

## **Episode 2, The Present**

**Artists: Emily Cook, Danielle Hyde, Carmen Papalia**

**Interviewer: Mary Anderson**

**Music: Eli Howey**

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[00:00:00] This episode explores the current realities in daily practices of access, creation and support, highlighting perspectives and experiences from artists Emily Cook, Danielle Hyde and Carmen Papalia. These conversations discuss what it looks like to feel at home in creative spaces right now, and what conditions make that possible.

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### **Emily Cook**

**Mary Anderson**

Hi, my name is Emily Cook. I am an artist currently based in Toronto. [00:01:00] I also have low vision. My main medium is papermaking and sculpture, but I've got a background in printmaking and book binding. And I've been involved in the sort of disability arts world for I'd say about seven years.

How many years have you been an artist?

20ish years?

Did you go to school for a specific trade?

Yeah, I went to art school and focused on printmaking, both in undergraduate and graduate. So I went to undergraduate at OCAD and then graduate school in the US at Louisiana State University.

Amazing. Okay. Can you paint a picture of your creative practice, in terms of Paperhouse Studio, or maybe just speak about Paperhouse Studio, in general?

[00:02:00] Sure. Paperhouse Studio is a kind of collective studio. It was started by me and Flora Shum, and at the moment it works in kind of like a membership model.

We've got a few, sort of permanent anchor members, and then we've got people who come in and out who receive papermaking training and then come back to make paper. So we run intro classes and then also do professional development for artists and then they come and train and learn a new medium.

In the sort of spirit of the printmaking studio – because there is a lot of equipment involved – we wanted to create a shared space where people could come and use professional equipment. And so that's what Paperhouse is. It's set up to do interesting experimental papermaking [00:03:00] and that is a kind of cornerstone of both of our practices, although we've got other elements, as well. We're both trained printmakers so there are some printmaking and book binding elements to both of our practices.

Very cool. So obviously creative space has been of particular value to both you as an artist, but also in Paperhouse Studio's success too. Can you speak to the history of how you started out in a particular space and ended up in Artscape Youngplace?

Yeah, we actually sort of started when the call for Artscape Youngplace happened. So I was teaching at OCAD and at the time they still had papermaking in the printmaking department, and they don't anymore, but, I was fresh out of grad school, had just moved [00:04:00] back to the city, and other than the school, there wasn't really anywhere to sort of continue experimenting and you know, there was limited access to the school. It was just for students and faculty.

So we wanted a space where once some of the students I was working with had graduated, would have somewhere to continue the kind of experimenting they'd started. I was pretty lucky – in my second year of teaching, I got to teach this third year class called From Paper to Book, which was a year long really experimental class where they kind of did every aspect of book binding and were creating these kinds of book arts projects. And from that I met some [00:05:00] folks who were really enthusiastic about it, and so it started as a larger group, but it kind of ended up being me and Flora who really had nothing else like the stubbornness to keep going.

It took three years from the call to when the building opened. And in that time we had like a couple of makeshift spaces. I was sharing some space with Clay and Paper Studio, and I was accumulating some equipment. So I had a beater, I had, you know, there's other things, and then we started to outgrow that space. And we were in the back of what was an old, like car repair thing, which we chose 'cause it had drains on the floor. But it was also like [00:06:00] pretty makeshift. It was backed onto a train track and we didn't have consistent access to a bathroom.

We had to go and use either the Portuguese bakery or beg the mechanics next door. We did some interesting stuff out of that space, but it was pretty makeshift and not accessible. And yeah, I mean, it was a fun space to be, especially in the early days.

And there was a lot of folks to kind of collaborate with. We collaborated with some dancers and then other organizations for school groups and stuff. I guess that's the history of making that space. It was one of those things where I don't know if we would've done it, if we knew how much work it was gonna be, but we've built something really special and [00:07:00] I think really welcoming.

The building is accessible, our workshops are – in a kind of jury rigged kind of access, we always work with folks and then whenever we've done like workshops and had extra funding, there are other kinds of access we can put in. Equipment wise, 'cause we're dealing with some old equipment, there are some physical access barriers to some of the equipment. So it's definitely not perfect, but we are in the kind of conversational kind of access where we will just find a way.

Conversational access – those words together – that's been the theme throughout a lot of these interviews. And obviously the value of community and having those open fluid [00:08:00] conversations about access needs. Can you maybe give some examples of how you practice that within Paperhouse? Do you have those conversations before a workshop takes place, for example? Or do you find that you learn while making?

I mean it depends on the situation. We've done some youth stuff that tended to be grant-based, where we were able to put some things in place ahead of time. As an example, we had someone we were working with who was one of our youth assistants that we were writing into a grant.

And so for that one we were able to put in place things that they needed to kind of get through the day. Like we had a [00:09:00] blowup mattress that was there if they needed to rest – those kinds of things. We would build in food as a part of access. We would build in active listeners and that kind of thing.

So sometimes we could prepare ahead of time. But also if someone wants to do something and we're not totally correctly set up, we will have a conversation and try and find a way. And then, you know, I've recently been – because it's my community – been working with other blind folks and finding ways of making papermaking more accessible. Like it's a really physical, tactile medium, which is part of the reason I'm drawn to it.

So I've been working with a [00:10:00] really wonderful friend, Melanie Marsden, who's a blind Indigenous woman who I've worked with as a consultant in other circumstances. And we're doing an art project together. So we're just sort of figuring it out together, in terms of what are some tactile, anchor points and ways of giving her points in space so that she knows where she is and what she's doing.

We'll figure it out, I guess is sort of the thing? A lot of these things haven't been...there's not a prescribed way of doing them in an accessible way, and everyone's needs are different. So I think it's always a conversation. [00:11:00]

Thank you for explaining all that. You guys obviously go above and beyond really to make sure folks feel welcomed and like they can participate in that space as much as they can.

I actually think we don't go above and beyond. I think that just like a lot of spaces don't meet what I would consider kind of a minimum of welcomeness. Like, 2025 is supposed to be the deadline for Ontarians with disabilities.

And there's a lot of work to do and I think that, you know, a quarter of our population has some kind of disability and the [00:12:00] fact that that's not like a standard as a kind of point of thinking, that that's not always there for organizations, is to me, kind of just absurd.

Like, why would you want to be excluding people? Your whole purpose of being is to serve various publics. So not having those conversations is like excluding a huge amount of a population and that's not interesting to me.

Do you recall the first space that you started to see these practices play out, as an artist in the past? If you think back, was it in university? Was it when you were out of school?

[00:13:00] I got to go to Blind Camp when I was a kid, so that was probably the first space. Someone I'm working with now is Kim Kilpatrick and she was leading a day camp for blind kids when I was little and that was probably the first space where I didn't feel like othered, I guess - where it wasn't like you're gonna get pulled out of class to meet with an itinerant teacher. And it was like, okay, we're all going tandem bike riding and everything that we do is going to be in a way that is made easier for you.

Yeah, I kind of had a lot of access to play. So I was pretty lucky in the way that my life created access, but I also, because of the way that school kind of was about you [00:14:00] adapting to the environment, I think there was a real kind of opening up when I was introduced to kind of the concept of like disability arts and places like Tangled.

And it kind of opened up this whole part of me where I had been adapting to, and this was a place that was adapted for me. I can't actually remember what the first thing was that I - where I started hearing about experimental description.

But I think I started getting involved with Tangled and hearing about the things that they were doing and realizing that there was like all of this potential for ways to kind of open up this world even more. And [00:15:00] it's a world that's been really wonderful for me.

There was a conference that I went to and because there was another blind person at the conference, they had live description available. And I didn't even know that that was like a possibility, and I didn't know what I had been missing. So suddenly I had this person in my ear who every time someone stood up to talk was saying this is who's talking. And so I now had like a voice and a name that were like attached. And in my entire life, all of those things had been just sort of like disembodied voices and I wouldn't know if I ran into them later.

And because I could never read the name tags. It's just little things like that where I was just like, oh, I don't even know what's [00:16:00] possible. And so that kind of expansive imaginary space of knowing that people had been doing like a bunch of work and there were things that I didn't even know could make my life better.

And just being around disability community who were like having those conversations and then realizing that I could do that same thing for other people. Like maybe create something where it was like, oh, this is like a whole thing I didn't even know could be a part of my life. And could open up some things.

So it was really like little pieces that built towards kind of realizing. And then I got, you know, the opportunity, when we were building some new things, to meet a lot of Deaf folks and have interpretation and kind of be in community and see what the Deaf community had done, in terms of advocating for themselves, and kind of [00:17:00] realizing that there hadn't really been that kind of coalescence around the blind community and learning a lot from how different communities had advocated for different types of access was pretty awesome.

[What do you think is currently working right now within accessible creative spaces? Those that are labeled as such, which aren't a lot here in the city.](#)

There's not a lot. So I think what's being done right at places like Tangled is that there is a place where you know you're not gonna have to do the work of like, introducing these ideas and like doing that labor, and where the artists feel really supported. I've talked to a number of artists who, you know, have worked with other organizations and then worked with Tangled and like the difference between being able to do your work there is that you're starting from such a supportive [00:18:00] place, right? You're not starting by justifying the need for access, period.

You're starting from what kind of access are we gonna do? What kind of standard accesses are we gonna do? What kind of social experiments are we gonna do? You don't have the exhausting process of justifying our existence, and the need for those kinds of supports. So, I think the more places are starting from that point, where you can come in as a disabled person or even a non-disabled person who just like is in community, and be starting from there so that we can build on it, kind of culturally and have more options.

'Cause like we're not a monolith and even within like the blind community, the kinds of description that we like, the kinds of tactile stuff that we like, [00:19:00] whether we want those interventions to be like personal one-on-one, or we would prefer that it was a recording, or like all of those kinds of things – it's more exciting to be starting from like, we're gonna have something and like, here are the different kinds of options that we could do. Let's figure out which one we're doing. Not like fighting to have anything.

[Can you share a few examples of what could enhance environments to better support disabled artists?](#)

I mean, I think that we need to get it to a point where this isn't considered an extra. And as a result, that in those same places that you would have like disability consultants on the film set while the film is being made so that you kind of are thinking through how you're gonna create [00:20:00] access as the thing is being made – that is a job that should be there, like all the time.

That artists have had enough exposure to what's possible, in terms of creating access for different disabled communities that it's in the back of their mind when they're creating work that like, oh, maybe I could do this and make it a bit sturdier or washable or whatever so that this piece could be a tactile piece. Or maybe I am going to make sure that some of my studio tests are available for touchings, even though this one is a bit too delicate, so that people have a better understanding of the materials – like all of those things are so much easier to build it in as the stuff is being [00:21:00] made and that you have disability consultants, both describers and Deaf interpreters and ASL interpreters in rehearsal means that maybe there's a way of smoothly building in a moment for the describer so that we don't have to pack in everything at the beginning, in terms of description.

And then like the blind audience are having to hold that in their head for the whole play, in terms of who everything is. And then the interpreters are trying to like jump in when there's a tiny gap. Like maybe there's a way of building in some breathing room in the script so that there are places for the interpreters to catch up, for the describers to catch up, [00:22:00] and kind of building in that sort of slowness into a lot of processes.

And I get again that like resources are a problem, but I think there are things we could be doing that are not resource intensive or that we are putting our resources into like other things that are, you know, just as resource intensive, and for some reason the priority has not been the disability community.

The more it becomes just a part of our daily life to be thinking about others and kind of having empathy for people with different experiences, the more it's just gonna be a part of the process of making. [00:23:00] In an ideal world, it's not even a struggle 'cause it's just part of it, right?

Like you're paying your dancers, you're paying your disability consultants – you're doing the things that you have to do to make that work and you're budgeting it into your early grants. And you know, all of these things just become a part of the making process.

The more that we don't have to use our energy to battle for anything at all, the more fun and interesting the access is going to be, the better integrated it's going to be. 'Cause at the moment, a lot of disability community is battling and advocating for just the bare minimum of access. And I think the more that different organizations can take away that burden from the community, in terms of battling [00:24:00] to exist in spaces, the more that the creativity and the joy and the innovation of this community can shine through.

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**Danielle Hyde**  
**Mary Anderson**

[So let's begin by introducing yourself please.](#)

Alright, so my name is Danielle Hyde. I'm an Indigenous [00:25:00] artist and persons with a disability. So I have CPTSD and obsessive compulsive disorder so that's a fun pair. And fatigue tends to come with that pretty chronically so that adds lots of challenge to that. So I create under Co-Creations Art, but I also am a longstanding member of an Indigenous artist collective, Red Urban Nation. So we do a lot to create and install murals, community gardens, and medicine gardens in and around the city of Toronto – so all across Treaty 13. And just really with this emphasis on, you know, bringing community together, co-developing space, really anchoring somewhere where community can come together and can sort of feel safe and still feel represented and see themselves in the art, in the [00:26:00] stories and the spaces, and sort of like build community connections around that.

And we do really like work a lot, in my practice, to sort of do that in a way that sort of acknowledges and honors many beings, human and beyond human – all working together. And so I've done a lot of work for Tangled Gallery, Doris McCarthy, Art Spin, I've done some with Street Art Toronto, as well.

So doing murals – EllisDon Smoke Architecture – doing work in the Centennial College building and being the co-chair of Tangled Art and Disability Gallery, and also on the board of directors for Charles Street Video. So really, I have a passion for working with community and seeing like these inclusive ecologies for communities [00:27:00] developed so that way we can build systems around care and relational frameworks – not just being in isolated bubbles, but really looking at how we can sort of be a driving force for bringing arts and artists together and bringing community wellness and care into sort of like all the work that we do and all of our relations.

So a lot of that ethical relationality is really, really important to a lot that I do. And it's kind of put me on some very interesting journeys, in terms of questions and things that I try and explore with people, with my work. So, yeah.

[How many years have you been an artist?](#)

So, okay, I laughed when I thought about this one 'cause you know, the cliché answer is, you know, all my life – I've always been an artist. And a lot of that is true, I think art's definitely been there for me and with me, pretty much walked with me in everything that I do. [00:28:00]

I also like to think about the ways that, you know, like in exploring my practice and how I've come to really see the land as our first art teacher. 'Cause it's really our first interaction with form and color and space and texture. So I think in a lot of ways, we all have this very early on, like artistic experiences and connections.

I feel like where I wanna anchor, where I was being more than just like an artist in the production sense, like the canon art kind of way – really finding some of the things that I really wanted to get in and talk about – was coming to see the land and seeing everything be co-creative and

co-authored – was around 2013, 2014 when I really started to challenge this idea of [00:29:00] artistic intent.

And look at the way, you know, it was so heavily connected to colonial ideals and these ideas of how art could be a vehicle for expansion and colonization and these power structures that all lead to serving, like having, you know, basic human needs and care being co-opted for empire.

And just looking at this, starting to ask these questions. How did art get to this point where we're really co-opted like this? And how can we, in our understanding of that, maybe turn the tables on that, with art, in conversation with art?

So like this really dialogical kind of approach – you know, so we can take that back and use that not to oppress, but to rebuild and revitalize communities, which are things that we've [00:30:00] been doing in coming together, around each other and knowledge, like well before capitalism, well before, you know, colonization happened.

These are things that we've always been doing and they persist under the conditions of capitalism. But how can we use art to really take back its fundamental generosity, in that its ability to work as a universal language to get back to these conversations that we really need to be having so that way we are reconnecting with each other and reconnecting to all of our relations and the spaces around us.

It's less of the performance of, or the production of the art that I see that makes it for me – coming to see myself as an artist has really been rooted in how we think about space and how we connect to each other and how sightlines, like the physical sightline of our [00:31:00] horizon or the sightline that we see and the storylines, you know, can allow our spatial intelligences to kind of flourish, right? How we can sort of see and imagine our connections to each other? And then maybe even the broader ecology in a more expansive way. As an artist, it's rendering a variety of spaces so that we can have new dimensions to the ways that we talk about things.

Because so much of your work is, quote unquote, public in public space, do you ever need access to a studio space, for example? Have you in the past? What do you think of that idea?

So I think that space is really, really important. I've never really had studio space, unfortunately. [00:32:00] Working with a disability, being on disability and things like that – everything is very very tight, and things are exhausted so easily that I've never had access to a studio space that I've also been sort of comfortable with. Being neurodivergent, having the obsessive compulsive disorder, which is something that you can't physically observe on my body, like when I'm fine in stasis.

It's definitely something that you can see when I'm performing the ways that my OCD expresses itself. So if I'm repetitively handwashing, right? You can physically see that and there are physical implications, because if I spend 45 minutes hunched over a sink, washing something til

my [00:33:00] back hurts and my knees lock, and then I'm, you know, 20 minutes to meet somebody 'cause I have to go or I'm late for a call or something like that – there's a physical issue there. But it's not really well understood and what that experience is.

There's a lack of language and understanding, so shared spaces, public spaces can be really difficult, right? Especially if you wanna come to and you wanna work. So it does end up kind of being a very much homebody situation, which is again, also super challenging. Because not all of the things I've made are tiny. I've made water fountains that I installed at Tangled. So you can imagine – you're talking about a sculpture and then making it into sectionals and trying to transport and things like that. [00:34:00]

The only time I ever got to enjoy something kind of like a studio space was when Tangled, which moved locations – their old location in 401 used to have a spot in the basement. And I had worked down there for I think like two and a half years until they moved.

It wasn't just me, there were other artists who had worked down there, but there was this whole thing where a table and all of this artwork got shipped back. And so it's kind of like, you know, hey mom and dad, can you get ready. They built a shed, not for me, no.

They built it to store things like lawnmowers that were outside. It's like three fourths the way full of art right now – one of which was attacked by a mouse, which is fine. It's this thing where I [00:35:00] wish 'cause I do operate at scale, and it would be nice to kind of have the space where you could go to, where you separate and just have things – come back to them how you left them, kind of a thing. So you're always like coming back to it. It's just an unfortunate thing – I think it's extra hard when you have a disability to make that work.

It can be a huge extra cost. It can have its own set of inconveniences, and like I said, OCD's not really well understood. If somebody says they're dealing with cancer diagnosis – even if somebody hasn't had a direct experience, there's kind of like enough there that there's an understanding.

But if I try and talk about the sort of things that are triggering for me in my OCD, it's, you know – eyes glaze over, [00:36:00] there's like confusion. Or if I raise something that is difficult for me to hear about or engage in, it's kind of like an awkward pause, awkward laugh. Like it's not really well understood. Or I get the response of, oh I have OCD too. Like, I make lists sometimes, right?

And it's not to the point where it is not that debilitating severity, right? It's not causing migraines, like it doesn't spread into other things that you do. And I think that having what's kind of identified as an invisible disability – it's great for the unique perspective that I can come to things on, but it makes other things like space vastly more challenging.

That's really [00:37:00] helpful, Danielle, to hear all of that and to actually take me through that because you're right, it's like a different layer and set of experiences on top of what other folks, who identify as disabled, already encounter. Because of the invisibility thing. And I think, like

you say, people throw that term out so easily and I think they feel like they can just, like you say, either relate or gloss over it. Thank you for sharing that. That's really valuable to hear that.

Would you say maybe the first time you came into contact with Tangled, is that where you kind of felt a sense of belonging? In a space where you could actually be yourself, where you can explore some of these ideas? Or was there a different space where you felt like you belonged initially? [00:38:00]

I'd say Tangled was definitely the closest, but I think even there, I find a developing language. Tangled really is one of the best, in my opinion, in terms of what a community hub can look like when it's grounded in ethics of care. It's amazing people – I just think it's a matter of where things are right now, you know, and the kind of conversations that need to be had. [00:39:00] It's interesting 'cause even for me anyways, I feel like part of my work is trying to create understanding.

So some of the forms my artwork takes is I actually perform OCD to activate spaces with art, to kind of have more difficult conversations, and allowing art to sort of hold that space. And that's part of trying to build that understanding of what OCD can look like and how it can impact bodies.

Can you give an example?

Yeah. So for example, for Contact one year, I had photographs that were done – the layout of the photographs was a part of recognizing all four [00:40:00] directions. And in the center of that, I was actually washing my hands or washing objects, and I would literally have conversations while I was doing it.

Again, it's sort of like bringing it into space, right? So if the community isn't there, you kind of build the community. If the space isn't there, you try and help create the language. And that's just where it feels for me – that foundation isn't just there yet.

In sort of like looking at the creation story, right? You create the good places first to send your ideas to. Because otherwise you're just sending them out into space, right? There's nowhere for that idea to go. When you create that good space, it has somewhere to sort of take root and kind of flourish and communicate back with you, right?

Because it's a lot about conversation and relationality. So, you know, you can't have dialogue if something isn't there. So I guess that's like, you know, when I think about studio space or any kind of [00:41:00] space, that is the kind of conversation I'm looking to start. And so having that foundation there first is something that's really important to me through the work that I do.

Would you say then, in terms of that, of finding that space for conversation, do you feel like that sparks your idea for the art? Or do you feel like you have an idea for an art thing and then you wanna find that space to actually create it in? Or is it both? Is it a mix?

I think it's a mix. Being multidisciplinary, which you know, I guess if you wanted to be a professional artist isn't great for the career 'cause the work is all so different, right? Your consistent style, right? I don't really have that. [00:42:00] Because if it needs a sculptural element, if it needs a performance element, if it needs installation, new media, right? It's kind of like – what's going to transcend the form to be whatever that story or conversation needs to be?

So I don't really necessarily have an idea or a blueprint in that sense. I'm kind of being pulled by this kind of epistemological curiosity that I don't really control, right? Like it's pulling me and I'm sort of seeing things tease out in their own time and way, but also recognizing that there's an urgency to these conversations.

[00:43:00] 'Cause I look at the wildfires, I look at the state of housing in Toronto, I look at the loss of creative spaces, the privatization. So there's plenty there to recognize – there's an urgency to all these kinds of conversations.

And so seeing where they're all connecting and weaving into each other makes me go, okay, so how do we listen differently? How do we reorient differently? It's that constant, through the curiosity, that kind of pulls me along. I don't really control it. And then sort of marrying to that is the way that, like I said, co-creation. I landed on that because all art is an act of co-creation [00:44:00] and co-authorship is really important to everything that I do. 'Cause I think that's part of how art kind of helps support this conversation around ethical relationality, right?

How are we connecting to ourselves wholly and everyone? And so all of that kind of comes together, in terms of square one in the work that I create. Because if it's all there from the beginning, that creates the good space with the art. So they kind of come together in that way.

And then when you enter that space and you're part of that space and you're conversing with that art, my hope is that it informs that conversation. So it's not like this sort of control one way – you recognize that art has agency and that you're talking to it, and that you're kind of developing this kind of quantum entanglement there.

You are observing it, but it's also observing you. [00:45:00] And then through that you're changing the space around you. And you know, maybe right now that scope of that change, that radius of that change is maybe just to a gallery. But as we continue to work that way and develop that further, maybe it starts to happen outside the gallery.

Maybe it happens with the trees, the water, the birds – how big can we make that circle, in terms of how we imagine the ways that we're cooperating again? You can't separate them, they're kind of all wound up together for me.

Regardless of whether you practice, quote unquote, within creative spaces – what do you think right now is working for disabled artists? What is out there that people are excited about, or at least working within and hopeful for? I've talked [00:46:00] to a few artists about the past and

how those kinds of conversations started rolling. People obviously have incredible visions for the future, but what about now? What's the story right now?

All things, like I said, coming with a really dialogical community centered practice, I just think conversations – it's an ever evolving thing. If I say love and light are toxic positivity is something, but I think because the way that we can spiritually bypass [00:47:00] systemic issues – you know, taking that approach.

But there's definitely this look to having conversations about representation and the kinds of safety that can flourish through that representation, I think is really really interesting to see evolve. I think finding ways to sort of bring the body back into the conversation. I don't think that there's any one organization that's necessarily doing something right. I think that there's just different perspectives and different takes, if that makes sense. There's different approaches to it because [00:49:00] there's no utopia to kind of get to.

And so it's always gonna kind of be in flux and be things that we're working towards. And sometimes that can come off as sounding kind of negative. But I actually think that that's really a positive thing, because I think that that ability to transform everything is important.

Like I said, I feel like always conversations, more conversations – where they do happen, it's great. Understanding people's access needs, where there's sort of an openness to change how something is done, right? Where there's some flexibility in things is great – starting to relax on how timelines for projects – I'm seeing that in public art contracts and a greater understanding there, which is I think really important. Because [00:49:00] having really constricting timelines – the capacity in the body, you know, often isn't there, and you're losing voices, especially in the realm of public art. I see that.

And the sad thing about that is people are not being represented in spaces when that happens. Something that kind of gives me hope is that I'm seeing a real interest in a confluence of disciplines and interests coming together.

And so I'm seeing more of, you know, art and climate action coming together. I'm seeing health and space, like architecture, come together more. And this is just generally hopeful for me [00:50:00] because I think that it's sort of like dissolving the silos that isolate knowledge and have done a lot to create a lot of division, which has done so much to impact how we've been organizing ourselves and how we connect to power.

Dissolving those barriers is allowing us to come together more and to work more synergistically and, you know, really starting to change how we do things. I like this line of like, you know, is it a zoo or an ecosystem? Right? Whereas a zoo is kind of like isolated and caged and everything's confined and nothing's really working together, versus like an ecosystem, which is, you know, has many smaller systems within it all kinda working together.

And I like the idea of us being constellations that are working together to inform a [00:51:00] greater galaxy in how we conceive of the world and the spaces around us.

MUSIC

**Carmen Papalia**  
**Mary Anderson**

My name's Carmen Papalia and I'm a non-visual social practice artist. Most of my work responds to my own access to the world as someone who uses their non-visual senses as a primary way of knowing the world. And also, my response to my experience of pain [00:52:00] from sickle cell disease. So yeah, I do a lot of different things – performance, installation, and curating, and institutional critique, and interventions. Yeah, all sorts of stuff.

I'm at my desk right now in my apartment, in the Hastings Sunrise neighborhood of so-called Vancouver, which is the stolen land of the Musqueam, Squamish, and Tsleil-Wautuh people.

[How many years have you been practicing, Carmen?](#)

I guess I started practicing as an artist maybe in 2009. And I didn't think of myself as an artist back then. I was just doing these things that I think of as performance now. But I was just doing them to better understand my position in the world as someone [00:53:00] who's disabled. 'Cause I just had adopted that label and started understanding it through the social model sort of framework at that time.

So since 2009, and I've been working as an artist since 2012. And I guess I kind of established my practice to be more sustainable – as like my main thing, in 2019.

[Okay. So you've described your creative practice a little bit, and I'm so excited to dive into this idea of studio space. I'm curious, do you have access to an accessible creative space right now in the city?](#)

I mean, I guess my apartment is that for me. I don't have a real studio that I go into to make things. I'm involved in a couple different things now where, you know, [00:55:00] I go to, to produce. I'm working on a full-length film right now, a documentary for Knowledge Network, and it's called Up in the Clouds Down in the Valley. And I'm co-writing the film with filmmaker, another Carmen, named Carmen Pollard, who's been making social documentaries here for over 20 years. And so we meet in her editing suite. We're almost finished filming. So we have like two more scenes to film, but right now we're writing audio descriptions.

So I've been going there to do writing. I make a lot of my work here and like I'm just thinking about what I've produced recently. One project that I did was I made an edible artwork with my brother Antonio and my sister Veronica. And it was for a 420 event at Tangled. And this is

[00:55:00] part of my and my brother's project, Impaired, that is about medical cannabis and disability culture.

And he grows medical cannabis for me, and his long-term goal is to breed a variety of cannabis that would activate my hallucinations that come about from Charles Bonnet syndrome. A lot of people with vision loss, they see these like dynamic, colorful hallucinations that take different shapes and patterns. And I particularly enjoy mine.

So my brother's figuring out how to amplify those through cannabis strain bred for that purpose. A couple of months ago we made an edible artwork that was dosed with hallucinogenic cannabis. And I think it's worth saying – and yeah, we did that all in my kitchen, basically.

What I have to show from that project [00:56:00] is like a container in my freezer full of cannabutter. There's some cookies that are stale in my cupboard, but I don't have like a big studio or anything where I'm making things.

When it comes to studio space though, I mean you probably know that it's so limited because of affordability here. And it's hard to find a studio anyways, let alone an accessible studio. I know some artists who don't have an accessible space in which they can work and they need to produce for shows. Like some of them are, you know, being invited into shows and [00:57:00] I mean, if you don't have like an arts council grant – sometimes even when you do – you can't find a space to rent that accommodates your needs.

I'm good friends with Sharona Franklin, who is a gelatin sculptor, and she needs a commercial kitchen sort of setup, but also for it to accommodate rest, and her ability to move through the space. And there's nothing like that that either of us could find.

And so I just think there's just like a severe lack of making a space, or a space that's set up for that. You know, maybe there's a growing amount of affirming cultural space? [00:58:00] But yeah, I do think that even that is fragile. I mean we're talking about these scrappy like nonprofits that are still – you know, their existence hinges on whether they continue to get grants – that can't be just the model for supporting disability culture.

What really strikes me whenever I get to go to Tangled is how small it is and how meaningful it is for everybody. You know, it's people's touchstone for learning about disability art and disability culture. And it's like a small space with a dedicated ragtag crew.

[00:59:00] And isn't that like most nonprofits – so many nonprofits in the downtown east side serving these specific needs within the community, and they're also just fighting for funding to stay open.

I thought that might be the case because so much of your work is very much rooted in public space, right? But I think for the purpose of this podcast, I was just curious. I've been asking folks if they recall kind of the first place or first space rather, that they entered where they felt like

they belonged, where they felt like they could be themselves, that it impacted their work in ways that non-accessible spaces, for example, can't. Do you recall any environments that helped facilitate that?

[01:00:00] I mean it's hard, you know – I felt a sense of belonging before I found disability community like within the publishing community that I was involved with and kind of making chatbooks and literary magazines before I went to grad school in 2010.

This is while I was at Simon Fraser University. I found kind of a sense of belonging in that grad program that focused on art and social practice, but I think it really deepened when I found disability community and other disabled artists. And for me, the person that really opened that up for me was a curator named Amanda Cachia.

And she was the first to show my work in a group show and was really kind of showing the work of other disabled artists, as well, who are living artists, who I could talk to and connect with, and share [01:01:00] stories with, and reach out to if I was feeling particularly alone. 'Cause I was the only disabled artist in my grad program.

And I guess when I started having these opportunities to be in Amanda's shows, you know, we were being curated alongside other contemporary artists, some of which were very prominent. And so I felt like, you know, someone was placing this value and importance on my practice and this activity that I was invested in.

And we also shared some of the same politics around disability and thoughts about, you know, disability experience being like a generative experience. So I think it was through meeting other disabled artists, [01:02:00] maybe in 2011, that I really started feeling like I had a community to engage with.

When I moved back to Vancouver after I finished grad school, I was looking for spaces where I felt like I could be understood or do my work – where I felt that sense of belonging. And it wasn't just in these moments where I was in a show or whatever, or could reach out to people that lived in other cities.

And I found an organization called the Purple Thistle Center, which was a youth-led space – it advertised itself as an alternative to school. It was pretty radical that youth participants ran the space and were decision makers and they invited me in to [01:03:00] share about accessibility with them.

And I just thought that was like the perfect space to explore and be experimental and just have these conversations – that's really where I started talking to other people about what could accessibility be if it was like a wide open space. Like if it was approached radically instead of more based on compliance.

That was one of my touchstones, sort of like community lily pads. And then the next one was Gallery Gachet, which is in Vancouver's downtown east side. And it has a mental health focus and it was collectively run by community members. It has a different structure now, but it was at Gallery Gachet that I did a lot of work since 2012, [01:04:00] with their community. And yeah, I guess those are my two local places.

[When you're thinking about creating a public art piece, for example, what goes through your mind when you are thinking about location or environment to share your work?](#)

I want it to be as low barrier as possible. In Vancouver, it's difficult because not many of our buildings are purpose built for accessibility, and some of the adaptations are not easily accessible for people. So it's limited, but you kind of do what you can to address those barriers.

And so right now I'm working on this project – it's focused on this instrument that is a weather responsive analog synthesizer. [01:05:00] And it was built for me by the musician Quintron, who's a New Orleans musician. I wrote this Canada Council grant for him to build me this instrument 'cause he built himself one in 2011 when he was diagnosed with stage four lymphoma. And he kind of used it therapeutically and really benefited from the grounding sound space that it provided. And then he put it on this website – it's a live streaming instrument and it responds to the weather in real time through these weather sensors that are interacting with various conditions.

And he put it on this site called Weather for the Blind. I was already a fan of his work and I was like, hmm, this might be for me, so I checked it out and, you know, first I had this thrill [01:06:00] that I was able to listen to a version of the weather in another place.

But then I started using it therapeutically as well, and I would use it to kind of focus or ground myself during a pain crisis. And I told him about it and he's just so happy, and he's like you're one of the few people that understand why I made this instrument. And so it lives in my apartment right now, and you know, like the cannabis project, I think of it as a healing sort of project.

I think I wanted to get these two projects off the ground and focus on them because I needed something healing and life-giving in my life. And so when thinking about how to share those projects with others, [01:07:00] I think about how to do it in the most low barrier way.

Right now I'm working with this studio in Vancouver, bringing The Weather Warlock there. Did I say that it's called The Weather Warlock? I forget.

[Sounds amazing. I can't wait to check this out.](#)

Anyways, it is pretty magical, and I'm working with this studio called Lobe Studio, and it's one of three venues like it in the world. It has like 35 speakers built into the floor ceiling and walls, it has like haptic feedback in the floor, and there's two steps that go up to the listening space. And the restroom is in the back and there's two steps down to it.

They do have a ramp that is functional, but it's not, you know, it's kind of steep. So there's different kind of [01:08:00] compromises to using this space, and I plan to show the work in other places too. These sort of disability informed sound events that I'm doing, they're sort of like these healing sound events where I'm sharing the instrument, demonstrating it, and then doing a performance and talking to people about how it benefits them.

I don't want to limit my creativity and the possibility of the project so I didn't write off Lobe Studio altogether, and I don't want to throw them under the bus 'cause it's an amazing space and they do so much great programming. But there are always accessibility barriers to address.

And so with the restroom we could always rent [01:09:00] a portable restroom so people don't have to go across the street to the library to use that restroom if they need to. And we can always make sure people can make it up those two steps or the ramp if they need to.

I guess it's just being responsive, trying to be responsive to the needs of community when they come up, and when finding space – I've just accepted that there's always going to be barriers, whether those are social, cultural, political, or physical, which, you know, physical barriers are a result of all of those things. The social, cultural and political.

Yeah, so no space is perfect, but I [01:10:00] just kind of figure out where I think the work fits and then make sure that I'm accommodating for the diversity within our community, in terms of the needs and desires that different folks have.

The word healing stands out for me a lot too, that you've been talking about. 'Cause I think a lot of folks have really referenced the practice of care, listening, feeling welcomed and obviously how that enables folks to make in a way that is healing, and safety too.

One of our partners is in Regina and a bunch of theater makers were able to access an [01:11:00] Indigenous center called the māmawêyatitân centre. And it's this really cool community center in Regina's North End, and it's a library, a school, a food bank. And I got to fly out actually and connect with people about how this space has really been a place of healing, because a lot of Indigenous makers specifically, felt like they could make work that was supported within that space, but also the surrounding community.

It was so healing for the artists. And I think it's been really incredible to just see how some of these physical spaces can really shape that. Like you say, there's nothing perfect by any means, especially when it comes to accessibility, but it sounds like the community steps in, in that regard, and [01:12:00] you support each other through those relationships too, right?

Yeah, totally. And I guess it's also just recognizing what your community's needs are. Like for Gallery Gachet for example, it's now in a different location. It's still in the downtown east side, it's on 9 West Hastings here in Vancouver. It's right next to what's known as Pigeon Park, and Lobe Studio too, it's on East Hastings. And I mean, both of the spaces consistently have food for people. Gachet has a drop in sort of vibe and they always have the makings for sandwiches and

stuff for people who need that. And Lobe Studio always invites community members in for their [01:13:00] programming and anyone who wants to check it out. And Lobe is a small space – Alex Penney who runs it – just the space in general, it's understood as like a therapeutic sort of sound space.

They run events anywhere from like, you know, noise experimental sound to sound baths. And weird things like my Weather Warlock thing. I think it's a commitment of the space to recognize and respond to the needs of their communities.

Yeah, absolutely. What do you think is emerging in this field, in terms of enhancing some of these environments [01:14:00] to better equip them to support disabled artists? Do you find anything that's in the works that you're looking forward to or there's conversations about?

More and where it's always been alive are at these grassroots organizations that serve multiple purposes. They're art production spaces, but they're also like social spaces and cultural spaces. And, you know, a place like Lobe, it doesn't say that we're here to attract people with disabilities, or we're not here specifically for them, but, you know, bringing in a project like mine with The Weather Warlock – these events are called Weather for the Blind.

I really think of the instrument as like a beacon for anyone who could benefit from it. I've been writing about it as a public utility for people with pain. [01:15:00] And I think programming that sort of project, it brings a community with it, and a space, accessible space with it.

So I think an affirming, sort of disability informed or centering space with it. And I think it's harder to hold that space within the context of a top down sort of institution.

SOUND CLIP FROM THE WEATHER WARLOCK INSTRUMENT

[01:16:00]

And this is a great example. So there's a tiny gallery here called grunt gallery. It's been around for a while, it's right across from Emily Carr University. During the pandemic, one of my friends, Kay Slater, who works there, really started encouraging them to learn – the entire staff – different accessibility practices and to really implement new accessibility measures.

And I think grunt gallery maybe does the best job of accessibility in the city, and it's like so tiny. And right now they're doing a learning exchange with the Museum of Vancouver, which you know, holds the city archive. I'm working on this show right now at the Museum of Vancouver, co-curating it with a friend, Raven John, who is a two-spirit trickster. [01:17:00]

And their senior curator and collections manager, Viviane Gosselin, and it's about disability activism in BC, and it's their first show about disability so they have a lot to learn about accessibility and disability and like, how do you tell these stories? Recognizing that some of the issues we're talking about are still issues.

So grunt gallery and Museum of Vancouver in this learning exchange where, you know, Museum of Vancouver can share certain resources with grunt, but grunt can kind of guide Museum of Vancouver in their process of adopting new accessibility practices and making new commitments to accessibility.

And you know one thing that I think Museum of [01:18:00] Vancouver does really well is the way they develop shows, it's always with community advisors. They have representatives from each of the host nations on their board, each show is developed with a group of sometimes 10-15 experts from the community that range from academics to just community members, enthusiasts, people who feed into the development of the exhibition components, over like sometimes two or three years.

Our show has been in progress for a while, and one of the things it will do too that I think is pretty impactful is that it'll start an initiative for the museum to collect disability [01:19:00] through its existing initiative to collect objects that tell stories of protest. It's building an archive, it's recognizing a culture and a community and a history. And this is alongside their repatriation program, their involvement in knowledge repatriation for Indigenous communities and their belongings, and I think they just think about their place and the history of the museum as an extractive sort of enterprise. And they're trying to change that dynamic so that it's more reciprocal or it even gives back.

Wow. That's so [01:20:00] amazing that you get to be part of that process.

It's pretty cool. I've known Viviane since 2012, and we've been talking about a show about disability for a while and now we're working on it, and it'll open next summer around this time. Our community advisors are all people that I feel are doing great work at small nonprofits, including Moroti George, who's at Gallery Gachet, the artistic director there, Keimi Nakashima-Ochoa who runs WePress, which is a small letter press organization in the downtown eastside, Kay Slater who is at grunt gallery.

I feel like I have this like dream team of people to imagine this exhibition with. And it's also a research project because we're putting a timeline [01:21:00] of disability history together. And I think more than ever it's important to acknowledge our history and protect and nurture our culture because it's under threat.

I think people with disabilities need to be valued and protected, and their ways of being and the ways that they live on their own terms. I think it's a special exhibition and it won't be perfect, but it is a great starting place for I guess the wider community to recognize that there is this community and culture of disability.

And it's not just, you know, [01:22:00] the athletes that people know, or the figures that we know who kind of have done something significant, like Terry Fox or Rick Hanson or whatever. But it's really about these grassroots movements that led to deinstitutionalization and are still resisting

the expansion of the medical assistance and dying act for example, or who are involved in harm reduction. That sort of grassroots work to preserve disability as a way of being, I guess.

Do you have anything that you [01:23:00] wanna add before we wrap up?

Like, where I'm at right now, in terms of my belief in the work that I do, I guess for years I was very into helping guide institutions, larger institutions too, in their practice and commitment to accessibility. I think where I'm focused now is just in trying to grow a space that's accessible for me and the rest of my community without institutions. And I think that's where a lot of people are at, because we kind of are the most equipped to host each [01:24:00] other, to respond to each other's needs, to understand, to provide the context that we need for our work. You know, I don't think that's available in most places, especially in places that are not disability-led.

So yeah, I think the focus on community from within community is where I'm at right now. And I think that that's a powerful sort of space and also a place worth investing in. [01:26:00]

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