

# Art & Power: Disability and Accessibility

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September 25<sup>th</sup>, 2019

Humberto: Art & Power is a program of the Regional Arts & Culture Council that aims to amplify the voices of artists historically left out of the dominant narrative. The conversation is rooted in the philosophy that, in order to make progress in our equity work, we need to center the voices of the communities most impacted by systemic oppression. Each conversation explores a different topic under the themes of create expression and power structures, and features local artists of color who share the lived experience being discussed.

On September 25<sup>th</sup>, 2019, we held “Art and Power: Disability and Accessibility” at New Expressive Works, featuring artists Bemnia Latham, Leaila Hale, and Luann V. Tan, with moderation by Elea Chang.

We would like to acknowledge that this event took place in Portland, Oregon, which lies within the stolen and unseated traditional homelands of the Multnomah, Clackamas, Oregon City Tumwater, Tualatin Kalapuya, and other Chinook bands who made their homes along the Willamette and Columbia rivers. We extend our deepest gratitude to those who have stewarded this land, and offer respect to their elders past and present. Please take a moment to consider the many legacies of violence, displacement, migration, and settlement that bring us together here today.

Elea: Hi everyone. Welcome. My name is Elea Chang and I'll be moderating the panel tonight. My pronouns are interchangeable between she and they, access needs; My body's a little bit of pain tonight, so if I'm like twitching around more, that's normal for me. If I'm making faces, that's normal. Just, you know, if you would be polite and pretend like you don't see it, that would be awesome. Thank you.

Luann: Hey everyone. My names... I had to look at my notes for that. My name's Luann and access ...` And my pronouns are she, her and hers. And access needs: I'm a little foggy right now. But, but present, or trying to be present. I'm like really trying to disguise that right now. So, but otherwise I'm, I'm here. Thank you.

Bemnia: Hi, my name is Bemnia. She, her, they them.

Elea: Access needs.

Bemnia: I'm pretty anxious right now, so, but that's the fun of this, right. Doing good though.

Leila: My name is Leila Haile. I use they and them pronouns, access needs. I'm also feeling a little twitchy today. So it'll enjoy the same courtesy extended. But yeah, I've gathered the spoons to be here and I'm really excited to see everyone's faces in here and how full this room is right now. So thank you for being here.

- Elea: I'm just going to take a moment and be like, "Yay! Thank you all for this panel tonight." All right, we're gonna dive in. Let's start off by talking about the cool projects you're all working on. Who feels like starting, we could just go in order, too. Okay. Right. You're the winner.
- Luann: Yeah, the cool project that I'm working on right now or have been working on for the last couple of years is a web series, a comedy web series called "Gabby Antonio Smashes the Imperialist White Supremacist Capitalist Patriarchy" or "Gabby Smashes" for short. And it is based on my experiences of working in nonprofit organizations here in Portland, Oregon, the whitest major city in America. I still think it holds that title. Or that yeah, that label. And yeah, I've been, I was a creator, and I star in the series, and it's just about like all the trials and tribulations of like working in nonprofits but also like being a woman of color in Portland. That's the cool--That's the only cool project I'm working on right now.
- Elea: It's very cool.
- Bemnia: I will be doing tender table this Sunday, which is a storytelling event with food. And so I'm really excited for that. If you guys want to come, it's going to be at the People's Food Co-op at 6:00 PM, and I'm also working on a makeup series featuring BIPOC, and you can see that on my website soon.
- Leila: All the things. Well, this morning I was with some comrades of mine at city hall pushing forward a disability justice civic engagements data collection study, which was unanimously approved. So I'm really stoked to that work is going forward because if the numbers don't exist, the people don't exist. Right? I also co-direct Ori Art Gallery on Mississippi. I'm really excited to push forward our interns into more stable permanent positions and to do leadership development feels really good in that arena. And I'm trying to do a bunch of illustrations, based on African utensils and tools. So that's my personal art project that I'm really excited about.
- Elea: Awesome. So one thing that came up when we were talking about this panel is that, there actually have been a lot of disabled artists throughout time, but their disability somehow gets erased through history. So I wanted to have us talk about who some of our favorite disabled artists are and shout them out a little bit. Does anyone want to start?
- Bemnia: Okay. Yeah. So I wanted to give a shout out to Lady Gaga. A lot of people don't know that she has fibromyalgia. She's like a little superhero to me and another person I wanted to shout out is Frida Kahlo. Which now is recently starting--more people are starting to know about her disability and her struggle. And I also wanted to shout out one of my friends, Sashiko, you can find her on Instagram @wishcandy. They are one of my favorite disabled artists.
- Elea: Could you hold the mic a little closer when you talk by the way? I think someone just said that they couldn't hear that well. Thank you.
- Leila: I feel like always at the top of my list is Missy Elliott. A lot of folks don't know that she's chronically sick and ill. And that she was definitely like one of my hugest inspirations. Also no one knows that Harriet Tubman was also disabled and that she did all of that work,

freeing so many like, enslaved and stolen Africans while disabled. Which is just like this is lifting up that ancestor real quick. She had a couple of, physical disabilities that are like, not really that well documented, but we are pretty sure like 80% sure that they were the results of the abuse that she suffered at the hands of her slave holders.

Luann: The only one I can think of. Not necessarily a favorite artists, but one that I know of is Selena Gomez. She has lupus, which is also what I have. And she has lupus nephritis and so we had the same exact diagnosis. So, and she is someone that I, I don't really like listen to on the regular, but I admire the fact that she kind of talks about it openly. And doesn't shy away from, I mean she, she did at first, but then, you know, more recently is more open about her, chronic illness, as well as Toni Braxton, is also a lupus and has been talking about it for a while I think.

Elea: And now that we've got the easy question out of the way. We wanted to talk about, and by we, I mean that, all of us got together before this panel started, to prep so that none of these questions are surprises. And we talked about how we want to talk about disability and the industrial medical complex, specifically disability as defined by the federal government and disability in diagnosis. Leila, I believe you had some thoughts about this.

Leila: That's just trash. [Inaudible] in short form. Yeah. There are just so much, access to resources that's solely dependent on whether you fall within this very, very narrow margin of whatever, right? Like if you're disabled enough to be recognized as such, if you're black enough to be recognized as such, if you're poor enough to be recognized as such, Oh, then you can have access to this very, very slim, caveat of resources. And it's just the worst. It causes... It takes up so much precious, precious energy that could be spent making art. But instead I have to be on the phone with, you know, bureaucrats for hours at a time, bouncing in between different sources where the left hand isn't talking to the right one and people don't realize what a vortex of energy that can be and how much that takes away from, you know, even folks with more spoons than the average bear. Right? Like there's, there's like not, I don't know if there's a human in existence who has the energy to navigate these bureaucratic systems the way that you must navigate them in order to get the resources that you need, but just it's, it's Kafkaesque like you just keep running into all of these hurdles where you have to prove over and over again your existence and you have to keep justifying and validating your existence to people to, again, able-bodied, cisgendered, heteronormative folks who have no concept of how trying these systems are.

Elea: Bemnia, did you want to talk a little bit about disability and diagnosis?

Bemnia: Um yes. So a lot of the time doctors, especially, act like diagnosis is everything, which it's not. It can be kind of bullshit a lot of the time. I myself do not have a diagnosis for a lot of the issues that I've been facing. And doctors will just kinda act like if you don't have a diagnosis, then you must not have the symptoms. And that doesn't change the fact that you're still going through everyday dealing with your symptoms. While just still trying to navigate getting medical care. Yeah.

Leila: And the fact that like nobody believes black women and femmes about their pain. Like we've had to have like decades worth of studying to prove that no one believes us about our pain. And I just read in some article that when germ theory became a thing, black doctors

were actually completely nixed out of the doctorate, the doctoral process. So for like decades we didn't have any black doctors taking care of our bodies. And that, that legacy continues today. I know like I don't interact with certain parts of like the medical industrial complex or like resist interacting with them as much as possible in order to not have that violence over and over again. I get mis-gendered every time I go to the doctor, there's usually some sort of racist comment that happens every time I go to the doctor. I was misdiagnosed with high blood pressure because of one racist nurse who made my blood pressure go up every single time I had to deal with her. And that's just a microcosm, a microcosm of the diversity of bullshit that we have to go through.

Elea: Does anyone want to talk about mobility aids and what goes on around them?

Bemnia: I mean they, doctors, generally are very discouraging about it. In my personal experience. It's like they don't want you to get the help that you need. They think that you are overreacting in some way, shape or form, that you must not need this. And the fact that you're trying to advocate for yourself that you think that you need this so that you can function. It's almost like they take it personally. I have a cane and I was strongly discouraged by doctors to get it, even though I told them that sometimes I can't walk. But that doesn't register to them a lot of the time.

Elea: I have something to add on this. That's my mobility scooter on the side there. And I had to buy myself because I also have been undiagnosed even though I've been disabled for over a decade. I got misdiagnosed with, they didn't even call my symptoms the right name for a while. So that for a while they told me I had one type of muscle disorder symptom. And then in the past two years, another doctor was like, no, that was the wrong name altogether. So they couldn't even get the name of my symptoms right. And they can't diagnose me. And, a couple of years ago I stopped being able to walk as far. And they sent an occupational therapist to my place and they were like, well, you can get to the bathroom. Where, where else would you need to go? And I was like I would like to live my life and leave my house. So it didn't, I didn't even know that.. I like many other people, who first, you know, do the research. We didn't know that we could actually buy our own mobility aids. I feel like if the biggest, thing we can tell people is like, you can buy your own, I mean, assuming you have the money, but most people actually end up buying their own mobility aids because it's not approved by insurance because insurance actually really only cares about, hat you need inside your home in proximity to the restroom. They're not really that worried about you eating really, but you can go to the restroom. So, that was my medical gatekeeping story. I bought it on my own. And my doctors called me dramatic. So, eh, par for the course.

Leila: It just reminded me of this tweet that I saw where someone was complaining that a accessible parking spaces should have a time limit. Like after 6:00 PM, it should be regular parking. And the response was "We're not werewolves!"

Elea: I did reference that joke. Well like the guy was actually asking why would any disabled people need parking after 6:00 PM and that's when the joke came in "we're disabled Daniel, not werewolves!" So yeah, I still don't have a disabled parking pass because you know, I would have to have I guess a diagnosis, a doctor who backs me and all sorts of other things before I get a parking pass. Otherwise I'm just "taking advantage of the system" to leave my house and try to make money. Taking advantage of the system. Such a drain.

Leila: Oh that's so wild. Like I complained a lot about the accessibility of Portland and then I went to New York [laughs] and I came back and I wanted to kiss the MAX, but like there was seriously, there was a person using a wheelchair and one of the, one of the bus stops and I was like, A, of all, how did you get here? And B of all, how are you going to get out if there's an emergency? There's like literally there's, it's, it's wild. It's really, really wild in there. And like if you can't, if you're unable to access like trains or buses and there's a number you can call to apply for a ride service, which is just like super bonkers to me. And it's like another example of like bureaucratic eugenics. Like if we just keep finding little ways to push you out and push you out of the system, then you're not a problem 'cause we don't see you.

Elea: Sure. was it, did you want to add something Bemnia? Okay. Sorry. I'm trying to be very mindful of everyone on the mic. Let's move on to how has disability or accessibility impacted your art? How does it inform your practice? I think if no one wants to talk, that means we've cycled back to Luann.

Luann: Well my chronic illness is fairly new. I feel really loud right now am I loud?. Oh good. Okay. you know, my chronic illness is really new. I was diagnosed last year and so I, it hasn't, I haven't done art really the last year, which sucks. But I was able to film the first the season.... I'm sorry. I'm like really like, like foggy. I was able to film the first season of Gabby Smashes earlier, like a couple of months ago with very little energy. But we were able to do because we have a RACC grant, so we have to do it. [Laughs] Thank you RACC. But yeah. It hasn't, it has, I don't know if it's informed my, it hasn't informed my art practice quite yet. I think I'm, I'm excited to see how... Well I don't know if excited is the right word, but, I'm intrigued I guess at like how my, writing and performing and all of that will kind of shift with these, new limitations. Cause I, I do see it like when we were filming, like how tired I was. Like they were 12 hour days for two weekends. And there would be times where I just would have to like stop. And, and wait, you know, for, wait for me to gain energy back. And then after that I think I took like a month to really recover. So, yeah.

Bemnia: I would say... Is this on? Okay, there we go. I would say that there are definitely times where being sick has made it so that I can't do any art. And you just have to rest during those times. The way it has affected me, I would say I just have to be really mindful of how my body is at any given moment so that I know how much I can push myself. If I can actually get a project done. Also taking lots of breaks and I've learned to take advantage of sitting. Yeah. Sitting is really great.

Leila: I feel like for a while there were certain types of like artistry that I didn't feel like I could claim. Like I feel like, Oh, I wasn't a real dancer because I use a cane and it's only been in the last couple of years where I've been able to like actually say like, well, fuck that. I dance, so I'm a dancer, like and take the advice that I would give to like my youth and other things. Like if you do the thing then you're doing the thing and that's all the validation you need. And so that's really allowed me to expand what my practice is. This last summer I did a residency where I got to try aerial for the first time and [inaudible], like my bones really like hanging upside down like a bat. And that's a really essential part of both taking care of myself and my artistic practice. And I don't think I would've had the notion to explore that if I hadn't been able to like slough off those old ideas about what art is and who was allowed to claim to be an artist. And I feel like a lot of that is like, not only like institutionalized ableism that I absorbed, but also all the other isms, all the other, you know, white

supremacists, hetero patriarchy, beaming down on us with their messages about who isn't and who is invalid.

Audience member: Do you like, have any shows? Coming up? Doing Aerial?

Leila: Oh no, [laughs] I am definitely, I appreciate the question. I'm definitely not at a point in that practice yet where like anyone other than my very trusted, very close instructor can my foibles in the air. But the universe will know if that time ever comes

Elea: As a slight favor to us. And since we're recording, could we save some of the questions more towards the end? Just so, one we can make sure that you know, they're read through the mic and recorded for posterity. Thank you. Not to interrupt the conversation, sorry. Do you want to talk about institutional traps at all?

Leila: I forget what the impetus for that bullet point was.

Elea: It was part of how disability impacted your art. And I don't know specifically what you, what you are going to go into for that. You just said make sure we include it.

Leila: You still have it as a bullet point. Damn you past Leila!

Elea: I'm referring to a past bullet point. You said, can we talk about it? And I said absolutely.

Leila: Oh man. What ramp was I on that day? Huh? I think maybe we were talking about the institutional traps of being not enough or less than and like having to pretend like you're always on your very worst day when describing your abilities to somebody in order to justify getting what you need.

Bemnia: Yeah, definitely.

Leila: Yeah. And like, Oh yeah, I think we're talking about an institutional trap of also like the very, very fine line between advocacy and like showing off versus inspiration porn and feeling like you're, yeah, you're always always pushed into that into just laying your soul out bare in order to get like \$2,000 for a project and that feels really, really gross. Especially as a black human being, especially as like a trans person, especially as a queer person. Like I don't feel like I should have to list out the kaleidoscope of my identities and all of the institutional oppression that I go through in order to get funding for this comic book. I want to make, you know...It feels like a lot. Could you just look at my comic? Feeling like I have to like weaponize my disability in that way. It's really gross. I don't want to do that.

Elea: That goes into, I'm just going to move some of our questions up cause I can, but if you're looking at your notes and wondering what I'm talking about: we had a bullet point where we specifically wanted to talk about productivity and capitalism and how that intersects with our identity as disabled folks and how we're always having to mask or pass or, downplay our symptoms or, emphasize our symptoms more. But it's like either on one side of the scale or the other rather than naturally getting to be who we are. Did anyone want to piggy back off that?

- Bemnia: I think, yeah, capitalism definitely. It just, it puts pressure on you to sell your art for sure. Make it for some type of consumption. But it also pushes you to mask your pain a lot of the time so that you can get work. It's been incredibly difficult to find jobs. When I do tell people that I'm disabled and that I do, I will call out sick. I will need to sit more often. I need breaks, I need other things so that I'm able to do the job. And so sometimes it's easier to just try and mask what you're going through so that other people don't have to know so that you can just deal with it on your own. Which inevitably puts you in situations where you wish you hadn't. That is what I have learned from that for sure.
- Luann: Yeah, I, Oh, I was just going to say I'd echo that. It's something that like, again, it's relatively new for me, so I don't even... One, I don't know how to speak my needs in general. So there's that. And then being able to articulate the symptoms that I'm having in a way that will, like it doesn't garner pity. And but fosters understanding of what I'm experiencing. I don't know how to have those conversations quite yet. So learning from folks on this panel, other, other folks with disabilities has been extremely nourishing to be able to have community of folks that like kind of understand those experiences.
- Elea: I would say in my experience, I think it's been interesting that a lot of times people will specifically ask for a certain marginalization. By the way, I want to call out that our panel is completely QT POC, which is Queer Trans People of Color. We're all a QT POC and we're all disabled. So we are here...
- Leila: We're here. Hire us!
- Elea: So we have a lot of marginalizations, multiple marginalizations, and maybe some unique perspectives when we're in the room. And just, I think it's always interesting that people want a certain diversity. In theory, like they're like, "I want this", but then when you're there and then you speak up, sometimes that's not appreciated. It's like they want you for who you are on paper, but not who you are in reality,
- Bemnia: They don't want to have to do the actual work to accommodate you.
- Elea: If anyone has anecdotes. Feel free to share. You don't have to, but if you want to...
- Leila: I'm just like folks act like accommodations... Like people will do like the wildest... Like able-bodied folks will do the wildest stuff like put scooters all over town and like and like, give people like free laptops for joining an organization. A friend of mine just joined Airbnb so I'm like on one about it but they'll go through all these loops like providing hot meals and like all of these accommodations that able body people don't really need but like fixing our sidewalks and somehow too much like making sure that people don't leave stuff in a doorway is somehow too much. Like hiring like, you know, an interpreter is somehow too much. Like "Oh no that's too much money." It's just wild to me. The excuses that people will make for like... Accommodation is actually like not so challenging when you really think about it. Like it's only challenging because of the barriers that able-bodied folks can't wrap their minds around, dismantling that. That's the biggest hurdle I guess is like your own brain, your own brain.

Elea: I feel like, one of the biggest things that companies do is a lot of companies combine your sick days with your paid days off, you know, or they limit your sick days and a lot of times when you're disabled you're like I guess I got to pretend to be cool today cause let's see on my pain scale, is this normal? Is this really terrible? Do I feel, I don't know. You know, you're always having to...

Luann: If it's not a seven, can I call in sick?

Elea: Yeah, yeah. Because you have to pick your battles and you know that even though they hired you and they know who you are, there's like always a limit to people, being willing to work with you somehow.

Leila: That's like, after a certain point it becomes like, it gets this air of like punitive-ness to it. Where all of a sudden like, Oh, I didn't ask for this like accommodation to punish you or to inconvenience you on purpose. This is just my body. Like, sorry for taking up space and time and air.

Bemnia: They start to act like, "Oh, you're needing that accommodation that you asked for?" A lot. So that's kind of, yeah, "Why are you needing it so much? Why are you needing this accommodation so much? Can you stop needing it so frequently? Because it's really inconvenient." That's how it feels anyway.

Elea: You also feel the pressure of I'm sometimes having to be like the "good" disabled person versus the "bad" disabled person.

Leila: I feel like I sloughed that off awhile ago. Like you get past a certain point where like, I'm no longer afraid of being the bitch in the room. We just need to get this done and we don't have time to wait for all of your insecurities and foibles to like get it done. This could have been done a long time ago if you would just listen to us. I feel like as a situation I end up in a lot.

Elea: Let's talk about what accessibility means to us personally or means to you because everybody has different needs. And let's not call them special needs ever. Thank you. But let's talk about what would it mean to us for something to be accessible.

Leila: I mean, I guess first and foremost, the willingness to have a conversation around accessibility. Knowing that I'm going to be heard in any point is I feel like the hugest hurdle,

Bemnia: Definitely. Personally, things that I need for a space to be accessible, it has to be near bus lines. That's something. And I have to have seating, I have to be able to sit that is a major one.

Luann: I answered that question specifically about how, what would make art more accessible for you personally? And so I got very specific and I was like, "no more time limits on completion of grants" because that's dumb and, and art takes a long time to make and flexibility around that. And then less admin and reporting for the grants that you get, too, especially for, I mean, it's just like, I don't know, I mean for anyone that's received like an arts grant, like



there's always like reporting, on the back end, you know, at the tail end of a project. And, I just want to focus on my work. I just want to focus on doing the thing, doing what I set out to do. And so making, I feel like having more accessibility, for me personally, would require, not having that, not having like admin, that kind of like, tedious work. I'm just working on that right now. So it's like at the top of my mind,

Leila: Wouldn't it be great if like all these major funding organizations with all this money and resources just sent folks out to gather the information that they want us to gather instead of putting the onus on us?

Bemnia: Right, right.

Leila: To send someone, send somebody to my work site with a clipboard and a camera.

Luann: What are site visits for? I don't get site visits. Y'all are coming to visit. You see work, so you've seen it... Now give me the money. I mean I'm just saying that like project grants you know, for artists, it can get a little difficult to, to manage when you are also disabled.

Leila: Yeah. And nobody knows bureaucracy better than us, like honestly, no one can streamline that process better than us. And I'll add on to that like, Oh, "hire, hire us?" Again? Especially for things like this, like if you are truly trying to like serve the people and make sure that no one is left behind, then hire the people who can make sure that no one is left behind. Hire the people who are left behind, that'll solve that problem.

Elea: What about what the art scene or the disability scene in Portland is like versus other places we've been? You talked a little bit about New York. Does anyone else want to do any other comparisons? Luann I know you're from California. I don't know if you have any specific Southern California experiences you want to talk about? No. Okay. Totally cool.

Luann: Do you, though? From being in Northern California?

Elea: I do, but I think Bemnia was going to say something.

Bemnia: I was just gonna say most places that I've been, aren't as good as Portland accessibility wise, but port-- That, that's not to say that Portland doesn't have a lot that it needs to do to be better. And I would say one thing that I noticed living in Berlin, there's a lot more public transportation, which is always like a big, big plus for disabled folks like myself. So yeah, we could definitely have better public transit

Elea: For sure. Art wise, I was going to talk about the fact that we're all artists and yet I feel like a lot of art galleries aren't very accessible. And I feel like Portland isn't unique in that regard. But I recently visited, I'm originally from Northern California and I visited the Bay area last week. And I got stuck in a BART station for four hours cause the elevator to the street wasn't working. And then it was rush hour so I couldn't get to another BART station with a good elevator. I shuffled back and forth and was on hold with customer service for a while. So even though we're not super accessible, I think, I appreciate that Portland people seem to have, I don't know, less, "you are lesser than us" attitude than the Bay area people had

when I was, looking to them for help because, it was kind of interesting and disconcerting, just seeing how people treated me because they were like, "Oh, you're in your scooter. And I feel like you are also poor because you are taking Bart, by yourself and needing someone else to take you to the street." Because they were, because everyone's solution was for me was like, why don't you just call a Lyft or an Uber? And I was like, eh, scooter, luggage... Don't want to get into that conversation. Couldn't the system help me somehow? Spoiler, the answer was no, I got stranded so long, the elevator got fixed by the end. That's how I got out. No one helped me. Just at the end the elevator was fixed by the time I was there. So, in that way, Portland was slightly better. Never had that experience here yet. But Leila, I know you wanted to talk about specifically Portland and, we-Luann touched upon this earlier, we're a super white city. And I say white with a capital W, cause there's like being white and then there's whiteness as a culture, which is buying into white supremacy. So that's what I mean by Portland being super white is not just in demographics but in that a lot of people do buy into white supremacy. And it could be passive or active, but they buy into it either way. And I know you wanted to talk specifically about white supremacy and eugenics. So, now is your time...

Leila: Give me all the, all the fun topics. [Laughter] Oy, well let me help, for those who are not unfamiliar with Oregon's history, we were founded as a white Homeland where slavery was illegal, not because of moral issues, but because we wanted to establish, employment for white folks up here. And that I feel like is, the, the residue of that is very, very obvious. You know, we still have the sundown laws on the books. And the, you know, bio regionalism is also very closely tied to white nationalism and all of those things of course, feed into eugenics and to, limiting or filtering the natural diversity of life as we know it. I mean, I could, I could go on [laughs].

Elea: Yeah, it's just, Portland is a unique city. People know the city as being super liberal and everyone in the Bay area specifically likes to like to ask me like, "how is Portland?" You know, "what is, what is life like there? I heard that it's super great and everyone's very liberal and it's all great." And I'm like, yeah, yeah, it is. It is sort of, I think it's super great if you're white and if you're not white, there's like one level. And yes, there's a lot of queer folks here, but when I've tried to go into queer spaces, I don't know, I feel like some of you have had this experience, but going into a lot of queer spaces is super scary here because you show up and you're like, I'm the only person who's not white here.

Bemnia: Everyone stares at you.

Elea: Yes,

Bemnia: Everyone stares at you. They're just like, Ooh, exotic fruit. It's not nice.

Leila: Not to bring up Twitter again, but you just reminded me this thing I saw this morning where someone was like, people don't even say that they're like not racist. That they have a single black friend anymore. They just say that they're non-binary.

Unknown: [Many Gasps].

Leila: The tea is hot! But yeah, and that's, that's something that's really, really pervasive in the queer community here is that like whiteness will always win out. Like even in feminist spaces, whiteness will always win out and folks do not know how to de-center that and to, you know, not be tender, but resilient, I would like to see some resiliency. Especially when it comes to white fragility and like talking about those things. I feel like folks will do that thing where they co-opt language and they co-opt, social justice concepts until it is morphed into something that is completely alien to what it was supposed to be addressing in the first place. Like people, I feel like the word intersectionality is the new diversity and that no one knows what it actually means or how to apply it. And that's frustrating to watch happen over and over again. And especially with folks who are supposed to be, you know, in cahoots with you are supposed to be your comrades and you're like, Oh, you're, you haven't read enough. You keep on using that word. I do not think it means that you think it means.

Elea: And what about disability? I feel like a lot of times when you go into disabled spaces, again in Portland, there tends to be a certain demographic and it doesn't always include people like us on this panel. And that can be really hard. I think trying to go into spaces where you share an identity with someone, but at the same time you're like, maybe you were not on the same page and I don't belong. Like maybe this, this, this space that I thought would be safe isn't quite as welcoming and safe as I thought. And that can really hard.

Leila: And not to take up too much room. Sorry if I'm talking too much. [inaudible]

Elea: You are playing. Take up room. Please take up room. [inaudible].

Luann: I don't get out much so I can't really answer that question.

Leila: I've been organizing in Portland for a hot minute and I'll just say that like white folks who hold a marginalized identity are some of the hardest to work with. Sorry y'all. But it's important to know that like, just because you have one marginalized identity doesn't like, it's not like a pass. And I feel like especially folks who hold any type of privilege, view an oppressed or marginalized identity as some sort of like cut to the front of the line pass or like a badge of honor of some sort. And that's not it, boo. Like we're out here struggling and we want you struggling beside us. You know, not weaponizing our identities against each other and playing the oppression Olympics. Like that's, I'm not gonna watch that, NBC can cut it.

Elea: My friend and I have a joke that I'm, I was like, "Oh man, what did I do in my past life? I feel like this time we, we hit reset and I like hit the hard mode for some reason". I was like, you know what? My previous life as like a, a rich cis white dude was like, "cool, cool. Let's see what life is like on just like a different end. Let's, let's restart and see how to play from like different sides." That's what I like to think. And it makes me feel better about this cause like a lot of times, I don't know if you've gotten this talk, but a lot of times when you talk to like friends or family, sometimes they're like, or the people closest to you, they're like [sighs] like they're not so cool about my being queer, my being bisexual. They're not so cool with that. And they're like, why though? Don't you think you have life hard enough? And my mom is also like, why do you have to call yourself disabled? Like isn't... Isn't life hard enough? And I'm like, yeah, taking on labels that are helpful to me doesn't actually marginalize me further. In fact, it's me taking up space and claiming my power. And that can be a really hard

concept for people to grasp. Like they, I dunno, they somehow see it as like you trying to victimize yourself somehow or like,

Bemnia: Yes, they definitely do. They, I think they look at it as you trying to get more pity a lot of the time naming your symptoms, naming what's going on with your health. People think that you are just doing it for the sake of attention a lot of the time, especially when you are a brown or black person and you are queer. It's like, it's really frowned upon. Especially within our own communities too where there's this idea that we have to be strong, especially as like a black woman, the idea of being a strong black woman, all the time. That's something that other people will put on you and they don't want to see that you have other issues and other problems and that maybe everything isn't perfect all the time.

Leila: But we know that black people don't feel pain like that. So yeah, I feel that you make a really good point in that, that that trope of the strong black woman is incredibly detrimental because that just adds to the many reasons why no one believes our pain because they believe that we, there was, there was a study that happened where they revealed that black doctors and nurses literally believe that black people have super powers. It was an implicit bias test where that came out. And that wasn't that long ago. I think it was only like five, seven years ago. But that test, that study came out.

Elea: Can you tell us more about the study? I don't know about this study.

Leila: It was basically like an implicit bias tests that asked if basically I think the series of questions was like, do black people experience like A, B, C or D? And basically folks thought that black people basically had like supernatural powers or the ability to tap into supernatural powers to handle pain and things like that. And like it was along the lines of like a woman's body can shut that down. Like if it's not legitimate, it was like, yeah, I'll see if I can cite that for you later.

Elea: Good times.

Leila: But also the disability community is really awesome and we're not just pissed off all the time. We make really beautiful culturally relevant art that is necessary to like move to move our culture and I think it's important to lift that up and celebrate that too.

Elea: Earlier you mentioned that you use aerial sort of as a way to help your body and to express yourself. I was wondering if you had any other examples of art being a tool to push accessibility forward?

Leila: I feel like tattooing is definitely that for me. I had to stop in the middle of tattoo school because of my illness and then come back to tattoo school with major nerve damage and still continue through tattooing myself and learning to practice that on other people. And that became a huge, a huge turnaround for me, both in how I deal with my own pain, and process that, and how I channel and help move the pain of my clients as well. So learning body work from that aspect really changed the way that my craft operates and made me kinda tilt, my lens to focus more on the crossover between, disability justice and tattooing, which I never thought of before. But yeah, that was a huge learning point for me.

- Elea: I feel like sometimes as disabled artists, just us doing the art kind of pushes accessibility forward because we're out there existing and doing the work. And sometimes if people just don't see that, they don't think about it, they don't realize that we've been here, we've always been here. And we need to take up spaces just as much. So I think just being here, both in the space but also generally in life, I think it's really helpful. Let's wrap up with the best ways that everyone can support you going forward. So these can be big or small asks. Everyone, I want everyone to drop links, drop some links, you know, hopefully they're short and readable, but drop some links. Tell everyone where they can follow your work, find out more about you and just, you know, what would you like to put out in the universe and for the universe to give you, Leila, I'm going to start with you because you've had the hard questions, so I'm going to also start you on hopefully a nice question. Fun question I mean.
- Leila: I was trying to make space for the people to talk.. The Instagrams. I am @enbyonce. E N B Y "on-say"... who else... Follow disability, art and culture on Insta as well. Who else? Public annex. Ori Art Gallery. I'm like, what other organizations I've been working with right now and I should.
- Elea: Just in case they haven't heard of it. How do you spell Ori Art Gallery?
- Leila: O. R. I. A. R. T. G. A. L. L. E. R. Y. Ori Art Gallery. Never was part of the spelling bee, growing up. You can tell.
- Bemnia: You can follow me on Instagram @bemnia. So it's B, E. M. N. I. A. And, that's also my cash app. If you want to send me money. Or you can check out any of my links on my Instagram. I did "Disabled and Queer" with Elea, so you can check that out.
- Luann: You can find the web series I created online at gabbysmashes.com. And you can find me online on Instagram, Twitter @BGdecolonized. BG decolonized. Yeah. And I'm yeah, I'm also part of "Disabled and Here" and so you can also find me on there as well.
- Elea: If you want to follow me after this, I guess the best place would be Twitter and I'm just @Elea, which is spelled E L E A . Nonintuitive. And "Disabled and Here" is a project that I do that features disabled people of color around the Pacific Northwest and everyone on this panel is part of this project! Woo! If you find me on Twitter you'll be able to get to "Disabled and here" or if you want to go to it directly. The URL is kind of long, but it's affecttheverb.com/disabledandhere. So it's A F F E C T T H E V E R B dot com slash disabled and here. And let's talk about, so we talked about the small stuff about following each other. What about big stuff? Is there anything that you would really like to be able to do art-wise or non art-wise? If the universe granted your wildest wishes or an art project, what would you want that to be?
- Leila: I just instantly thought of all of my friends projects I want to fund. Like if I had access to like \$1 million, I'd be like, yeah. I don't know if you know folks who are rich and bored and or have a lot of free times, send them to me. Yeah. Or if you have an organization that would like actual equity training that will cut to the core and to help you mess some stuff up and redo some systems, I am hireable for that as well. Also come be a part of Ori Art Gallery. Come volunteer, come bring your projects to us. If you have a community event, we offer

free space for folks. Join the community, do something, join an organization. Everyone should join an organization. That's my big ask is that your individual activism can only go so far and you will burn yourself out. So please join an organization that will help you sustain this work for the long haul.

Bemnia: If you know any BIPOC, which stands for black indigenous POC, that would be interested in being in a makeup series hit me up cause that's what I'm doing.

Luann: What was the question? Big things that you want? Yeah. Okay. Just watch Gabby Smashes [laughter] watch the show, share it and tell people about it. I think that the big wish I would have is for it to be funded so that we can focus on creating episodes and not focus on fundraising all the time.

Elea: I feel like the general theme is we just want the universe to rain down money on us [laughter] and not stipulate how we use it.

Leila: Yes

Luann: Right, Right

Elea: Everyone's online, universe. Get online and find us. All right. We have some time for Q and A's. So if you've written questions down on your index cards now's the time that they're going to be collected. And then we're going to answer some questions.

Elea: The question was for us to all repeat social media handles.

Bemnia: Mine is @bemnia, so that's B E M N I A.

Luann: Mine's BGDecolonized, B G and then decolonized, D. E. C. O. L. O. N. I. Z. E. D. [laughs] I almost didn't know how to spell it.

Leila: I feel like I was scrunching my face in empathy with you. I was like totally, get this together. Can I get through it? Whatever. English is fake. My handles are @enbyonce, E as in Edgar, N as in Nancy, B as in boy, Y as in "yon-say" [laughter]. And through that you can pretty much find everything else that I do. I post a lot about the other organizations that I work with pretty frequently.

Elea: I'm on Twitter as Elea. @ E, L E A. But our info I don't know what the RACC URL is, but there's also an event page for all this where it has everyone's names too. If that would help you look people up. If only I knew a short URL for that. I don't actually... Apparently if you go to racc.org somewhere, you will find it. The art and power page with our information. It doesn't always have our social media handles, but it has our names. All right. We have some questions. I'm going to try to read this first and then read it out loud so that I can, do this a little bit more smoothly. All right. This says, "I recently agreed to do a video shoot to support a program I strongly believe in. I communicated my boundaries, but when the finished product arrived in my inbox, they had totally ignored my parameters. This was a mental

health org. So my question: How do you navigate requesting accommodations? Do you have any suggestions?"

Leila: Get it in writing. Having, having some sort of paper trail so that you can have restitution after the fuckup that you know is going to happen. And I just always expect those, excuse me, foibles to happen. Unfortunately, you kind of have to expect that someone is gonna not read through your contract. Someone's not going to read through your email that you CC them on eight thousand times. Be prepared with a paper trail. And also, I'm sorry that that happened to you.

Elea: Next question. What collective spaces, communities or relationships have been important to you in finding your artistic voice?

Bemnia: BIPOC, the queer BIPOC community has been a huge factor for me, a big inspiration and a big source of support. I don't think I would be here without my community.

Luann: Similar, I guess. I mean, yeah, everything is so new to me, for me. And so being able to lean the folks that [inaudible]. Well I'm gonna back up and say, knowing also the folks that are I think when, when everything went down for my diagnosis it was refreshing to know who was actually down for me too, and being able to know like the true, you know, friends and even family members that were going to be supportive.

Elea: For me, I love disabled Twitter. It's not an actual org or anything, it's just a bunch of, it's just a bunch of disabled people on Twitter. Cause a lot of times I'm, I do leave the house, but I also live in Portland and we talked about some of Portland's limitations. And so I don't always get to connect to all the beautiful queer people. I want to connect with all the beautiful disabled people I want to and all the beautiful people of color I want to connect with. And so Twitter has been helpful, hugely helpful for me for that. Especially disabled Twitter, which often has a lot of people who share all those identities with me. So talking to them online has really helped me be more confident about being open about bringing my full self and who I am and what my identities are.

Elea: The next question, I don't know, I don't know if this is a question for RACC or for us specifically. But we can pretend it's both. It says, "are your content captioned?" my stuff "Disabled and Here" does not really have any videos, so no. But yes, it's all... There's a lot of text. There's a lot of texts and there's image descriptions, cause they're disabled. And there is stock photos plus interviews. So the interviews are textual by nature with some pictures. And then I also do image descriptions. I don't know if you want to answer the RACC question about captioning. No. Okay.

Luann: Oh for Gabby Smashes, for the pilot for Gabby smashes, it's captioned and that's what we're also working on for the first season too.

Elea: By the way. Sorry I didn't totally catch the response the first time, but the answer for "Is RACC stuff captioned yet?" It was, no, not yet.

Bemnia: Um none of my art has captions. It's visual.

Leila: I mean same thing. If I ever create video it will be captioned.

Elea: Yeah. Captions usually refers to video, but you can definitely add, what's the opposite of visual? Textual. That was the word I was looking for. You can definitely add textual accompaniments to visual media. Those are the words I want. I'm tired. Yeah, so pictures can definitely have image descriptions too. And that can be really helpful to people with low vision or who are blind. The next question is, "as a disabled senior, how important is it to reveal a hidden disability when I look fine but have a serious vestibular disability?" This is really more of an opinion thing. I don't think any of us can answer for you.

Leila: No. Yeah, I really feel like that depends on so many different circumstances in a person's life, whether or not they choose to quote unquote "come out" as having an invisible disability. And that depends on so many safety factors for different people. I think you made a point earlier about folks in communities of color not, identifying as disabled or discouraging that identity, for fear of the increased marginalization that comes with that?

Bemnia: Yeah, I think it's going to be a kind of case by case type of thing. It's very situational and you're just going to have to decide for yourself who you're comfortable sharing that with.

Leila: But there isn't a wrong answer to that. You choose what's safest for you. And that's it.

Bemnia: It's okay to keep it to yourself.

Elea: Let me digest these new questions. Okay. "How do we come together as disabled artists considering spoons and energy and activate for..." I can't tell what this says. I'm sorry. Funding? Oh, "activate for funding that truly works for our intersectional communities."

Leila: Show up to grant writing info-sessions, and yell at people. I mean that's, I feel like that's something that I've been working on for a while. Trying to get funders to pay attention. And that was something we talked about at the panel during PICA or during TBA at PICA.. Was the fact that funders need to take on the responsibility of funding accommodations for us so that we don't need to take that money out of the money that we've earned. So like, you know, if I write a \$5,000 grant and one thousand of that goes to accessibility needs, that's money that I could have used to pay other disabled artists. That's the money that I could've used for supplies. You know that, that onus needs to shift.

Elea: I think a lot of times coming together can just be coming together as a small group. Like definitely there's powers in numbers, so the more the better. But don't underestimate the power of even a small group. Not being alone I think is hugely powerful. So coming together... Like the definition will vary. Who are you going to, who are you talking to? How many people do you think would be important to make someone pay attention? And sometimes if it's a small event or if it's a small nonprofit, you don't necessarily need to mobilize a gigantic million people group. So I would just say don't underestimate your power. Also, there's a card here with RACC's Instagram, which has all the panelists' Instagram handles. And RACC's Instagram is @regionalarts, in case you need that spelled, it's @ R E G I O N A L A R T S. and then that's all the questions I have for now. Thank you all



for being here. We really appreciate you coming. Yay! Thank you to our panelists. Thank you. And thank you to RACC for hosting. Yay. And I'm going to hand this back.

Humberto: Thank you everyone. Thank you all. Really appreciate it. Thank you.