On the all-inclusive society, or how to leave no one behind – A conversation with Dan Goodley, Yanki Lee, Jos Boys, and Sarah Glerup

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Introduction

Since the beginning of the US disability rights movement in the 1960s and 1970s, the establishment of disability studies as an academic field the following decades, and the adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006; inclusion as a political, scientific, and legal phenomenon has been widely debated, investigated and celebrated as a common goal for societies all over the world (Barnes & Mercer, 2010, p. 255f; Oliver & Barnes, 2012; Slee, 2018). This development has gained traction recently because of the United Nations Sustainable Development Goals (SDG) and the Leave No One Behind (LNOB) agenda with a pledge to end discrimination and exclusion by reducing the inequalities and vulnerabilities that undermine the potential of individuals (United Nations, 2015).

The Bevica Foundation's *Universal Design PhD and Postdoc Research Network* is an interdisciplinary network whose aim is to facilitate and strengthen academic work with universal design (Ostroff, 2001; Story, 2001) as a research-based field of knowledge in Denmark. To discuss questions of how to create an inclusive society the network organized a conversation between Sarah Glerup, a Danish activist, disability advocate and cartoonist; Jos Boys, an architect, author, and activist working at The Bartlett School of Architecture at University College London; Yanki Lee, an architectural designer, design activist, and expert in social innovation and design research for social inclusion and participation; and Dan Goodley, Professor in Disability Studies and Education at the University of Sheffield. What follows, is an edited version of the conversation that took place in late 2022. We conclude by carving out key learnings that, in light of the recent Danish national campaign #UndskyldViErHer (see e.g., Eric, 2023), remain current.

Look, it's a bird! It's a plane! It's the Super Cripple!

Yanki: Let me be the devil's advocate. First, I always ask my students: why are you doing all this inclusive design; *universal design*? Do you only want to feel good, or do you actually want to be critical of society? I always say, are we making a mess or are we trying to contribute? I was surprised, here it's still quite extreme that you either become a superhero to inspire the others when you have a disability, or you will be totally discriminated. What is the in-between? I think it's not about the inclusive society; society itself is a problem. Because an inclusive society means there's a lot of judgement. But by having the freedom to confront, to be critical, and be part of society is important, rather than naming it inclusive. In the UK, my mentor always says that it's not about inclusive design, it's about the design of social inclusion. It's ongoing, not a naming thing.

Sarah: When you say that you can either be a superhero or a tragic victim, I guess those are the two options you have in Danish society now, and that just brings us back to the question of responsibility. Because when someone wants to cast you as a, I would say, *super cripple*, then what it means is that you get applauded for doing something that other people wouldn't get applauded for. Like saying to someone like me, "It's so impressive that you smile" or "It's so great that you're here at this bar". And to some extent, it might not be completely untrue. Because if you've been pestered by people like that all evening, it is a little bit impressive that you keep smiling. Also, if you have to get four big guys to carry you up the stairs to the bar. Then yes, that's a little impressive too. But aside from that, a lot of the time, it's a way of putting the entire burden on me. It's only something special if you acknowledge that surroundings are really, *really* shitty. Raising me as someone who is a super cripple that's a way of saying: "See, she can do it, so everybody else can do it", so we don't have to change anything in society. If anyone questions whether this is what happens in Denmark right now, just go out and see the election posters that have still not been taken down, because the party that got the most votes from young people has had posters up that reads "I am weak". But on the poster, the word "weak" has been crossed out and replaced with the word "strong". So now the poster reads: "I am strong". It's about individualizing issues that should be something we all deal with together and saying: if you have the right attitude, if you decide that you're *not* weak, then you're strong and you will find a way to conquer those stairs on your own and keep on smiling.

Disability and ableism in neoliberal times

Jannick: I wonder if there is a connection between this example from the recent Danish election and then this term that I've found in some of your writing, Dan, *neoliberal ableism*. Can you unpack this a little, because I think it might help us understand what's going on with this discourse of everybody being able to do anything if they set their mind to it.

Dan: From Boris Johnson through to Marxist organizations in the UK, there is still an ableism in place. An ableism—precisely like what you described Sarah — that disability is not expected to be here, and that given the right conditions, people are ready, willing, and able to get on with their lives. It's clear that we are still not prepared to interrogate our own ableism, our own assumption of ability, of an able body/mind. There's so much work to do there. And the starting point for any of this work must be with disabled people's organizations. I think that what disability studies has done is, it's said a lot about disablism but has more to say about ableism. This is also where we connect with other political organizations. We talked in the break about queer activism and disability activism. I think we're challenging something together that could be called a particular kind of neoliberalism, which is neoliberal ableism.

Jos: The concept of ableism is incredibly useful; so is the concept of sexism. Which also didn't really get developed until the 1970s. Language really helps you say things; it unpacks for the non-disabled too. We have societies that emphasize individualism, productivity, competitiveness, and work obsessiveness, and see this as aspirations, when actually they harm non-disabled people too. It's harmful to us all that way of operating. Within the built environment discipline, there is a culture of overwork, of working all hours of the day, of being unencumbered and not ever mentioning that you've got caring responsibilities, or that you're ill. Not to say that ableism isn't dangerous, but this is something people can connect to because it's affecting everybody's lives.

Can the blind see? Ways of knowing in disability research practice

Jannick: You are all, in one way or another, knowledge producers. You're engaged in research, activism, and other critical practices that often draw on activist experiences. But how do you avoid becoming overly focused on observation and visible data when producing empirical research? Yanki, you mentioned the possibility of conducting an event like this in the dark, which would necessitate immersive listening and the use of other senses. Do you incorporate these alternative sensory methods in your own knowledge production?

Jos: At the DisOrdinary Architecture Project we do something different. We're really interested in provocation. To go back to the issue about how you might think about things differently from the perspective of blind or visually impaired people. We run a foundation course into architecture at the Bartlett School, led by blind and partially sighted designers, artists, and architects. It has 10 to 12 blind, visually impaired participants every year. The whole point is to critique the extent to which architecture is a visual profession, as well as building confidence and enabling those people to get portfolios to go into architecture schools, as they are very often and still met with an attitude of; "*what*, a blind person being an architect!?" We also explore different design methods that are non-visual, like audio description and performance, and then we bring those into mainstream design education. This we do by making things and experiencing how you change the assumptions you have about how you design by learning to change your own body and map things out and perform different ways of being in the world. It's small scale but hopefully it has big ripples.

Yanki: We use the term body-storming instead of brainstorming. What we did is we invited a group of older people coming into the school and using their bodies to design the housing for themselves in the future. The experts are those already living in existing elderly housing. They know how bad it is. Then they use their bodies to draw on the floor and walk around and the students just become the workers, following them, making the map on the floor. For us, this is co-creation, but then, it needs to be led by another expert, which is the designer. I think this knowledge transfer is very important. Also, how we make our knowledge accessible for others to make decisions with us. It's a power thing.

Dan: I think you're both talking about "ooh" and "aah" moments. One "ooh" and "aah" moment that disability studies and activism bring to the table is the idea that disability is sort of something to desire, which is a very different conception from how we know it. An example: we have a research project where I interviewed a young disabled man who had a colostomy bag and during school time, he told one of his friends that the reason he didn't play sports was because of his colostomy bag. His friend told two school bullies about this, and he was then known around the school as piss boy. Don't worry, the story ends well. The next day, piss boy decides that he's had enough of this, gets his colostomy bag and empties it into the school bag of one of the bullies. We chatted to him about this, and he said, this colostomy bag is really helpful. A very different notion of the colostomy bag to perhaps what it was designed for.

Sofie: We can all agree that research is important, also for this area. But in Denmark, we don't have a lot of researchers in disability studies. So, how do we make disability research cool?

Sarah: I wish I could give an answer, but the sad truth is that right now, in this moment in time, there's a huge backlash against anything that could be considered identity politics in Denmark. A lot of disability studies and activism would fall under that category. I think, sadly, that the only way you can make anybody want to fund disability research right now is if you claim that, "Oh, this is a way of getting more people into the workforce". If we make an inclusive society, then more disabled people will work, and capitalism will rule! Unfortunately, that will only help the disabled people that are able to work.

Dan: I think you may need to do several things. One, we need to bring disability studies and disability activism into the center and not the periphery of all disciplines. This is a demand of every single discipline to engage with disability studies. And two, we need to have disabled academics and researchers. It's obvious. But they're not there, they're not present and when they are there, they have to be careful that they work harder than non-disabled people to keep their jobs and for goodness sake, don't mention access or support. The third area we can exploit is the global trend within higher education around things like intersectionality, equality, diversity and inclusion.

Sarah: Usually there are two ways in. Either you convince people that they can make money on anything related to accessibility like, "Oh, you'll get so many customers, if you make these ramps". Which usually doesn't work very well because disabled people are also generally poor, so we don't have a lot of spending power. The other way is to go, "If you live long enough, you're going to be disabled too" and this holds true for almost everybody in this world.

"Piss on Pity!"

From the audience: A book has just come out written by a super athlete who is the world paralympic champion table tennis player. He's got one and a half legs and only two fingers. The name of the book is *Pity? No, thank you* or, in Danish, *Fri os fra medlidenhed*. I would like to hear the panel how best to address pitifulness?

Jos: I have to butt straight in there because there's a very famous campaign in Britain from the 1990s which involved the powerful slogan "Piss on pity". It was from disabled people campaigning, handcuffing themselves to buses, to get public transport improved, disrupting charitable telethons where you go on a telephone and people give money to poor disabled children and it's all based on exploiting pity.

Sarah: When I saw the book you mentioned, I thought, oh no, this is a perfect example of inspiration porn! In the interviews I've seen with him, he talks a lot about how his attitude made everything possible for him. In that way he plays right into that neoliberalist way of thinking that if you have the right attitude, then you can do anything regardless of your disability. But no matter what kind of attitude I have, I won't be able to climb stairs right now. As for the pity, I love the piss on pity. I wish we had a similar term in Danish. But I actually don't think pity is a big problem in a Danish context. I think it's something that, again, the neoliberalist trend would like to tell us is a problem, because then the solution would be to stop the pitying, stop paying taxes to help disabled people because they don't need the money nor the pity. They can just change their attitude. The only reason I'm here today is because I have a guy with me who can help if my ventilator stops working. But I know people who are not getting these hours anymore so they can't leave their homes. And in that case, I think pity is in place. It is pitiful that some people don't get the right to leave their homes. But we should also act on that pity and change society so that no one is stuck at home just because they need assistance to get out. I think we're almost at a point where we (society) don't even feel pity anymore. We just think that people should get a different attitude.

Jos: In terms of discussing inclusion, it must be disability-led. For the DisOrdinary Architecture project, we have 25 artists that we work with all the time. And when we work internationally, we tend to work with disabled artists in those different countries. The reason I'm going this long-winded way around, what we mean by inclusion is in some ways the wrong question. I want to change the mindsets of people, particularly non-disabled people. That's the goal. It's an impossible goal, but it's contained. I studied architecture in 1970s and now here we are, and disabled people are still being asked: What are the barriers for you? I mean, this is really important, but disabled people were also being asked that 40 years ago. So, we know. That information is already there. And then the other aspect: when we talk about inclusion or *universal design* there's this idea that it is somehow common sense. That we should just do it. But it doesn't happen. It is not like people in the world in which I operate would say, "Ha ha, we're not letting those disabled people in". They don't mean to do that. Instead, it's about a set of attitudes. What we understand as inclusion from an architectural point of view is design solutions, a one-off answer or a notion of *universal design*; that at some point we can design things that work for everybody. For me, inclusion starts with recognizing that this is more nuanced; it's very contradictory that the different types of access needs that people have are really complex and they don't fit together. There is no single solution. If we aim for this notion of finding *the* solution, we're just in the wrong space. Disability and difference are a good creative generator that if we start from the obvious, from body/minds that are different rather than from norms and standards. Then we might have some fun and find out something interesting about the things we can do to make change.

Equity tourism

Jannick: Yes, I can relate. I come from a business school in critical management studies focusing on diversity and inclusion. And my take would be that inclusion is one of those buzzwords, fad and fashion in management that we can all only really agree with, but it also easily becomes an empty signifier. Which is why a lot of people are putting different meanings into it; and culturally, historically, and socially "diversity" will change then. It's the same with a term like inclusion - what do we mean by inclusion? Because hopefully, society will become increasingly aware of its own diversity. Then again, from my critical background in queer studies, we would ask: *who is to include whom?* It kind of assumes that there is an original; people fitting organizational and societal norms already, who are in a position to include the other. How do we not just work with the people we want to include, but engage everyone and make it "majority-inclusive", if you will?

Yanki: Ultimately, the more interesting question is, what does exclusion mean? Who is being excluded? I remember meeting Professor Roger Coleman, the godfather of inclusive design, who turned the whole thing about "we need to design for social inclusion" on its head. For me, inclusion is an ongoing questioning: who is being excluded by our discipline? There's never one answer because it varies. When Roger did his work in the 1990s in the UK, those being excluded by design were older people and people with disabilities. You're asking how we can create an inclusive society for all. As an educator, I would change it to "Why do we need to make an inclusive society?" Because I think you're asking the question of who are the others, right? Who is part of "all"?

Dan: I consider myself a recovering psychologist. Disability in psychology is always present as a problem and it's rarely as a scholarly authority. That is to say, disabled psychologists, there's not many there. So, I understand, like people have been saying here, that inclusion immediately evokes exclusion. I'd like to borrow the words of a friend of mine, Roger Slee, who said that inclusion is not dead, but it smells funny because it's still not really something we're interrogating politically. One of the main reasons that inclusion fails, for me, is because inclusion practices often do not work with disabled people as the experts, with disabled people as the designers, or as knowledge generators. I think inclusion has become part of *equity tourism*. Equity tourism is the idea that, in the UK for example, if you want to get research money, you've got to show that you're engaging with equality, diversity, and inclusion. It's hilarious watching some of my colleagues demonstrate that they are into this. Right now, they are equity tourists and that's why I throw bricks through their windows. Metaphorically, obviously not literally. Inclusion can only be something that we grapple with critically, if we do so alongside the expertise of disabled people.

Sarah: I went psychologist browsing for years until I found this one person in Copenhagen who calls herself a norm-critical psychologist. I came to her, saying that I have these issues, these vulnerable spots, that sometimes I will easily feel like a burden. And this is a button that people can push. I wanted her to help me get rid of this button. But she looked at me and said, "I don't think you can do that, because that's not a problem with you, that's society telling you that you're a burden". So, to remove the button would mean to change all of society. And frankly, that's a lot to take upon yourself. Really, you just have to stay with people that are not going to push the button even though it's there. Years ago, when I was a student at University of Copenhagen, we all had this one obligatory talk with a student counselor. A lot of people wanted to study abroad for a semester. I also considered it because there was no such thing as disability studies in Denmark at the time. So, I went to the counselor thinking that I'm going to talk to this guy about finding disability studies abroad. But the guy just looked me up and down and said, "Well, I guess you can't really go anywhere, can you?" I know I technically probably could, but when that's the level of assistance you're given from the official counselor at the university it just becomes too much. That's for me a pivotal point in this discussion: whose responsibility is it? Is it the university's, should they be prepared for a student like me to show up? Should this event that we are part of be prepared for deaf people to show up? Or is it the person who shows up? Whose responsibility it is to explain their needs and ask for them to be met? I think that's tricky.

Normality and responsibility

Jannick: There are two things, I'd like to pick up on. One is what Yanki mentioned about the context and the situation being important, it reminded me of one of my all-time favorite texts by Rosemarie Garland-Thompson. In the text she introduces the term *misfit* as a feminist materialist disability concept. I think she would say that you can be impaired one way or the other, but you become disabled in certain situations. She is using this metaphor of a square peg in a round hole. Many of us, I guess, played with this toy when we were kids, where you have these little figures, like the triangle, the circular shape and the square and then you have to put them into the corresponding holes. But of course, if you put a square peg in a round hole they don't fit, and the question is; is the problem the square peg or the round hole? You can work with one or the other. But the problem only really emerges as these two shapes meet. Hence the context and the situation being very necessary to look at. The other thing is what you said, Sarah, about responsibility - because, at least in my case, working with businesses, there are more and more workplaces where they establish employee networks to include the groups of people that they want to attract and retain. The diversity subjects, if you will. They include them in this diversity work, so you don't just assume on their behalf what they need. But the employer also potentially exploits freely this diversity labor, which often sits on top of regular work as interest hours and non-promotable tasks.

Yanki: I'm known in the design school for being honest and giving people critical comments. The one I made earlier about no sign language in the room we're currently in is actually a drive for innovation. Have you guys heard of Dialogue in the Dark? It is a German concept where all go into a dark space and then you have a conversation with people who have a visual impairment. Essentially changing the concept of the environment. And now I'm thinking: can we have a conference in the dark? Or in silence? When doing a conference like this about disability, could we try to have a dark session and then people with visual impairment will be the ones guiding us around? This is a disability inspired innovation.

Sarah: I agree that it's probably wise to see it as a tool for how you could do things differently. But I also think it's very important not to go into what I would call *disability tourism*. This is something that I see a lot, especially when elections are coming up. Then people will come to town squares and try to be blind for an hour. So, you'll know what it's like. And that's usually quite misguiding because if you've never been blind and then are blindfolded, you'll be completely lost and it will be nothing like what it's like to have been blind for ten years. What happens when someone "tries on a disability" for a few minutes, is that all you can really focus on are the differences, as opposed to the things that connect and unite us.

Jos: I think it is a good question about exploiting disabled people's labor. We have a rule in The DisOrdinary Architecture Project, which is that the artists and the disabled architects that we work with always get paid. And the non-disabled people don't get paid.

Sarah: And the thing about free labor is that sometimes you also have this situation where somebody else does the work, but then you are expected to be grateful for it and make sure that people see the work they did. Like, if I've been in charge of accessibility for something, then everybody just kind of expects it. That's fine. But I've had a couple of experiences where someone has called me and said "We're going to try to get a ramp this time for the premiere of this film festival, so can you explain to me how I get a ramp?" And then I give them a bit of information and they do the rest. On the night of that premiere, I might have a cold. But if I don't show up - if nobody in a wheelchair shows up - then they'll think that they shouldn't have spent time getting a ramp and they'll never do it again. So, if I'm too sick to go, I have to make sure that at least a friend in a wheelchair will show up. You have to be there, or it will ruin it for the next generation! And that's also something we should talk about because whose responsibility is it that something is in place? I have another example, which is a bit more extreme. I used to work for a political party, and we had this yearly Christmas lunch. Part of it was in a relatively accessible room. I don't think I could go to the bathroom, but that's pretty common. At least I could eat with everybody. The problem was that they only had the room until 11 pm, so what to do when the clock stroke 11? It's like a Cinderella story. Will I turn into a pumpkin? My boss called me. He's heard that you should ask your disabled employees about their needs. So, he says, "Sarah, do you think that after dinner you want to stay all night, or do you think that maybe you just want to go home? Because if you're going to go home anyway, then we could just proceed to the inaccessible bar across the street. But of course, if you want to stay, we'll think of something else, so you can come along". Obviously, what happens is you go, oh my, if I say I want to stay and then I'm tired because I had too much schnapps, then what am I going to do? Then everybody will think that it was just me being difficult. So, you just go home.

Dan: One theme that seems to be emerging here is "access work". There are expectations about what happens when disability turns up, and when it does turn up it's very much expected to stick with the norms of that space. For me, the definition of true inclusive education in schools would be when disabled children are excluded from schools for taking drugs and having sex rather than for having a disability. When the doors are open, the ramps are up, are we prepared to continue to be open to disruption? According to Alison Kafer and Robert McRuer one of disability studies' great political offerings is disruption. Disruption to norms, you know, not this either/or, are we going to go accessible or not? But to actually say: How might we rethink spaces – collectively – in a more disruptive fashion?

Design a hammer, not a ramp

Barbera: This is making me think of the history of disability activism and how it has informed the design of the built environment. If you think of Berkeley University and the wheelchair users there smashing the concrete and creating ramps, there is so much political intention, like the beginnings of universal design and inclusive design. We now live in a time where, as you said Jos, we've mapped out all the barriers, but we're still asking the same questions. We have forgotten about all the incredible initiative, activism, knowledge making, and culture that is led by disabled people, and that is somehow never recognized in the same way as neutral design. I was wondering if we could all think together about whether universal design or inclusive design could ever be neutral or if we need to be political? And whether, in our different disciplines, we need to take a stance because otherwise how can we create change? The knowledge, the people, and the communities are there. But somehow, especially within academic contexts, we still have to act and be an activist in disguise.

Yanki: I think they should think about designing a hammer, not a ramp. Because the ramp is already there. This is what we tried to talk about, moving from equality to equity. And then also ask our students: “Do you really care about people having access to your design?”

Jos: It becomes about professional compromise and battles. In disability studies, activism in particular, it's the language around social, spatial, and material justice. And once you start talking about justice, you bring in power and really flip the debate. But I'm very aware there are certain circumstances where I use that expression (justice), I think, to many audiences that I speak to it's a step too far. Whereas for me, it's like the first step really, to think about it as justice.

Sarah: I think the context is a bit different here in Denmark because we are very much behind in many of these debates. You brought language up to begin with, and it got me thinking about the whole distinction between being disabled and having a disability. And then personally, when we're having this discussion in English, I use disabled because there's this whole change within disability justice activist groups in English speaking countries where you ask why would I take my disability out of myself and make it something that's separate? Something to be ashamed of? Why would I say I'm a person with a disability when it's also part of my identity? I am also gay. I wouldn't say I'm a person with a gay sexuality. But the thing is, that when I speak Danish, I do not do this. Because we have not had that discussion.

Concluding remarks

While bringing together Dan Goodley, Yanki Lee, Jos Boys, and Sarah Glerup constitutes a contribution in allowing for interdisciplinary scholarly dialogue, we would, conclusively, like to foreground another two key insights that emerged from the conversation. First, thanks to the diverse backgrounds of the panelists the conversation spanned several countries, thereby highlighting important differences across these contexts. In Denmark, as Sarah Glerup points out, the critical vocabulary with which to conceptualize, problematize, and, eventually, become agenda setting politically as well as in research is underdeveloped. As such, we hope that the conversation will inspire the use and further theorization of the concepts that surfaced. These include neoliberal ableism, the super cripple, and equity tourism.

Combined, these three concepts enable us to understand how neoliberalism and ableism feed off each other in presuming and prescribing that we “Live alone. Atomised. Self-serving. Never needy” (Goodley & Lawthom, 2019, p. 237). They enable us to realize that when elevating and celebrating people as super cripples, that is, someone who—despite disabilities—achieves what other people would normally not get applauded for achieving, we are indulging in 'inspiration porn', reinforcing neoliberal-ableist individualism. Finally, they enable us to grasp the phenomenon that previously unengaged researchers and practitioners alike with no prior experience or commitment latch onto accessibility and disability as well as other issues related to diversity and inclusion, just touring for funding opportunities or due to institutional demands while paying lip service to equity, SDG, and LNOB more generally (see e.g., Lett et al., 2022). Yet, going from theory to practice—and this is the second key insight – things get muddy, as it is difficult to keep up and, thus, operate from neat and clearly defined categories of difference. In lieu of simple solutions to the initial overall question of how we can create an inclusive society for all, we leave this conclusion open-ended, offering only extra layers of complexity.

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