

## **SYPartners**

### Designing for Humanity

#### Episode 7: Advocating for inclusivity through art and conversation, with Shannon Finnegan & Sugandha Gupta

[Music]

**Rie Nørregaard:** [00:00:03] This is Designing for Humanity, a podcast by SYPartners about designing a future that's made for all of us, and the best in us. I'm Rie Nørregaard, and I'm talking with some of the most interesting people I know about how we, as designers, can tackle the most complex challenges our society faces right now. How can we use design to reimagine the ways we interact with each other and with the world? I'm here to start the conversation about what new ways of thinking and methods are needed.

**Rie Nørregaard:** [00:00:40] Today, I have Sugandha Gupta and Shannon Finnegan joining me in the studio. Gupta is a textile artist and maker who uses a variety of materials, everything from paper to wool, to create a holistic art experience that spans the senses. Shannon Finnegan's work explores disability cultures and access through different modes of design, art, and writing. She's done projects for the Invisible Dog, Friends of the Highline, and the Wassaic Project, where she created the Anti-Stairs Club Lounge. Sugandha and Shannon are both WITH Fellows, a program run by the Disabled List that places creative disabled talent with top design studios and agencies in New York City for a three month fellowship. WITH is expanding to San Francisco in early 2019, which is insanely exciting. I'm so happy to have as Sugandha and Shannon here to talk about their experience with art and design. Welcome to both of you.

**Sugandha Gupta:** [00:01:32] Thank you for having us.

**Rie Nørregaard:** [00:01:34] Sugandha, what was your process to understand yourself as both a designer and an advocate?

**Sugandha Gupta:** [00:01:40] I think I was following design throughout my life because it was not a choice. It was just a way of surviving. So I have albinism, which is a genetic condition that affects my vision and makes me really light sensitive, and also I don't have pigment in my skin, eyes, and hair. And so I always stood out of the crowd, especially growing up in India. I really started understanding design when I was enrolled in undergrad, which was in the National Institute of Design in India and

## **SYPartners**

there was a lot of pressure because it's a very prestigious school and very few students. When I was faced with the challenge of competing with those students and really surviving, that is when I started thinking about how I can change the way I'm doing my tasks.

[00:02:31] It was really difficult to look at a ruler, for example. Like, I could not even see the steel ruler because it reflected so much light. And so my professor suggested to me, because I was so frustrated and so sad, he said, "Why don't you design your own ruler and make one with cardboard so that you don't have to keep on measuring again and again?" And it was a really simple idea but it was really daunting for me at the time, like, "Oh my God, now I have to create a ruler?" But really, as I thought about it, by the end of my undergrad I realized that it's really my approach that I need to redesign. I can do anything as long as I approach it in my way, and ignore what others are doing or what the trends are seeing. And so I think that's really when I understood design.

**Rie Nørregaard:** [00:03:18] That's amazing. You had to make it your own process to really make it matter. And I want to ask you, Shannon, as a visual artist: looking at some of your bodies of work, I think the idea of activism is in there and probably has been with you for a long time. But I'd love to hear about your journey putting together your art, or your idea of making, with advocacy.

**Shannon Finnegan:** [00:03:45] I think for me it really started from my own experience. I have cerebral palsy and I grew up really isolated from other disabled people. And it wasn't really until I was in college that I even understood that lots of things that I had thought of as very personal, individual experiences were actually shared experiences that were shaped by culture and larger societal forces, and so that was a really eye opening moment. Later on, I was starting to integrate thinking about disability into my work, but often in ways that I think other people wouldn't necessarily have seen directly. In the past few years, I think, just looking around at representations of disability in mainstream media, I was just like, there's really nothing that feels like my experience at all, in terms of capturing the nuance of my kind of day-to-day experience that you know, some things are hard but some things are funny, or some things are weird, or some things are really interesting. And so the start for me was like, how can I at least add my experience to some of the narratives and representations that are out there, and kind of start building connections from there. So, what are points of connections between my experience and the experience of other disabled people. What are points of connection between my experience and the experience of non-disabled people.

## **SYPartners**

**Rie Nørregaard:** [00:05:21] I think we should focus on the recent project of yours to understand what your art is about.

**Shannon Finnegan:** [00:05:30] A recent project that I've been excited about is making benches and seating. I started with making seating for museum and exhibition spaces, really kind of starting from my experiences of visiting exhibitions and just how hard it is on my body to move through those spaces, and so basically it's a line of benches that have text on them. So, an example would be a bench that says, "This exhibition has asked me to stand for too long, sit if you agree." Or one that says just, "I'd rather be sitting, sit if you agree." And part of this project comes out of the idea that for me, a lot of accessibility and access measures are going to take a lot of really radical change and are really long-term projects, but some things seem so doable. Like, more seating in museums feels like such an achievable goal.

**Rie Nørregaard:** [00:06:27] It does. I agree. It feels like... it feels like we could make it happen. (laughs) Yeah.

**Shannon Finnegan:** [00:06:33] Yeah. This project is also connected to some thinking that I've done about, just, forms of protest, or forms of... I guess advocacy. And thinking about how we often think about protest in very ableist terms, where we're talking about "standing up for something" or marching. But there's also a really rich history of seating and and sit-ins as protest. And so I like the way that the benches offer kind of a voice while also offering comfort and rest.

**Rie Nørregaard:** [00:07:10] Sugandha, do you think you could describe for us either a current project or something that you think will help people who are listening, given that this is a podcast and your work is highly experiential?

**Sugandha Gupta:** [00:07:23] When I came to grad school, to SCAD, I had the clear idea and vision that I want to take forward what I learned from my undergrad and really research and delve deep into it. And at that time I was really thinking about disability as an overarching theme, but in my very first quarter at SCAD, in my art history class, I researched an artist known as Judith Scott, who was disabled and who had Down syndrome and was institutionalized for 35 years. But her work eventually, as a fiber artist, really got recognition and really communicated with the audience. So that's when I really started thinking about like, what other artists or individuals doing to use their disability as their strength, because really that is what I found through my journey. And so I started

## **SYPartners**

reflecting on myself and I found that my strongest senses are my strengths, basically our sense of touch and the sense of sound. Because that really eases me in general, to navigate or to even work—especially when I'm reading, and there was a lot of reading in grad school. When I started listening to things that made it a lot easier for me to learn.

[00:08:39] So my thesis body of work which I titled as Sensory Textiles was a way of creating art through textiles that can be experienced by a wider audience through their senses, like touch, sound, smell, and of course, also sight. And so this way I not only wanted to offer a broader experience for the audience to experience art, you know, in a new way that doesn't inhibit just looking at it, but also touching it or smelling it. Because what I learned was that we gather information around the world through all our senses, not just through our sight. So why not let everyone experience art through all their senses? And just like Shannon, I do have difficulties, like when I go to exhibitions or museums, because all the tools are designed to be navigated through sight and it's really challenging for me to appreciate the artworks completely because I'm never able to read the titles. In even the audio devices they have, you really have to look at the numbers and it's really not designed just purely based on audio. It's not thoughtfully designed, I would say. And so that's what I've tried to do. For my thesis show I was associated with Savannah Center for Blind and Low Vision, and I often went and met their clients and got feedback from them, so I created a lot of textiles that have a lot of different textures through different fibers, so when they came to my show I also had my artist statement printed in Braille, so they can understand and appreciate what my thought process is without me necessarily having to tell them, or having to read it to them. So they could be independent. And it was a really fascinating experience in my thesis show, because everyone could touch. Irrespective of whether you're sighted or unsighted, deaf or not deaf, you know, if you can't hear, you can smell; if you can't see, you can touch. So I really wanted to offer a diverse experience.

**Rie Nørregaard:** [00:10:48] So it's interesting when you describe an audio guide as really being a visual experience supported by audio; why does that happen, you think?

**Sugandha Gupta:** [00:10:56] I think that when we design things we don't really consider a holistic approach when we are designing. We often are very narrow when we are designing something, and I think that's the problem. Another thing that I feel that is lacking is inclusion from the start. Really like, how many disability study courses have you ever had in school? How many art history classes include artists with disabilities or visionary art for that matter? Really rare to find those things. And so, when we lack inclusion at every step, we don't even think about the things that are existing that

## **SYPartners**

we are ignorant about. We continue to be ignorant. And the other thing that through my own life experience I've found, is that when people encounter something different they ignore it and are indifferent to it, because they don't know how to deal with it or they just are arrogant sometimes. So I feel that if there is inclusion in society in everything—in friendships, in including people like a diverse population from a very young age, then people would be more accepting to change. And so it really starts from scratch, from the roots. I think that throughout history the problems that we faced or the problems that the world has faced are because of the tendency of human beings to discriminate—whether it's caste, color, sex, creed, race. And so disability is no different. And it's really ironic that even today we segregate people with disabilities so much, it's like us and them, whereas to me I think everybody has a disability, but it's just that the people whose disabilities are more visible carry the burden of being called disabled and carry that label throughout. Whereas, even perfection is a disability to me, in my opinion.

**Rie Nørregaard:** [00:12:58] Hmm. That's fascinating. Shannon?

**Shannon Finnegan:** [00:13:00] Well, just something that I thought of in terms of the audio guide example and something that I think I see a lot in terms of solutions is: to me, it's suffering a little bit from a kind of universal design framework, that one audio guide should both augment the experience of sighted visitors and also be the primary mode of engagement for visitors who aren't sighted or aren't learning visually, and that there might be a way to integrate those two experiences but it sounds to me like that's not working currently. And that's something that I'm really interested in, is how a lot of times I think the needs of disabled people have to be justified through broader good because of the popularity of universal design, and the success of things like curb cuts, but that sometimes we just need to design for a specific experience and it might mean that a design solution really is for a smaller group of people or even one person.

**Rie Nørregaard:** [00:14:08] You're just describing the distinction between getting it right and really serving one person's need versus believing that you could serve everyone's needs with the same process at all times. The more you know about different modes of human experience, the better you can account for them. If it's something that exists in your life and it always did, then you widen your aperture and your sensibility naturally. With the WITH Fellowship, we're sort of going into the middle of the process—we're starting post-design education. But still, really trying to change the dynamic between input, who gets to provide input, and who ultimately creates the output and solutions. And

## **SYPartners**

so I would love to hear, from your perspective, what that looks like and what can we do to make it better?

**Shannon Finnegan:** [00:14:57] Something that I've noticed coming to design environments is that I think design is often searching for this elegant, smooth, easy, effortless solution. I think that's part of what the appeal of universal design is like, oh, if we just think about or design for a specific need like, we're gonna make everything better! And there are great examples of that happening. But I think I'm interested in the ways that there might never be a simple solution. Like there might always be a lot of complexity. It might be really hard. And so I think of my role in some ways as bringing friction to some of the design process and kind of pointing to complexity and trying to expand complexity, when I feel like a lot of what's happening is about simplifying and distilling.

[00:15:57] I was working with Liz Jackson—who started the Disabled List, which started WITH Fellowship program—on designing a logo for the WITH Fellowship program. And that process brought up a lot of interesting conversations around to what extent do we want disabled people to be able to integrate into design environments, and in what ways do we want to continue to kind of stick out. And just through, kind of, conversations about what that logo should look like, I think there's one way of thinking about it, which is "design has not been inclusive for us," and kind of embracing an outsider status; where there's another approach, which is, if this fellowship is about, kind of, pathways to design and creating entry points, then this program needs to be legible in a design context and look quote-unquote official, or quote-unquote professional in a certain way. And so it's interesting trying to combine some of those elements. And what we ended up doing I think is kind of marrying the two of those. Or that's the hope I think, of kind of creating something that feels designed, but still has a little bit of friction and is pushing back a little bit on what has been considered good design.

**Rie Nørregaard:** [00:17:17] So we have a general idea of a design process that we learn in school, right? We research, we ideate, prototype, get some feedback hopefully, refine... does the process that you're experiencing, working with other people in industry and in design, is that working? How can we look at that from your perspective?

**Shannon Finnegan:** [00:17:38] For me, I think something that I've been noticing is around the research piece. There's a lot of general context that designers are missing about disabled people, about our history, about disabled people as an identity category, as a political category, and that's

## **SYPartners**

something that even I think needs to come in before a specific project because it's kind of much broader. It needs to be an everything, I would say, that designers are working on and it can't just be kind of research around a specific problem or project. And so that's something that I've been thinking about is, how can there be more communication around these really fundamental pieces of what disability is, and how it has operated both historically and now, and making sure that that's something that people are learning about and is on their radar.

**Rie Nørregaard:** [00:18:35] That's really helpful. And I think the other part of that is who: who's in the room, who's on the project, who do we listen to, and who executes. And so, having a person with the experience of being a disabled artist or designer is helpful. It makes me wonder what other voices we need to add into the process. Subject matter experts are not necessarily expert in life, or in representations of people's experiences. And in the design field we're very good at "projectizing" solutions, you know, that are different from our own experience. And I think what I'm interested in exploring now is how do we put ourselves back into the work and really use our own life experience. And so, you need many people's life experience. Sugandha, I'd love to hear from you also about the process that you've experienced in your fellowship and how, if we are to make more inclusive products and experiences, how do we also adjust the process?

**Sugandha Gupta:** [00:19:39] I think that something that we're missing is the human interaction. We are so heavily dependent on Google that we forget that there are books. And if we remember the books, then we forget there are still people. I feel like we need to have more open dialogues, more platforms where we can really connect with people on a one-to-one level or in a group. I feel this way because I was a speaker in a conference, Embrace Conference, where I was talking about what opportunities come out from disability and how my disability is really my superpower. And so I found that when I spoke openly about my disability and when I shared my experiences, more people opened up to me and a lot of people asked me questions about how they can collaborate with people with disabilities, because there's such a big disconnect as to how they can approach a person with disability. And that's because of the way that society is functioning and how disconnected we are, because we are constantly in our own bubbles. So I think that's the need we really have. Like how can we have a real human interaction, and have an environment where we can induce that conversation and have a free-flowing dialogue.

**Shannon Finnegan:** [00:20:56] Yeah, I think what just kind of came out of that for me is thinking about how do we build the support for disabled people to share their experiences. Because I've had

## **SYPartners**

moments where I'm walking down the street and someone asks me a question about my disability, and they're asking for this very personal story. And so I don't want to be in a position where I have to share always, but I think building structures like WITH, where in this scenario that's part of my role is using that part of my experience and sharing that kind of experience, and yeah, I think that's really important in terms of the sustainability of having different voices in the room is making sure that there's support around that and that people don't feel tired or exhausted of revealing themselves and advocating for themselves and the other groups that they're a part of.

**Rie Nørregaard:** [00:22:02] That's a good point. I mean I can hear both what you're saying Sugandha, the opportunity you give for many people to express themselves by going first if you will, and letting them into your life and what you're going through, is very beautiful. But it's also a big responsibility and not something that's always possible or should even be expected. One of the things that I'm finding in this podcast is that a useful shared language and starting point lets us know that we appreciate some of the same things, that we're interested in exploration and questions. That allows you to connect more easily. That's perhaps the value that we're missing is the uniqueness, the friction, the point of view that doesn't have a voice if it's not there in the room and part of creation. How can we prepare ourselves, and how can we prepare people to ask better questions and not be worried that needs can't be met or something? Sugandha it makes me want to ask you about your experience as a WITH Fellow.

**Sugandha Gupta:** [00:23:07] For me, I think what it's doing is it's really bridging the gap between the able and disabled world. That the intervention is happening because of lack of inclusion. And I think for me, it's been a great platform not only to talk about these issues, which I'm really, really passionate about, but also to give me access. Because unfortunately, there is a lot of hidden discrimination in the world. And I feel that I'm really privileged that here in the U.S. I found that people are much more open to talk about different issues and different scenarios and situations, but still when I came and I started applying for jobs in the industry, if I would openly tell that I have a vision disability or if I have albinism, out of ignorance a lot of people would ask me if I can see color. And it would often lead to the conversation not going forward, but through WITH Fellow I was able to get that access and that gap was bridged. I think that the important question is to ask the employers who are enrolling WITH Fellows how normal are we for them. And that would really help to really gain understanding about how different we are, and how different we're not, because we are all different in many ways, and so even though I acknowledge that there are some quote-unquote disabilities that



## **SYPartners**

need more assistance or that need more help, they are all special in their own ways and they bring something unique to the table.

**Rie Nørregaard:** [00:24:47] Shannon, you look like you're thinking about something there.

**Shannon Finnegan:** [00:24:50] Yeah, I mean I think any WITH Fellowship is going to involve an element of unknown, right? It's a person and an organization coming together who don't know each other, and don't know how to collaborate. And I think something that I've been grateful for is that there's been a lot of flexibility and willingness to be uncertain about what the collaboration will look like, or exactly how everyone will benefit from the partnership. And I think that's left a lot of flexibility and space to observe and learn and even just kind of have more casual conversations that I think have been really fruitful and interesting.

**Rie Nørregaard:** [00:25:35] So it's as much in maybe allowing for conversation to happen because you're actually together in an environment that would stimulate that, versus only being project specific and thinking about it so directly.

**Shannon Finnegan:** [00:25:49] Yeah, I mean I think, going back to what Sugandha had said, like, disabled people have just been so isolated and so separate for so long that just having a disabled person as part of the organization, in a way that the organization is kind of open and listening to, has a lot of value to it.

**Sugandha Gupta:** [00:25:49] I feel like the problem is that we are always thinking about when, and how, to communicate about our disability. And I think design, and any venture, whether it's business or whether it's design, it always starts from the human communication and how we connect and form relationships with one another. And I think with a platform like WITH, it's really significant and it's just really helpful that we can actually be free and not worry about when I should talk about my albinism or when I should talk about my XYZ disability. So I feel like that's the environment that needs to be cultivated more. How can we stop thinking about how we communicate about our disability, because even though that identifies us that doesn't define us.

**Shannon Finnegan:** [00:27:06] I think I often have the experience going into situations with new people or where I'm navigating unfamiliar circumstances, where I really want to be likeable and I want everything to kind of go smoothly and everyone to get along. And I think the Fellowship is designed

## **SYPartners**

to be a space where there can be authentic dialogue about different experiences. And so, I think it's interesting to kind of reflect on that as you enter the process.

**Rie Nørregaard:** [00:27:36] This is an amazing conversation. I think it's really helpful on many levels. I have a question that I like to ask on this podcast around your basic orientation towards life. I like to ask if people feel hopeful for the future, if they're optimistic. Because saying that we're people who solve problems would almost indicate that you have some idea that you could affect the future and that it could be better. Designers are very quick to say, in general, that they are optimistic. It is almost like a knee-jerk response. So I want to keep asking that. Shannon, are you an optimistic person?

**Shannon Finnegan:** [00:28:16] I think of myself as an artist. I generally think the art world is a very pessimistic place. I was thinking about this on the way in today because I was actually using a tote bag that I have from the organization Triple Canopy. And on one side it says, "bright pessimism," and on the other side it says, "dark optimism". I actually really identify more with the bright pessimism side of it, that I feel very cynical, I think, about a lot of the work that we have ahead to make the world into a place that's more aligned with our values. But I do have a sense of lightness and I definitely find moments of joy and enjoyment within that.

**Sugandha Gupta:** [00:29:01] I'm all about the optimism and the positivity and excitement because I think it's really hard to move forward in life in general without that. And I think that as a person living with disability and in general, as someone who's researched about individuals with disabilities and artists with disabilities, I think it's really unique that the more hardship we have in life, the more mature we become. An optimistic attitude, that resilience to just face it and not hide from it, can really help you think beyond what you feel like you can think about. So yeah, I think that the future is really bright. I feel really privileged that we are in a time when we're talking about it even if it's a little late, even if it's taken us a couple of centuries to talk about it, I still feel happy that we're we are having this discussion.