



Join our free membership site, The Duke Humfrey's, and get access to full transcripts, past episodes, exclusive downloads and more. You'll find it all at www.MBS.works/podcast

MBS (00:01):

Look, I wouldn't call myself old, but I guess nobody does. I mean, old is always about 20 years further down the track to where you are now. But I'm in my 50s. I mean, early 50s mind you, so I'm no longer calling myself young. And honestly, I'm unlikely now ever to be tagged high potential anything ever again, that time has come and it's gone. Being this age, I'm starting to feel the slight insults of my body breaking down. I've just had a phone call today from a doctor mentioning some slight indications of arthritis in my shoulder. Come on. And I sometimes make undignified noises when I'm trying to get out of a chair, my running speed has gone from very slow to barely moving. But, all in all, I'm fine. I adapt, I change the way I do things, I try to make them easier and to accommodate my new limitations.



MBS ([00:58](#)):

But all of this is happening to me within the bounds of what you might call normal. I'm cognitively and physically pretty much somewhere in the middle of the bell curve. But what happens when you or somebody who's central to your life find yourself or their self on the end of the bell curve? What deep adaption is asked of you, and more importantly, how might the world better accommodate and welcome who you are?

MBS ([01:28](#)):

Welcome to 2 Pages with MBS, the podcast where brilliant people read the best two pages from a favorite book, a book that has moved them, a book that has shaped them.

MBS ([01:38](#)):

Sara Hendren grew up in a highly conservative religious small town in Arkansas. Now, she's a professor at Olin College of Engineering, just outside Boston. So, in the liberal northeast of the United States. Just as she has a foot in each of these two geographical worlds, her work also finds her straddling two worlds, the humanities and technology. Her book, *What Can a Body Do?* shares her insights as someone who's a design engineer.

Sara ([02:09](#)):

I'm an artist trained as an artist and a historian and really like a humanities culture person. And for the last seven years, I've been teaching all students who study engineering and major in engineering at an engineering school. And no one is more surprised than me to find that. But that insider outsider is a powerful muse and friction for me. So it's like really fun for me to have to find new languages for both for the arts and then to be a lifelong learner in engineering, which is something I never took up as a young person, but I love



that kind of beginner's mindset that it's created and I just am finding that that's how I feel the most alive is that super steep learning curve.

MBS ([02:46](#)):

I always love talking to people who are both outside and inside a profession. It's so often where innovation, disruption and provocation come from. It's also often a wellspring of humanity, humility, and empathy.

Sara ([03:02](#)):

When you're inside and outside with kind of a foot here and there, you keep the granular humanity of lots of different kinds of people fully intact. So I can think of lots of people who I was raised with, who I disagree with in a vigorous way on politics, on religion, on all kinds of cultural matters, feminism, you name it, raising kids, and yet I can still imagine a really dimensional humanity to those people because I still see them and they're people who raised me.

MBS ([03:30](#)):

So Sara left home to live a life and be a person different from what her upbringing might have suggested was her destiny. That was by choice. But sometimes, I mean, often in fact, our lives are turned upside down by the unexpected.

Sara ([03:45](#)):

Like a lot of times our adulthood is about assimilating new stuff that happens to us into what we already, our story of ourselves that's pretty formed. like, this new data's coming at me. I have ways to assimilate it into what I-

MBS ([03:59](#)):

Right. My adjective.



Sara ([04:00](#)):

My story [crosstalk 00:04:01], yeah, that's right. But that sometimes something comes along that is so disruptive that sometimes you need to accommodate instead of assimilate. And that means your own story has to shift and change. And that for me, having a son with Down syndrome as the first baby that I had, first of three, was a moment where I really could not assimilate his arrival and everything that comes with that arrival, with the story that I had been built with thus far. And I did have to accommodate. And for that, that was this kind of like shove out of insidersness. It is the direct line to how I ended up teaching at an engineering school. I never would've imagined that.

Sara ([04:42](#)):

So, it was a kind of shove from life that, again, so much of adulthood, just the inertia of adulthood teaches us to assimilate. I did have to accommodate and so that has been both really challenging and also the most productive and creative set of intellectual and personal changes of my life. That was 15 years ago now.

Sara ([05:04](#)):

So then I had to sort of go, "What does culture, art making, the power of language, where does it meet up with technology?" And I mean, we can talk about that at length if you want, but it's like, that was the thing that got me to go, "I need to actually be speaking in a context of technology around the politics of disability, because I see a world within which there is this disjuncture that I cannot assimilate. It can't be done."

MBS ([05:34](#)):

So tell us about the book you've chosen to read.



Sara ([05:37](#)):

Yeah. So this book is a book that landed in my life right after my son Graham was born. A friend just sent it to me, kind of on a lark but... It's called *Life As We Know It: A Father, a Family, and an Exceptional Child* by Michael Berube. And it's part memoir and then part kind of like super theoretical treatise of normalcy and bodies and kind of bioethics and genetics and all kinds of things mixed together. And it arrived at a time of my life. So my son was born with Down syndrome. We got a diagnosis after birth and same way that Berube and his wife did.

Sara ([06:19](#)):

And, my life just kind of filled up with these messages from people that actually were kind of in the most well-meaning way, kind of reduced the humanity of who my son was. People would say to me like, "Well they're the happiest... They are the happiest people on earth, people with Down syndrome." Again, they're trying, they're fumbling in the dark to be supportive, but I was sort of looking in vain. This is in 2006, before the internet sort of became a kind of a centralized social medium that it is. And so I was like, it can't be that the planet has never seen a creature like this, with radical individuality. It can't be that on a Tuesday, he was a radical individual and then on a Wednesday he became a type.

MBS ([07:02](#)):

Right.

Sara ([07:02](#)):

So I was, really desperate for images that were not like hearts and puppies of Down syndrome in the world and a lot of people were sending me that stuff. Again, well, meaning. So then my friend, Carl, bless him, sent me this book and I thought, this is what I've been looking for. And I'll tell you why Michael. Because it was this memoir of like, yes, okay, here's some people who had my



experience. Sure, a memoir does that, but this was the kind of book that said, you are going through a particular story. It's part of something big. It's part of a huge history in disability rights. And right, the legacy of eugenics and the construction of normal and all kinds of stuff. And I thought, "I'm actually not alone here." I mean, in this powerful way, I mean, literature always does that for us, but in this very concrete way, I'm part of something big.

Sara ([07:50](#)):

And that it turns out has shaped my own work and my own book for the last 15 years, which is just to say, the things that happen to us are not these kind of over come therapeutic stories that then we only make sense of. Of course, we are the protagonist of our own lives and we do have to make that sense for sure. But, a much bigger story is also waiting to collect and organize us and energize us if we see it as such. And so, this was a book that said to me, you are part of something. And I wanted my book to also in highlighting so many voices of people with disabilities and the vivid language of design to say, "If you find yourself in a changed body one day to the next, or looking at your body in a different way in your experience, you too have joined something really big, really big. It's bigger than you in the best way. And so this book sort of set me on that path.

MBS ([08:41](#)):

Right. Well, what is it about being connected to a bigger story that gives you solace?

Sara ([08:52](#)):

I think maybe it's just that old humanist affirmation, which never runs out of profundity, that nothing human is alien to me. So if nothing human is alien to me, then when I read books, I both see the mirror of my own recognizable experience, but then even more importantly, I see other people's experiences that on the surface seem alien to mine, but in fact, because they're wrapped in a



story I recognize, and that moment means what? That I am not just trapped in this hermetically sealed consciousness. We are made to connect in our many varied ways. I am connected then to a story of humanity that is, if not relatable, I sort of hate that word, it is recognizable. And I think recognizable supersedes that, like, I need to see only the mirror of my own experience. No, I need to be extended from my own experience. I guess I experience that as a kind of freedom from the personality and the blinkeredness of how I walk through the world.

MBS ([09:58](#)):

I think there's a quote from a poet Muriel somebody which says "The universe is not made up of atoms. It's made up of stories." And I think you're speaking to that in some way.

Sara ([10:09](#)):

Yeah. And the physicist too would say like Carlo Ravelli, the physicist says, "Time is more like a key than a stone. It's actually-"

MBS ([10:17](#)):

I love that.

Sara ([10:18](#)):

The time is like interaction. Yeah.

MBS ([10:20](#)):

Yeah.

Sara ([10:21](#)):

And that really, if physicists are being honest, we think of it as these kind of chunks of, the time is this kind of hard thing against which we live our lives, but it is the fabric, the interaction is all... I find that both energizing and galvanizing.



It's not just like, I feel comforted by the fact that my story is not my own and I'm not alone, but it's that I also feel like, my lizard brain is always competing to sort of tell me that how I see the world is the way to see the world. And I think it's the dignity of consciousness to go, that's not the case. So how can I keep filling with that invitation to see beyond my very real limitations?

MBS ([11:10](#)):

Will you tell us about the two pages you've selected from the book? It sounds like a powerful book.

Sara ([11:14](#)):

Yeah, it is. Again, I just have never... This is about prenatal testing and abortion. Talk about issues that people tend not to want to talk about and I had to very carefully write about it in my own book, but it is nonetheless a profound kind of bioethical conundrum that I think is worth investigating and to refuse to take a right versus left talking points approach to this issue. Because it's about the serious matter that is human reproduction and the decision to parent. But I love the way that Berube has both really shown himself to us, being present to the reader, it's hard to do and also has a distance in an intellectual sense. So let me read a full passage if that's okay.

MBS ([12:01](#)):

Lovely. Thank you.

Sara ([12:03](#)):

So, I'll just preface it by saying Michael, Berube is the speaker here in the first person, and he'll refer to Janet, who is his wife and to James or Jamie, they're the same person who is his son with Down syndrome.



Sara ([12:22](#)):

Our decision to forgo amniocentesis was deliberate. We debated it for some time, knowing full well that for us, this constituted a quote passive decision to carry the pregnancy to term if the child did in fact have something like Down syndrome, something that a mere sonogram wouldn't detect. I honestly did not recall the conversation Janet has often related to me in which she said, quote, "You realize that we're taking the chance that the baby will be born with Down syndrome." End quote. And I apparently replied, quote, "Well, we'll just love him all the more then," End quote.

Sara ([12:59](#)):

This seems to me a nice if somewhat blithe and uninformed thing to have said, but I cannot actually vouch for having said it. I remember very clearly arguing against amniocentesis, figuring that it was an invasive procedure that would only quote, "catch things didn't think we wanted caught," and that might induce a miscarriage to boot. Under those circumstances, it seemed unquestionably better to take the chance that our child would have downs than to take the chance that he would not be born at all. But although Janet will tell you that she and I certainly did discuss the subject explicitly at least once before Jamie's birth, I've managed to repress any such memory.

Sara ([13:37](#)):

So I suppose that if we had found out that James had Down syndrome when he was still in the third or fourth month of fetal development, we would've started learning about Downs earlier than we did and we'd have done what we could to prepare for a potentially difficult birth. We are a strongly pro-choice today as we were before James was born. And our personal decisions regarding Janet's pregnancy with James were consequences of not exceptions to our deeply held convictions about abortion and reproductive rights.



Sara ([14:08](#)):

But what if we had been told upon receiving the results of an amniocentesis that our baby would never be able to live a quote "normal life?" What if we had been told that he would never become a conscious being, never learn to talk, read, or recognize his parents? What, in other words, if we had been as seriously misinformed about Jamie's prospects in the spring of 1991 as were most previous generations of parents and providers? In that case, I have to admit we would've been faced with an extremely difficult decision. And if we were persuaded that our child's life would be nothing but suffering and misery for all concerned, James included, then it's quite possible that we would've chosen to have an abortion instead. Perhaps we would've sought a string of second opinions. Perhaps we would've clung to the hope that our child would be an exception.

Sara ([15:01](#)):

But so much depends on what kind of information is available to whom. If we had no way of knowing how loving, clever, and normal a child like Jamie can be, we would simply have to rely on the advice of experts. And if those experts told us there was no way to raise such a child, we would probably believe them.

Sara ([15:24](#)):

The questions themselves are as complex as any moral dilemma we humans have yet devised. Who has a right to know about possible fetal abnormalities and what should be done and by whom when abnormalities are detected? What about quality of life considerations for the parents and child? At what point if any, do the unborn accrete to themselves right to life? Should parents' decisions to bear children rest on financial concerns, on the state of their medical care and health insurance? Should some forms of prenatal testing be mandatory or prohibited?



MBS ([16:05](#)):

Wow, that's really powerful. Sara, what's at the heart of this for you?

Sara ([16:12](#)):

I mean the heart of it for me is this the capacity of this person to not be like, I was a thinking person, then I had a kid and I got religion kind of thing. Got religion I mean that in the broad way, in the sense that, I was so sentimentalized by my own experience that I can no longer have any analytic powers, do you know what I mean? So part of it is that. But he was able to say in the same way that my husband and I were, we're, pro-choice, we're also really profoundly troubled by the way that pregnancy is structured, the presumption of risks and defects, the rhetoric around difference. And more than that, I just love that Berube here is able to both take us to the scene of his having this conversation with his wife and really, the humanity of that and also not backing away from the struggle of it. Trying to be honest about it in a way that your fierce animal protectiveness sort of tells you not to.

MBS ([17:09](#)):

Right, you want to rewrite history.

Sara ([17:10](#)):

Yeah. That's right.

MBS ([17:11](#)):

To explain where you are now.

Sara ([17:13](#)):

That's exactly right.



MBS ([17:14](#)):

As opposed to-

Sara ([17:14](#)):

That's right.

MBS ([17:16](#)):

Not have an arc of a narrative that's somewhat constructed in retrospect.

Sara ([17:20](#)):

That's right. That is exactly right and I needed to learn to do that so I have loved Berube's book for that reason, for the transparency of it. But also then for his effortless, what feels like an effortless weaving in to really philosophical issues that collect all of us. And that again, did that work for me of going like, "It's not just me."

Sara ([17:42](#)):

Modern reproduction, including its technologies is shaping profound decisions and to be glib about it in either direction about right to life so-called, or about disability rights, to be glib about abortion again, in either direction, I think is fool hearty and I just think it doesn't take seriously what we're talking about here. And we don't actually have the ethics near to hand for addressing it.

MBS ([18:13](#)):

One of the parts of the passage he talks about, if we'd followed the experts opinion, the experts guidance, things might have been different. I'm curious to know how your work keeps bumping into experts opinions?



Sara ([18:30](#)):

Yeah, absolutely. This is how I got into Graham's birth and arrival and then all the material culture of the therapeutic context of his life. So PT, OT, early intervention, preschool, all those settings were lit up with prosthetics and assistive technology. And because I was trained in kind of visual culture and history, I was like, what is the history of these objects and what are they telling us about who Graham is and what he means to people and identity and so forth.

Sara ([19:02](#)):

So, my life was full of doctors and those therapists of many, many kinds immediately. So lots of people were making pronouncements about statistics and what it meant to be high functioning or low functioning, all that kind of expertise. And meanwhile, here we were, with our child in a very granular and specific life. So it again ushered me into a big story, which is, I see. All of the narrative of expertise as useful as it may be, is also doing this powerful reinforcement work about who's normal and who's abnormal, whose bodies are broken and whose are whole. And the best narratives that people were offering me in all their forms of expertise so all the medicine and all the developmental education were about the success story, the predetermined success story of his good life would be his proximity to normal. So how high functioning, that's what people mean? How much like a recognizable person will he perform as?

Sara ([20:05](#)):

So seeing that in my own life and then meeting in the last 15 years, all kinds of people with atypical bodies so I have lots of friends now who are blind or deaf or use wheelchairs or any number of things and saying, these people too were organized by that expertise. That again, in many cases is very well meaning and humanistic in the way it's delivered in the doctor's office or whatever, but it's driven by a really powerful idea of the average, which is a 200 year old idea and



the social sciences are the way we talk about people at population scale. Those are useful. Stats and averages are useful to us at population scale, but they fall away when they try to describe our individual lives. And moreover, they have a way of kind of organizing us. Statistics and averages sort of broadcast to a parent like me, "You should get about the business of making your child into a project of quasi normalcy." Why? So that he'll be respected more?

Sara ([21:02](#)):

And this stuff is just so tricky. And again, I met in the context of working in an engineering lab where technology is of course created by experts, falls away from the needs and the wishes and the desires of people who occupy all positions on a spectrum of normalcy and abnormalcy and all the slippery ways that that gets mixed up for us.

Sara ([21:27](#)):

So for instance, in a really concrete way, in engineering context, most people, students and professors in that context would say, "If we have a collaborator who's deaf, it must be the case that the only use of engineering would be for better cochlear implants and hearing aids." That can only be the desired trajectory and that can therefore only be the proper application of technology.

Sara ([21:51](#)):

I learned in educating myself in disability studies, reading lots of voices of disabled people that in fact, there's a whole set of people who are deaf, who are not interested actually in hearing and who have a vibrant culture signing and education structures and rich quality of life. So then it was like, "okay, well how can we use the expertise of design and technology to actually organize in a really attentive way around what people are actually asking for in their own idea of the good life? I don't mean like a radically bespoke world for each one of us, that's never going to happen. But I do mean what we call in tech, a human



center design process, which is just to say, let's organize our expertise around people's actual questions.

MBS ([22:36](#)):

How do you help yourself and others navigate that line between the way statistics roll up to a population and the fact that all of us have individual your needs? The old saying is we're all fighting battles. Be kind, because we're all fighting battles. And, that's one way of going, "Look, people with disabilities have more specific ways that they're meeting the world." Like I'm 52 and I'm starting to get slightly arthritic hands say, and I'm like, "What the hell?" How does things need to change for me?

Sara ([23:15](#)):

Yeah.

MBS ([23:17](#)):

How do you find that line? It feels like that's part of what you wrestle with in your work.

Sara ([23:22](#)):

It's true. I think the work of adaptation and that is so much the theme of the book, how are bodies adapting every minute, every minute, just from the way that you walk up to a door and find the most advantageous way to lean it open, all of that deep adaptation that's happening for everybody in every state. So assume that people with ALS with very little mobility are also that profound adaptive machine. Some of that adaptation is in the direction of repair in the sense of you would probably like to find a way to not have as much arthritic stiffness in your hands full stop.

MBS ([23:55](#)):

Yeah.



Sara ([23:55](#)):

You would like for that to go away. Great. So that adaptation may be in seeking kind of cures or fixes in pharmacology or in technology or something thing.

Sara ([24:05](#)):

Sometimes people are looking for adaptation that also has a kind of critique about it. I have a friend who's a wheelchair dancer who came to my lab and said, "Can you build me a ramp? But I don't want a ramp for getting into a building as important as those are. I actually want a ramp for stage. I want to use the physics of the ramp, acceleration and resist to make beautiful movement."

Sara ([24:28](#)):

Okay. So now I'm asking, not the world to fix me, I'm actually asking the world to adapt with me, its expectations of what a normative form of a locomotion through the built environment really is. In other words, for my students and for everybody watching, Alice Shepherd, who's this wheelchair dancer, for everybody who's watching Alice, they're having to adapt their own ideas about whether wheelchair use could be, yeah, difficult in some circumstances also, balletic and energetic and poetic. All these things that you don't think of as being part of wheelchair use.

Sara ([25:06](#)):

So, we can be excited about adapting in both those forms. And when I ran the lab, I was sort of like very, very adamant that we would in the same room, be partnering with children's hospital, looking at adaptive bottle nipples or whatever for tiny babies, very solution oriented, very tinkering, very fix it, very adaptive in the repair sense. And that across the same room, we'd be working with somebody like Alice Shepherd on a ramp for dancing and we would call it all adaptive technology. We would call it all humanistic kind of work. We would put problem solving in the same room with question finding. That's where an



artist lands in an engineering school. That for me just felt so important to say, "This is an undivided house." Why? Because no one fix it, no one address, no one approach would do justice to this magnificent thing, which is the body and all its variety. So let's just be attentive to that.

Sara ([26:06](#)):

So I'm living this out, with my son too, there are lots of really hard line progressives and disability who would say that my son Graham shouldn't have to be made ready for the workplace because work is a capitalist construct and we've gotta get rid of all that. I understand those critiques. But the fact is that probably Graham, he talks about having a job now. He probably will want that, that normalized and normalizing way of being in the world. So I have to honor that. It's his life not mine. So that adaptation has to be this big supple category that can include both... I often say, repair and critique, critique and repair, both, having our critical wits about us and saying the inherited world, the notion of average is a monolith that is trying to organize us all the time. We can push back against that. And also, we can ask for better mousetrap fixes to the world that are clever, ready to hand in the big box store.

MBS ([27:03](#)):

What's the moment for your students that shifts a perspective on this? Because I suspect if it's true for your student, it's true for all of us in terms of a thing that will make you suddenly go, Right, hadn't really thought of that. Is there a thing that allows the scales to fall from the eyes?

Sara ([27:25](#)):

It is the classic work of art which, at its best, does that kind of de familiarizing. It takes the thing that you thought you knew and it turns it utterly on its head.



Sara ([27:38](#)):

For example, we worked with an art historian named Amanda Kasha who has a form of dwarfism. So she stands about four feet tall and she came to my classroom and said, "What I really want is a lectern, but foldable portable at my scale. I actually don't want to be made-"

MBS ([27:57](#)):

She's the opening chapter of your book, right?

Sara ([27:58](#)):

Yeah. That's the opening chapter of the book. I tell that story to sort of say, that moment in art, that de familiarizing moment or sometimes in art circles, we call it estrangement and that's not a jargony term. It just means the moment where the very familiar thing that you thought by the device of an artwork just makes you go, "Wait, now I see it again. I'm sort of jolted out of that just like my ordinary categories and my executive functioning and list making and getting things done." Because Amanda walks into the room and now you're looking at where are the light switches placed on the wall and oh the levers on the doors and you see that the world is organized around a kind of normative stature. And, when she comes to the room and says, "I want a device that is like this nimble way of actually bringing the room to me." So we built for her a lectern that is foldable, portable, travellable but it's a lectern at her scale. It's a really short one that packs flat.

Sara ([28:53](#)):

So what that means is every time she goes into a room, she brings the room, the dimensions of the room to her body in a way, and only art really can do that. So in other words, my students are there thinking, my goodness, I have this hammer like literally and also figuratively, that's looking for a nail which is, where are these poor people who need help? I'm here. In the best way, they're



like I have a technology tool and I wanna use it for good. So surely somebody needs my help. And she's walking in and kind of going, "The thing that you think is a prosthesis is not the thing I'm going to ask you for." And so now, that's when they go like, "Wait a minute. Might Amanda be happy in that body? Might she be having, the full complement of human experiences in that body? My goodness. What does that mean about everybody else I've looked at on the street and thought, thank goodness I'm not them? Now I have to undo all those categories." And to me there's nothing quite like art.

Sara ([29:48](#)):

And I mean, this art in the most prosaic sense. You are reading a novel about somebody unlike you and you are just jolted out of your ordinary categories because you say, "My gosh, I would make a completely different choice than this character would." What does that mean? We all are seeking this out in our shows and our books and all that stuff. And it turns out that the engineering lab can also do that. Sometimes it's called critical design in my field. So it's like design that is problem solving. And that lectern, man, I mean, it had to be engineered. It had to work. But it also is like resonant with a question that is not resolvable in a quick, space of an ad.

Sara ([30:30](#)):

I just love it when Amanda comes out and has this lectern and everybody... She doesn't comment about it. She does it in her classroom too as a professor and she often won't even remark about it, but everybody is getting the message because that is very potent object is in the room. For me, there's nothing better than that.

Sara ([30:46](#)):

Now I just want to say, are my students going to go on and do this? They're not, they're going to software companies, they're making stuff at scale, I understand that. But what I am banking on is the very old idea of what an education does



for you, which is to enlarge your categories and to make you productively uncertain about the kind of story that you've been shaped with. That is the work of an education. It's always been that way and it always will be.

Sara ([31:08](#)):

In engineering context, people are very much using an ROI transactional form of education. They're going to be launched into the most lucrative careers on offer. Education's expensive, but I feel like I owe it to them in that exchange to rearrange their categories too. And to say, "Before you rush out to build your app for blind folks, you should ask them, what do they actually want? Because the thing that you can't imagine is how deeply adaptive their bodies are. And also by the way, how rich their lives are in turn."

MBS ([31:42](#)):

Save your complex. Talk about the broad categories white people going over to the subcontinents to kind of save the day and it's-

Sara ([31:50](#)):

That's right.

MBS ([31:51](#)):

[crosstalk 00:31:51] out in a different way.

Sara ([31:52](#)):

That's right. There again, it's that humanist refrain that if nothing human is alien to me, I mean, I find that's the most productive work that disability can do where you go, I too live on a planet in a body that has needs. Okay. That doesn't mean my body is the same as my friend Steve's who has ALS, advanced ALS. The differences matter. Nonetheless, a body that's assisted adaptive, uses technologies in all kinds of ways has needs. If we reduce the alienness of that



idea, then we're asking better questions. What do we want, what is a good life? How would we build it together?

MBS ([32:32](#)):

How has the idea of common space changed for you through the work that you do?

Sara ([32:38](#)):

Yeah. Well I lived in LA for almost 10 years, which is a place where people tend to have beautiful tiny jewel like gardens behind walls. Or, not even rich people, just lovely patios that they can use 12 months of the year, whatever, but kind of private sphere, good weather, indoor/outdoor living, and almost nothing in the way of public space. And great weather, 350 days a year or something. So, my first two kids were born in LA and I couldn't find many parks with just proper shade structures and investment in mature trees and so on. So I moved back to Cambridge Mass. where we have six months of winter.

MBS ([33:29](#)):

Yeah, I lived there.

Sara ([33:29](#)):

But in one warm season.

MBS ([33:31](#)):

I understand your winters. Yeah.

Sara ([33:33](#)):

Yeah. But in one warm season, I had met 10 families in the neighborhood with kids like mine. Why? Because of commonly held space and by city planners who invested in and nurtured those big trees that give a shade all year long and who thought about lining the play lot with a bench for you to actually sit down



for a second and still be able to see your child's safety. I mean, just all this investment in the public commons. And once you are moving through the world, like I have with stroller and a baby strapped to your chest, now you're thinking a lot about where are the bathrooms, where are the elevators. You notice then the way that stairs have been built in a kind of relentless way in lots of our cities with just the assumption that people who move the culture are not people who are beset by a toddler who's learning to walk or an older adult and whose company they're walking or, are using crutches or a cane or something else.

Sara ([34:29](#)):

And certainly not somebody with a disability legibly permanent. So then you realize, my goodness, the commons actually bears out, both bears out the idea that cities have been built with that is that the idea the citizen, the idea of the kind of productive, economic worker, but also then our choice to intervene in those public spaces, reshapes then who can be in public space.

Sara ([34:52](#)):

I tell the story in the book about Ed Roberts, who was one of many activists in the 1960s and '70s in the United States, who lobbied for the implementation of curb cuts, so just that slow ramp that cuts the corner of the sidewalk into the street. And the pushback they got at the time was like, "Curb cuts, why do we need curb cuts? There are no people using wheelchairs in the sidewalks." And Robert says, I quote him in that saying, "They didn't realize that their reasoning was circular. Of course, you don't see people while on the streets unaccompanied-"

MBS ([35:23](#)):

Right, because they can't.



Sara ([35:23](#)):

Because they can't be there--"

MBS ([35:24](#)):

They can't get up there in the first place. Yeah.

Sara ([35:25](#)):

Right. What a profound idea that actually the built environment in its literal material structure might hold a kind of structural bias that we would talk about now in the actual material. And that conversely, intervening in the actual material makes a different civic space possible. What an idea. Now you have curb cuts rolled out at infrastructural scale. I mean, the improbability of that, and also the sort of both very modest movement of it. It wasn't like high tech or anything, but rolled out across the country, after the Americans With Disabilities Act and laws like it in other countries in the world. That actually, it intervenes in the built environment that then also makes a kind of commons and public space that is always about the public sphere. So it's not just public space. It is in that very practical sense, can you get onto transportation? Can you get to the voting booth? Can you get to your school and throughout it. But it is also can you get into the public's sphere so can you be an enfranchised citizen?

Sara ([36:25](#)):

So I just have never gotten over how design has this both mirror kind of work of reflecting downstream and also this kind of galvanizing work. It's silly to be either techno determinists or think that tech is only a reflection of the culture. Neither of those is true. It's much more interesting to think about it in the bidirectional way of these things pushing and pulling. Yeah.



MBS ([36:50](#)):

So it's been a great conversation. Feels like I could roll on for another couple of hours, but it's not going to. Here's a final question. What needs to be said that hasn't yet been said in this conversation between you and me?

Sara ([37:05](#)):

Well, let me just say in the most plain terms that I think the places where disability meets design invites people, invites all of us to look at both our very every environments and at our own bodies and the bodies of people that we love and the people that we see on the street with new eyes. And it really, neither of those things is a specialist enterprise. I mean, neither the word disability or design is in the title of my book on purpose, because they seem like areas of expertise that you seek out if you think they're relevant to you. But I just want to say in the strongest possible way that this is the most interesting meeting of the body and the built world that I know of. It's not a kind of tragedy overcomer story. It's really just the most fascinating thing with high political stakes that I can think of. How do bodies make it through their kitchens, their offices, down the street, into the world. And what's the built world that each of us wants to live in for our whole lifespan, if and when our bodies change?

MBS ([38:18](#)):

Time is more like a kiss than a stone. After our conversation, I went back to this quote from the physicist Carlo Ravelli, and I couldn't find it exactly, but this is one of the organizing ideas in his book, *The Order of Time*. The world is not things it's happenings. It's not the world, it's the way our humanity meets the world that animates the universe.

MBS ([38:44](#)):

I deeply admire Sarah's work because as much as it's about inspiring people to make things, it's really about freeing us, all of us to have happenings. To have



experiences that allow us to meet fully the universe, to kiss the universe, to kiss life.

MBS ([39:05](#)):

If this conversation's moved you, there are a couple of additional chats you should take a listen to. First, Christa Couture's episode entitled, I am disabled, but not broken. Brilliant and inspiring. Second, Ximena Vengoechea's episode, which is called, how to overcome loneliness. At the heart of that conversation is the need to listen, to be present and connect.

MBS ([39:29](#)):

For more information on Sara, sarahendron.com is a place to go. And of course you can buy her book in all those places you would regularly buy a book. I'd encourage you to buy local before you buy from Amazon.

MBS ([39:41](#)):

Thank you so much for listening to the podcast. It's always a pleasure to have you along for the ride. If you're so moved, a review or a thumbs up or something on your podcast app saying you like the conversation, you like the podcast means a lot. It's one of those small incremental ways that this podcast grows and becomes more successful. Word of mouth really helps. So if you think of somebody in your life who'd like to listen to this interview, please pass it along to them. And maybe you'll join the hundreds of people who are now part of the Duke Humphreys. It is a free membership site and it gives you access to downloads and transcripts and other bits and pieces as well. Thank you. You're awesome and you're doing great.