

Woman's Voice: From DisArt, it's DIStopia

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Chris: Hi everybody. Welcome back to the DIStopia Podcast. This is Christopher Smit...

Jill: And Jill Vyn.

Chris: and we're back with a conversation with Sandie Yi today but we wanted to let you a little bit more about why DIStopia exists. So, DisArt is the organization that Jill and I run together and Jill, what do we care about at DisArt?

Jill: (laughs) We care about a lot of things but, specifically, we care about creating and giving opportunities for expressions of the Disabled cultural identity to come forward because we believe that it can transform a society from awareness to understanding to belonging and, in that, creating a community that enjoys the full and equitable participation of all Disabled people.

Chris: That's right and we turn often times to art to make that happen and S Y who is an artist exhibited in our Process and Presence exhibition is a great example of someone who is also taking this cultural expression into a larger world.

Jill: Yeah, yeah. She is doing a lot of work. Her homebase I would say is in Chicago but she spends a lot of time in Taiwan which is where she was originally from.

Chris: and her work is deeply attached to the Disabled culture that we are trying to promote with this podcast so what's you'll hear in this interview is

her talking about her own connection to the Disabled culture but then how her art becomes symbols of that relationship.

Jill: Here, take a listen.

[music plays]

Chris: Sandie, welcome to the DIStopia Podcast. Thanks so much for hanging out with us. Of course you are one of the artists in the Process and Presence exhibition; Contemporary Disability Sculpture and so that's the reason you're with us today but, of course, we've known you for quite some time so it's fun to get some time with you. How ya doing?

Sandie: Thank you Chris and Jill. I'm very happy to be here. I think it was 2 years ago when I came her for the festival, the first DisARt festival. It felt like it was yesterday. Wow, time has really flew by quickly and it was really exciting to see the show and engage in conversation and, of course, visit with you guys, old friends. So, it has been a lovely trip here.

Jill: So, could you tell us a bit about your work of art that's in the exhibition?

Sandie: Sure. I'm showing three panels of skin pieces and their called Skinny S-K-I-N-N-Y and I will just provide a basic description of the images. So, three panels they each have maybe 10 or 8 little pieces of skin pods. So the pods are made with silk organza so it's like a sheer fabric and I make them into little holders. My British, I mean Scottish friend, I'm sorry Clair Cunningham said, "Oh they look like teabags." So, I'm calling them tea bags right now. So little tea bags I put skin inside. So, they're skin flakes and I stitch them up with sewing thread and then embroidery thread. Some people have told me that they look like ears but that their not fully formed ears. Just very organic shapes and the overall color is pretty light, skin tonish and you see the red embroidery thread that is suggestive to be blood and some people get that visually. So this piece I made with my good

friend Rodney Patrick who is a disability activist in Chicago. Rodney and I have been friends for many many years and she was actually one of the very few Asian sisters that I recognize from Disability communities here. For a long time I did not see any other people who identified as Asian in the Disability community and I often times wondered, "Where are they? Are they hiding in their houses?" So, Rodney is half Thai, half white so she and I talked about our Asian identity and what does it mean that we have disability and all that. So, a couple years ago I started helping her as her personal attendant and so during the time that we hung out together of course we chatted with each other as crip sisters. We shared intimate conversations about our bodies, our lives, our stress, you know, jokes and all that. There was one time that I was finished supporting her with removing excess skin from her body because she grows skin 100x faster than average people. So, after removing the skin, putting lotions on and massaging. I was about to toss her skin flakes away and there was a moment in me I just felt that, "Wait, am I tossing a part of her away? Am I tossing her disability away?" I did not like that idea because I think the gesture of throwing a part of her away was also saying that throwing disability away and I feel that as disabled people often times we're told to erase our disability by getting corrective surgery, by getting ways to shape ourselves into the form and the movement that most nondisabled people do. So, I talked to Rodney and am like, "Hey, can we work on some art together?" She agreed and so I started collecting her skin flakes each time after I helped her. So this long process has been ongoing since 2004, I want to say, but I just stopped in the middle because I was trying to figure out, "What am I going to do with them?" So the whole process has been very organic and there were a lot of conversations about looking at our bodies. A lot of times when we talk about our body experience we also talk about our emotional connection. For me, this piece is very much about documenting the emotional and the sisterhood, the crip sisterhood, the connections that we have and it's about our care of relationship.

Jill: It is a very beautiful piece and when you first view it it's very delicate and it's intriguing and it draws you in. So, you've been in the gallery now and this is something we've talked about before. You've been in the gallery and we have a very general audience coming to view all of the work at Frederik Meijer Gardens & Sculpture Park and while this audience is coming, as you know, they will look at your piece, they will look at the wall text that says "skin flakes and organza" and then they will have a reaction of one form or another. Could you speak to that and what that's like as an artist? What you've notice as you've been in the gallery now with the audience and the visitors?

Sandie: In the past when I show my artwork, they capture my hands and my feet and my body, of course. That's like photographic images. This time I'm going to hid and blend myself in the crowd and observe what's going to happen. So part of me was like, "Maybe I should hide my hands so they don't identify me" and then all of a sudden I realize, "No, I don't have to!" because this piece does not show any Disabled bodies. So, some of the conversation I overheard included, "That's really creepy. That's so creepy. That's so creepy" and then they try to get away from it. It did not offend me. I just thought, "that was really funny" just to watch people's reactions. And some people were like, "What?! Human skin? I did not know human skin can go into art." I love the moments when people seemed to be very puzzled and they go back and forth between the text and the sculptures themselves and they're like, "huh." I tried to give them some space. I don't want to be hovering around them and be like, "Hey, want to ask me questions" and "I'm the artist." I kind of leave some room there and a couple of them did notice that I was here if they have any questions. Once after we engaged in conversation, I feel like it's a very subtle connection that people are recognizing. For example, from a caregiving perspective. There were many elderly audiences and they were like, "Yep, we have caregiving experiences a lot. We get that." Some people were like, "Oh, I did not realize this is an experience." So, I like the fact that this piece is not as obvious like, "This piece is about disability." Or, "This piece is about

getting to know your sisters.” It’s there for people to engage or not to engage and I’m perfectly fine if they choose to “I don’t know. I don’t know what this is,” and they go away and that’s fine too.

[music plays]

Chris: As you talk about your work, I think a theme in Disability art or a couple themes that seems to be alive in your work too. As you explain it we can hear that there are some things that are hidden. There are things that are secret. But then there are also things that are exposed and there’s a balance between showing and not showing that I think is really alive in this piece, in particular. But also alive in other Disability arts. Does that resonate with you?

Sandie: Yes, definitely. I’m so glad that you recognize the hidden secret part of my work. Looking back all my body adornments that I have made they do have a thing. There are some messages that I only make them for a specific group of audience. Such audience is my crip family. So, earlier I was talking about how some audiences get it and some audiences don’t. Before I came out as a Disabled artist, it was often times trying to figure out what’s going on between the nondisabled world and myself so I felt very lonely and feeling like I have to show them that I can do it. “Don’t worry about me. You don’t need to help me because I can.” A lot of time spent on trying to convince people that, “Yes, I can.” And after awhile it’s really exhausting and I’m pretty sure that many Disabled people might resonate with this feeling. Asking for help is hard but after I came out as a Disabled person, I slowly learned that I’m not in it all by myself. There’s a family. Right now as I am taking on the role of not just Disabled artist but then also arts administration for Bodies of Work (It’s a network of Disability arts and culture in Chicago), I feel like I get to have a platform to advocate for other Disabled artists work and I’m seeing that it’s so important for me to save my energy and focus my energy on building a platform. Building a network for fellow Disabled artists and such connection, for me, is carrying on the

heritage of Disability culture. I was telling my advisor and also my mentor, Dr. Carrie Sandahl, "Carrie, I don't want to make art for nondisabled people anymore. I don't care about what they think. I don't care about them." And in a way it feels really liberating. That's not to say that I don't love my nondisabled friends anymore, but I think it helps myself to voice that, "Hey, I just don't care." I know that Disability art is the genre, is the movement that many colleagues and I are building and I feel strong about it. I was recently in many conversations in London during the Unlimited festival were talking about, "If we put ourselves in Disability art is that going to be ghettoizing our work?" and "What if people don't see the beauty of it? What if people don't know that we have abilities?" I am not thinking about it that way anymore. It takes a lot of emotional labor and energy out of us crips to constantly thinking, "Oh, I have an audience. I have to educate and to teach." So, I feel that right now I am in a stage where I am making art for a specific group and I feel really comfortable; feel home in it.

Jill: That's really beautiful. It makes me think about how you've been on such a journey. Can you tell us a little bit about your journey over the years to get to this point where you seem so confident and comfortable in your Disabled identity? Has it always been that way for you?

Sandie: How long is this podcast?

[Chris laughs]

Jill: Go for it!

Sandie: Well, I'm 37 so we might need to take 37 hours. (laughs)

Chris: No problem.

Sandie: I was born in Taiwan and I came to the States when I was about 16 as an exchange student. Disability runs in my family so I was born with two

fingers and two toes on each limb; two digits on each limb. In my family that's not something we talk about. In fact, I think my dad has this idea that I'm more emotional and vulnerable as a little girl and I will eventually grow out of it. He has always been a strong figure in my life but something about our hands and feet is a no-no, we don't talk about it. After I came to the States, I felt like my disability wasn't an issue. Now looking back people didn't know how to talk about it or people were like, "Oh, she's from Taiwan. She's different altogether." I don't know. Coming to Chicago for both my undergrad and graduate degree in art and art therapy, I started making art about my hands without recognizing, "Oh, it's a disability experience." None of my critiques, none of my class conversations talked about, "Oh, you have a disability." I want to say that people were pretty supportive. For example, when I had a critique one time and the work was about my way of dealing with a woman who screamed at my hands in a store. One hand piece was a jewelry piece I made for myself. It really talks about how I wanted a weapon but growing up I was always told that, "You know, people always ask about your hands because they care about you. They wanted to know what's wrong. They wanted to help you. That's why they approach you." So, I actually grew up with this mentality that because I am the one who has a different pair of hand, it's sort of my responsibility to comfort whoever approaches me. "Oh yes, I'm okay. Don't worry about me." And then I have to show that I can, but I think deep in my mind I'm like, "Oh my gosh, I have to hurry up and make this work otherwise people are going to come and rescue me and I don't want that." In a way it gets me pretty good with my art because I want to focus on my art and I wanted to make it into the quality that I know that I want to see. Like I said, that has good and bad but back to the art piece that I made. I talk about like, "Yeah, this woman screamed at me and I didn't know what to do so I made this weapon-like jewelry piece for myself." And my classmates were like, "You know, this could be a really interesting performance that you could stand in the middle of a public space and we'll each hide at different spots and you show your hands and somebody screams and we will all scream from various spots at the location." I don't think any of my classmates had any

disability awareness or political relations at all. I just thought, “Wow, performance art, huh?! This sounds like a great idea.” So I started to pick up strategies about how I combat this huge thing which I am now able to name is ableism. For four years in my college, I made art about my hands and feet all the time again without recognizing that it’s called impairment, it’s called disability, it’s called oppression until very very later. I was in art therapy training to be an art therapist and I was reading about disability studies and it took me a long time to read and, of course, English is my second language but I haven’t found myself having a difficult time with reading understanding. What was so difficult about reading Disability studies was that for the first time I feel like, “Oh-my-gosh-how-do-they-know? How do these people, how do these scholars know that’s my experience.” So I would read a paragraph and start to sob, “Oh my gosh. This is too much.” And then I realize that it was really empowering and I am finally heard in a very deep way. So I think my exposure to Disability studies and especially 2006 I ran into amazing Disability artists do amazing work in Bodies of Work festival. And I came out as a Disabled person because of the presence of my fellow Disabled artists and all of a sudden I had crip brothers, crip sisters and it was such a relief that, Hey, I don’t have to explain to them. They get it. I don’t have to try to comfort them because they get me.

Jill: I was just going to say that that’s a consistent theme that we’ve been hearing as we meet volunteers or people who are models in our fashion show or people that we work with who are disabled who, when they become part of community, who you identify as your crip sisters and brothers. Whether they identify them as crip sisters and brothers or not there’s this common experience of...relief. When you get to be with someone who you don’t have to explain yourself. And we’ve heard that again and again and I think for DisArt that’s what we’re trying to move toward. It’s having more and more of those experiences for people.

[music plays]

Chris: I'm getting really curious as our work develops and as we listen to your story and the stories of other Disabled artists. You know, you talk about coming out as disabled and you talk about finding your culture. I had a very similar experience. I'm wondering...just reacting to, then, you saying I want to make art for my people. Is there room in Disability culture for nondisabled people? What's the place for them? Do you know what I mean? That's a question we deal with all the time. What do you think?

Sandie: So, I think a lot of time when we say nondisabled we do make some people feel alienated because they're like, "Oh, I want to help with the movement and you're putting me into this category." When I was in London doing the Unlimited Festival, one gentleman from Ireland was talking about in his community many people do not like the term "allies" because they feel that allies, nondisabled allies are less important. I think it's important for us to look at the context. Why do Disabled people make this distinction between nondisabled and crips and I think we need to look at the context and understand, "Oh, this is how history has been written and how the power dynamic and the power structure has been written." And how phrases like nondisabled and crip help us identify where we want to position ourselves so I do find these terms very helpful especially they're apart of identity politics and it helps us to see, "Okay, how are we going to connect with each other." I think this is the key. How do we connect with each other? There are many people who identify as not yet disabled and they come into Disability community by being spouses, by being family members, by being children. It's their culture too. So, in Taiwan where I was born and raised people are talking about how disability activism so much more than in the past maybe 10 years and I do start seeing people wanting to be part of the group. And they're like, "Well, I have family members. I have a sibling who has a disability and I have a say in it." There's a pressure that, "Well, you're not suppose to say anything because you're not disabled." We also find that we need disability representations to speak about disability issues in various town halls or government meetings

and now I'm also seeing that people kind of just flock in like, "Oh, there's a Disabled person. Put this person in" without checking if the person has the expertise or has the training in the issue. So, a lot of time what I do in Taiwan is like, "Let's take a look at what this person is saying." When you are a Disabled person, it doesn't mean you have Disability politics. It doesn't mean that you're in the culture. It doesn't mean that you are politicized so let's look at what this person is doing, how this person is carrying out the messages. I think the same thing applies to people who identify as nondisabled. Like, "How are they talking about Disability culture?" I think that's what brings people together and I have so many friends who identify as nondisabled but they are politicized in terms of Disability culture and Disability concepts. So, I don't know if that answers your question. Yeah?

Chris: You know when you were talking about Taiwan and talking about plopping Disabled people in before knowing whether or not they can articulate or have training or have deeper understandings of disability. That could be the source of a lot of cultural confusion actually. I think it's really interesting. I can't think of an example in DisArt when that's happened, but I can think of examples in which somebody was chosen to speak because of their disability and when they get up to speak they just perform a sort of able-bodied or nondisabled version of disability. In other words, they say the things that they think people need to hear or that they think people want to hear not necessarily what people need to hear. What I'm finding really interesting is that as a Disabled person navigating that world, you've said and we know this personally too, that navigating that can be exhausting. And, yet, even when we get the opportunity to say what we really feel like last night when we had this panel in front of an audience and we're talking about Disability art and maybe they've never heard about Disability Art. So we have this opportunity. I still think it's exhausting sometimes. It's my life's work and I love to do it, but there are times in which being on stage or being on any stage whether it's eating in a restaurant or literally being on

stage where this work can be really tiring. There's no question there. Does that resonate with both of you? What do you think?

Sandie: Yeah, I do feel that it is something that us Disabled people are expected to be responsible. As a Disabled woman of color, I do experience it at multiple levels and sometimes people don't recognize my disability in the first place and I find people like, "Oh you have a disability. Oh my gosh, I'm sorry." And I'm like, "Oh, did you do anything? No." I will have people coming to me asking me questions that has nothing to do with my art. It's interesting to see how that plays out, but I do recognize when you talk to general audience, I do need to remind myself that I'm not in my own Disability culture community so I do have to be sometimes more patient. And one thing I actually learned; I think in the past I was always, "Oh, my gosh, I have to show them and they just didn't know" so I always had to put up my best face out. And, then, after awhile I'm like, "You know what, I'm just not in the mood today" and it's okay for us not to be on all the time. It's okay if nondisabled people encounter a really grumpy disabled person. That's perfectly fine. I don't want to carry the burden on me feeling like I have to teach all the nondisabled people all the time. If I'm in a crappy mood, I am. And if you're not that educable, I'm not going to say too much to you. I'm just going to reserve my energy. So I'm finding a balance and also seeing some pretty radical and pissed off Disabled people helps and knowing that, hey, sometimes it is a strategy.

[music plays]

Jill: I'm very interested in hearing about what projects you're working on now and what are you imagining for yourself in the future as an artist and as a scholar.

Sandie: Right now I am working on my dissertation and the focus will be on disability and fashion. I started describing my work as *crip couture* since a couple years ago. One thing about making art in an art school back in

college was I got exposed to a variety of art including fashion but I was too intimidated by fashion people. They were famous to be the snob in my school back then I was also like, "You know what? I always want to do something about inner beauty." I think back then I was dealing with a lot of body image experiences and just like, "Oh, yeah, how do I show my body?" So at that time I was like I want to do something that's more internal and I don't want to do anything superficial and, besides, fashion people look very scary to me. They are just too cool. So I did not take any fashion classes. Only one shoemaking class in my masters training. Years later I find myself that I really want to go back to it. By going back to my fashion for fashion but I want to highlight a nuance that I see in fashion and disability. So, right now I am working on creating theories on crip couture and I'm thinking about it how crip couture is like high fashion for Disabled people. I think it's great that many industries, many companies and many Disabled designers are creating adaptive clothing that's easier for people to put on or are tons of show representing Disabled people on the catwalk. I do find value in them but at the same time I find that some shows are problematic in that they only choose pretty Disabled people of single race. Often they are white. For example, I think of New York Fashion Week. There was an amputee with great body, six pack and he had beautiful body paints on him and then there was a beautiful woman in a wheelchair and she was wearing a chiffon dress and the dress flares out. I was like, "Who wears that when you are in a chair?" It's unreal. The clothes was not made for them. It was just put on the show and then people are like, "Yeah, diversity." Yeah, well you put on a show featuring people whose certain feature only fit the mainstream beauty standard. That's not a show that I want to see. If New York Fashion Week is going to have the model with breathing tube and trach and with weak muscle or being flat on a bed, I think it's going to make a different message. Just yesterday meeting DisArt models. I love the community energy that are bringing people together because I think maybe for many of them it was the very first time that they got to connect with Disability culture. So I see crip couture as a way to reframe what does high fashion mean in the context of disability. The care,

the attention I am putting into the stitches, the designs are mingled with the care relationship that I provide to other people or I witness other people provide to Disabled people. So, this attention that I am trying to capture in my work I hope it demonstrates what it means to bring people together to see the meaning of Disability culture and also its complexity. I envision that the work captures personal experience and one specific garment or adornment is made to reflect this person's story.

Chris: I do have a question that has come up in our work with fashion industry stuff and that, of course, is the economic question. Crip couture, high couture we're talking about clothing that is very expensive oftentimes. Are you dealing with that element of it to because that, of course, many of our constituents, many members of our culture are underemployed or unemployed and so how do we reconcile that part of it? Have you thought about that or are you thinking about that?

Sandie: Yes, that's a really good question. So, I'm thinking about crip couture more as conceptual art just like, yes, there are many types of fashion. Fashion more like the marketing part or the more conceptual art. More just art for people to think about. And I am leaning toward, I want to create a conceptual space and that's open for more dialogue because I am really arguing that the intimate relationship, the care relationship that exists in disability culture can generate vocabularies for designers to think about their creative inventions as they work with Disabled people. So, I don't have interest in building a line for Disabled people to purchase in stores. I think a lot of people are doing it and I support their work and, for me, I'm focusing my energy crafting a way of interacting with my crip sisters and brothers and, again, using the concept of high fashion but, then, redefining that such high fashion in crip community is basically. In a way is already borrowed from the already exist care relationship that we share as a community.

Chris: Do you and your people at Bodies of Work, how do you envision what you guys are doing? I think that we are sister organizations in some

ways because we're fighting, certainly, for the same kind of things but how are you guys making it work? What are you finding is challenging? What are your issues? Because I think that's the other part of it that I really want our listeners to get from is that you're not only an artist but that you are an administrator of this larger process and I think that that's really good.

Sandie: So, at Bodies of Work we are a very small consortium. I mean, there are a lot of consortium members but we only have a few people. We do a lot of collaborations. I think I do find similarities between what you just said and the way that we try to push things forward at Bodies of Work and we don't have money. A lot of times I'm like, "Oh, no money." I think Carrie is really helping me to see, "Right, we don't have money. We will also welcome more money but how do we collaborate and bring pockets of resources together?" And the goal is to produce quality work that reflects the complexity of disability so I think having that on our agenda really helps as we are developing artists in residence programming with 3 Arts Foundation and so the artists are able to use the university resources on campus which is the University of Illinois at Chicago. We want to set up a training or a supportive program for Disabled artists to really bring their visions forward and we do encounter Disabled artists who are not yet familiar with the cultural terminology or the practices that we are use to. I think it's great working, learning process. It's also about community building and one thing that Bodies of Work insists on is when we bring in Disabled artists, let's say, from out of the town or out of the country, we make sure that there is one conversation lecture happening in the academic setting and then one connecting to local mainstream theaters or venues and the other one with independent living center which is Access Living. Carrie has this amazing idea that we want to make new works, communities, and build conversations into the academic but also bring the academic and mainstream art people into grassroots organizations. So we see that this is the way that we use Disability art to create a larger movement to create spaces for us to talk about things that we do not know yet. Quite often when we present Disability art, we have audience who have not spoken

about their own disability their entire life and we actually have people coming out like, “ Oh, after hearing your story I realized that I am disabled too!” I don’t want to say that, yeah, I’m surprised when it happens. We often get people from the communities which Jill identified earlier. There are maybe in transition or they don’t know that this is something that I can see myself belong to. I certainly have been there myself so I do see the value of the work that DisArt and Bodies of Work are doing. I think we are building a larger culture.

Jill: A larger culture that people are proud to be part of because some of the questioning that I’ve heard is that people not be confident that they are ready to be part of the culture. If the culture is strong and empowering and positive and supportive well, to me it seems that it will become an easier process for people to identify.

Sandie: When we program our events and talks at Bodies of Work, we also talk about the complexity of disability. It’s not just something that, “Yes! We are proud and Disabled.” Because having disability pride, it does not quite exist in many communities especially in communities of color. It’s like, “No, that’s not the way that we think about self identification.” So, I think one of the complexities that we’re talking about is, yes, we all have facades as human beings. Our art can be articulating the pain experience. What does that mean to ask for help? What does it mean to be vulnerable? And how all the strengths and weaknesses and everything in between can co-exist.

Jill: We’ve spent a lot of time with you and we really appreciate your time. Thank you for being here with us.

Sandie: Thank you. I really love being here.

[music plays]

Jill: It's always a pleasure to spend time with Sandie. We hope for those of you tuning in that you take away a bit of her personality and an appreciation for her work in the ways that we have come to know her.

Chris: Again, we want to point you to DisArtNow.org where you can take a look at the Process and Presence exhibition. We have a virtual reality tour or a 3-D tour of that exhibition so you can see Sandie's work, you can hear audio descriptions of her work and a whole bunch of other DisArt stuff.

Jill: It's a place to hopefully go and hang out. And, as always, please contact us. We love to hear from people. Tell us what's going well about the work that you see us doing or you're experiencing. Or tell us what you think we're missing.

Chris: That's right. So, until next time this is Chris Smit.

Jill: and Jill Vyn.

Chris: See ya.

[music gets louder]

Woman's voice: Subscribe to DIStopia on iTunes and make sure to visit our website DisArtNow.org to find transcriptions, all of our episodes, DIStopian news, and much more.