

## **SYPartners**

### **Designing for Humanity**

#### **Episode 2: Building a runway for change in fashion, at 3'5", with Sinéad Burke**

**Sinéad Burke:** [00:00:00] We look at accessibility as something which is ugly. My question always is, well why can we not look at this as an opportunity for innovation and creativity?

[Music]

**Rie Nørregaard:** [00:00:09] 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.

[00:00:45] Today, I'm so pleased to be joined by Sinéad Burke. Well, not in person exactly. Sinéad is kind enough to join us all the way from right outside Dublin, did I get that right?

**Sinéad Burke:** [00:00:55] (laughs) Yes.

**Rie Nørregaard:** [00:00:57] We first met a couple of years ago when we were traveling together on Amtrak to D.C. We were both heading to an event celebrating inclusive design at the White House. We had the luxury of time then, and we were able to talk about everything from teaching children table manners, to celebrity obsession, to fashion, and what design might be good for. Sinéad's a writer, an academic, and a brilliant advocate. She spoken at TED, at Davos, and always brings such an important perspective on the conversation about designing for humanity. I can't wait to get into talking to you about your perspective on inclusion and design today.

**Sinéad Burke:** [00:01:37] Thank you for having me.

**Rie Nørregaard:** [00:01:39] Of course! I want to start with this notion of impact through design. Design, as I know from you telling me personally but also from your talks, has always impacted your life. When did you first become aware of the idea of design as the thing that was impacting you? As the thing that was either helping or not helping you in your life?

## **SYPartners**

**Sinéad Burke:** [00:02:05] I probably shouldn't admit it, but it's only in the past two years that I've been using the language and vocabulary of design, because when I was younger I used to explain it to myself and other people, particularly the students because my background is in education, that the world wasn't built for me. And I used to use the language of construction because I found in many ways that it was the bricks and mortars that impeded me, rather than a design process, because I didn't have a background in design. It wasn't until very naively I was invited to do a TED talk in New York, and they said, you know what we would like you to talk about is the idea of design. And I kind of replied back into an email going, that's really interesting but I'm not a designer and I have no expertise within design. I really don't think I'm the best person for this idea. And a wonderful woman named Chee Perlman came back to me and said, you absolutely are, because everything that you speak on and everything that you advocate for is framed around the domain of design. And I began to consciously take a step back and reflect on it, and I realized actually, what was inhibiting my independence was not necessarily just construction—because the construction was the physicality of the design—but it was the design and the design thinking that has occurred for time in memoriam almost that is impacting upon me on everyday life and everyday kind of interactions. And it's less about design being implemented as a way to create a barrier for me to the rest of the world. It's actually just that those who have been in the position of power have never considered me within the design process.

**Rie Nørregaard:** [00:03:50] So when you think about how you now combine your passion for fashion and pop culture with being an advocate, and now with this language of design, how does that make you think differently of your work, of your platform?

**Sinéad Burke:** [00:04:06] Fundamentally, it's trying to change the conversation, because particularly with designing for inclusion and designing for disability, historically we have always looked at it through a medical model and the function of designing for disability has always been about lessening an impairment. And why that is important is because many people who were designing these products came from the majority and an able bodied background, often they only viewed it through a medical model and never considered the form of a product, all the while considering the function. And for me, I'm a little person. I have Achondroplasia. I have dwarfism. I stand at the height of three foot five inches tall. So one of the designs and one of the products that I use most regularly is a footstool, which seems really simplistic, and it is. But when they're designed they are usually

## **SYPartners**

designed in mind for children or for people with disabilities symptoms, and only the function is ever considered.

[00:05:02] I'm currently sitting on one now, and it is clickable in place and it is cerise pink and blue, but it's not something that I would use in public spaces because my dignity nor the emotion attached to a product has never been considered. So the form is not considered. So actually what I do in public spaces instead of taking my stool, which is designed with function in mind but not form, I actually just go without and struggle or ask for assistance. For me, in regards to the design conversation that I try to have at each of those different levels of the ecosystem, it's about pairing the emotional impact, but also the importance of respecting an individual's independence and dignity, but also the aesthetics, because we sometimes forget that people who are older in society also want things to look beautiful and they want to put their money and invest in products that gives them a sense of pride too.

**Rie Nørregaard:** [00:05:58] I mean that can be an act of exclusion rather than inclusion to not consider another person's need from an emotional perspective when it comes to design, right?

**Sinéad Burke:** [00:06:11] Exactly. Or we prioritize aesthetics and beauty. In Ireland, we have beautiful Georgian buildings, they are exceptional. But we, as a government and as a society, have labeled them as protected buildings, because we don't want to interfere with their aesthetics because they feel like they symbolize a particular historic moment, which is very fair. But actually legally, those who lease the building, those who own the building, are not in a position to make them accessible because that would interfere with the aesthetics of the building, because as a society we have said that to make something accessible undermines its aesthetic because again, we look at accessibility as something which is ugly. And for me, my question always is, well why can we not look at this as an opportunity again for innovation and creativity? Why are we not creating a bursary and bringing in leading architects and pairing them with design students and leading designers, and asking the questions of how we can enhance the aesthetics of these beautiful, historic, symbolic buildings. All the while increasing access to society.

**Rie Nørregaard:** [00:07:19] That's an amazing example of a shift in mindset.

## **SYPartners**

[00:07:24] So you talked a little bit about being a teacher, and I remember when I met you the first time you were describing some of your experiences, and how do you think that fits into this conversation?

**Sinéad Burke:** [00:07:35] The way in which design impeded my independence in the classroom also offered opportunities that otherwise wouldn't have come about, because it was never designed for the children to have independence, only ever the teacher and the adults. So I couldn't reach the blackboard. I couldn't reach the windows. I couldn't reach the light switches. I couldn't reach the walls where there needed to be art put up. But what I did instead, was build up this relationship of mutual respect between me and the students, and found opportunities where they could have leadership. Where I couldn't hang up the artwork on my walls, I had groups of students every week becoming curators of our in-house museum. And in many ways, had I have been the authoritative adult and the teacher in the room who was, you know, physically just a greater size and being able to do things more independently because the design fits, I actually wouldn't have instigated this conversation to my classroom because I just would have done it myself. And I kind of take a step back, and realize that initially what looks like an enormous challenge, particularly to employers or perhaps to parents was a huge opportunity for children to develop skills that otherwise they wouldn't have had to.

**Rie Nørregaard:** [00:08:44] So inclusion is a teachable skill, and you've had a unique opportunity with lots of challenges, but you've really had a unique opportunity to teach in that manner. So let's talk a little bit about design now, because we talked about passion as an advocate but then there's also passion for design and fashion in particular. You've met amazing people — artists, designers, et cetera, and you have made it your life to surround yourself with people who create, and make, and it's clear you get so much joy out of it. So I want to hear about what makes you excited also, and your experience now in using fashion as a tool to teach us a new way to look at beauty.

**Sinéad Burke:** [00:09:30] Yeah, I have been infatuated with the industry of fashion since I was a teenager, and primarily that came about because I felt left out. I would go shopping with my sisters who are younger than me but average height, and realize that they had access to clothes and wardrobes that were just so out of my reality that it just felt unfair. And my way into the industry was through education, because I felt like if I couldn't buy the things that I want, the very least that I could do was at least educate myself so that I could speak about it. And through the internet and through blogging, I started a blog because I was irritating everybody around me when I'd say, did you know that Kim Jones has just been appointed to menswear at Dior, and this is going to be

## **SYPartners**

revolutionary for LVMH as an entire group. And my mother would say, that's lovely Sinéad, but is there anybody else that you could talk to about this? So the internet became a space where I could talk about it, in a way that was initially just getting the information out of my head, and then it began to find an audience. The internet was a space where my disability didn't impact upon what people thought of me. That bias wasn't at play. And not that I deliberately hid it, because my profile photos all indicated that I was a little person, but it gave a space where it wasn't immediate thing that you recognized and what was important was my ability to articulate an argument. It was my curiosity in asking questions.

[00:10:57] But I think even for me, growing up as a woman interested in fashion and as a disabled woman interested in fashion, a lot of society either intentionally or unintentionally belittled my interest because I think fashion can be seen as facetious. And you so beautifully articulated the fashion industry there as a powerful tool for beauty, but also for transforming how we view women and the world. Yet I think because it is an industry dominated by female voices, there is habit in which we belittle it and undermine us.

[00:11:30] And I often make the bold comparison between sports. I think it's almost hilarious that at the end of every news bulletin we have a notification that a ball has been passed from one end of the field to the other for 90 minutes and a successful outcome has been reached. But yet we consider fashion, an industry in which everybody has to interact with, we all have to wear clothes, and yet continuously it was undermined. But I always feel empowered by fashion when I am dressed well. Because growing up, people always made the assumption that I was younger than I am, because physically I stand at the height of perhaps a six or seven year old, whereas if I walked in wearing a top hat, a cape and fitted trousers. It's quite unlikely that you'd think I'm seven, or I have a very brave and bold mother and parents who dress me extraordinary well for a seven year old. So it kind of eliminates that question and curiosity about my ability or about my age.

**Rie Nørregaard:** [00:12:33] So tell me your Burberry story. From what I can tell on social media, it's been a very special experience.

**Sinéad Burke:** [00:12:40] An Irish woman who worked at Burberry—her name is Alice Delahunt, she's now working at Ralph Lauren—she emailed me, and we had never met before, and she said, hi Sinéad, I saw your TED talk. I see you're speaking at The Business of Fashion Voices conference. Would you like to wear Burberry? And I reply back going, thank you so much for thinking of me for

## **SYPartners**

this incredible opportunity, but I think this is going to be harder than you might envision it is, because you've never dressed anybody like me before, and this is not going to be easy. And she came back and really muted all of my fears and concerns and said, no, we do this all the time. We have the skills in house to be able to do this. And that really changed my belief in design, because I think one of the fundamental barriers to adaptive fashion is that there is this fear and nervousness from the larger houses that they will have to do something new, that they will have to create a bespoke line for people with disabilities and although some brands are doing that, and doing that very effectively, actually what's most required is an appetite to use the skills that are in house, including tailoring, alterations, and adapting, which they do for almost everyone, whether it is couture client or even celebrity clients. They have to alter collections to fit. And I think as a disabled person, all I want is for that service to be made available to me. Not at a lesser price, not in any way that will inconvenience the brand, but just as an opportunity, and getting to go to my very first sitting with Burberry in the Regent Street store, it was extraordinary, but immediately the team realized that actually much of the design of the store was inaccessible to me, because again, they hadn't had a client who required those needs. And on my second sitting when they dressed me for Davos, I did it in Horseferry House, which is their headquarters in London. And that team had redesigned that room to fit me. So they had bought a low rail that was exactly at my height so that I could reach all the garments. They had cut the legs off tables and chairs so that everything was in reach. And I remember just feeling it was so surreal, thinking this is how it's done. It was the first time that I had been ever able to go through a rail of garments, outside of my own personal wardrobe, where I could reach things and have a look at it and have a look at the price tags and feel the clothes up close, as regards the neck line. I mean those are the various different technicalities that are just required within a brand, and it's more the thought, and the retraining of staff with empathy built in that training, rather than redesigning a whole collection.

**Rie Nørregaard:** [00:15:23] Right. So thinking inclusively is something that we can teach each other, and if we do that, the solutions come with this new knowledge. Yeah that's it. That's such a great story. It made me so happy. Let's talk a little bit about you going to Davos for the first time this year. Tell me a little bit about what that experience was like for you, going as a woman, as a little person and as an advocate in this environment for the first time. What was that like?

**Sinéad Burke:** [00:15:58] I had spoken at a conference in Dublin probably in April or May last year, and there was somebody else speaking at a different part of the day in the conference who worked at the World Economic Forum. And he heard me speak and he came up to me afterwards and said,

## **SYPartners**

you must visit our offices in Geneva and speak to our staff. And I very kindly said, that would be lovely, thank you so much. And I went to the office and I met the entire team and we had a very frank and honest discussion in relation to inclusion and diversity, and how as individuals who shape a global agenda for some of the key power players in the industry, the responsibility that they have to also be inclusive, and the responsibility that they have to be reflective of the wider society. And at the end of the conversation, individuals from the Civic Society Group said, do you have any interest in coming to Davos? And I said sure! And they said, well you're not a political leader, nor are you CEO for a large global conglomerate, so we will have to do some internal work in terms of making the rationale for the validity of your voice at Davos. And I said, brilliant if it happens. And then the invitation came in, and I said, great. And they offered me a number of speaking opportunities, and I kind of thought, oh that sounds great. And they said, Sinéad, do realize that there are three thousand delegates at Davos with 600 opportunities between the 3000 of them, and you have four? And I went, Oh okay. Big deal. Sure. No problem!

[00:17:24] And I think Davos was fundamentally transformative for me, in terms of my own self-confidence and self-efficacy, because I think within the space of advocacy and advocates there is not necessarily a level of imposter syndrome, but it's trying to pair this idea of the lived experience and validating it within an industry where qualifications are perhaps more important or at least considered in a different way. And although I have both, working within the design realm, particularly coming to it from a new space, I wasn't sure about the validity of my voice and Davos proved that. It gave me a real sense of confidence coming home about what I could do and what the responsibilities I had to do. But getting to speak alongside individuals such as Tim Brown, getting to speak to, you know, Queen Rania of Jordan or the head of the European Research Council or getting to speak with Lonnie Bunch, who is the founding director of the National History Museum for African-American Culture of the Smithsonian Museums in Washington, and getting to speak about the pairing of advocacy and art and culture and how we can retell stories in a very empathetic way, was extraordinary. And one of my key questions within this is, what then happens to the advocate? How were they stabilized and ensure that their advocacy can continue? And we had a really challenging wonderful conversation about whether or not advocate should be supported by companies and organizations that required their in life whether or not they need to become consultants whether or not they need to hone and define a particular expertise in order for their voices to be valid within the domain or whether or not they need to become part of design companies in order to fully benefit this relationship. And we didn't come up with an answer which is also wonderful because since I've come home from Davos, I'm still percolating on all of those different responses. But it was incredible.

## **SYPartners**

**Rie Nørregaard:** [00:19:22] Fantastic. You know I've been thinking a lot about when we went to D.C. together a couple of years ago to celebrate inclusion and design at the White House. And I noticed then, for many advocates there is this tension between representing people with their own specific, and granted, underserved, needs versus coming together to create a much larger platform like a voting block for all disabilities for example. So when you think about your role as an advocate for people with disabilities, as well as someone who can hold a conversation around inclusion in a much broader sense, do you feel a tug one way or another? How do you navigate that tension in your own identity?

**Sinéad Burke:** [00:20:08] Absolutely. And for me, I think that identity piece is probably entrenched in language. It's probably best documented in terms of how my own language has changed as I have grown up. In my early teenage years, I would have always described myself as "just Sinéad". It wasn't until I began to go to college and realize that there was quite a few injustices in the world around me, that I began to look up the legislation, and what I began to quickly realize was that there was no legislation that provided for the safekeeping and equal access to people who are in quotes, "just like Sinéad". As I got a little bit older I began to refer to myself as a person with a disability, because I felt like the person aspect of it really amplified and resonated that I was a person first, and then I had a disability. And it wasn't until I was probably in my mid-twenties that I began to realize that what I was unintentionally doing was erasing my disability and was putting it in this framework of negativity, and almost embarrassment, and I'm not in any way saying that that's what people who use that language are doing, but that's the way in which I was thinking about it. It was in my mid-twenties that a shift in language and identity occurred, that I would now describe myself as a disabled feminist.

[00:21:38] And I'm very proud to be disabled, because a lot of the skills that I have, and even the personal traits and characteristics that exist within me, have been shaped and formulated by my disability. So I would often say that I am organized, creative and articulate by nature, but that's not necessarily because I have wanted to be, but because I've had to be. Being a little person has demanded those skills be honed. Walking into a public bathroom I cannot reach the lock on the toilet cubicle door, so my immediate reaction is to try to bend upside down or to use my phone, or to approach a stranger and ask them for assistance. And I have been doing those things since I was eight or nine. So understandably I am a fan of language, and able to use vocabulary probably far advanced than an eight year old should have been. And in many ways that identity piece has really been formulated also within my advocacy. I think there is always the friction of wanting to just be

## **SYPartners**

Sinéad, and to be allowed to be the person that you are, all the while conscious that you are the person that you are because you are disabled. I think anybody who is an other or a minority voice, this friction exists, particularly within an open forum, whether it be in the media. You know, we often critique interviewers who speak to a woman and ask them about what they wear, or ask them about pregnancy, or ask them about childhood and childrearing in a way that we wouldn't with a man or somebody who you know adheres to those binaries of gender. I think it is a broader conversation that needs to happen within society, that perhaps there is a space in which you can be an advocate for the minority community or the community that you represent, but there also has to be a space in which you can just be yourself.

**Rie Nørregaard:** [00:23:35] Thank you for getting into that. You just gave me an idea, or a note for future interviews with men. I need to remember to ask them about their wardrobe and their families. (laughs) I don't really do that with women, but maybe that's the point is to just practice turning it around!

[00:23:57] So ending with this moment that we're in, what gives you hope and optimism? Who's doing something right? What can we learn from them? If you have other examples that you've come across or any other collaboration that you've had recently, I'd love to hear.

**Sinéad Burke:** [00:24:15] I think it's about collaboration. It's what the root of success is or at least that's what I'm seeing. And whether that is incredible individuals like Open Style Lab, who continues to collaborate with Parsons and designs shoes and purses, and you know, people with disabilities and disabled people entering the educational process all the time. And that for me was working with design students. It's not necessarily the education that occurs in that moment that's important, and it is, but we have no idea where those design students will be in 10 to 15 years. And it's the possible opportunities of that that then opens for the conversations and the curiosity that they may instigate in very large conglomerates, or within their brand and making those decisions that again is making that change sustainable.

[00:25:04] I think also what the Smithsonian and design museums are doing in regards to exhibiting accessibility both as a motif of function, but also as the motif of form—and I know they've had incredible people like Lucy Jones just being added to their permanent collection—and opening up the conversation not just within the disabled community but within society at large, because I think one of the things that we often forget about is disability and design and adaption and inclusion, is

## **SYPartners**

that at any moment within our lives we can become momentarily disabled, whether it is crutches that we need because of a broken bone, or even looking at the aging population that continues to exist within our society. Has our inclusion and our design thinking been incorporated into how we are evolving communities and what the needs of those individuals are? So I think often we can think about disability and design as something which, well doesn't impact upon me, but actually it might, and maybe not now, but it's still something in which you should have care for, consideration for, curiosity for, but also it should be rooted in empathy because I don't think we can continue this conversation with an us versus them mentality, but actually it's something that we will all require at some stage within our existence.

**Rie Nørregaard:** [00:26:23] I couldn't agree more. It is such a really important way of looking at ability and disability for all of us.

[00:26:29] Is there anything that comes up for you that you would like to talk about, given that you have time and you have an audience and that I haven't sort of touched upon?

**Sinéad Burke:** [00:26:40] I would love for us to be more inclusive in the development of design standards, particularly for the disabled community, and for it to be more reflective of the spectrum of disability that exists but also the symbolism of disability because what we have from an international standard at the moment is the symbol of a wheelchair user. And while that is very much adequate but also incredibly important, I would love for some thinking to be undertaken, and for some design to be undertaken, as regards to creating a cacophony of symbols almost that fully represents the disabled community because to the best of my knowledge there is no standard symbol for being a little person. And I think there needs to be a broader conversation around that representation within design structures, design proposals and design for people who are outside of wheelchair users.

**Rie Nørregaard:** [00:27:30] Yeah, the symbols that we use as a society and that we make us as designers are really powerful, in that they really reflect where we are emotionally and socially as a culture at any given time. And once they're out there in the world it takes sort of a movement to change or to rev, there's no doubt about it and you know, what comes to my mind when you're talking about disability being depicted as a person in a wheelchair is that we're not even talking about disabilities that are not visible, or that may be temporary. But to your point, because we all are at certain times and certain points. So what's the biggest frame that we might be able to create for including everyone? Right? So maybe it's moving away from depicting certain states of ability and

## **SYPartners**

disability, to actually focusing on the real deal, which is to make environments, experiences, and things that actually truly are shared by everyone.

**Rie Nørregaard:** [00:28:34] Thank you so much for joining me today.

**Sinéad Burke:** [00:28:37] Thank you. Enjoy the rest of your day. I hope it's warmer in San Francisco than it is here in Dublin.

**Rie Nørregaard:** [00:28:42] I'm pretty sure it is. Yes. Have a good one. I'll talk to you soon.