GIVING PEOPLE WITH DISABILITIES THE TECHNOLOGICAL TOOLS TO SPEAK OUT

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Speaking Notes

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I want to thank Monica from the ISSP and the organizers for the opportunity to participate in this panel discussion. I am particularly pleased that the issue of technologies as they pertain to people with disabilities is the focus of this event.

I have been asked to talk a little about the policy implications associated with technologies that might be used to assist persons with disabilities. What happens when these innovative technologies are not accessible to people with disabilities? Does it lead to an uneven distribution of benefits, one might ask? The short answer is yes – but I would like to return this to later.

Before I begin, I want to say a few things as a way of framing my intervention, a few caveats as it were. I am a public policy scholar – yes, I know how exciting that sounds! – who is particularly interested in policy problems or challenges that are difficult to disentangle because they are controversial or deeply contested. I am also especially concerned about the

role of individuals who are considered marginal to policy making – how do folks who are on *the outside* of policy making find their way in, how can they can compete with elites, authorities, experts? What tools can enable their participation in politics, in society, in collective life?

Which brings me to the theme of the panel: public policies (and specifically technologies) as they affect folks with disabilities. Michael Prince, also a political scientist, has been quite eloquent in describing people with disabilities in his book as "absent citizens".

Policies and interventions and technological innovations are enacted and mobilized in the name of people with disabilities, *but without them*. I guess you can say we have come a long way since the 1970s and the regressive policies and programs that kept disability hidden from public view, but it's also appropriate to say we have not come that far at all. There is an 'absent presence' of people with disabilities, and only a stubborn acceptance, I would argue, that people with disabilities are full citizens with all of the benefits that come along with that. I hope it is clear by now that I firmly believe that how we collectively respond to challenges associated with living with disability is not simply a niche topic – or something that matters for people over there. How we deal with, live with, disability, and the technological fixes that are summoned to respond to disability/inclusion/accessibility, are potent reminders of our humanity in the face of embodied difference.

First, the importance of lived experience is absolutely central to how we move forward in thinking about the role of technology and people with disabilities. Public policies do not emerge in a vacuum. It is simply immoral to think about technology without asking people with disabilities what they imagine, what they desire, what they want. As an able bodied, privileged, white person, I am conscious of the importance of active listening to folks whose lives are affected by seemingly mundane public policies.

Second, I think we need to be mindful, and especially careful when it comes to how our interventions, policy interventions, some of them grounded in access to particular technologies, reproduce ableism. What is ableism? I quote disability activist Lydia Brown, who uses the term to refers to "the systematic, institutional devaluing of bodies and minds deemed deviant, abnormal, defective, subhuman, less than".

Challenging ableism might lead us to ask different questions, questions that do not take as a starting point what constitutes the "normal". I have asked this of Lundy Lewis in a previous interaction, so this is not a surprise! When thinking about the role of robots in assisting autistic individuals with forms of human interaction, what if we posed the question differently and asked how technology could assist non-autistic folks (autistic people use the playful term "neurotypical" to describe people who are unlike them)? The focus on using technology to help autistic people is not always informed by a disability politics sensibility that recognizes different forms of being in the world, different ways of interacting. Lacking facility with social interaction

may not necessarily be a deficit, unless we frame it in those terms. And of course, how we understand what constitutes normal social interactions is influenced by a range of factors – race, gender, class, for instance. As those who have studied in autism in girls demonstrate, living as an autistic girl is particularly challenging because we have certain gendered assumptions about sociability in girls, which we do not always extend to boys.

Being progressive in our politics and in our policy interventions can often stop at a recognition of some forms of oppressions over others. The feminist theorist Sara Ahmed has been helpful in getting us to see beyond our own limitations when it comes to progressive thinking. She reminds us to be wary of claims to being progressive or critical. As she explains, it can mean people who claim to be critical fail to see how they are implicated in forms of oppression. Many well-meaning liberals have contributed to a long-standing tradition of pushing disability to the political margins, and it would be a real tragedy if we continue to relegate technology to a supporting role as a form of charity to help people with disabilities be or become less disabled.

This is why it is exciting to hear more about inclusive design… What if we started from the presumption that technologies be mobilized for inclusion – full stop – without necessarily targeting people with disabilities? There is a danger associated with technologies that are designed uniquely for folks with disabilities, in that they can reinscribe the stigma that accompanies disability.

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In the art world, folks talk about "touch tours" as a way to think about accessibility differently. An organization called Doing Disability Differently in the UK writes:

> For many blind or partially sighted theatre-goers, a touch tour is an essential part of the theatre experience. Having access to the stage and set before a performance is a way of firming up the descriptive information they may have already received and provides them with extra detail to allow them to engage with the production. Patrons will explore the space, and may like to handle selected props, costumes and furniture. Touch tours usually last approximately 30 minutes. They need the involvement of the audio describers, front of house staff, technical staff, stage management and the company in order to work smoothly.

This does not require a big technological fix but rather a sensibility to the reality that experience itself is mediated through a range of embodiments.

Socially responsible firms have jumped on the accessibility bandwagon too, even if they make an important distinction between accessibility and inclusive design.

> While inclusive design considers from the very beginning how something might be easily useful and enjoyable for as many individuals as possible, accessibility traditionally means making special considerations for people with disabilities. It's the difference between

designing a watch that can be read by touch or sight, and taking a standard analog watch and adding braille instead of numbers. The first example considers the functionality and beauty of a watch that doesn't require sight, while the second example tries to take something designed for vision and make it work for touch without addressing some of the problems this modification creates.

Assistive devices aim to remove a barrier for people with disabilities. Inclusive design strives to fundamentally redesign a product so that the barrier does not exist in the first place. Assistive technology is reactive. Inclusive design is proactive." Taken from **https://www.eone-time.com/magazine/the-difference-between-inclusive-design-and-accessibility/**

Third, there is good reason for folks with disabilities to be particularly suspicious of technology as holding the master key. What has been done in the name of technology has been particularly harmful to people with disabilities. There is, of course, the debate about the role of Cochlear implants, a technology that is used to ensure cohesion with the hearing world, but it is viewed by Deaf activists as an attack on Deaf culture, especially if you regard culturally Deaf people as members of a linguistic minority. And of course, in the world of reproductive technologies, there are grave concerns about preimplantation genetic diagnosis and its potential to screen out disability, to prevent disability as it were. As Jonathan Glover writes, "Consider the theoretical possibility of screening to ensure that only a disabled child would be conceived. This would surely be monstrous. And

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we think it would be monstrous because we do not believe it is just as good to be born with a disability."

When we think about technologies we are best to focus on issues of access – differential access - rather than the more ableist way of thinking about technological fixes or ways to make disabled people less disabled. According to one recent report on the Canadian situation, "In Canada, 81% of individuals living with a disability reported using at least one aid or device to assist them to more fully participate in society" (http://agewell-nce.ca/wp-content/uploads/2015/09/age-well_jurisdictional-scan_2017_June-30_FINAL.pdf

Yet, according to the same report, "27% of users of aids or assistive devices indicated needing at least one other aid or device that they did not have… For those with severe disability, 44% reported having unmet assistive device needs."

I would like to end with one of the most elegant and eloquent voice in "disability country", Catherine Frazee, an activist, scholar and artist, who insists on the value of living with profound disabilities: "The slings that lift us, the tubes that feed us, the instruments that fill our lungs with air and empty our bladders of urine are understood as tools for living, rather than as markers of spoiled life."