I certainly hope so too. It's it's hard to find therapists now that are like at least newly minted therapists that aren't seeing things in a systemic lens.

Kennedy: Uh huh.

Justin: Yeah.

Bri: But there are definitely people out there that like and this, yeah, like not many, but I guess there are some, some folks still practicing that are very much like, well, let's, let's address the anxiety or the depression and without looking at everything impacting it, which, you know, that's just more of an older way of thinking...

Justin: Right.

Bri: ...that people are these islands...

Justin: Mhmm.

Kennedy: Mhmm.

Bri: ...that experience these things outside of their context. That's just not true.

Justin: Right, exactly. That's just not true at all.

Bri: Mhmm.

Kennedy: Yeah it's interesting because like, I'll see that in like my the health care I get for like physical ailments, too.

Bri: Right.

Kennedy: And like, nothing's um like black and white, but like you can kind of see like who went to school when...

Bri: Yes.

Justin: Yes. Mhmm.

Kennedy: ...and like how the training has changed around bedside manner and like all of that. So yeah.

Bri: Yeah. My grad program was very systems oriented, almost to the point where like, like I we I would almost say we lacked a clinical education at times...

Kennedy: Mhmm.

Justin: Yeah.

Bri: ..because but I've in some way, though, I'm grateful for that because I feel like that clinical stuff can be learned pretty easily...

Justin: Right.

Bri: ...like by reading books and just like knowing things. But like, yeah, I think there's something to be said about a therapist that just like, really does their best to like get it.

Justin: Get it.

Kennedy: Mhmm.

Bri: To get it and like, admit when they don't understand something or just acknowledge a person as a whole person.

Justin: Right.

Bri: And really like so much research out there says that like the really only effective thing that like always stands true and making sure people feel better and supported is like that therapeutic relationship and trust. So the more therapists are thinking about like all peoples and their identities, I think it will create like a better therapeutic experience and hopefully make people actually feel like seen and heard and yeah. Get the support that they need.

Justin: Exactly.

Kennedy: Totally. Yeah. Can you talk in that vein about why or how disabled people, multiply marginalized people and people from other marginalized communities, struggle to find mental health care that affirms all their identities?

Bri: Well the dominant like the identity of like the the the what's the word hegemonic. (laughs)

Justin: Yes. (laughs)

Kennedy: Mhmm.

Bri: Like the norm of a therapist, right, is a white woman, which I am. And, you know, that is mostly able bodied, young to middle aged, wealthy, educated, all of that.

Justin: Right.

Bri: And I think I don't know why, but this field is an attractive field for for that demographic. And because of that, first of all, being a therapist involves having a lot of privilege to be able to access higher education, to get a master's degree to do all this, like this extra training. And there are so many systems at play that I think limit people from even getting to that point to become this, quote unquote helper. And there's also this idea that as a therapist, you have to have your shit together. Can I curse?

Justin: Yes, please fucking curse.

Bri: (laughs) Thanks, Justin.

Kennedy: We broke that rule, I think in the first 5 minutes.

Bri: Awesome, awesome.

Kennedy: It what it is.

Bri: God. So there's just a lot of there's ableism, there's racism in higher education...

Kennedy: Mhmm.

Bri: ...which limits people from going into this field. I think therapy as it stands is a very or at least has been a very white thing that this kind of Western mindset that we have to be able to help ourselves, like on a very individual level versus a collective level.

Justin: Right.

Bri: And there's these kind of like silos of like the therapist and the client in this room. And it's all about like self help. Versus like collective care and, and caring for each other and, and seeing us in the context of our relationships and our communities. So I think for that reason, therapy was just a very white profession for a long time. And it still is. It's still very dominantly white. And I know a lot of great therapists of color that are really trying to critique that and expand the definition of what is therapy and what is supportive to clients of color or queer clients. And of course, I'm coming at it from a disability lens, but I'm certainly I know that I hold a lot of privilege as a white woman still, even though I do identify as disabled and my disability is apparent in the world and in my when I work with clients who often do identify as non disabled or able bodied and there's a power differential there where I wonder what they think of me, I wonder if they think, oh, is she like, you know, she's not the kind of therapist I would have expected when I look on Psychology Today or whatever.

Kennedy: Mhmm.

Bri: And so yeah, I don't know if that, did I answer the question? (laughs)

Justin: (laughs)

Bri: Yeah. Like it just there's just not a lot of representation out there for therapists that represent the kinds of people that really are in the world.

Justin: And I think that's the that's the main thing, especially, you know, for me, you know, being being a black person and being a black disabled person...

Bri: Mhmm.

Justin: ...and actually finding a therapist that can relate to you. Yes. And oftentimes, I have been like if I looking looking for a therapist, you know, I have been referred to often by two white, you know, middle aged, white aged women who are, like able bodied and don't really relate to who I am as a person.

Bri: Yup. Right.

Justin: And so it's very hard even now, you know, you have more more therapists of color, more more queer therapists. It's still hard to find them. And it's hard to navigate in a system that is often benefited white people, white therapists.

Bri: Yup.

Justin: That and it's been a privilege system.

Bri: Yes.

Justin: And so it's hard to still find therapists that you can relate to that understand what you're going through.

Bri: Exactly. Exactly. And there's something about just like getting it. And yeah, it's it's it's it's hard. And I struggled the reason I wanted to be a therapist because I sought help for my internalized ableism and some of the things I was dealing with as, as a person with a disability navigating the world. But there's so many you're speaking about this, this other side of it, too, like there is privilege in being a white disabled person that you know. And so, yeah, seeking representation and understanding is so important because you shouldn't have to explain things to your therapist and like like you're paying them to have them support you, not for you to just spend your hour educating them...

Justin: Right, educating them, yes.

Bri: ... on why you experience what you do and how it feels.

Justin: I shouldn't have to do that.

Bri: Yeah

Justin: Like, as a disabled person, we shouldn't have to do that. You know, I'm tired of, like, explaining about, like, disability rights to people that it's like if you're working with me, I think you should at least, you know, have that knowledge yourself or at least look look it up yourself about it. I shouldn't have to be the educator. And that's oftentimes, like a lot of us are tired of doing that.

Bri: Yes.

Justin: And I have friends who speak about that who are just like I'm tired of like explaining myself and explaining my disability and explaining the struggles that we constantly have to go through and the barriers that we constantly have to break. And so if we're going to see a therapist, I don't want to sit there and spend my entire hour just bitching about the system and like bitching about how how people are not educated enough. Like, no, I can't do it. I can't.

Bri: Yeah. Exactly. Exactly. It's it's just unfair.

Kennedy: Totally. Yeah. I feel like there's so I've heard so many horror stories about like things therapists have said to people or...

Justin: Yes.

Bri: Mhmm.

Kennedy: ....having to educate them. When I started therapy, I took. Like texts, like I took readings...

Bri: Did you?

Kennedy: ...and resources to my therapist and because yeah, it just becomes traumatizing...

Bri: Yes.

Justin: Right.

Kennedy: ...to sit there and educate. So I was like, I got to give you like something to go off of, which she was receptive. So that was good. But it was also like she, she's doing professional development by like reading this stuff and like should have gotten this somewhere or like should be getting some kind of credit or pay for this too. Like, it's like, yeah.

Bri: Right. God.

Kennedy: Like I shouldn't have but like I felt slightly bad that like, like it's like this extra thing she had to do for me as her client that should have been covered in her education elsewhere.

Bri: Right. Right. Absolutely.

Kennedy: But I'm curious, because you talked about like the more clinical setting, how does that differ from like the therapy there versus like the community work you do and like therapy as healing, like what you're talking about. Like I've been in rooms where you facilitated art, like healing art projects that were community based. Yeah, I'm just curious about, like, how you use your skills in like both settings or...

Bri: Yeah, yeah, they're very different and I feel fortunate to have a balance. I will say that, like working full time allows me to like pay my bills and do like this, this clinical work. And I'm actively every day thinking future based, like how how can this be more accessible to people that, you know, don't have a PPO insurance plan or can afford it? But I'm grateful to have the space at Access Living to do work that is community based and is accessible to folks. And that's definitely where I would say, like, my, my heart lies. It's what I feel I love to do. And those spaces that I feel at home as a person, like I can just be a peer in those spaces. So I'm really thinking about peer support and what that looks like as a being a peer, being a fellow disabled person, facilitating space amongst other disabled people, and knowing that inherently there is like power in being the facilitator of sorts or leadership I suppose. But also, yeah. Is, is, I don't know. It's something I'm grappling with all the time like. It's like we need to create something new that doesn't already exist sort of thing. Because like art therapy, being an art therapist, I, I'm grateful to, to be in this field and have that title because I think there's a lot of flexibility in it. But being an art therapist, oftentimes in disability settings is very like, you know, not serious. Like, let's make art together and like in the hospital or in the rehab facility.

Kennedy: Mhmm.

Justin: Yeah.

Bri: Or this is not serious art. This is just for us to to for therapeutic... it's therapeutic. It feels good, which there is totally value in that art is for everyone. And it doesn't have to be serious or for sale or for viewership necessarily. It can just be for the sake of making because we we as people are meant to make and that feels good. But I think there can be like a lack of seriousness for disabled people when it comes to art making and it can be often done in an art therapy context versus like a professional art setting. And Justin, I know you're a professional artist and, you know, it's just it's blurry. And there are a lot of disability activists that are very anti art therapy, and I completely agree with, that in a lot of ways, like, I don't just like get it. I agree. And so it's complicated to to be a therapist and have that that role while also knowing that there's a lot of power and it's a lot of nuance to it. So to be honest, it's something I really thinking about how to do it in the best way possible that is illuminating that power dynamic and is about empowerment for for everybody and about the collective as well and advocacy and bringing bringing us spaces where we can be safe and make together and heal, but also like bring forth like a collective vision with art making and yeah.

Kennedy: Yeah. It's interesting. Like I've heard... I used to work in disability services and I've heard critiques where people are like some people with certain disabilities, usually like intellectual disabilities, like everything is therapy. You go to like art therapy, music therapy, horse therapy, ABA therapy is just like, can people just go to like a class? Like.

Bri: Yes.

Justin: Yes.

Kennedy: Or an event. Like, it like, becomes this whole. And the insurance and like all the bureaucracy of it. But, yeah, I think because those spaces have been so inaccessible at the same time, like, it's weird when there's like, it's like both. Like some people can't access it and some people are like, coerced into it. But like, yeah, you see, like, like the healing justice movement is like people of color led. Like, because these spaces are so inaccessible and like just so many communities, like finding like joy in art and creation and community, like as an alternative to these things. So I love how you like merge it all and like you still get a paycheck and doing the things.

Christea: I'm kinda just trying to balance it. It's messy and you're again dealing with these systems that are limiting. And sometimes it's about kind of outsmarting the system a little bit or or saying you're doing one thing and doing another...

Kennedy: (laughs)

Bri: ...thing like, okay, this is art therapy, but like, wink, wink.

Justin: Nudge nudge. Yeah.

Bri: Like, we can use insurance to bill for this and like afford it. But also like this is this is different. This is not about, like, cure or, you know, just yeah.

Kennedy: Yeah. Well, if you can, like, tack your degree on something and then, like convince a parent to, like, change your. Practice or whatever.

Bri: Right. (laughs) Yes, yes, exactly.

Justin: Now we're thinking and see. Yes.

Bri: Yeah. Play your cards right. You know.

Kennedy: Exactly. You touched on this a little, but are there other barriers you see disabled people come up against in accessing therapy and any solutions on how to push against those?

Bri: Yeah, totally. Yeah, we kind of grazed over this a bit, but yeah, accessing therapy is is a privilege. Absolutely. Where I work in the private practice takes takes private insurance. They do take Medicare, which is great, but that's rare. And a lot of disabled people, particularly that aren't aren't employed are they have Social Security income or Medicaid. And a lot of therapy services don't don't take Medicaid, especially those that are private. And so a lot of people are filtered into more like agency based programs. And those are very you know, I worked for an agency for a couple of years out of grad school, and it was a really like I had a mixed experience. But overall, I loved the people I worked with. I loved the the people we worked with. And but it was it was complex. And I often felt that the resources were so scarce that people didn't get a quality level of support and care. But the employees are vastly underpaid. They're burned out. They're you know, they're not all bitter. But it's easy to be bitter. It's easy to feel like you're being used as a mental health professional, especially early on in your career where you're kind of ready to go and you've got all this energy. But like you're put in very, very difficult situations with, you know, rightfully very traumatized people that that just need so much more especially basic needs before you can even address therapeutic things like, like symptoms or like a lot of times it's just like, can we get you groceries for the week? And this kind of Maslow's Hierarchy of Needs sort of thing, where you're, you're addressing the basics until you can even go to like having relational difficulties or these things that you can really address when you're when you're safe and when you're secure. So, you know, for people that want to see a therapist, like I've had people reach out and be like, you know, I only have Medicaid, can I see you? And it's just like this, this, this moral and ethical thing that I keep coming up against where it's like, I would love to. I just, you know, there's an I do see some clients that are at a more reduced rate, but that's hard to do and still practice and make a living and all of that. So there's a lot of barriers and I've actually looked up like for my future, like, can I get contracted with Medicaid? And you see all these kind of forums with therapists that talk about how hard that is and why that's hard for a reason, because Medicaid doesn't want to pay for this. They'd rather make it hard and only give to these agencies that are you know, they barely give them enough to to run those. So solutions. I mean, it's I feel like a lot of the solutions that I'm thinking about are just these community based efforts where, I don't know, at Access Living, my colleague and I Sandie, are thinking about how to offer like free one on one sessions with folks trying to get behind organizations like Access Living or like just these independent living movements that really care about disability rights and disability justice to kind of funnel in these other programs that are helping people more with their their mental health. So dreaming up that solution right now, it's complicated.

Justin: It truly is. And like, you know, I know we talked a little bit about this, but like, why is it important for people to have therapists from their communities?

Bri: Yeah. Yeah. It's just this element of of getting it is is huge. And, you know, therapy is it's meant to be, you know, individual therapy at least is about a relationship. So at the heart of any strong relationship is trust. And trust can be built much better when you feel like you're seen and you're validated and you're known for who you are. And there's no one... there's no way that any therapist could understand any other person's lived experiences, even if all their identities were very similar or matched completely. But there does need to be a level of of humility and understanding and vulnerability, I believe, on behalf of the therapist, to admit that they don't know or understand but want to learn more and not at the expense of the client educating them. So that might mean like what you did. Kennedy, like a therapist. I this may not be necessarily always the best thing, but to be like, hey, like what's a resource or book you'd want me to read or a site or an Instagram account you'd want me to follow to learn more about this. But, you know, ideally it is wonderful when we can have therapists from our own communities because so much of that legwork and extra effort is is not even necessary. So I think as higher education becomes more accessible and equitable, I do hope that there are more people going into the field that can represent the vast diversity of of the population.

Justin: Right. Because we always need, like, therapists that like especially from our community, that's like very that's very affirming. And like, how do we go about doing that outside of, you know, does this therapy is require Medicare does this therapy require certain insurance? How do we go about doing how do we go about doing that?

Bri: Yeah, it's we we often can't yeah. Yeah, we often can't. There are so many limitations and disability affirmative therapy. Like that's I think a phrase most people don't know about. It's something that I am learning about and essentially it's not pathologizing folks and their experiences. And I find it as like a way to just offer even just a different perspective to clients that may not even identify as disabled. For one example, I was seeing a client last week and she was talking about how she's so frustrated that she cries so easily and that she can't control her emotions like she wishes she could and what's wrong with her. And she, you know, has had some knowledge of like ableism and disability already. So she was kind of ready to hear this comment. But I said, well, do you think like there's a little bit of ableism or internalized ableism in what you're experiencing, this idea that you have to always be in control of your body and your mind and be able to turn it on and off like that you should you should always be able to do those things. And, you know, just that switch of being like maybe it's not bad or wrong, maybe this just is ableist like that this is actually a normal thing. And even just offering that reframe for people can be very, very helpful. So I feel like disability affirmative care and just normalizing the variance in our bodies and minds and connecting people to communities to disability studies is like more healing, quote unquote, than like anything that you could do to just be like, whoa, try mindfulness... (sarcasm)

Justin: Thanks. (sarcasm)

Bri: Or, you know, it's just like, let's look at the bigger picture here. Why do you feel this way?

Justin: Yeah.

Kennedy: Yeah. Are there certain, like websites or resources that you would suggest if someone's looking to find a therapist who shares even some of their identities?

Bri: Sure. The best one that comes to mind for me is inclusivetherapists.org. I don't know if you're all familiar with that, but it's kind of like a psychology today, but for social justice centered therapist. So it literally their whole mission is about matching you with a therapist that matches your identities in the best way possible. So I actually do have a profile on there and I've been matched to a few people through that that have disabilities, which is a wonderful resource. So yeah, inclusivetherapists.org is real good.

Kennedy: Nice. Amazing.

Bri: Yeah.

Justin: Hmm. That's awesome. And so I think we talked talked a bit about this, but like, how do you use disability arts and culture in your therapy practice? Can you give us an example?

Bri: Yeah. Disability arts and culture is, you know, it's a broad world, but it's essentially a way to, you know, to make art from your disabled experience and I find, at least in my own art practice, that making art from my disabled experience has been just profoundly healing and offers me a different perspective of my own life when I can see my experiences externalized in a form of art. And so there's been times where I've just offered clients the opportunity to do that. And I say clients, I should say clients in my clinical work, but also just disability community members in more community based art spaces, just allowing people to use their disability as their own unique art aesthetic. Like, for instance, if you. You know, if you had a tremor or something and you made a painting and your your line work was was more shaky, how can that be beautiful versus trying to correct it? So, you know, helping people put their art into their or their disability into their art and how they can see that as a really cool thing instead of something that's wrong.

Kennedy: Yes.

Justin: Yes, yes, yes. I think like that that's like really it's really awesome because it's just like, yeah, like there's so many forms of there's so many different artists with disabilities that come from various backgrounds that are either like doing painting or are doing like dancing or like or like from from my perspective, doing like doing photography. And so it's just like for me it's just really cool, just really seeing folks from different disability backgrounds, just highlighting and showcasing, you know, what, what they love and what they're passionate about. I think that's something that I've been like, you know, really seeing like more of in the last few years, especially during this time. It's just seeing that that our expressive forms of like who we are as people. And I think it's just beautiful to me, just seeing seeing everything and just seeing that all, you know?

Bri: Yeah, exactly. You just made me think about how, like, there's so much like there's different kind of modalities within therapeutic work. One of them being like about like this idea of radical acceptance, helping people to accept their circumstances and embrace those and also know what is theirs to change and what isn't possible to change. And I'm thinking about how disability culture is so much about like just acceptance, acceptance of the reality of your lived experience and the, the, the power we have and also the limitations we have and how to use those to the best of our abilities. And it's just funny how like when you think about like disability community or arts and culture, how that movement is already doing, what's so much what I think of therapists are trying to impart onto their clients, but they're just not using the same language.

Justin: Right. Right. Like for, you know, for me, the the work I kind of learned this about myself in the last couple of years is that I see the work that I do as being therapeutic for me.

Bri: Yeah.

Justin: You know, actually just traveling around the city and taking photos and you know, seeing, you know, having people see from my perspective, you know, I think that's something that has been really therapeutic for me. And it's, you know, there's different forms of that and that that for me is just been something that is really helped me during during this time.

Bri: Yeah.

Justin: Because it's just really been beneficial. Just like, okay, I'm in my element. I'm kind of like mostly by myself, but I'm like in my element, I'm in this relaxed state and I'm just like, okay, yeah, this is, this is what I want people to see and, you know, see it from my perspective. So that has been like very helpful for me.

Bri: Yeah.

Justin: You know.

Bri: Yeah. It sounds like both the act of making is therapeutic, like just the process of being out in the world photographing, but also what is like is bringing you a lot of connection and validation is showing it to others and that that response that you get.

Justin: Yes, exactly. I just I just absolutely love it. Like it's been like I said, it's just been just beneficial, you know, really for me because like, you know, I've been doing this for a decade, but it feels like now, like this is where I'm like, oh, this is this is something of importance. And like I this has really been helpful for me.

Bri: Yeah.

Justin: Through this, through this whole process of living with, you know, in this COVID world, dealing with all this bullshit, you know?

Bri: Mhmm, that's really cool.

Justin: Yeah.

Bri: I love that Justin.

Kennedy: Yeah. I also think for you, the point you made about like like what you can change and radical acceptance. Like its this fine line between when we talk about like the social and medical models of disability or other models like both. Trying to figure out how to phrase this. Like, obviously, a lot of people go to therapy to work on themselves. Right. But like also these institutions can like try to change disabled body minds from out of a realm of possibility. So it's like, how do you like... sometimes I struggle to like, give myself enough grace to like, toe that line. Do you know what I'm saying?

Bri: Yeah.

Kennedy: And, like, with change, like, I think disabled people are huge, like agents of change. Yeah. Like, how much can we take on as individuals?

Bri: Yeah.

Kennedy: And like, yeah, what is each person's responsibility? It's like.

Bri: Yeah, this is blowing my mind right now. Yeah. Oh, yeah. It makes you even think about like I go to this chiropractor who is like, well, like, how are you feeling? I'm like, same. I'm in pain all the time it will never end and he thinks it's his job to, like, make sure I'm never in pain again. It's like, you know, how do you. And it's like you said, like there's always a possibility to, like, get better and feel better and be at this, like, perfect state. Eventually, this idea that, like, life is supposed to exist without pain or suffering in any kind. Not saying that being disabled is pure pain and suffering, but like this idea that like we can always move out of that when that's not necessarily true. And sometimes it's just about like validation and maintenance and just like acceptance as well, and recognizing that we have a community that we can rely on.

Kennedy: Yeah. And what are disabled body minds teaching us about like the value of impairment and like, the value of, like, slow, sustainable, like. (Siren noises.) Here we go again.

Bri: This ambulance is like, yeah. Red alert. Hot topics.

Justin: Hot topics, yeah.

Kennedy: Maybe it is cheering us on?

Bri: We're on fire!

Oh, my gosh. But yeah. Like what? Yeah. Like, I think half of it is that disabled people will always exist, and a lot of it is that we are forced to exist in such an ableist world. So. Yeah. All of that.

Bri: Yeah.

Kennedy: Are you making art right now?

Bri: Not really. To be honest...

Kennedy: That's fair.

Bri: I would love to.

Kennedy: Or like to want to like hype up any recent project?

Bri: Oh, gosh. I feel like COVID just like, really shot a lot of that down and it's so. Before I was much more of like an artist that did therapy on the side and now it's kind of like switched because I feel like there's just been a high need of, of people that need support during COVID. So I've kind of taken off that artist hat and gone more into that, the clinical slash community based therapist role. I do make art sometimes in between sessions just to like ground myself, and I tend to just really make weird abstract stuff and just kind of like make shapes that mean nothing because I feel like everything's a lot, so anything I can do that just is non representational right now and are filled with like happy colors makes me really happy. So I have like a bunch of just like loose papers in my office that are just full of like sketches like that. That's kind of what I've been doing, but I would love to get back into making more work, that is... yeah, I don't know. I can talk about some of these things, but I kind of am enjoying honestly right now, like just goofing off. Yeah. Like, I feel like I just really need that, like, lightness and... Yeah. Not taking myself too seriously as an artist right now.

Kennedy: Awesome.

Bri: Yeah. Yeah.

Justin: Yes.

Kennedy: Hopping back to the therapy.

Bri: Yeah. Yeah. (laughs)

Justin: (laughs)

Kennedy: Is there certain therapists who have disabilities and work specifically with disabled clients that you want to like name for folks or...

Bri: Sure.

Kennedy: Here or elsewhere.

Bri: Yeah, that's a great question. I could definitely do my research because I'm sure there are more out there and just not necessarily at the top of my mind. There is one person I can pull them up on Instagram. I believe their name is Kate Walsh. Kate Welsh, let me make sure I know their name. Kate Welsh. Their Instagram is Crip Counseling and they do disability affirmative counseling through telehealth. So they are somebody that you can definitely check out and they don't know that I'm naming them, but I follow them and they're really cool. I also know of another disabled therapist in the Chicago area named they go by V and last name is Lozano and they are under on Instagram @ enlightened therapist that I believe you two might follow because I think I see right here that Kennedy and Justin are fellow followers so yeah but there are definitely. I think there are more folks out there and I think inclusivetherapists.org and is a good place to look and I'm certainly trying to build a network of fellow disabled therapists that I can learn from and we can all kind of, you know, consult with one another and talk about our experiences and also work to just like not do this on our own and feel like we have support. So you can kind of feel like an island and not sure if what you're doing is the right thing because there's nobody else doing it. And you're like, ahhhh.

Kennedy: So all the disabled therapists get in touch with Bri.

Bri: Yeah. Slide into my dms. (all laugh)

Kennedy: Please, we need this network so much.

Justin: Please.

Bri: We do.

Kennedy: Yeah, that can be hard, too, because, like, you know, it's like we get mad when someone assumes we know another disabled person, but like, a lot of us do know each other, so that if you're looking for a disabled therapist like that, you know, someone who knows them that you're trying to complain about therapy is like, yep, kind of high.

Bri: Yes, that is very true.

Kennedy: So other barriers. (all laugh) What in terms of if folks are struggling to find a therapist, that's a good fit or like considering therapy for the first time, what sort of things can therapy help with? What some red flags to look out for when conversing with a new therapist? And like what... How do you know when it is a good fit?

Bri: Yeah, for sure. It can be so daunting to find a therapist like it's. It's like dating essentially. Like, because so much of it is about chemistry and fit. I definitely encourage folks that if you are exploring a therapist, like if you're looking online and you come across a profile, that's interesting, don't necessarily right off the bat, schedule a session, maybe ask for a consultation. A lot of therapists offer free consultations. I prefer doing consultations before seeing someone because I can really ask like, what are you here for? Like, what do you feel like you need support with? And just kind of assess even just like if our personalities mesh well because it really does make a really big difference, especially if you're looking for a therapy that's a little bit more like long term and you really want to establish a long term relationship, but you can go to therapy for just about any anything. I first started going to therapy when I was right out of college, actually when I was in college and didn't find the right fit for a while. But I was struggling with just like tense anxiety. I had just moved across the country for the first time and didn't know anybody. Like I just was going through so many life transitions and I just felt like I needed support. And it was so interesting because when I went, I realized I had so many issues I hadn't even addressed yet. That was actually the root of a lot of my problems. But yeah, the first time I was like, I'll be fine. I sat down and on the couch and just like cried harder than I have ever cried in my life. And it was just this realization of like, I'm talking to a complete stranger about my deepest things.

Kennedy: Yes.

Justin: (laughs) Yes.

Bri: Yeah, but it can be really healing to just have that space and know that, like, that person doesn't know your friends or your family. They don't judge you like you can, and it's just for you. And, you know, sometimes people just need space to like, like just talk and have somebody genuinely ask, like, how are you doing? Because sometimes until people ask, you don't really think about like, how am I really doing? And right, right. Yeah. You'll be amazed how much space you can start to fill up in an hour by just like talking and hearing yourself speak and learning about like, why are you the way you are and how do your lived experiences or traumas or identities or relationships make up who you are. And some people just want to have emotional support and maintenance. Some people are a little bit more focused on solving a specific problem. I had one person come to me for one session and one session only because she was struggling with something extremely specific and we talked about it and I never saw her again. So sometimes if you just have like a problem. Or something that you don't want to talk to anyone else about because maybe you're ashamed or you know, you've never said it before. A therapist is also a good place to do that. So yeah, consultations are good. Don't be afraid to say like, Oh, I don't think this is a good fit. Therapists are very at least I am extremely open to feedback. We don't know what we don't know. We actually cannot read your minds. So just I think having a therapist that is humble and that is willing to accept feedback and not think that they know you better than you know you is something that is something to watch out for. Yeah.

Justin: Yeah. Because like if you go back to like when somebody asked you like, how are you? And you're just like I'm good everything is good, you know.

Bri: Yeah (laughs)

Justin: Oh my goodness so I think maybe a couple of years ago I was doing a project for I was doing a project for 3 Arts, right? And we were, I was talking to like, like really cool, awesome, like disabled artists I was talking to like Rebecca Torres and Miriam Pare and Riva Leher, just like legendary and like so I was like moderating this conversation with them right? And my role as a moderator was to ask them how they were doing. And, you know, we were having a conversation. It was great. And then like Riva like, turned it back on to me. And I was like, well, you know, I fine. And then I just started bursting out crying. I was like, What is going on here? No! It's like sometimes it happens that way. It's like sometimes you're like a simple how are you? And can turn it to like you're just bursting into tears and it's like, Oh my goodness. But yeah, I like you. But you talked about that when you referenced that. I was just like, Yes, yes. I think we've all had that experience. I'm just like, so ask you a simple, simple question. And just burst into tears because it's so much shit that we're carrying so much trauma and there's so much shit that's just happening. That, you know, you're you try to hold you try to hold it all in, but that's not good. It's just not good.

Bri: Absolutely.

Justin: Because, yeah. You're just like one minute, just in a random conversation, you know. Okay, you start crying and you're just. Like, Well, all right, what's going on with me? What is happening with me? You know, it's it's yes, I totally can relate.

Bri: Don't even realize it. Until you actually like, kind of like do a self check, you know, you're like, oh, actually I have like a ton of things stored up inside. Yeah, much better out than in. For sure. Yeah. When you are doing a lot of advocacy activism work like you do put yourself last a lot of the time.

Justin: Right? You don't you don't think about that. I think we... you and I had had a conversation about this before, before we recorded about that. And like, we don't really put our, we always put ourselves on the back burner and never put our care or our like... we never put ourselves first because we always feel like it might be bad or that, you know, might be a bit selfish. But sometimes you have to be selfish to protect yourself, you know? It's important, you know.

Bri: It's about sustainability. Like we will burn out so fast if we don't fill ourselves back up or...

Justin: Get our shit together. Yeah. We're gonna burnout.

Bri: Yes, exactly. Exactly. So, yeah, therapy is a good way to just, like, take up some space for a while and, like, know that it's yours and you don't have to, like, fight for it or. You don't have to, like, be like, oh, but how are you doing? You know? Because it's not about that. So it's nice to know that you don't have to like, have that like always worry in the back of your head of like, oh, I'm hogging the air kind of thing.

Kennedy: Totally, yeah. In terms of seeking therapy. Like what are some times or signs that it might be good for someone to seek out therapy? And how do you know when you're done?

Bri: You know? Good question. Yeah. Yeah. Oh, gosh. Any time is a good time to start. But I think that it can be confusing to start when you really don't have necessarily a specific idea of what you're looking for. Sometimes I feel like and this is a good thing at its core is that this this I think therapy's been very normalized as something that's a healthy thing to do for like our wellness. It's it's like going to the gym kind of thing or whatever, drinking lots of water, like, oh, going to therapy is good. Like, this is just something you do. But I've definitely had people come to therapy and like expect me to guide them through the process as if I'm going to give them like a treatment plan and they just follow it. It's so much more of like a conversation of and the client is the leader in my, in my work at least and my style. And, you know, and I think that's how it works best is if you're showing up to sessions with like something specific that you're really thinking about or want to address. And it might be something really severe. It might be that you're really grieving something. It might be that you've you've gone through a breakup or you've moved or you are really struggling with getting out of bed or being productive. It could be anything. It really can. But I think just knowing like at least like one kind of way in, like what's what's bringing you here. And then oftentimes you can find a lot more to talk about from that point forward. But yeah, it's hard to know when to stop. For me, I don't know if I'm ever going to stop because I feel like for me it's like I need it for all the things I take on. So I feel like every therapist should, if not always have a therapist, but at least they have been through lots of their own therapy and done their own work. And, you know, but also I think it's good to have that support because you just need space oftentimes that's only yours because there's a lot of holding to be done. But for somebody that is not a therapist, I think, you know, if you're finding your your therapy to kind of turn into more conversational like like in terms of just like small talk or, you know, shooting the shit with your therapist, all the things are good, you know, like it may not necessarily be worth your money at that point to do. So I think if you're starting to feel like you're in a grounded place and that you have like a good support network already established, not saying that our friends or family can be our therapist, but, you know, sometimes we don't necessarily need that dedicated time, weekly, bi weekly, monthly if we're feeling that we're in a better place. And it's always okay to like switch therapists when you feel like you've maybe done all you can with a therapist or you want to take a break and find a different one like a year or two later or whatever. But hopefully, though, as we normalize therapy and even just conversing about mental health, we can all learn how to hold better space for each other and actually have like better relationships and just understand our trauma and boundaries of boundaries and like a big cultural conversation that we're learning more about. So I don't know. We'll see where it goes. I feel like there's a big shift, though, in terms of this conversation on mental health.

Kennedy: Totally. Y'all probably just heard the cat jingle.

Bri: Hi Natalie.

Kennedy: We are back in person with some COVID precautions and Natalie Maines my cat named after the country singer...

Justin: I'm just looking at her butt and she's just like, okay, yeah.

Kennedy: ...is Joining us. Awesome. Yeah. Thank you.

Justin: Like, before we go, is there anything else you would want to add?

Bri: (jingles) Oh, Natalie just made a little cool sound. Anything you want to add, Natalie? She's sitting right by the mic, like she's ready to talk.

Justin: Tell us. Tell us. Please.

Bri: I'm gonna take a picture.

Justin: Take a picture.

Bri: Oh my god. No. I feel like the only thing I would really add is just that I'm definitely not the only expert on this topic. And, you know, I have my own set of identities and experiences that make me who I am. But I feel like on this conversation there aren't many people speaking about it, but that can lead to this danger of the single story. So yeah, I just encourage folks to just explore disability for affirmative therapy, like for themselves and do their own research and yeah just just reflect on what this conversation means to them and take what you need and leave the rest sort of thing. But yeah, this is very much a conversation that is happening in real time that

I'm thinking about in real time, that I have no definitive answers for a lot of the questions that you ask are two things I really think about a lot.

Kennedy: Are there resources financially that we should highlight? I mean, there probably more locally based. I don't know.

Bri: And yeah, I mean. To be honest, not a lot that I can think of. Access living, like I said, is doing some really cool stuff in Chicago. So I think getting connected with our Arts and culture project, there's a lot of all of our events are free. The mental health support group is completely free. So there's there's things you can definitely join in terms of community based initiatives that are completely free and really wonderful. Yeah. But in terms of like accessing therapy, definitely there's always the chance that therapists are doing pro-bono work or sliding scale. I think during the time of COVID, that's been difficult to find because there's just not much space left for that, but never to be afraid to ask, even if it's just for like a session or two to see, like if a therapist is willing to just like meet for for a couple sessions or so at a very reduced rate and just get the help that you need so.

Kennedy: Totally. Yeah. Did you want to share more details about the group?

Bri: Sure. So Monday night's from 5 to 630 Central Time. We host a virtual mental health support group over Zoom. Every month. We take on a different topic. So we've done coping with depression, we've done self-compassion. I think for April, we're doing healthy boundaries for the group, and it's just essentially a peer support group where I facilitate space. And we have a few interns with us from the School of the Art Institute of Chicago that help me facilitate. And it's just a space where we kind of just talk about our experiences. It's not necessarily therapy. It's just a supportive and safe space to talk about what it's really like. And so I offer some resources in those groups, like actual coping skills and and certain tools that people can take away. But it's been a really, really healing space. And we keep we're going to try to keep doing it for as long as we are able to.

Kennedy: How would someone get the zoom?

Bri: Yes, that's a great question. How do you get on zoom?

Justin: Zoom zoom zoom.

Bri: You can follow on Facebook. It's called DCAL, D, C, A, L stands for Disability Culture Activism Lab. And that's a part of our arts and culture project. And that's where we post all the events that we do, including the Mental Health Support Group. So you'll be able to access the Zoom link from there. If you want to reach out to me, you can reach me at my access living email, which is bbeck, b, b, e, c, k @accessliving.org. And I'm happy to send you the link.

Kennedy: Awesome.

Justin: Awesome. Yes. Yes. DCAL is awesome. I can attest to that being a part of some of their events. Yes, I can definitely attest to that. And so, Bri, we want to thank you for being a part of this podcast with us. We love having you here.

Bri: Thank you. Thank you for having me. This was a great, great time. Great conversation. Good friends. I'm thankful.

Kennedy: Yeah. Thank you for coming.

Justin: That's right. So and that is episode three of the Crap podcast. Holy shit, Kennedy.

Kennedy: We did it!

Bri: Woohoo!

Justin: We're doing this, we are doing this. And so thank you all so much for being a part of this episode. We will be back with episode four. So, hey, stay tuned. Enjoy the rest of your day.

Kennedy: Stay tuned.

Christea: (instrumentals)

Kennedy: Thanks, everyone, for listening. We just want to say we love you. We affirm you. If you're not crying right now, you're not paying attention. And if all you've been up to is surviving, that is enough.

Justin: Yes. Just remember that you are you are enough. And yes, we we we love you. We we love all of y'all. And we appreciate you all so much.

Bri: Yes. Your experiences are valid. They're human. You don't have to be happy all the time

Justin: Right?

Kennedy: Take good care. Bye.

Bri: Bye.

Justin: Byee.

Episode #4: Critical Comedy with Nina G

Episode Description: This months guest, Nina G, is a comedian, author, speaker, and consultant. Justin and Kennedy ask her about her work, experiences as a comedian with a stutter, and the relationship between disability and humor.

Christea: (instrumentals)

Justin:
All right. All right. Hello, everyone. Welcome to the Crip Crap podcast. My name is Justin Cooper.

Kennedy:
And I'm Kennedy Healy.

Justin:
All right. Episode four, we are actually doing this Kennedy. Making moves, making strides on our podcast. I'm so glad that we can do this podcast today.

Kennedy:
Yes. Episode four. Sounds like a big number and we have a excellent guest Nina G here with us. Hi, Nina.

Nina:
Hey, great to be here. Thanks for having me.

Kennedy:
Thank you for being on. A quick background on Nina. Nina G is a comedian, professional speaker, comedy historical consultant. She has been featured in and on everything from NPRs 51%, BBC's Ouch, Psychology Today, Ted X, KQED radio, and multiple daytime talk shows and podcasts. Nina is at home practically anywhere from a dingy comedy club to college and corporate gigs. She is the author of three books, Bay Area Standup Comedy: A Humorous History, Stutter Interrupted, The Comedian Who Almost Didn't Happen. And children's book, Once Upon an Accommodation, a book about learning disabilities that helps children and adults advocate for their rights as a person with a disability. Welcome, Nina.

Nina:
Thank you.

Justin:
Yes, we are so glad that you were able to join us on today.

Christea:
(Instrumentals) ...that's just some Crip Crap, don't you know…

Justin:

Oh, so, but first off, how are you feeling? How are you doing today, and how's everything going?

Nina:
Pretty good. It is early in the morning here in California, so it's 10. So yeah, there hasn't been much to mess up my day. So I'm good so far.

Kennedy:
Awesome. For our listeners who are less familiar with your work, could you describe your work a little more and yourself as well?

Nina:
Sure. I've been a standup comic now for 12 years and focused in the San Francisco bay area. And that's where I got my start, and perform a lot in local clubs, local shows, but also do a lot of colleges, a lot of corporate events. Luckily, because of Zoom, I've been able to perform all over the world. So collaborating with different organizations around the world, like recently I did the Stammering, which was the British Stammering Association. They call it stammering over here, we call it stuttering over here and they gave awards to the best and worst in images of stuttering. So I've gotten to do some really cool stuff within the disability world and stuttering world, and beyond that.

Kennedy:
That's awesome. Yeah. Have to check that out.

Justin:
Yes, for sure. For sure. What else should our listeners know about you?

Nina:
Oh gosh, let's see. Oh, I guess I should say, yeah, I am a person who says stutterers and I also have learning disabilities. I went to Catholic school in the 1980s with those things. And what I always tell people is you should never pity anybody for having a disability, but you can pity me for going to Catholic school in the 1980s with those things.

Kennedy:
Totally.

Nina:
And so that adds a lot to my experience. I found stand up comedy when I was really, really young. I remember being introduced to it when I was five by my family, and just grew up on it. And when other girls had crushes on rock stars, I had crushes on standup comics. It was my constant thing. Always wanted to be a comic. When I was a kid from like 11 to 17, I'd write jokes, I'd look for open mics, but because of my stuttering, I never thought that would be a possibility. So in the early '90s, the dream died. It got picked back up 25 years later after some significant events in my life. So that gives you the background before the comic part.

Kennedy:
Got you. Yeah. So how did you first find comedy work?

Nina:
Oh, like a stage and open mics and stuff?

Kennedy:
Yeah.

Nina:
So I started at the San Francisco Comedy College, and it's not a real college, it's just like a place to take classes. And I took a couple of classes there. They had some open mics and some shows there. And then from there branched out to the rest of the San Francisco bay area scene. And that was all six months after I went to a conference for people who stutter. And that was my first conference in like 20 years. And when I was there, I realized, I started to understand that how much space I relinquished up to other people. I think as a woman, you are socialized to not take up space. And as a woman who stutters, you are especially not socialized to take up space, because I would feel guilty for people to sit through my stutter.

Nina:
And when I was at that conference, I realized how much... and that's why the book is called Stutterer Interrupted, because we are interrupted all the time. But the part that really was the problem really was the barrier was when I internalized it, and I interrupted myself. And so, came back from that conference, did a number of changes in my life, including ending a 10 year relationship where I realized how much my own needs and desires were being interrupted, that I wasn't seeing them, I wasn't sharing them, I wasn't getting them. And then starting comedy six months after that, after I established a brand new life.

Kennedy:
Wow. Yeah. The power of finding other disabled people.

Nina:
Right. That community. Yes.

Kennedy:
Mm-hmm.

Justin:
Can you share about your experiences working with other disabled comedians?

Nina:
Sure. Yeah. And so let's see. For about 11 years, I've been part of the comedians with disabilities act, and that was the brainchild of Michael O'Connell, and he got some help from

Keith Lo Jensen to start it. And Michael had MS.... No MD. MD it's a Jerry Lewis one because he had a bunch of jokes about Jerry Lewis, of course.

Kennedy:
That's MD.

Nina:
As the natural progression. And so he had MD and he just started the group, and quickly another disabled comic in the Sacramento area in Michael was in Sac, and Eric Meak, who is blind, he doesn't do comedy right now, but he was a big part of that group as was Steve Danner, and Steve is a little person who lives in Napa. And so they were doing shows, and I was pretty good friends with Steve at the time. And I was like, "You need a woman in that group. You need someone with a non apparent or a semi apparent disability in that group." And so they quickly had me on, I quickly became a member of the group. And Michael passed away a few years now. But being part of that group was such a gift because it was one of the few opportunities where your disability could be in the forefront. It's always in the forefront anyway, my comedy, because I stutter and comedy it's like running a marathon. If you have a physical disability, someone's going to see it. It's going to be there, it's going to be front. So it's good to talk about it, and also to talk about it, and get past it to do other stuff. But when it's a show of disabled people in the audience, it's a different vibe, and it's just... like to do comedy for your community is just so cool and so amazing. And so, I now produce shows under the Comedians with Disabilities Act to keep Michael's legacy alive. But also, it's really exciting to bring up disabled comics who this is the first time that they've been able to do comedy for an audience who wants it, who is there for disabled jokes, and who have that insider knowledge, because that insider knowledge is so much fun and so great to build on.

Kennedy:
That's awesome. Yeah. I want in. I've never done standup, but no, that sounds awesome. It definitely like interesting. I've never even thought about doing... I do create a lot of stuff for disabled audience, but you would figure at a show like that, it would just be non-disabled... predominantly non-disabled what's coming. You never know. Sometimes I feel like when I give workshops sometimes people come, like, I'll be a cater to non-disabled people, and then multiple people come up after and reveal their disability to you. But yeah, that's great. So in that vein, I'd love to hear your take on the relationship between humor and the disability experience or disability culture. Because I feel like it's just so ingrained.

Nina:
Yeah. You get a bunch of disabled people around. They're going to start making fun of the experiences we have with the able bodied world. And that's also where some of my comedy just writes itself. I just have to report on it, and that's it. Once I had a guy after a show tell me I stutter because I had the wrong kinds of orgasms. And I was like, "Oh, so what do you mean by that?" And he told me, and I won't say what kind he said, but in my act I say, I don't think you stutter through that orface. You could imagine what he said. I know, right? And so there's all

kinds of very weird interactions a disability experience comes with. And not because of us, it's because of them. It's because of the able bodied world, let's get that straight.

Kennedy:
Totally. So yeah. This is stuff people come up and say to you one-on-one?

Nina:
Oh, yeah, yeah. No, people are so weird. And I think it's amped up because I am a comic. But even before that, once I gave a talk on adaptive technology at a library and a woman came up to me afterwards, a older woman and she was like, "You're such an inspiration. If I talked like you, I wouldn't talk at all." I was like, ah not really a compliment.

Kennedy:
Yeah, really runs the gamut of different responses. Yeah.

Justin:
It's unbelievable. Just the things that we hear from other folks, and how we're inspirations to them and you're just like, "Oh, come on." Just…

Nina:
Inspirations for leaving the house. And your name like, oh.

Justin:
I said my name, you're an inspiration. So what barriers do you encounter as a comedian with multiple marginalized identities?

Nina:
Yeah. So as a woman and I am white, just you know, this is on the podcast. I come from an Italian-American background, have Italian-American features. And as a woman who has a semi parent to non-parent disabilities, I think some of the barriers are that I think people... at least in the comedy world, people think that I'm just a disabled comic that I might not be able to do a more mainstream thing. And that's where like, that's when you lean into the comedians with disabilities act. But I did a show last night where the disability stuff, I did one joke on it, and that was it. There were so many other things to talk about, that's all I did. So I have other stuff, but I think people see it as that. And also in the comedy world, people are like, "Oh, it's a niche, it's a niche. Oh, oh, you're going to get famous because you stutter." Is like, "No, that doesn't happen that way." Especially for... to talk about multiple identities, the comics besides Jerry Jewel, Jerry Jewel got in early before Hollywood wrote the script on this. But most of the comics in America who are disabled are white dudes. And I feel that executives feel that if you represent multiple identities that people's heads are going to explode, that America's got to, "Oh my God, two things, I can't handle it."

Kennedy:
Mm-hmm.

Nina:
And that's where it's like, I do the stuff I do. I write books, I create the stuff that I want to represent because I don't have confidence that Hollywood will want me. And that's also why we live in a very exciting time where creators can represent themselves without those gatekeepers and filters, and do them instead of doing what the industry wants of them.

Kennedy:
Totally. Yeah. Yeah. I feel like some of the... this came up a lot when we named Crip Crap, and whether that should be the name. And I think a lot of disabled people like the inspiration and pity we're talking about brings out the crassness in us because no one's expecting it or allowing it. And so yeah, love it when it just swings the other way and…

Nina:
Yeah, you're right. I would be much less dirtier on stage if people just calmed down and accepted me for me.

Kennedy:
Uh-uh. Yeah. Well, and then the more marginalized you are, you're like, well, I might as well go all in. Because, yeah, these institutions aren't going to have me at the level of respectability that they expect. So, yeah. Thanks for a really good time, I think.

Nina:
(laughs)

Justin:
Yes it does.

Kennedy:
Do you have any advice for aspiring disabled artists or comics?

Nina:
I think I have advice for the industry more.

Kennedy:
Yeah.

Nina:
And that is, get your shit together on accessible stages. Because like, "Oh, I'm in the bay area, we are... Berkeley happened here. The disability rights movement happened here. We were the first to have curb cuts." There's the first curb cut on like Channing and shutter group, something like that. Like, "I can bring you to that place." And it's not gold. I think it should be gold paved. I think the curb should be gold paved. I think there should be a mural there, all that. But anyway, yeah. So we're supposed to be the best here, and how many accessible stages are there? Not a

lot. And that's bathrooms and stuff too. And so, I see some very talented people who don't get access to the stage because they can't get access to the stage. And if they had to pee, where would they pee? There's all of that stuff. And I just feel that there need... comedy is one of the last art forms that you don't hide behind.

Nina:
There's no rhyming that you do. There's no music, there's no nothing. It is, these are my words. This is my opinion. That's why we sometimes get slapped because there's nothing that hides that. There is no camouflage there. And oh, disabled people have so much to say and they need a place to say it.

Nina:
And this is where allyship comes in to put the pressure on your comedy clubs to have an accessible stage, to put the pressure on representing disabled voices of all kinds and just not white ones, because we got that. We got that. We're good. But having ones that are representative of the disabled experience. And sometimes disabled people may not always like what those disabled voices say, and that's why I think it's good to have something that is ableist. People will share like, "Oh, this person is so awful. They said this ableist thing."

Nina:
Yeah. It's good to call people out, it's good to do all of that. But what about the voices that you do want to hear? Because the voices that you do want to hear need to be amplified more than those other voices. In comedy, it is free speech, and the best way to fight free speech that you don't like is to fight it with another opinion. And that is where I think disabled comics come in. And also there are comics who won't do certain disability jokes around me because they know it might hurt me. And I think that is a great way to kind of... the more you're in, the less people are willing to... it's a more that they'll understand your perspective. And that's also why I think it's important for us to get those opportunities that we don't always get.

Kennedy:
Totally. Yeah. I appreciate you saying that because... and I get it, but I know a lot of folks who will do some... put up with some ridiculous things around access and stuff, just to get the gig. And I totally like, if you need the money, you need the money, but I'm always like, hey, because I do consulting work. There's folks out there you can refer even to intervene on your behalf. And yeah, it's just all those little things that make big changes over time.

Nina:
Mm-hmm. Yeah.

Justin:
And it's just so interesting, the theme of accessibility. Being brought up, and I know you and I have had conversations about accessibility. I have a whole series that's focused on inaccessibility. And it's just a common theme. And like I said, it does take allies and people who are not disabled to raise their voices as well. It shouldn't continuously have to be us to raise the

voices. It should be everyone around us who know us that knows that, "Hey, these are issues that need to be brought up." So we shouldn't always have to be the ones that have to make the statement or stand out and say, "Hey, this is inaccessible, do something about it."

Kennedy:
Mm-hmm. Yeah. And it's interesting right now with the COVID mandates lifting, there was a letter here in Chicago that a group of grassroots, disabled activists wrote, just trying to get people who planned big events to keep mass on for a while longer.

Nina:
Yeah.

Kennedy:
And so yeah, you see a lot of different response. And instead of creating more opportunity for people to show up masked, and intervene on different things, and yeah.

Justin:
Yeah. Exactly. And so Nina, did you have any role models coming into the industry? Were there people that you looked up to when you started out in the industry?

Nina:
So disabled comedy, which is to me a term to describe what I do and what a lot of other people do, which is more comedy that reflects the disabled experience and comes at it from a cultural point of view where the comedy isn't that it's making fun of yourself, but it's making fun of the people around you. And that to me is like the cultural and social model, the activist model being reflected in the art form, which is way too intellectualized for anything about comedy, but that is what I see. We haven't seen a ton of that. There's a handful of comics, and Jerry Jewel was the first one. She was on the facts of life and she did comedy. She was the highest profiled disabled person in the 1980s who couldn't get any work, how F'ed up is that? She's like one of the disabled comedy Eves, she was one of the first. But for me, the way that I learned about comedy was through a lot of black American comics, because they were talking about racism in ways I was like, "Oh, I understand this experience better now because of standup, because of people like Dave Chappelle and Chris Rock, who recently had some missteps around disability and trans issues. Probably more than a misstep for Chappelle on the trans issues. But their work in the 2000s really showed me what social justice could be in comedy, because they were talking about things in a way that were really exposing a lot of the discrimination in America, and seeing people like them or Paul Moony, which is a big influence on me. I was like, "Oh, I want to do that, but from a disability point of view." So to me, that really established the groundwork for what I wanted to do, because I didn't see it as strongly in the disability comedy world.

Kennedy:
Mm-hmm. Nice. Yeah. I think the self deprecating comedy always rubs me the wrong way. Because I'm like, aren't we past that? Like, aren't we as a society able to, yeah, make more

critical work? But that's great. In terms of switching back to your books a little bit, is there more you want to say about those, or maybe some of your speaking related to those?

Nina:
So the book, Bay Area Standup Comedy: A Humorous History is the first of its kind to explore San Francisco Bay Area comedy from the 1860s to the pandemic. And San Francisco, Chicago, where you all are at gets a lot of love, second city, all of that. We also have a comedy scene that changed comedy history forever and ever, and ever, because we had Mort Saul, who was the one who really took comedy to a different place. And Lenny Bruce, this was where his first arrest was. And so important comedy town that even we don't acknowledge, even the San Francisco comics don't acknowledge. So during the pandemic I was bored, and I contacted my friend OJ, and I was like, "Dude, you want to write a book?" And he was like, "Okay." And so we did. And there's lots of pictures in it, also talks about a brand new club in Alameda, California in the Bay area that put in a ramp, can you believe they put in a ramp on the stage, on the stage? And that's where we recently had a comedians with disabilities act show there, and stage got some good use. So that is that book. Stutter Interrupted is just my journey into stand up, looking at my entire life. But a lot of the things that I had to overcome, not because of my disability, let's get that straight. I had to overcome my own internalized ableism and overcome the barriers. I always say, as a disabled person, the main barrier I have is assholes. So that's really where we need to overcome. And so then the other book is, Once Upon an Accommodation, and it is a book for kids, but also parents and teachers get a lot of use out of it too. And it's about a kid who is diagnosed with a learning disability, and just trying to show how to advocate, and also that like, oh yeah, you can have dyslexia, you can have ADHD. You're also part of this larger community of disabled people who have thought for your rights. As a dyslexic, I wouldn't have shit if it wasn't for blind people. Thank you, blind people. I want to be part of your family because I am. And so trying to build that across disability family and understanding that experience.

Kennedy:
Nice.

Justin:
Nice. Yes, that's the main thing. It's just really all of us coming together and just realizing, yeah, we all need each other. And I think the way that we all work together is just amazing to see. And so it's like, it's just awesome. I just love just seeing that from our community. And so is there anything else you want to add or share for our listeners?

Nina:
Let's see. Is there anything else? No, I think I got a lot of it in. I do college gigs, I do corporate gigs. I'm starting to travel more, but I do a lot of stuff on Zoom. I think just please amplify the disabled comics that you like, and de-amplify people you don't like because they all get enough attention.

Kennedy:

Totally. Yeah. Is there anything soon that's coming up that you want to shout out, or where can people find you generally?

Nina:
I am at ninagcomedian.com. I have a list there of my appearances, both online and in person. Most stuff right now is in person in the Bay Area, but I find myself traveling a lot. I'm doing some college gigs with my friend, me and Dave, he is in recovery. And so that's under the ADA. Nobody knows that, whether they're disabled or they're in recovery, and he's trying to bridge that gap there. And so we have some college gigs coming up, and we do a lot of those and as well as... and stuff like that. So if you need a comic, please hit me up.

Kennedy:
Awesome.

Justin:
Yes. Awesome. Awesome. I think that's all we have. Is there anything else we needed to add, Kennedy?

Kennedy:
I don't think so. This has just been the Crippest. Thank you for coming on. This was a lot of fun.

Justin:
Yes. Yes. Thank you so much, Nina for being a part of this. Yes, we will definitely amplify your work for the masses.

Kennedy:
All right. Well, that's-

Nina:
Thanks for doing that.

Kennedy:
... that's episode four and we'll be back next month with more.

Justin:
Yes. Take care, everybody.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow

That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don't you know

Episode #5: Care, Photography, and Storytelling with Marley Molkentin

Episode Description: Justin, Kennedy, and Marley discuss care work and systems and the photo project Marley and Kennedy shot of their care routine. Justin and Marley dig into the function of photos and their photography processes. For more resources on care visit https://linktr.ee/carephotoproject.

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Justin:
Hello everyone. And welcome to the Crip Crap podcast episode five. Wow, Kennedy, we're doing, we’re we’re here.

Kennedy:
Episode five.

Justin:

I'm so happy to be here. By the way I am Justin Cooper.

Kennedy:
I'm Kennedy Healy.

Justin:
All right. Awesome. We have an awesome guest for you all today, so we're going to jump right into it. Today's guest for episode five is Marley Molkentin. And little bit of background on Marley. Marley is a bisexual photographer, videographer and digital project manager from Cincinnati, Ohio. She received a VA in multimedia photo journalism as well as an MA in civic media from Columbia College Chicago. Her work is centered around collaborative, creative storytelling that helps educate and broaden perspectives on social justice issues. In order to tell the most holistic stories possible, she roots her creative practice in relationship building, authenticity and trust. She has created media content for the Chicago Women's March, grassroots political candidates and local non-profits. You can see more of her work on her website, www.marleymolkentin.com. Or follow her on Instagram at Marley Multimedia. Welcome Marley.

Kennedy:
Marley.

Marley:
Thank you for having me. I'm seriously really honored. And I did not expect that you guys were going to want me on the pod.

Justin:
Oh no, we are very happy for you to be on our podcast. And so how are you doing today?

Marley:
Pretty good. I mean, it's kind of a holiday weekend here. Cincinnati is an extremely Catholic city. So all of the people in my life are off doing Catholic things and I'm very glad to be here talking about care and photography and all that fun stuff that I love.

Kennedy:
Yeah. We're recording this a bit in advance on Easter weekend. Marley, for listeners who aren't familiar with you or your work, could you describe yourself?

Marley:
Sure. I was born and raised in Cincinnati, Ohio. Decided to pursue my love of photo and video in Chicago Columbia, definitely one of the best decisions I ever made. I don't know, since I was maybe 14 or 15, I've pretty much just been making videos. That's kind of my thing. I got into photo a lot more in college because of my programs that I was in. So about me, I really love people. And I know that seems kind of generic, but that's kind of what fuels me. I'm a really extroverted person. Meeting new people that have really diverse backgrounds and stories and perspectives is just my favorite thing. It's really motivating for me. I've met a lot of cool people

throughout my life, especially once I was living in Chicago. And projects would just kind of happen. That's kind of how I approach things a little bit is I do really care deeply about a lot of social justice issues, but I've had to learn that I can't help all of them. I can't do something about everything. What's really grounding for me is if I'm in a point in my life where there's a non-profit person that I know that runs a non-profit and they have an event coming up, I'm like, "Do you want me to make a promo video for your event or what's up?" Whatever is happening in my life, whatever people bring to me that are in my life, I just kind of go for it and see what we can make by bringing together our skills and different perspectives. So yeah, that's somewhat what me and Kennedy are bonded over is creating projects together about care work during the pandemic. I'm getting way off topic at this point. But about me is I'm extroverted and I just love people. I love learning about their lives and bringing my skills of photo, video and storytelling to them to help create just storytelling pieces together.

Kennedy:
Yes.

Justin:
Yes. That's awesome. And so is there anything else our listeners should know about you, Marley?

Marley:
Should know about me?

Justin:
Yeah.

Marley:
I'm an extremely passionate person about quite a lot of things. Sometimes if you hear me getting really passionate people think maybe I'm a little intense or strongly opinionated, but maybe I am, but-

Justin:
No.

Marley:
... I think that's something about myself that I enjoy. So things that I'm passionate about are LGBT issues, specifically bi issues are super important to me, bi frameworks for gender and sexuality is a big part of my life. I like to bring that kind of, non-binary very fluid perspective to a lot of other aspects of my life. So that's one thing that I'm very passionate about.

Marley:
Also now like disability and care work is another area that I'm very passionate about and you will definitely catch me ranting to people about it. If I'm out drinking or something, someone will be

learning a lot about disability that night. And usually they're pretty interested. There's a lot to learn, there's a lot to talk about in a lot of areas. And I could talk about a lot of stuff.

Kennedy:
There you go. All right, Marley, let's dig into it. We're tasked with the three of us having a conversation about care that isn't like seven hours long. But yeah, so Marley and I created a photo project when she was working as my caregiver from August of 20 to August of 21. Right in that mid pandemic vaccine moment. And Justin saw a piece we published and was like, "We got to get Marley on the pod." And I was like, "Oh yeah, self-promotion, that's a thing I should learn to do." So yeah, thank you for being here and making things and caring about all these things. But from your perspective as a care worker, this was your first experience with that, just like, well, maybe a little bit about what it was like.

Marley:
Yeah. I'll just intro our little story that we have told at this point so many times in a row. But I think it's a good intro to our story. Essentially it was summer of 2020, the pandemic was raging nice and strong. And I was graduating from undergrad. I had job opportunities that all fell through as the pandemic hit, everything had just gone to ship. I searched for a job throughout the summer and it wasn't until later in the summer that I found Kennedy's job posting on Facebook, in a group on Facebook. And I read through about the job, she talked kind of about herself and what kind of person she was, what her values were, what she was looking for in a care worker. And I don't really know why. I just felt like I've worked a lot of odd jobs in my life. I've worked as a server in a lot of restaurants. I've worked as a babysitter for a lot of different families all over. I've worked as a receptionist in a nursing home. I've just worked a lot of random jobs. This one seemed like it could be a good fit, even though I didn't have any training necessarily in care work for an adult. I had done baby stuff, but this was just totally different. But it's like a good fit just because very people oriented. It's very like communication oriented. It's hands on, just like important to me in my work, whatever it is that I'm doing, I really like to be hands on with people. This was essentially that. So I felt like, okay, this is something I think I could try. We interviewed like on FaceTime, I think just liked each other. I liked how you were so open about your boundaries around care. You weren't afraid to talk about past issues that you had had with care workers, which I really liked and respected, because it just gave me even more context so that I could just be better in the future. And I loved your honesty and openness about all that, it really aligned with my values too, of just open communication, even about things, topics that may be a little scary or vulnerable. It can only strengthen relationships and strengthen communication. We gave it a try and I ended up really liking it. Kennedy, I think ended up liking me working for her.

Kennedy:
You're on the pod.

Marley:
I'm not going to speak for you. You could speak to what kind of a care worker I was before we got into deciding to do a photo project together that came months after I had been working with

you. I was also in a master's program at that point too. And I had to kind of think of what a practicum project was going to be. And my master's was called civic media. So that is all about creating media for social change and not just shooting a video of a protest, but having an in depth plan doing a lot of research beforehand on the issue that you want to tackle. Like creating a plan, planning a project and acting the projects, how to write a grant, how to fund your project, how to later distribute and pitch project. So it was all levels of how to make a project that's going to make tangible impact.

Marley:
Obviously I learned a ton about care work from Kennedy, from the job. And by the away obviously knew, notice what the issues were. And so I knew that I wanted to do a project somehow about care and care work. But it took a while to figure out what that was going to be exactly. And the idea really came from Kennedy I think when she just kind of mentioned she'd always wanted to do like photo shoots about care and about her experience with care. And it just kind of snowballed from there. I don't know if you want to add to that, Kennedy?

Kennedy:
Yeah. Well, and I think you were also frustrated with the way people in your life would respond to you having this job. And I have been trying to ... I had given academic conference papers about care or like I've always wanted to grow that discussion. And I think the photos along with some of like the texts that we've paired with them or will, have really ... Here's the cat for everyone who's been hearing her on the audio and is watching this maybe on video. Natalie, can you ... Always, the star of the show, is in the photo project.

Marley:
Yes.

Kennedy:
But yeah, I think, what's that old saying about photos, saying a thousand words or? I think it demonstrated to people differently than me just talking at them. People just do not know. And so I've always felt like it's a really invisible part of my life. I don't know if you feel that Justin. And just all kind of like merged at the right moment.

Justin:
Yeah. I think it's interesting that you bring up like the invisible aspect of it. Because like you said, a lot of people don't know what it takes for us to function, to start our days. And that care work is so vital and so important to us continuing to live as people with disabilities. And I think the work that you both did with this project was really bringing that to light, especially in photo form. Because like you said, a lot of people, you could talk about it and people might get in, or they might not understand all that goes with it. But I think when you put it in photo form, when you put it visually where people can really see that, oh, okay, this is what you have to go through to actually start your day. And I think that is a sign of that relationship between care work and having that trust and communication that those, and having those intimate moments shown for people to see. And I think from the visual standpoint, I think it was just really an excellent job in

showcasing that. Because a lot of people, like you said, don't really see what it takes, and for them to finally see it in your face and it's right there in your face, you don't run from it, you can't hide from it, it's there.

Kennedy:
Totally. Yeah. I think there was something you said like the whole, the state system that funds care here in Illinois is so precarious, so fragile. And neither the PAs or the disabled people who ... It's not a system that gives either the PAs or the disabled people receiving care a lot of power. And so things get fraught with abuse and neglect and manipulation and folks misusing people's services and things, which I don't know how much that actually happens. The state wants to think like everything's a ton of fraud. And I was like, "Well, if you fund it, then people won't have to commit fraud."

Justin:
Exactly.

Kennedy:
But it is very just fragile. And so I think that's something for people who have never experienced it. I hope that somehow comes across in the photos.

Justin:
Right.

Marley:
For me, I felt like I had just moved to Chicago. I had just started going to Columbia. I was in the multimedia photo journalism program. And then later, like in the civic media program, so I'm surrounded by all these young people that are really into activism that are really, really left leaning, I don't know, like liberation politics kind of people surrounded by so many people that are working on so many issues and disability was just never part of any conversations that happened in those circles, at least that I was aware of. And I knew a ton of creative people that were doing like activism work and no one was freaking talking about disability or prioritizing accessibility and the work that they were doing. When I started working for you and was really enjoying the job and it was seriously one of my favorite jobs I've ever had and would tell people that were around my age like, "This is what my job is." They're like, "Oh wow. Really? What do you have to do? Do you really help somebody get dressed and help them take a shower? That would make me so uncomfortable or that would be so weird or that would be so gross or something."

Marley:
A lot of jokes about like, "Oh, you have to wipe somebody after they go to the bathroom and stuff?" I got really frustrated with the responses that I would get and the lack of understanding for just disability and care work in general from these groups of people that are supposedly so forward thinking and progressive, I guess. I could just tell there was a really big gap in a lot of activism, people not knowing about disability and care and accessibility. I think that was a big

part of my frustration was like, I'm surrounded by all of these young people who I guess claim to be so progressive. And yet they're making a lot of really kind of like educated and shady comments about my job and devaluing it a little bit in the things that they're saying, which was really frustrating to me. Because it's so clear to see, I guess when you're in the job and when you're doing, it's so clear to see the obvious importance of the job, and that it's not awkward and it's not gross. And it's not like any of these things that people think, I guess, because it's taboo I guess to care for somebody's body. I don't really understand necessarily where that was coming from. But I also noticed that a lot of old people in my life, like parents and grandparents were more open minded to that because I think they had seen like their relatives and stuff aging and they had dealt with loved ones using care services before. Whereas young people my age haven't really even breached that subject much in their life. So it's just totally not even on their mind at all. That was another part of why I was like, I just want to create something so that people can see for themselves what I'm talking about and not have this first gut reaction of like, "Ooh, that's kind of awkward." No, it's not. It's actually a dope job.

Kennedy:
Yeah. And it's not a contest, but it is interesting what things get left out where, because disability is in all these movements. If you want to talk about climate change and which groups of people are going to suffer the most as climate change progresses. If you want to talk about police violence and how mental health intersects with all of the violence that goes on. Yeah, I'm glad you set them all straight, Marley.

Marley:
I don't know how much I set them all straight, but I think I at least put it on their radar. This is something that I should be learning about more and centering more. I remember just telling a lot of different people in my circles like, "Hey, maybe you should be following like Imani Barbarin or some other activists on social media that you should just be seeing their content on the regular and be trying to incorporate disabled perspectives into your activism. And I have noticed actually that a lot of the people in my life have shifted their perspectives too, because I really wouldn't shut up about it for like I still haven't.

Kennedy:
Justin, I don't know, you're a little older than me. Is there anything you want to say about your experience with care or the system or?

Justin:
My experience with white care and this system in general is kind of like, it's a pretty fucked up system. I've been in this system, man, geez, it's almost over 20 years of just being in this state system and dealing with trying to get PAs and all of these other things and it's been a mission. And so I don't tell a lot of folks that like, "My mom is my personal assistant, she takes care of me."

Justin:

And sometimes it's hard to explain to a lot of folks because I think a lot of ... I still live with her. And that's like, "Oh, well, you still live with your mom?" In the system that we're in is very difficult to live on your own, and so you require care. And so my mom has been very supportive of me literally the past 20 years as being my assistant. And so there has been a lot with that, there comes a lot of trust. And I trust her a lot in handling my care. She knows the things that I like, she knows the things that I need. And it's like, yeah, I've just been ... for me, that type of support has always been there for me. And as I've gotten older, there's been more of concern for that. Because my mom is an old older person and I want to make sure that she's well protected and well safe while she's taking care of me. And so those things always are in my mind, as I've gotten older. Its like, okay, well, I'm close to 40. My mom's not going to be here for you. You know what I'm saying? Just in that thought process. And so for me, I think a lot of people don't realize that, yeah, this is a lot of work. But also sometimes your family has to be like the person who takes care of you, family members have to be like your PA. And sometimes this just happens. And as much as I would love to have multiple PAs and multiple folks to help me out, I don't really have that, also because of my financial situation. So that also plays a role in this as well. And so I think a lot of people don't understand that the whole care system itself and how important it is to us in our community and how difficult it is to find folks that one you can trust, and two that you can really share and be honest with in terms of your communication on what your needs are. And that's something that I often think about every day.

Kennedy:
Yeah. And I don't think it's uncommon for family to provide care. The state has some like trainees for PAs and that's a lot of who is in the room. But yeah, people who don't get it don't always see that. But yeah, that is sticky too. My family still helps me out, as a backup to the PAs that are hired. That can really affect your relationship. Communication is key and all of that.

Marley:
I think you bring up a good point too, about family care. I have noticed that it seems like a more unique situation to have care workers that aren't your family, majority of care workers that I've met and talked to has been family members giving care to family members. And just hearing that you have friends tell you, Justin, that like, "Oh, you still live with your mom." Just the fact that that's even a shameful thing at all or considered a negative thing in our society just emphasizes how our society is geared towards individualism. And the ultimate goal is you should be able to self sustain. And if you're not able to, then that's some kind of a knock, some kind of points against you. It's just like, I think if I've learned anything from this job and from learning about care work and disability politics has been independence is really overrated. And interdependence is the way to go. And if you think you're truly independent, you're wrong and you're living a lie.

Kennedy:
Yeah.

Marley:

We all depend on each other. We need each other. The illusion that you don't need anyone, it's an illusion.

Kennedy:
And I hope that COVID drove that home for folks when they were locked down out alone. That is not any kind of way to live. And yeah, even though disabled people always say, "You're not disabled yet." When people have strong reactions to something another PA does wrong or people who are my PAs critiquing my PAs or people like, I don't know, just have an expectation around all of this stuff that's so far from reality and the resources that are there. And I'm like, I hope you never need care, but everyone will at some point in their life. So you have to learn how to interact with people. I don't know. And just in life, even if it's not about care. There's a quote in Mariame Kaba's new book, We Do This 'Til We Free Us, that's like anything worth creating is created with other people, something along those lines. And I think that's definitely something that Crip politics taught me. As a young person, I really wanted to be able to do things for myself. That was the ultimate goal. And now it's like so different.

Justin:
Right.

Kennedy:
You're so old.

Justin:
It's so weird because I look back like when I did The Wheelchair Chronicles a decade ago and I look back at some of the stuff where I was just like, "Oh yeah, I got to be independent." And I was really fighting for this independence. And I just sometimes look at myself, I'm just like, "What the hell are you talking about, man?" Having a community is so important, especially within care work, having that community and folks is so very important. And so yeah, we all have been taught that we need to be independent in that we all need to do our own thing. But being a part of this community has taught me that no, that's not the case. And I've learned so much from just being a part of this community and learning about what we need in terms of care. And with care work, I've learned so much that having that community and collaboration because we're working together to achieve the same goal. And so for me, just having to get out of that mindset was something that took me a very long time to get out.

Kennedy:
Yeah. I think the way that there's like this under capitalism, there's this little bit of money set aside for care and PAs aren't paid very well and there's not a lot of hours. I just had my assessment and they literally told me because the PAs had gotten a raise that it's going to be harder for me to get more hours because the pot of money hasn't changed. I was like, "Oh, so you're literally pitting us against each other." And so my PAs being paid more definitely still benefits me. But I was like, "Whoa. Who's doing this math?" And then everyone else is working 40 hours a week to barely pay their rent. And just this weekend I put a Instagram story up that was like, who wants to come help me with my plants? Because you know DHS isn't funding

anything fun. I need like the plants are in, I mean the ones on screen look all right, but some of these plants need some work and it is not in the service plan for the amount of things I need to do. I'm asking friends to just volunteer and I got three responses and I was like, "This is a gold mine because no one has had energy for my plants in four years." Things are ridiculous. I mean we couldn't even have people over for however long. But it's like I just wish things just operated so that care was at the center instead of this side thing that individuals ... I don't think people know how much time we spend on it. We're just forced to figure out. And Marley you are so affirming. For me as a manager, which I don't do my best because I'm also supposed to be making money to pay for my life. It's not a thing I would choose to do or my only priority. But you kind of have to make it a main priority because it's so important. But some PAs get really frustrated with how I do things or just the way the system is. I don't know, Marley's always hyping me up.

Marley:
I feel like you are a really organized person. You did a great job keeping all of us, all the schedules, all the shifts. You always had someone for every shift and we always had enough hours. And there was maybe a couple times where someone has to call out sick and we are putting in more hours that week and we're a little more stressed. But even in being a PA like interdependence of me and the other PAs was so important too. I wouldn't have been able to be as good of a PA if it wasn't for your other PAs supporting you too. And also there's this perspective that some people take when talking to me about this, where it's like, "Oh, you take care. Kennedy needs you. We need care workers." And it's also like care workers need the people they work for too, we need you too. It's completely interdependent. I wouldn't have a job without you. You wouldn't have care without me. We need each other. And even more than just like the job and the job being done is like you also supported me in so many other ways, like mentally and emotionally, which obviously we worked on boundaries about that. And we talked about not like trauma dumping in the shower and stuff, but also at the same time it's like, if I'm having a super rough weekend, we need to put a little break on shooting the project for a while. That was totally fine. And you were always there to support me too.

Kennedy:
Yeah. COVID kind of changed all that because I needed more emotional support from PAs than ever before, they were my only point of contact. So things that I had written before COVID looked different, because no one was okay. But yeah, I think there's so much to say, but yeah, that kind of gets at the wobbliness I was talking about, where it is interdependent but it's not in ... the system doesn't make it like a fruitful interdependence, sometimes it becomes like-

Marley:
Survivalist.

Kennedy:
Yeah. Sometimes I feel like it's like a spider web and I'm the middle. And every side is pulling on me. But in terms of like, I think we could all talk about this forever, but do you both have resources? We'll probably do more podcast episodes on care in the future. For now if listeners

are new to the topic or new to managing care. I mean the obvious one is a book by Leah Lakshmi Piepzna-Samarasinha called Care Work. What else?

Justin:
Yeah. That's one of the main books that I could think of right off the top of my head. But I wanted to ask you both. You guys were obviously doing this project, how did the connection with Disability Visibility Project come about?

Kennedy:
We just started pitching at places and Angel Miles helped us get in touch with Alice Wong. So yeah, if you're looking for a breakdown of our photos or critique of the system, there was a word limit that we really struggled through. But there's a piece called Care Under COVID or I think Care During COVID that shows a few of our photos that is also good for contextualizing things in that way.

Marley:
Something that I just thought about that could be interesting to explain to people is how we went about shooting the project so we could still operate under DHS's really strict rules and still make this project. Something that I think is a really interesting point is people living under state care, it would be extremely hard to make a creative project about that experience just due to the time crunch that you're always under of trying to stay within the hours that you are allotted by the state. And then also there's care plans, so they tell you exactly the tasks that you're allowed to use your hours to do. And anything outside of that is considered fraud. So yeah, like we said, like watering plants, feeding the cat, that's not on the care plans. So if they were to find out that someone did that, or someone reported that, you would be at risk of losing your services, which is just ridiculous. Something that we worried about a lot, this project and had to brainstorm a ton was how are we going to shoot this project and not have it be on state time and not have it happen on the clock so that you don't lose your services. But also so that we are not burning out and doing a bunch of unpaid labor essentially to do this project. One of my professors from my civic media program helped us apply to a grant called the Diane DeMeyer fund. We ended up getting that grant, which was really cool. So we were able to do the care shift and clock out and then take some photos and stuff off the clock and still pay ourselves for that extra time that we were spending doing that. We were logging all of our hours in a big Google Doc. And there was a lot of logistical elements to make sure that we have the time and the energy to do this. And we're not basically committing fraud against DHS. I think that just goes to show how many barriers there are to even being able to capture this experience and share it with others and how we were really lucky to be able to get past that using the grant money.

Kennedy:
Yeah. And I think it's interesting too, when you're asking about like how we went about pitching. Some of the more formal pitches we did backfired and it was just like disabled people who helped us get stuff out there. Like friends of friends and like we're still talking to folks like a friend of mine saying like a long list. We were kind of overwhelmed for a while, but some of the more cold pitches, I don't know if we even want to get into it.

Marley:
We don't have to get into it, but we did cold pitch to a journalism outlet and it was not received well whatsoever. That's a little bit more to the story, but we're not going to get into that.

Kennedy:
We got sub tweeted, Justin.

Justin:
Really?

Kennedy:
Yeah.

Marley:
The reporter we pitched to tweeted saying basically that someone pitched them really inappropriate photos. We were already a little wary of approaching the journalism world with this story just because I know from my program with the photo journalism program and my short time working for a newspaper that our story wouldn't necessarily be our own in a journalism sense. So if a journalist wanted to tell our story, they would interview us and write the story their own way, which we weren't too keen on. I think that's why when we had the opportunity from Alice and she was literally just write me 2000 words and you're going to be on our website. We were like, "Okay, awesome." Also that's a lot of pressure, but we get to do it our way and we get to control the narrative, which is really important, especially because in journalism a lot of times disability narratives are not well written.

Kennedy:
Totally.

Justin:
No. That's why it's important for us to tell our own stories. I definitely am glad that you guys went that route. It's just like instead of going the traditional journalism route because holy shit…

Kennedy:
Yeah. People can’t handle like fat butts but I’m like, “you have seen this stuff before."

Justin:
Oh, too much.

Kennedy:
Yeah, it was a lot.

Marley:

We admit we know the photos are a bit intimate for sure. And I think we give a content warning before showing anything. But yes, this reporter was not keen on our pitch, which in the end it led us to actually publishing with Alice Wong who is an amazing connection, understands, she's just on the same page. She let us tell our story how we wanted to tell our story and was just open to whatever we wanted to do. So that was a blessing in disguise kind of that opportunity came up instead.

Kennedy:
Yeah. Shout out to Alice Wong and the Disability Visibility Project. They've been doing disability media for so many years.

Justin:
Yes. And so that's awesome. And I'm glad that you two were able to do that and there's a lot of things we have to do in order to make projects work and you all made this work. And so that's like there is very awesome and I'm happy and I'm proud of both of you for what you all have done.

Kennedy:
Thank you, Justin. Honestly to say what people's reactions were like what kept us going, like yours and other friends of mine. When you were like, "We should talk about this on the pod." I was like, "Oh, yeah." A friend of mine was like, "Oh, I'm guest lecturing in a classroom. I'm going to assign this." Now it's just seeing people feeling affirmed by it, that was the whole goal. Because we both felt so invisible at the time and it was funny too how we were in the Disability Visibility Project. I was like, "Yes, that was the goal." I was just meshed perfectly again. And the photos will eventually probably be public, but right now we're trying to get them in different galleries and publications. So we don't have all the details on times or COVID protections yet, but there's a cool show coming up in Chicago where the photos will be up called unfolding disability futures with a lot of other disabled artists, which is really exciting to be alongside folks. Marley, what are the dates on those?

Marley:
Okay. The show is going to be running June 4th, June 5th, June 11th and June 12th. And we're not sure exactly what time, but I think they're going to be afternoon and evening.

Kennedy:
Yeah. And then I think it might stay up after that, but that also is not for sure yet. So just keep an eye on the Crip Crap Instagram. Follow Marley on Instagram, Marley Multimedia. And we'll be sharing out the details of that. This episode will probably drop closer too, so by the time this comes out, it should be on our Instagram. Okay. I want you both to geek out about photo. I was like, "Yeah. Okay. We can all talk about care and then Marley and Justin could just like," I don't even know, like as a photographer, I don't know really what I'm asking. But I guess stuff about process, I think like the power of photos, I didn't even realize, because I'm more of a writer. Until we did this, the difference and like, I don't know, I feel like y'all's work leads you places. I don't know, it's interesting to watch.

Justin:
Yeah. It's been a very interesting process for me in terms of photography. Because I originally was a filmmaker and I was doing that and you're focusing on that type of work. And then kind of transitioning maybe four or five years ago into photography and really doing it, mostly as a hobby because I love travel all over the city and really just take photos. And that was pretty much what I was kind of doing and then COVID hit. And so when COVID hit, that kind of, I didn't know how I wanted to approach what I do as a photographer. Because we were still on lockdown and there was a lot of things that were kind of happening. But then I think COVID was a blessing. I don't want to say it like that, but it was a blessing in disguise for me, because it really gave me an opportunity to really highlight and just go out there where there's not a lot of people around and I could just take photos. And that was something that really kind of brought me joy. But it also has just created a lot of excitement for me because I didn't realize how important my photography would be during this time. And with that, it is just taken me so many places from a visual standpoint and it's made me think about the process of how I take photos. Because from other people's perspectives, a lot of my photos are just kind of ordinary photos until I start telling the story behind how I took these photos and how I got these shots. And then that sort of went into, okay, it made me think more about the work that I do and the importance of the visual aspect of it because people respond so much to what they see visually and then adding the story element to it where it became an accessibility issue. And it took me a while to figure out, well, yeah, the work that I do, there's a process that goes into it. It's not just having the camera and just shooting. It's really just going to places that I know are either going to be accessible for me or inaccessible for me and highlighting that and telling the background of how I got these photos. And now people, they're really taking aware of what I do now. And that is amazing thing because now my photos are being highlighted in different galleries and all of this stuff that's kind of happening all at once. And I'm just stunned because now I'm just stunned by it all, because if you would ask me maybe a year and a half ago where I would see my photography work taking me, I wouldn't have an answer for that. But now the work that I'm doing through my lens, highlighting accessibility, inaccessible places and talking more about the process of me like the physicality aspect of it that comes to when I do photography work. Because I wasn't thinking of these things until recently, but now I realize it's like, oh, holy shit. Everything you do, there's a physical aspect to it. Everything you do as a photographer, there's a process that goes into it, because you're not just point click in all of that. But for me, the process is just, it's made me really think more about the process of everything that I do because there's a lot that goes into the work that I do. And now it's like I'm at this point in my life where people are paying attention to this and people want to learn more about it and people want to talk more about it. They want me to talk about it and do workshops about it. And so I'm at this point now as a photographer where the process is so important to me and people want to learn a lot more about it.

Kennedy:
Totally. That's so exciting.

Marley:

I have a question for you, Justin, about your process. I'm wondering if you use any different accessibility modifications with your camera for the physical shooting process.

Justin:
It's interesting that you bring that up because that's sort of what I really want to do really going forward is now that I'm in this position where people are taking notice of my work, I want to be able to take photos from different angles, from different points of view, while in my chair. Because normally when I'm taking photos, 99% of it is basically in my chair. And so if there's something that I see, I have to lean over and I have to position myself to where I could take a photo. And I really want to add extra things to my chairs when I'm traveling. I have different perspectives and I have different vantage points from my chair where I'm highlighting all of these different issues. And so yeah, my mind is really thinking about, okay, what steps can I take as a photographer? What can I continue to do to showcase what I do and to highlight just my surroundings? And I think I'm like, yeah, I had some really cool ideas as to how I want to add accessories to my chair and really doing that type of thing. Because I'm just like, yeah, my mind is racing and I'm like, okay, yeah, I got some really cool ideas for this.

Kennedy:
That'll be awesome. We need grants for that, listeners. Send us the grants.

Marley:
There's this photographer that I follow on Instagram. He's gotten a lot of press this year. His name is Robert Andy Coombs. And he's a gay disabled man. And he does a ton of photography work. He's had his work featured in a ton of different places like the Saint Louis Art Museum and somewhere in Miami, I don't know. He's just popping off and shout out to him. But I've noticed that he uses this different types of tripods and stuff that are really interesting that I've seen. And I'm not sure what his whole setup is. And he also uses Polaroids and digital and film and all this different stuff. And I know that he has a bunch of different modifications for how he's able to use different gear and stuff. And I was just wondering if you used anything like that right now, or if it's just like you have the strap around your neck or like it's in your lap.

Justin:
For right now, most of my work is in my lap. Mostly I have the camera positioned kind of in my lap. And I have to make sure I'm finding a particular spot where I'm comfortable enough to basically set myself up in a position to where I can take photos, because obviously for me it's a little bit more difficult to take photos just like in the position that I'm at right now. But for me, if I'm leaning over, I'm sort of like in this position where I'm more suited to take pictures. And I want to expand on that. And so yeah, I want to have different tripods and different accessories to ... I really want people to see from various perspectives. I just want people to see from my position in the chair, I want for people to see something from the position from my wheels or the position of my headrest or my leg rest. And I want to just highlight, I want to take photos from different angles, just so people can really see what I see ultimately, because that's pretty much what I really want people to see, people to recognize that my wheelchair is an extension of me. And so I want to use it in as many ways as I possibly can.

Marley:
And I think it can't be like overstated enough, just like you were saying, it's important to you the different perspectives that you're able to even get your camera at to show others very specific different perspectives, because that's the draw of photo is that you're able to kind of transfer your perspective to others, which is so powerful, especially what we've seen during the pandemic and with so many other issues in the world. People don't really care or understand until they've had a conversation with someone that's had a different experience with them or than them, or that they've looked through the eyes of somebody that sees things differently. And I think photography and videography is such an amazing medium for that. It's like this pseudo transferring of perspective. And something that I learned in my master's program about visual media is we view the world through the lens, through the knowledge that we have already. So if we haven't seen something before, if we haven't heard of something before, if we haven't known about something before, how is that going to be a part of our worldview? The power of a photo or video to someone is, literally you could be able to expand their perspective on the world by just lending your own perspective. People don't know things exist until you show them sometimes. So it can just be so powerful. And then also for the photographer themself. Photo does so many things for me. I think it's like a true merging of the mental, the physical, the emotional. It's like when you're taking a picture, you're not just clicking a button. You're also thinking about the content that you're capturing and like you're responding, you might even be capturing it because it made you feel some type of way. For me, it just feels so fulfilling. At the beginning of the pandemic, I can relate to what you said, Justin, where you start going out on these photo walks, where you're just kind of by yourself. And you're noticing stuff because you're cooped up in your house otherwise. And you're just looking around and you're just saying, "Today I'm just going to go out and take photos of whatever interests me." And it's a very grounding practice.

Marley:
Especially at the beginning of the pandemic, I had a ton of really terrible anxiety, like very bodily anxiety of just always feeling shaky and feeling like my stomach was upset and feeling headachey. And just the pandemic really gave me a ton of anxiety. And going outside, walking around and just noticing the things around me, it was so grounding. It was like therapy. It was therapeutic. And just the pictures that I took of little things in my neighborhood of some CPS worker handing out lunches to students that came and got free lunch. And I don't know, just noticing things. It was so grounding and became a practice of just the photo doesn't have to be amazing. I'm not here to take amazing photos today. I'm just here to be with the world and kind of do something about it, like just clicking the camera shutter. I don't know, like I said, it's the mental, emotional, and physical all coming together, and that can be so powerful.

Justin:
And yeah, exactly. And from the early stages of the pandemic, being outside like by myself, but it was like nobody around and it was just interesting to be able to capture some of that. One of the photos that I captured, it's kind of been like a very prominent photo of mine is near where I live. And this area is normally full of people walking around, people talking, cars coming by, the

trains coming by. And the photo that I took was just, it felt like it wasn't amazing, but it just felt eerie because of the silence. Especially in that area where you just hear noise and there's just absolute silence. And there's nobody, with the exception of one person kind of crossing the street, but there's no cars parked on the street. It's just this empty void. And being able to get that. And I was able to get that shot because hey, it was accessible to me. It would never have been in any other time accessible for me to stop in the middle of the street and take a photo, it's just impossible. And so just really seeing during this pandemic, really it was just kind of eerie, just kind of rolling around taking photos and different places and going to the beach and it's like almost empty. It's like there's nobody there and able to get different photos and stuff. It was just so weird to me. And then I think took it to another level was like when they started opening things back up for the city. And then I started noticing during my travels where there was a lot more people out, but that freedom of accessibility was kind of not there. It was not there to the point where everybody was happy to be out and happy to be back outside and be on the patio and have lunch or dinner or whatever. But I think for me was just seeing like the lack of care when it came to accessibility issues. All the things that were good for me outside was just not happening when things started opening back up and being able to highlight in my neighborhood where they had put these little flimsy, like yellow plastic ramps on curves that were supposed to be like, "Hey, you can go around our business and you could still get back on and off the sidewalk." But for me it was just like, there was not ... nobody cared anymore. It was just like, okay, we're outside, here's your little ramp. We did this for you. We saw the accessibility and everything is great. And just from the experience of seeing like how people view that and taking a photo was like this ramp that I took a photo of that was like on, not on a curb, but just on the street. And for me that was just really like, oh, you got be kidding me. So it's just like taking a photo of that. And that's like another photo is highlighted during this time, like the lack of care that I feel people have towards accessibility issues and seeing that ramp out there just on the street, it was just an example of what that was and then there was another. I wish--there was photo I wish I would've gotten because I was in and I think I was going back home. I was in a vehicle. And when I passed by that area, one of the ramps was underneath somebody's car. And I wish I would've gotten a photo of that. That was just like, "Come the fuck up. What are we doing?" And it just fueled me as a photographer to be like, okay, this is like a bucket issue. And I'm going to take photos no matter what I see in terms of accessibility and all of these things was culminated during the pandemic, especially dealing with how people view people with disabilities, how they view our needs, going back to care, how they view our needs and how we view accessibility and inaccessibility. And so yeah, just that journey of really highlighting that is something that has been very valuable for me. And people want to know more about the work that I do based off what they've seen.

Kennedy:
Totally.

Marley:
I think like I said earlier, there couldn't have been a better time to share your perspective and our perspectives and stuff, because so many narratives about the immunocompromised and that are most vulnerable were in every news article that you were seeing. But there was no face

to that void list, that void of a name of immunocompromised, like who is that? What does their life look like? What do they care about? What does their day look like? That's so important to really flesh out the full story and make people truly understand like who we're fighting for right now. And that was again like something that really deeply compelled us to do the photo project that we did was just like, it's so important to us that people start to put a face to this nameless experience that they're hearing about so that they can actually build meaning within themselves for this experience and start telling their friends and just orienting their perspectives towards that. And even when we were shooting the project, like going back a little bit to the photography process, when people ask us about our project, they're always like, "Who's the artist? Is it just Marley? Is it Kennedy's film?" It was definitely both of us. Obviously we had varying roles within it and stuff, but both of our perspectives were in every photo and in the planning behind every photo And we did a lot of planning work to where we sat down and wrote down what scenes we felt like were important to capture and stuff. And then at the same time we starting and then something just happens and we're like, "Oh, we got to capture this. This wasn't on our list, but this is a really good shot." And there was so many times when we had a shot in mind and then Kennedy would say like, "Hey, wait, what if you move the camera behind us instead." And then I'm like, "Okay, let's try it." And then it ended up being like one of the final photos in our project. So just working together in that way to do the planning and then also in the moment let photography and our guts guide us and tell us where the photo is right now in this moment. And to do that together was really fun and it was a really unique experience for me in shooting, because I don't think I'd ever had like a partner in photography like that before. And I think obviously adding more perspectives, I didn't want to just be like a care worker's perspective of her working for ... you know what I mean? It wasn't ever about that. It was always about both of us and how the relationship and how both of our lives came together in these different ways. And then both of our experiences shaped our relationship and our experience together. I don't know if Kennedy, you want to talk about how it was like shooting that the project together or what photography like brought to you?

Kennedy:
Because yeah, it was like, oh, this is always something I want to do, but I never had a PA who was a photographer, and that is kind of what led to us doing it. But I think it was interesting how it was hard for people. And I'm fairly visual, I don't know, just like driving a wheelchair around. You look at things a lot. But it was fun, but it was interesting how it was hard for people to wrap their heads around the fact that it was a collaboration, especially in spaces that weren't just really specific at your university or other things. But yeah, it was a lot of fun to play around with and almost like have, because like doing that on my own would be very different. Almost like you were my PA for photo too. I don't know, y'all got to collab. Marley edited our film, disability Easter sales, disability film challenge entry last weekend and from Ohio, did a lot of virtual editing and I was like, "We got to get Marley down here doing some cinematography or something." But yeah, I just love the way you all engage with your audiences, but also how it is and change their perspectives and keep conversation going with them. But then how it also is like a very internal thing. I remember once Marley and I were having ... we had these deep shower talks. If anyone needs to work through their queer Midwestern childhood, we got you. But as I take a shower often, that was the largest chunk of time to have a fairly uninterrupted

conversation, like once a PA is trained. And one night we were talking about religion and you were talking about how photo was spiritual for you and photography. And I was like, "Oh, I need to get in touch with my craft." That makes a lot of sense, but it really struck me. So yeah, y'all are killing it. Keep doing what you're doing. Marley, is there anything else you want to add as our guest? I mean, Justin too-

Marley:
Anything else I want to add. That's so hard. I always got way more to say. I would just like to explain, if you include this or not, whatever. I would like to explain the spiritual comment. I said it because I've always felt that I'm not a very spiritual person. I don't know what that feeling of spirituality is necessarily supposed to feel like. But then I think one day like my mom was like, the way that you can run up to a person on the sidewalk and be like, "Your pink hat is so cool. Can I take a photo of you?" And then take a photo and then we have a great conversation. And we connect and something in my gut just told me, like run up to this person because they seem really dope. That I guess is the closest thing that I can maybe compare to a spiritual experience where you can't necessarily explain it. But you feel compelled in that moment to use the craft that you have to interact with the world and just bring yourself closer to life around you. And photography for me is an act of very much like appreciating the beauty around us. And also again, like the problems around us too, like some of Justin's pictures have highlighted too, like the beauty of sharing your perspective in whatever medium that is, is it can't be overstated enough, whatever your medium is, lean into it, use it, share your perspective. Right now that's what people want in media is new perspectives and to feel like they're in someone else's shoes that they haven't experienced before. People want to hear and see projects about diversity, about diverse experiences of marginalized communities that have not had as much of a chance to get their voices into mainstream media and control their own narrative. Whatever that craft is like get out there, it doesn't even have to be for the purpose of creating some big project that goes viral, like creating from your gut and from your heart in the moment of what you're feeling strongly about is going to create something strong anyways.

Kennedy:
Totally. Beautiful.

Justin:
There you go.

Kennedy:
I did want to share, Marley, what is the Instagram that is about care work rights? Do you know?

Marley:
I follow two different Instagrams. There was one that like posted us, but they were based in North Carolina. They were kind of North Carolina specific, I think.

Kennedy:
Yeah, there was maybe New York based one.

Marley:
Let me see. Something called like care can't wait. No, that's not it. I would have to go look through my following. Let me see.

Kennedy:
Yeah. I can't think of it off the top of my head, but there are more resources out there like Loree Erickson in Canada has volunteer care collectives because she doesn't qualify for services there. You can Google her.

Marley:
Is it the National Domestic Workers Alliance?

Kennedy:
I think so. Yeah.

Marley:
It's on Instagram, they're literally just called Domestic Workers. They post a lot of stuff just about different movements that are happening for reform for different care systems, so that's a good account to keep up with. But there's other ones.

Kennedy:
There's stuff on Loree in Leah's book and on just the internet, she's been covered in a few things. And then if folks are new to managing care, you can just reach out to me. I have a Google folder of all the materials I used that I just share, no one should be doing this on their own. We shouldn't be recreating these things. It's a lot of work. I'm happy to share that and you can adjust it to your needs. And I think that a lot of where I got it from is seeing other people's ads or other people's applications and just pulling ideas from Crip community.

Marley:
Okay. I actually found the correct account now, the last one that I said, it is a good account, but this other one is called hand in hand domestic employers and they are based out of New York and they really follow a lot of the different reform movements happening.

Kennedy:
Awesome. Okay. Cool. Yeah. So both of those are kind of right space.

Marley:
Yes. It's specifically about reforming care systems and getting care workers better rights.

Kennedy:
Yeah. There's a lot happening with that right now in Illinois. They're trying to get like ... Do you know if it passed for like spouses and parents to be able to PA and things or just spouses.

Parents can once you're 18. There's a lot of intricacies to all this, so those are some starting places if folks are interested. Yeah.

Marley:
Look, here we got featured on the account. I don't know if you can see.

Kennedy:
Oh sure.

Marley:
Anyway.

Kennedy:
Hype us up.

Marley:
Yeah. Kennedy, we still need to have our own other meeting about how we're moving forward with our project because it's ever evolving.

Kennedy:
Yeah. It's happening. So stay tuned folks.

Justin:
Yes. Stay tuned. So to wrap up, outside of your website and Instagram, where can people find you slash hire you?

Marley:
Okay. Well, if you want to hire me in person to do shoots, I'm in Cincinnati until August. And then I moved to Philly for two years, so I guess Philly after that. I don't really travel. I don't have a big freelance business or anything. I do individual shoots and stuff, but yeah, it's not necessarily enough to sustain myself sadly.

Kennedy:
Is there a form on your site for that or just an email?

Marley:
There's an email on my site. You can contact me through my site or literally just DM me on Instagram. I'm very responsive no matter what platform it is. And also if you want to connect in some other way that's not like doing an in person shoot, just email or DM me, because I'm always accessible to talk about literally whatever.

Kennedy:

Awesome. Thank you for coming on. I did not expect this either. But yeah, it's great to ... I think our project really changed our relationship a lot than from like ... I have a ton of former PAs and now we're just making stuff all the time and having a little chosen family moment.

Marley:
Yeah. Honestly, I mean, you can put this in the pod if you want or not. But I was so serious when I said like a couple weeks ago or something maybe a month ago we had friends over and we were having a big drinking night and the night ended with me basically explaining to some friends asking me about my care job and stuff and just turned into me being like I literally missed my job so much. My current office job is so boring. I miss not only my job, but also just like miss Kennedy, you became my best friend that year. I also didn't see anybody at all. And you were my constant, so like miss you so much. And I just also want to get back into care work because it was just a dope job. I don't know if it was just because you were a dope boss, but I would love to find another situation like that again, where I could also sustain myself financially pretty well, which I don't know if that's going to be possible, but I would love to get to a place in my life I could do care work again.

Kennedy:
Yeah. Like Philly listeners, hit Marley up for like substituting.

Marley:
Yes, please, for real, I miss it a lot.

Kennedy:
Yeah. No it's good. I have so much respect for care workers and it's such a unique relationship. Thank you for coming on.

Marley:
Thanks for having me. I'm seriously really honored to be on a disability podcast. I don't even feel worthy, but I am glad to share some care work perspectives if I can.

Kennedy:
Yeah. After you edit that video for 12 hours, we made you an honorary disabled person.

Marley:
Stop. The most able bodied person, I'm freaking right now.

Kennedy:
We have the power though, we can do that.

Justin:
Right. We can do that.

Marley:

I don't need that.

Kennedy:
What's that called that like when you get a degree that you didn't-

Justin:
Honorary doctorate.

Marley:
It's honorary.

Justin:
Yeah.

Kennedy:
You have it.

Justin:
Thank you, Marley.

Marley:
I'm going to stay in my lane for now.

Kennedy:
We're going to drag you in our stuff.

Marley:
I'm already in it. It's too late.

Kennedy:
It's too late. Okay. We'll talk soon.

Marley:
Okay. Yeah. We'll text. Bye guys.

Kennedy:
Bye.

Justin:
Bye.

Episode #6: Race, Gender, Trauma, and Art with Blaq Gurl Fya

Episode Description: In this month’s episode, Fya, Justin, and Kennedy discuss Fya’s work. They touch on how acquiring a disability shifted her arts practice, her current event series, being gentle with ourselves when the world is crumbling, and more.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don't you know

Justin:
Hello, everyone. Welcome to Crip Crap Podcast, Episode 6. My name is Justin Cooper.

Kennedy:
I'm Kennedy Healy.

Justin:
This is Episode 6. We are here, while the world is falling apart and being held on by duct tape. We're still here. We're going to give you the awesome podcast that we normally do. Today, we are please to have a very, very special guest join us on this podcast. My dear friend, your good friend, Fya. Kennedy, please introduce our good friend, Fya.

Kennedy:
Yes. Fya is an award-winning mental health trauma and creative release advocate and speaker, who has created a technique of art and storytelling to create artistic healing experiences for individuals who have experienced trauma. Ideal clients include individuals, organizations, and companies who have a desire to shed light on traumatic healing by providing a voice for the misunderstood, unheard, and unseen, by turning their trauma into artistic healing experiences. Fya is a 16-year-plus traumatic brain injury survivor and a multimedia artist with over 10 years' experience of creating and performing through various mediums, including filmmaking, fiber work, and curating. She is a multi-talented and multi-dimensional creative director with proven skills in event planning and project management invoking afrofuturism to create healing

experiences for communities. Her experience includes working with various organizations, including ADA, or the Americans with Disabilities Act, 30 Lead On Celebration, and NDEAM, the National Disability Employment Awareness Month Production. She has curated and moderated the panel discussion for NDEAM and is the artistic coordinator and product manager for the ADA's Black Future Month Production. Among being the recipient of various awards, Safiya's signature creative release system has helped many. Welcome, Fya.

Justin:
Yes. Welcome.

Fya:
Thank you for having me.

Kennedy:
How are you doing?

Fya:
I'm getting it together. After this past Mercury retrograde and eclipse season, I'm still trying to get it together. It's like, even though Mercury retrograde ended on the 2nd and 3rd, but the residue ... I still feel the residue, but I've been learning. I'm learning so much about myself and just working on understanding myself, being more kind and gentle, and just not putting so much pressure on myself and understanding the fact that I am a person living with a disability and I don't have to overcompensate and be perfect, like I thought before.

Kennedy:
Yes, absolutely. This episode is for July, but we're recording right now in early June. Since we checked in with folks, so much has happened in the news. I think we all just need to be super gentle with ourselves. Yeah, all these issues, whether it's the mass shootings, abortion ban, more, affect people with disabilities differently than the rest of folks. I'm glad you're being gentle, and yeah, having grace with yourself.

Justin:
Yeah.

Fya:
Yeah. I can just say it's easier said than done, because I'm a very obsessive person and thinker. I like to have everything T's crossed and I's dots, so I'm really out of my comfort zone right now. I just feel like the universe is teaching me about faith and just trusting myself and not being in a aware of operating from lack and self-doubt.

Kennedy:
That's amazing, yeah. It's just so difficult to exist right now.

Justin:

Right.

Kennedy:
That's the only way forward.

Justin:
Exactly. Fya, can you describe yourself for listener who aren't familiar with you and your work?

Fya:
Okay. Well, I'm a Black woman. I'm in my 30s. I like to call myself a self-expressionist, because just having traumatic brain injury and having to re-learn everything. I can say, before my accident and when I woke up from the coma, it was like I was in a new world. Society still feels foreign to me sometimes and just trying to understand people's perspectives and point of view and being able to communicate my ideas better. I like to call myself the silent rebel, because I like to think I know best in my ways and people just got to catch up to my brilliance. It is what it is. Yeah, I'm learning to be in the moment and just enjoy life. I like to try new things, just explore. I like to call myself a disruptive artist, because I'm disrupting the norm. As we finding out, it's not working for us. Yeah.

Justin:
Yeah.

Kennedy:
Absolutely. Is there anything else people should know about you or your hobbies or personal interests that you want to share?

Fya:
See, that's hard, because since the pandemic, I've been in the house and working non-stop on my project. Right now, because I've been going out more, going clubbing, I like to have a good time. I like to party and stuff. I'm learning how to live again, to just experience life and be fully in the moment.

Kennedy:
Awesome.

Justin:
Yeah, exactly. That's what we got to do. We got to have some fun, live it up a bit. These times have been very rough and very depressing for us. We got to be out here, expressing ourselves, and being out here and having fun and having disability joy and doing all those things.

Kennedy:
Absolutely.

Justin:

Yeah. Fya, can you tell us about your work, how you got into it, and how you got started doing it?

Fya:
Okay. Ever since I was a little girl, before my accident, I used to ... My family used to always laugh and make fun of me, because I always be in the kitchen singing and dancing, wherever I could. That's me. I used to be mad at my mom, be like, "Mom, you should've put me into acting and modeling when I was younger," but it is what it is. Then the car accident happened when I was 13. Before my accident, I used to write poetry a lot. I always been a writer all my life. When I woke up from the coma, I literally had to learn everything all over again. It was like I was being reborn, like a newborn. For a long time, I couldn't talk, I couldn't walk. Everything, my comprehension skills, it was like I was a baby being reborn. When I wasn't able to talk, I had my ability still, writing skills. I was writing and writing, creating stories, short poems and stuff. Then after I graduated from high school and I thought of I'm now entering the world as a person who acquired disability and knowing that the current structure of society isn't made for a person like me, so I started thinking, "What am I going to do? I can't do a normal job because my focus. I can't stay in one position. I need breaks."

Fya:
I wanted to model. I started experimenting modeling, acting, and all that good stuff. I did go to Truman Junior College. I was literally a semester away from graduating, but my granny had transitioned. She was the only living grandparent that I grew up, so that literally broke me, where I ended up in a psych ward. I determined I can't go back to regular college. I decided I'm going to apply to the Art Institute of Chicago. That was the best decision I ever made. Even though I applied to get into the writer's program, but I got into the studio arts, and that allowed me to put me in a position to start experimenting with the different types of arts of how I can create. That's how I got into it, just healing from the car accident.

Kennedy:
Yeah. As someone born disabled, I've always been interested in acquiring disability and the narrative that gets put around that experience, which is so different than always having always been disabled, I think. Being pretty young, but you were already creating, how would you say your disability changed or influenced your art?

Fya:
Okay. I can say I really found out how it influenced my art during my second year at SIC. My first two years, I felt like a complete failure, because I was trying to do what everybody else does. Because I have really bad muscle spasm and the left side of my body is paralyzed, I still have a hard time moving the left side of my body. There's been times, even with my ADHD, where I'd be working on metal. One time, I busted my finger wide open to the white meat. I'm thinking I can't create physical art because of, even though after my accident and I'm now able-presenting body, but I still have challenges that limit my mobility. Since I came in as a writer, that's when I start wanting to get into film and telling different stories and using my mind. My hands and stuff, it gives out on me sometimes. In my second year, I started thinking about telling my experience

of being a member of the African diaspora woman and a person living with a disability and just document my experience. I didn't see stories being told from my perspective.

Kennedy:
Absolutely. Yeah, I feel like that's a turning point or multiple turning points people-

Justin:
Yeah.

Kennedy:
As they, usually around that age, if you're lucky, find community before that, but you come into those different marginalized identities and the power there. Can you tell us a little bit more about your current projects in the ongoing event series?

Fya:
Yeah. My current project is called the I Am Event Series Disability, Our Life and Culture. My goal with this event series is to create high-end and luxury events for bipod people with disabilities. Since I've been really working in a disability community and I see events just being slapped together, just put together, and I like luxury. I think we all deserve luxury. People with disabilities are just seen as a afterthought, just seen like when two people who get SSI that have disability get married, they check get cut in half. That's crazy.

Fya:
I wanted to create something that allow people with disability to know that they worthy. They don't need to accept being tolerated by people and feeling like they a burden to others and that they deserve the best that life has to offer. With this series, I had three events that I'm producing and a event that I am collaborating on. The first event would be a virtual film screening of the film Welcome to Our Healing Sanctuary. That film is a experimental film. It's myself and another Black woman that had traumatic brain injury. We are sharing our healing experiences and how art and nature has saved our life. We also providing people with statistics about TBI and PTSD. We are creating a healing sanctuary. In this film, we are inviting people to join our healing sanctuary. That event would happen on the 22nd. A lot of events have been pushed back. The next event, I'm partnering with Justin with the Disability Pride Parade. With that, in creating that collaboration, I wanted to help bring more disability resources to the south side and exchange to let more people know about the Disability Pride Parade. My vision for the disability community is to be like the Gay Pride Parade and just how it's a big celebration. That's what I want to see for the disability community. Then, the third event would be a expo, where my goal is to teach bipod people with disabilities how to use they skills, talents, and creativities to create opportunities for themself. I'm collaborating with a lot of workshop facilitators and speakers to create workshops to show people with disabilities how they can use they skills and talents and the importance of protecting they brand and intellectual property. The last event would be a disability gala. It's just to cap out to be luxury, to just enjoying the moment and just having the best and just celebrating what it is to have a disability.

Justin:
Yes.

Kennedy:
Awesome.

Justin:
Exactly. See, there you go. Luxury, that's what I'm talking about. That's all we need. We should be celebrating ourselves. All them times, this world don't really celebrate us. They often ignore us. They often don't care about our issues. At this point, it's like, yes, it's all about celebrating who you are as disabled folks, having pride in who we are, and showing people that, "Hey, we can have a good time. We could celebrate. We deserve luxury, just like everybody else."

Kennedy:
Absolutely.

Justin:
Fya, what drew you to filmmaking and other mediums you use?

Fya:
Well, I felt like, even going back to when I was at SIC and just experimenting with the different art forms and having a hard time of doing different fashion, like sewing, creating metal sculptures, because some of the mobility issues that I have. I felt like film gives me the opportunity to use my imagination. It's boundless to what I can create through film. Through this process, it's a communication device where I'm able to communicate my ideas to people, because just being neurodivergent, not a lot of people understand all the time what I'm trying to say and it's hard. It's easier for me to express myself through art. Film just gives me that outlet to be free and to use my mind.

Kennedy:
Nice.

Justin:
Nice. Yeah, same. It's same here with me with filmmaking. It just drew me in, because for me, I didn't see a lot of folks that were telling our story or really those that were the able-bodied folks were telling it from their perspective. For me, filmmaking was a gateway. It opened up so many ways of how I could express myself and how I could share with the world what's going on with folks with disabilities. Yeah, I think that's where we have a connection there and how those things could connect us and gives us a voice and a space to really express ourselves.

Fya:
Yeah. As I've been learning about people with different types of disability, accessibility needs, I feel like film is the art form that's most accessible, where you can create it like that. You can include different types of accessibility, like audio description for people who are deaf. Wait, no.

That didn't ... Audio description for people who are blind and ASL for people who are deaf. You can create low lighting and sound for people who have autism, ADHD, or epilepsy. It's just so much you can create and include in accessibility features with film, opposed to different other art forms.

Kennedy:
Absolutely. Yeah. In terms of the content, a lot of your work is at the intersection of race, gender, and disability. We touched on this some, but can you speak to the importance of creating for or supporting multiple marginalized communities?

Fya:
Yeah. Just going back, because my time at SIC, even though I didn't get out of it what I initially wanted to get out, but it was a good breathing ground for me to develop a concept for my business. While I was at SIC and I started creating the concept of using art and storytelling to create artistic healing experiences, I started to think about people like myself who often feel misunderstood, unheard, and unseen. I create for my different multiple layers of identity, just being a member of the African diaspora, woman, a person living with a disability. I feel like, with all these different identities, they provide me with different obstacles and challenges. Sometimes I feel, within my different identities, they can clash with one another. I just wanted to create a space where I can be me fully and where I can invite people to be themself fully, because we all multi-dimensional beings. We should be allowed to express who we are to the fullest extent. That's what I want to do and helping creating change in who I am as a woman, as a Black person, and a person living with a disability.

Kennedy:
Yes.

Justin:
Yes, exactly. Fya, in the landscape that we are currently in, that it's just very chaotic, what's keeping you going in the current larger culture and political landscape? What's keeping you going throughout all of this?

Kennedy:
Yeah. You have excellent energy every time I see you.

Fya:
Yeah. It's this project, the I Am Event Series. I like the culture. A lot of times, when disability is talken about, it's often just associated with doneness, like accommodations, like the medical issues, the injustice. I've been observing a lot of people with disability online and I'm seeing we are full human. We have a life. We have joy, pain. We experience a life just like non-disabled people. I think that portion of who we are needs to be celebrated and seen. Those stories aren't talked about. It's not in the history books. I want to help start documenting the joy points of being a person living with a disability. Like I said before, I eventually want disability culture to be at a level what the gay community or the LGBTQ community is at, where it's a celebration. Yeah,

they have they pains and injustice that they fighting through, but on the other hand, you see how they celebrate they culture. The bar is at another level. It's balance. I want to see that balance within disability culture, because it's there. It just haven't been documented yet properly.

Kennedy:
Mm-hmm. Nice. I think one of my favorite ... We're going to get Fya's info at the end, so everyone can follow along. One of my favorite ways you're already doing this, is you'll post things on social media, like articles and video clips or whatever it is about disabled folks. You'll just say, "Disabled people are phenomenal." I think you're just bringing the crip love into all these spaces. It's there more you want to say about love for disabled people?

Fya:
Yeah. I'm currently in South Shore and I work with the South Shore Works Collective. It always been disability inclusion has always been my goal. Even though, like I said before, disability is still a taboo topic, especially in the Black community, it was like, at first it's like they hear what I'm saying, but they not fully grasping. Because I've been diligent and committed to my cause, they are thanking me for my voice. South Shore Works has been a very big help to me and helping pushing my mission and what I want to do and bringing disability awareness and inclusion to South Shore. I just want to shout-out Dr. Adams, Dr. Carol Adams. She's dope. She's just been a very big help in just all the mentorship and the advice that I get from these elders and just being younger. I'm able to bring my perspective with social media and with these different causes, when we thinking about disability. A part of disability that I'm bringing also is a spin on what is disability. A lot of times when people think about disability, they just think about a person in a wheelchair. Yeah, I've been in a wheelchair, but right now, I'm a person who's neurodivergent and have chronic illness. I'm a able-presented body person. Just thinking about what I learned about marketing and stuff, if I include the mental health and the neurodivergent and the chronic illness to disability, that's a big scope to help build the allies that we need to create the change that we see. A lot of people are talking about mental health, okay? You're talking about it, but let's add the disability component and where it's not like what is done, is we're feeling sorry. No, it's a celebration.

Kennedy:
Yeah, absolutely. I think the language and self-identification can get blurry, but cross-disability communities, I always find to be stronger and larger than these siloed groups doing work. No shade to them, but just I think there's a lot of power in the cross-disability work.

Fya:
Yeah. I think that's important just to know that. I know my housing situation and when I was going back and forth with the property manager and it seems like the property manager told me there are a lot of wonderful people with disabilities living in the building. Okay. You think all people with disability wants and needs is the same. No, we are different. We are human and we are individuals, as well as a collective. Our wants and needs needs to be adjusted according to who the person is.

Kennedy:
Totally.

Justin:
Totally, and appreciate your thoughts on that. I think it's something that, it's very important for us to discuss in the larger landscape of within the community. Before we go, is there anything else you would want to add for our listeners?

Fya:
Well, the one thing, is I want to tell people, even though life has been turned upside-down since the pandemic and it feels like things are falling apart right now, but this is the perfect time for us to speak up and make a change and make our mark in creating a new society that includes all people. I feel, right now, we are seeing the American society crumbling. Something new needs to rise from the ashes. A lot of voices before the pandemic wasn't heard, no matter if you want to be a part of LGBTQ community, a person with disability, a woman or a person of color. This is our chance to tell our story and take ownership of our narrative, especially with social media and digital technology.

Kennedy:
Yeah. Absolutely. I think a lot of people were pushed toward creative work, reflecting their experience in this time. I know I was. I do think there's ... Nothing fixed, but I do think people are paying attention in a way that they weren't before. I hope that that continues. To what you said about the cross-disability stuff, I think people think of allies or accomplices as someone who's non-disabled or outside the community, but we have so much to learn from each other and to build with each other. Thank you for bringing all of that to the pod. Before we go, where can people find you or hire you?

Fya:
Before that, I wanted to add another thing, what the pandemic have brought out.

Kennedy:
Yeah.

Justin:
Yes.

Fya:
A lot of time, when people with disability was asking for work accommodation, work from home, and employers said, "That's not feasible. We can't do that," but because since the pandemic, people are doing that and willing to see. It's just crazy. The whole had to come to a pause for others to see how important accommodations are, how important it is to include people with disabilities.

Justin:

Mm-hmm.

Kennedy:
Totally. Yeah, and all these things that, quote/unquote, "weren't possible before," are all of a sudden possible when everyone needs them, right?

Justin:
Right.

Kennedy:
Yeah. I hope we're going to have an episode about work soon and some of these other issues that have been coming up will hopefully become episodes. We didn't want the news to overshadow all you're doing. I think, yeah, the way you're holding all of that and bringing and having grace with yourself is a perfect message for the listeners right now. Yeah, thank you. Yeah, anything you want to share about how people can follow you and get involved or register for the events?

Fya:
Yeah. Okay. I do have ... People can email at blaqgurlfya@gmail.com. Black girl Fya is spelled the ebonics way, because just being Black ... A lot of people like to say it's ghetto and say ghetto is a bad thing, but ghetto is creativity. It's culture. It's fabulous. I take ownership of that, as just being a displaced member of the African diaspora. Black is spelled B-L-A-Q, girl is spelled G-U-R-L, and Fya is spelled F-Y-A, then it's at gmail.com. You can also follow me at, still the same ebonics way, at Blaq Gurlz, with a Z, on Instagram. The rest of my other platforms, I'm BlaqGurlFya.

Kennedy:
Awesome. All the event registration info, it's on those platforms?

Fya:
Well, they can go to my Facebook or my Instagram. I have the link to the registration in my bio.

Kennedy:
Okay.

Fya:
They can download the social app on Google Play or the Apple Store. It's free. Search for Welcome to Our Healing Sanctuary Event and you can download the app that way and register for the event that way, too.

Kennedy:
Amazing. I think this will air after the first event, but definitely check out the next two. Justin, do you have info on the Disability Pride Parade?

Justin:
Oh, yeah.

Kennedy:
How do people get involved with that?

Justin:
I've been working with them for the past two months and it's now over at crunch time with it. The Disability Pride Parade is actually coming back or going to be outdoors once again. After being all the hiatus due to the pandemic and due to other circumstances, we are back outside for the Disability Pride Parade. This is the 19th Annual Disability Pride Parade. It is the longest-running disability pride parade in the country. I always have to say that, because yes, it is a fact.

Kennedy:
Wow, I didn't know that.

Justin:
Yeah. It is the longest-running disability pride parade in the country. We are excited for people to come out to the parade. The Disability Pride Parade will be happening on Saturday, July 23rd. If you know folks who want to be a part of it, who want to experience what the Disability Pride Parade is all about, let me tell you that the president's been attending for almost a decade now. Jeez, I'm old. It's just a fun celebration, just folks coming out there, celebrating they disability pride, showcasing what they doing, and just overall having a good time. That's all we really want for this parade, is folks coming out there, seeing disability pride, and just enjoying themselves. If you go to our website, which is www.disabilityprideparade.org, registration and sponsorship is still available for the parade. We encourage folks who want to be a part of it, who want to march in it, to sign up and register. There's also information about Fya's Healing Sanctuary on there, as well. If you all are interested in checking that out, I highly recommend you check it out. Also, check out Fya's stuff. For me, it's the shit. She's awesome. I'm like, "Listen, you all go check this out." Anyway, the parade is on the 23rd. Registration and sponsorships is still up. Come on down and just celebrate with us, man.

Kennedy:
Yeah. July 23rd, right?

Justin:
Yes, July 23rd.

Kennedy:
Fya, you'll be there?

Fya:
Yes.

Kennedy:
Yes, okay.

Fya:
Definitely. Yes, because it's my goal to collaborate with Justin. Even I'm featuring him on the app, because I feel like collaboration is so much needed within the disability community. I thank you, Kennedy, for posting my stuff.

Kennedy:
Absolutely.

Fya:
Yeah. I took the video that you created and I used TikTok and I put a sound to it. I've been using that, posting that around. I appreciate that. I appreciate you reaching out to me after that incident happened with LCA. I just think that collaboration and unity is the most important thing that we need to learn as we pushing what disability, our life and culture is.

Kennedy:
Absolutely, yeah. Look out for Fya. Crip Crap will be at the pride parade. If you're not in Chicago, find out if there's a disability pride parade in your city or near you.

Justin:
Yes.

Kennedy:
Yeah. Fya, thank you so much for being here. Definitely want to keep collaborating. We'll keep posting your stuff, so you can watch our page to see Fya's events and get following her.

Justin:
Yes.

Kennedy:
Anything else?

Justin:
Actually, I think, no, that's pretty much it. Yes, that is Episode 6 of the Crip Crap Podcast. God, I can't believe we're still doing this.

Kennedy:
That's a half a year of episodes.

Justin:
Jeez.

Kennedy:
Yeah.

Justin:
It's good. Thank you all so much for being a part of this podcast. Just be kind and gentle to yourselves during this chaotic times. Hey, we love you all. We want to make sure that you all all right. Please take care of yourselves. We will talk to you again soon.

Kennedy:
Yes. Take care, everyone. If you don't mind sharing our episode, we would love to spread the word a little more. Have a great day and thanks for listening.

Fya:
Yeah. Peace out, beautiful people.

Justin:
Yes.

Christea: (in song)
Rolling down a shady street
Or walking arm in arm
Stumbling on my shaky feet
But no cause for alarm
Stop a while to take my meds
Traveling real slow
That’s just some crip crap, don’t you know

Read my lips or watch my hands
Or have me write it out
Listen to my speaker talk
Clear but not too loud
Let me say it how I can
Direct you where to go
That’s just some crip crap, don't you know

Episode #7: Preserving Disabled Stories as a Sacred Task with Whitney Hill

Episode Description: Whitney Hill, Founder and Director of SPORK! (https://www.sporkability.org/home), joins Justin and Kennedy to discuss founding her organization, documenting disability experiences, and upcoming workshop opportunities.

Christea: (in song)
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Justin:
Hello everybody and welcome to the Crip Crap Podcast, episode seven. Oh my goodness. It's been a long time since we've recorded and we are here. Hello Kennedy, how are you doing?

Kennedy:
I'm good. How are you, Justin?

Justin:
It's been up and down couple of months, but we are here. We are back for you. And we have a very special guest joining us. She is the Founder and Director of SPORK! and also the Accessibility Specialist at LCM Architects. Hello to Whitney Hill. Good. Hello Whitney. How are you?

Whitney:
Hey. Hi. Thank you so much for having me today, Justin and Kennedy. Thank you so much.

Justin:
How are you doing today?

Whitney:
I'm doing good, I'm doing good. I have to admit, the past few weeks have been all work and no play, but I'm enjoying what I'm working on so I can't complain too much.

Kennedy:
That's awesome. Yeah, I feel like everyone's trying to soak up the end of summer, so that would be hard to be working a lot. But yeah, thank you for being on and if you could just describe yourself a little bit for listeners who aren't familiar with you.

Whitney:

Yeah, so again, thank you so much for having me here. My name is Whitney Hill. I am an African American woman originally from Dallas, Texas and have been living here in Chicago, Illinois for about the past, what, 12, 13 years. And I, myself identify as having a small series of disabilities right now in my life. They predominantly align with mental and cognitive health and so far just about every second of my career has been all about the bigger disabled community. So that's a little snapshot about me and who I am.

Justin:
Awesome. Awesome. So what else should our listeners know about you, Whitney?

Whitney:
Oh my gosh. Well, if you will allow for a mini rant, I can give you a short little bio of what I've been up to recently. Outside of being the founder and director of SPORK!, which is a wonderful Chicago based nonprofit for people of disabilities that really kind of gives a sounding board for people who want to write and share about their experiences of having disability or being within the community. Outside of that, as was mentioned, I'm an accessibility specialist at LCM Architects. I help enforce Title II and III of the ADA, the American Disabilities Act.
And then in my spare time I am on quite a number of different boards and committees. The newest one that I've recently joined, been appointed to is equipped for qualities protection advocacy for individuals of Mental Illness council. I'm also a board member of Three Arts. I'm appointed member of Blind Services Planning Council. I am a 2020 fellow and a current member of disability lead. And then on top of that I also serve on the ADA advisory committee. Then to kind of round everything off, I'm also on the CTA's ADA advisory committee as well as the chair of CTA's ADA way finding subcommittee. So I have a lot of passions, a lot of things I'm doing within the disabled community and just loving every minute of it.

Kennedy:
Whitney, we're going to need you to take a nap that. That was... I mean, we have no room to speak, but that is hefty. I feel like boards do more than people realize.

Justin:
Right. Yeah, I thought I was busy.

Kennedy:
That's awesome though.

Whitney:
Thank you so much. When you're working and it feels like fun and it doesn't a hundred percent feel like work. So I've just been getting in that thought process.

Justin:
Right.

Kennedy:

Totally. Yeah. Well that's a perfect segue to our next question. If you can tell us a little more about your work and how you got started doing it.

Whitney:
Yeah, so as I mentioned, I was born and raised in Dallas, Texas and that really is kind of where my story really starts. Growing up in the South, all my disabilities were a lot more apparent when I was younger. I had a lot more apparent, obvious physical disabilities, had communication issues, had a lot of speech impediments, a lot of speech therapy, physical therapy. So going through just all those different systems while growing up and public schooling in Texas was incredibly fascinating and incredibly difficult. And it's really that experience of being around just different layers of support and the really kind of shaped everything when I got here into Chicago. When I came here, I came here for school, I went to school, the Institution of Chicago. The background of product design and at when I first attended, I had not been, at that point, formally diagnosed with my mental health disabilities.
And so it was just this really interesting kind of crux of knowing that maybe something's a little bit different, not really understanding why you're feeling the way that you're feeling. Going through school and then trying to also piece together some sort of career path that felt sincere and kind of in line before what I was looking for. And so anyway, when I was in the tail end of college, I was in a class where we were given an assignment to come up with a bigger type of project or pseudo organization, et cetera, that could be geared towards any type of community. I was paired up with this wonderful, wonderful person. She's still really active within the disabled community, Willa Crowes. And that's when we kind of put our heads together for SPORK!.
And so after I graduated college, I started to turn that into a nonprofit. And to be honest, it really helped me piece together my own journey with my own disability. That's the whole point of SPORK!. But it was just super cathartic because it really helped me with my experience. And then later when I finally got those firm diagnoses, it kind of pushed me into just a different way of thinking in general of what is my lived experience, what does it actually look like, how does that compare or relate to others, and how can I make others feel comfortable with sharing their lived experience with me? And kind of a wordy roundabout that, that's kind of how I got brought from Dallas to here Chicago and then to the whole nonprofit sector. Chicago is an amazing place. I feel like if you have a disability, if you're trying to figure out what your diagnosis is, if you're trying to find a space or support group, Chicago blows me away every single time. It's just a fantastic city that welcomes that type of journey and growth

Kennedy:
That is so relatable. Yeah, I feel like... I grew up in Nebraska and just coming here I feel like there was a moment where I was wanting to do social justice [inaudible 00:10:16], but resisting the disability, totally owning the identity and then the Chicago disability community just scooped me up and never went back. So yeah, that's awesome.

Justin:
Yeah, once you're a part of the group it's like, "Yes, you're a part of it," and you're just enthralled in all the things and just a part of all the different groups. So yeah, it's just being here and being

actively doing disability advocacy and activism and even disability art. This is definitely the place to be.

Whitney:
And so I do just want to also just kind of throw into that when I talk about my disability, it is because of my connection since moving to Chicago that I've been able to, I think just feel personally more comfortable with talking about what that looks like. But I was diagnosed with major depressive disorder, generalized anxiety disorder, and as well as PTSD when I was in my mid twenties. And I think the only thing that I just want to stress and just put out there for my own personal experiences, it's when you're dealing with anything mental health and it feels like you don't necessarily have the support at the time, it's really easy to take on and assume all of those side effects of that disability and assume that that's your personality.
So it's very easy, for instance, if you're dealing with depression, to just put that label of depression as who you are because if you've been dealing that your whole entire life, if no one told you otherwise that you're just actually dealing with some hardcore depression and that's not who you are born and raised as a person, et cetera, it makes a big difference. And I do definitely hold that close to heart and I always want to encourage other people as well, other Black women, other just Black folk in general because it's so topical within our community. If you feel like you need help, it's always worth it to try and seek that help. If it's therapy, a diagnosis, if it's going to a different doctor, whatever that self-care, deeper level of self-care, however that looks like for you, it's always important to invest in your own care in that way.
Because I can a hundred percent say that I would not be here today if I didn't force myself to invest in my own health in that way. And again, in our community, don't really talk about it. If it gets brought up, stuff gets mislabel, lost stigmas, just surround stuff and then that it pushes people away from trying to seek with that bigger help. So anyway, that's all I kind of have to say about that.

Justin:
And so Whitney, can you share more about SPORK! and by the projects you are currently working on?

Whitney:
Yeah, so as I mentioned, SPORK! got started in 2013 when I was still in college. And until now, it still functions largely as online platform for people to write in about their experience. So their lived experience of living with a disability, being a care giver. And so SPORK! is incredibly, incredibly excited because we recently partnered with this wonderful organization here in Chicago called Second Story. Second Story is one of Chicago's oldest story storytelling organizations. And before we partnered up, I actually had the chance to go through one of their full day workshops and I'm just incredibly excited about this experience.
The one quick thing I want to say about Second Story is that outside of they're just providing this bigger platform to develop a storytelling idea and concept, how they present the classes is just so incredibly comfortable and wholesome. You kind of come into the class not expecting really... You don't really come in with a whole list of bullet points of what you think they're going to push you to do. They come up with these very organic and collaborative storytelling concepts and

pitches when you're in group that really gets your mind kind of thinking in the creative way. But yeah, I do apologize, I'm not sure that in articulately explains how answers your question.

Kennedy:
No, that's great. So the SPORK! and Second Story are going to work together to put on a program for... What will that look like and who should get involved in how?

Whitney:
Yeah, so October, in October 14th, which is a Friday and October 15th, which is Saturday, we're putting together two workshops. The October 14th workshop is for creatives with disabilities. So rather you're an artist, you're a writer, musician, dancer, whatever that creative outlook looks for you. This is a really perfect workshop because it really focuses on how to hone in and take an idea or a concept and how to expand that and stretch that in a environment that's incredibly comfortable. And so that whole entire workshop, which is from 12 to two on Friday, very free form.
And then on Saturday, October 15th, that workshop is geared a bit more towards caregivers. We really want to really open up a space for both audiences because as we know, those who are in our lives and help support us, if we do have disability, their story is also unique to their experience. And it's I think incredibly important, especially if we're looking at honoring and really holding up the entire community, disabled community. I think it's incredibly important to look at all aspects of who makes up that community. And so that's one reason and really the big reason why we're also doing that workshop for caregivers. So if you are someone creative who has a disability, identifies as having a disability or if you are caregiver, we'll be more than happy to have you at our sessions.

Kennedy:
That's awesome. Can I ask too, so the workshops, will folks make their own work and then will it be theater based because you're with Second Story or what kind of form?

Whitney:
So there's no expectation of coming out with a final piece that is set to be performative or anything like that. If you're already working through a writing idea or if you're in the middle of a creative block and you're finding it hard to get into painting again, et cetera. This is just really, that is where in that creative process where this workshop will be kind of perfect for you. So if you're really looking to expand on ideas you already have, if you're trying to break out of any writing blocks, et cetera, that you might be experiencing or if you're just trying to attack this idea of how can I be creative and approach that in a different way, that's what these workshops are all about.

Kennedy:
Awesome. Yeah. And what about for folks who would consider themselves beginners? Should they sign up or is it more like a intermediate thing?

Whitney:

A hundred percent beginners are welcome, if you're advance, everything, everybody all ages, all demographics, all disability types are a hundred percent welcome. And the great thing is since this is going to be virtual, these are going to be hosted through Zoom, it really just opens up that net a little bit more of how we want people to get involved. And so it really is open to everyone who is interested. There is limited space. So please, if you want to sign up, if you have any questions about it, please email me directly at whitney@sporkability.org and I'll be more than happy to sign you up and to get you started.

Kennedy:
Awesome.

Justin:
Yeah, that's really awesome. And it's really cool that you guys are partnering, that you would be [inaudible 00:20:19] and putting this to together because I think it's really very important, especially for our community and involving those who are part of our community and those who are part of the caregivers and having them be active, being involved in this as well. So I think this is really cool.

Whitney:
Thank you. And it just means so much. As you guys probably know, having that outlet, that creative outlet, you don't need to be perfect at what that creative outlet is, but just having a creative outlet means everything because life gets hard, day to day can be difficult. And just having something there that can absorb some of that energy, it just means so much. My entire existence has been, especially when I was younger, was all about the arts when I was going through school and everyone make fun of me and no one could understand me. It was oil pastel and paper, that's how I communicated. That's for me is what set me up for what I feel like success down the line is just having that outlet. So I'm all about the arts, I'm all into endeavors like this that give back to community and in a way.

Justin:
Yes, that's so awesome and just being a part of that and this is really cool. And so all of the questions I wanted to want to ask, and I think you mentioned a bit about through emailing with us and talking to us about wanting to build an archive of digital media and that is something as a filmmaker and as now a photographer and an artist myself, what drew you to that and what feels so important about documentation, especially during these times?

Whitney:
Great question. So for me personally, I'm someone that it connects really strongly with not only a story, but I feel like it's really what goes beyond that story. It's the emotion, that feeling, that understanding all of those layers that come out of understanding and trying to understand someone else's experience, that for me is absolutely everything. And I feel like we definitely live in this world where it's really easy to feel like we are alone, that our story might be insignificant or maybe that... I feel like it's so standard to compare our experience with someone else and to judge and base our accomplishments based on others. And so the thing that I just love about

this archiving and the SPORK! that I got to do is it takes away some of those performative layers is what I feel like. It's not really about trying to impress anybody else, it's not about any of that.

It's really about speaking your truth, living in the moment, saying "This is what I felt," "This is after I came out of a surgery," or, "When I got diagnosed," or, "After I had an accident." And it's just being really truthful about what that looks like. But also, a lot of people that ride into sport are either undiagnosed or newly diagnosed. So they're grappling with this really tender point in their life and just being able to hold that and be able to help share that experience for them and to really take it in my mind to a sacred place means so much. Unfortunately, some of our past contributors, our past writers, unfortunately a number of them have passed because of their disability.

Unfortunately, we have had a number of people who they were writing about their experience of chronic illness as they were going through it and just the fact that they're no longer here but we get to hold their store and their experience makes me incredibly emotional every time I think about it. Because I can't think of anything more sacred, I'm just going to use that word again. And I think that that's the point. Even though we do live in this world that's complicated and layered and there's just always so much going on, it's just so important to keep in mind that what we're going through, our experience that is unique to us. And there is a lot that can be learned from that experience when we share it with others. And I think that, in my mind, there's nothing more important than that.

Kennedy:
That's amazing. Yeah, I feel like when we were first talking and discussing how there's just so few spaces that collect information about disability or disability culture and I definitely felt... Similarly starting Crip Crap like that disabled people needed a mirror, especially during the pandemic. Yeah, that's so funny. We were like, "Oh we are on this same [inaudible 00:26:25]." But I do want to ask too, how did you come up with the name SPORK!?

Whitney:
Yeah, so in college when at the time the other partner of SPORK! and when we were going around with names, we came up with SPORK! because as you guys know, a fork, it's neither a spoon or a fork, it's like that perfect utensil that's in between, it can do everything. And I kind of felt that if you have a disability, that's just kind of how you are in the community. Neither neither here nor there, you're kind of everywhere, you know what I mean? Disability is a lived experience, it is a fact of life. It is about being adaptive, it's being forced to be adaptive. And when I think of the greatest survivalists that exists, I think of the disabled community because we make things happen when people tell us it's not going to happen. And so to me that is a SPORK! that is this utensil that can do everything and anything in between and then [inaudible 00:27:45] still looks cute while doing it. So that's our community.

Kennedy:
Totally. That's what I thought.

Justin:

SPORK!'s rule. Yeah.

Whitney:
Yeah, right?

Kennedy:
Yeah, just wanted to confirm. Yeah, so versatile. I would say that, whenever people are talking about the strength of disability, versatility is definitely in there. So we talked about the workshops coming up. If folks maybe aren't as interested in writing but more interested in consuming things, what's your site broken down like? What should people check out? What's coming up?

Whitney:
So we at SPORK! have been incredibly [inaudible 00:28:34] because we've had amazing group of professional voice narrators. And so they literally are from all over the world and they volunteer with us and they just do amazing job with every article that is submitted, that's written and post it on our website.
Under our archive section of our library, you can go and listen to professional audio recordings of those pieces. And that was really important to us. That came out... Actually, I think that that started in 2020 when we started to roll that out. And that was really important to us because it's one thing to be able to fall into the written word and to fall into that experience, but if you're not able to, we want to make sure that you're still able to. To still get a feel for the writer and get a feel for the tone of the piece as a whole. So that's really important to us. So I would say if you're interested in consuming our work, in our archive, we have the written work and then we have attached to each article the audio where you can download and consume it through an mp3.

Justin:
Awesome, awesome. That's amazing and cool. And yeah, we will definitely promote that on our end so that our listeners could be a part of it as well. So is there anything else you want to add, Whitney?

Whitney:
Oh boy. Well, so this might seem so random, but this has been coming to mind so much for different reasons, but I feel like all of us here have had a different close experience with Disability Lead in some way or the other. And I love talking them up, I love talking. I know that they're doing some recruiting right now for their next class, I think 2023 and through Disability Lead I joined back in 2020 outside of the amazing networking of being a part of my cohort and meeting other go getters within the disabled community.
It has been a true pleasure getting to really be able to network with other organizations within the community. And a lot of that has been through disability leads. So quick little shout out to them. And what we're doing right now with Disability Lead is doing what Kirk Prep is doing, all of it is just so pertinent and relevant to the movement of our community. And so stuff like this makes me incredibly happy. So I'm not sure if it's so much of the question as much as just giving a high five to a bunch of people, but...

Kennedy:
Yeah.

Justin:
Yeah. Perfect. Yes, we should make that a segment. Just giving high fives.

Kennedy:
High five segment. That's how Whitney and I met. Did you all meet through disability?

Justin:
I actually met Whitney through an email. A friend of mine, Rebecca Torres, actually connected us via email and we actually did something from the MCA a few months ago and that's how I actually met Whitney. So I met Whitney through that and yeah, it is just so cool learning more about you, Whitney, and learning about SPORK! and work that you do as an artist and actually just really just so cool with everything that you're doing and your journey to where you are at today.

Whitney:
Thank you.

Kennedy:
And I just pulled it up. So Disability Lead for folks in Chicago is like a professional network for people with disabilities from all different fields and they are taking applications for their next class of fellows for 2023 until October 14th. That's also the day of the workshop. So everybody get registered for everything and then we can all hang out. Yeah.

Whitney:
Yeah. October can be a fun month for us all.

Kennedy:
Totally. So Whitney, where can folks find you or follow you or et cetera?

Whitney:
Yeah, so if you want to know more about SPORK! And about these wonderful workshops that we're doing in October, you can visit www.sporkability.org. My contact information is also on there if anyone wants to reach out to me directly. You can also follow me and SPORK! on Facebook, Twitter, and Instagram. All the fun, lovely social medias. At SPORK!, we're always looking to network, to connect with people in the community so we love getting to meet people. So please reach out if you're interested.

Kennedy:
Awesome.

Justin:

Awesome, Awesome. Anything else you might want to add, Kennedy, before we end?

Kennedy:
No, thank you Whitney for coming on and the work you're doing for letting everyone know how they can get involved and yeah, we're excited to keep partnering.

Whitney:
Yeah, thank you guys so much. And by the way, giving another, I guess like high five out, but another high five to you guys. I think I've definitely said this to Kennedy but I'm just going to say it again. You all's graphics and branding gives me life. I love it. I love it. I love it. I'm actually... And I'm going back and forth with the person who put together you all's website, everything to help with a little bit of rebranding on SPORK!'s side. So I just want to say what you all are doing is big hearts. I high fives everywhere. It's giving me life.

Kennedy:
Thank you. Yeah, we have to shout out Bree from us episode three.

Justin:
Yes.

Kennedy:
The one on mental health who did all of that. And we've said it before, I will say it again, accessible can be cute.

Justin:
Yes.

Whitney:
Yes.

Kennedy:
And yeah, if folks need resources on creating accessible branding or web stuff, definitely reach out as well.

Justin:
And beyond the lookout because we're going to be working on merch. We're working on merch, is that right?

Kennedy:
Justin's making promises pretty early here.

Justin:
We're getting there. Got to get the word out. People know about Crip Crap. So Whitney, thank you so much for being a part of this episode with us. We greatly appreciate it.

Whitney:
Thank you so much. Thanks so much. And I saw a taste of some of the merch that you guys had at the disability pride parade, so I like, "I'm waiting for that too." I want a hat. I want a shirt.

Kennedy:
I was going to say we're out of pins, my [inaudible 00:36:20] have finally calmed down, but the pins from the discipline pride parade are gone. But yes, we will definitely a goal someday to have lots of merch, but hopefully more pins soon. And yeah, stay tuned for all the things when you...

Justin:
All the things Crip Crap.

Kennedy:
Yes. Thank you so much. Maybe we can do a merch collab someday.

Whitney:
Oh my gosh. Talk about give me life, that would take my whole year.

Justin:
There we go. There we go. And that everybody is episode seven of the Crip Crap Podcast, Kennedy. We keep doing these things.

Kennedy:
We did it. Yes.

Justin:
Doing it again. So we're so glad. Thank you so much for listening. Also, where can people find us before we leave?

Kennedy:
Yes, we are on Instagram at crip.crap.media and we're going to be cross sharing some stuff with SPORK! and then we are on the general web at cricrapmedia.com. Yeah, thank you to all of our listeners and everyone goes sign up for Whitney's workshops, [inaudible 00:37:39] Second Story.

Justin:
Yup. And we will see you all on the next episode. So take care and have a good day.

[Instrumentals]