

Disability Rights and Robotics: Being There without Being There

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We are Sophie and Tillie, and we worked together on the Disability Rights and Robotics project, at the University of the West of England, as co-researchers in a diverse group including disabled people, carers, students, and academics from social sciences and robotics (Disability Rights and Robotics, 2020). Some members of our team had both lived experience of disability and were involved in teaching, learning and research. Sophie is one such member.

The project has included hours of video conversations, so we based this chapter on an auto-transcribed online conversation, in a similar spirit to Mann's and Mann's (2018) text message conversation. From this point I, Sophie, will refer to myself as 'me' and offer a narrative on how my understanding of rights links to a transformative perspective on education. Sayers (2018) insists that disabled children should be considered as having 'rights' to education, not 'needs' and for me rights to education go far beyond attending school.

Tillie

You've said before that this is your dream project. Why is it exciting for you?

Me

It allows me to be in a space where disabled people imagine a future that I was fantasising about as a child. A future that I never thought I was able to be a part of, and here I am. It makes me think of Wong's beginning of her new book addressing her younger self and other disabled children:

'to those who can't imagine their futures, the world is ours' (Wong, 2020: p. v)

And in this project, this is how I feel.

Throughout my childhood I had this vital relationship with education, asking big questions (Savage, 2018) and now, as a grown-up I am in research spaces, having conversations about rights and robotics design, where we're imagining exciting futures. It feels empowering as I was a disabled child who was a 'subject' in research. My voice, my choice, my decisions were not prioritised, my physical body was medicalised and split into these component parts that did not work which was the focus of my existence and why people found me intriguing (Savage, 2018). Now as a researcher, I am asking questions and I contribute my experience, not because someone wants to capture and utilise me as a 'fascinating subject', but because I can be in spaces generating knowledge. The 'space' we were working in was transformative and knowledge was co-produced. In this practice as Gillberg (2020) offers, disabled academics such as myself are perhaps uniquely positioned. In such transformative spaces, working with innovative robots and a group of co-researchers bringing their diverse lived experience, can start thinking and imagining choices regarding living life to the full.

Many disabled children don't get the opportunity to go through education in a way that's accessible for them or don't get the opportunity to become grown-ups. So, I am hugely privileged to be in this space and be acknowledged as an expert by experience and as a social scientist, especially as there are seemingly so few disabled academics. As Brown and Leigh (2020) explain because academia is traditionally ableist, so few are adequately supported in ways of working or in acknowledgement of the complexity, and additional labour in the lives of disabled people.

Tillie

Can you then tell us about rights and robotics now that you're working with robots?

Me

I'm working with robots! How cool is that? I love science fiction and how it allows us a space to think about the future imaginatively and playfully. As a child science fiction was my escape when I didn't want to be where I was, or I was excluded from being where I wanted to be I escaped into this expansive world of possibilities. When we were in the knowledge café together thinking about our possible relationships with robots, the idea of them being a non-judgmental companion was important. Thinking about these early relationships with robots and how that could empower independence is exciting. On the day of the knowledge café, I operated Double a telepresence robot, which you can use to drive around and interact with people. As someone who has an impaired immune system, physical spaces are inaccessible to me at times, but now I can envision fleets of Double robots in all public spaces. To be supported to access a physical space is essential, but I believe having the option to log in to a Double and be in that space has great potential. It makes me reflect on my experiences of accessing education and how young people's experience could be transformed. Robots, particularly telepresence robots can become a way of enabling creativity in specific spaces because without 'being' in a room, it's difficult to develop and contribute to conversations and understanding. My experience of being sent homework or catching up is a poor substitute for physically driving into a space and being there. As there was little in the way of meaningful connection to the classroom, my peers, or my teachers not only was I missing out on my education, but they were also missing out on me being in the classroom.

Tillie

That's very powerful! Isn't science fiction sometimes about terrifying images of the future? Do you think any concerns have come out of the project?

Me

Yeah, of course, in our knowledge café a variety of concerns were shared. They are about robots being used to replace reasonable adjustments or appropriate physical construction of spaces. Some innovations could be seen as a cost-saving exercise, which is not about rights. It becomes something more sinister. There is a lot to consider around who controls these robots, who pays for them? Are these robots yours? How do they store our data? Who sees my data? Can anyone hack in? Potentially these products could be made to exploit disabled people and they might not deliver on promises made because although robots might be able to learn not every robot will be tailored to everyone.

It is also important to consider how technology and disability have always been closely entwined. I'm thinking about assemblage here and how Shildrick talks about bodies being hybrid with an amalgamation of organic and machine parts (Shildrick and Steinberg, 2015). Just as Haraway (1991) argues that we are all 'already cyborgs', Weise's (2020) echoes this in her narrative regarding a 'fellow cyborg' when relating to the musings of an AI. For many disabled people this separation between self and technology is less boundaried. When considering identity and technology as a creative assemblage, others having power over that technology can be concerning. Disabled people have been integral to the progress of design in many realms of life, through lobbying and, increasingly participating in the process of design in a move towards design for all (Williamson, 2020). If you're not having diverse groups of disabled people who have different experiences who traverse the world in different ways and face various forms of barriers and oppression, if those people are not in the spaces driving design with robotics engineers, from the very beginning, then there's really no point to further innovation. You're creating things that are in some ways potentially worthless.

Tillie

So, in a nutshell, Sophie, what is it you want us to understand?

Me

Without genuine and authentic inclusion of diverse narratives around almost anything, you're not capturing enough. As a research community, we are responsible for addressing traditional problematic power relations that exist in research (Gillberg, 2020). Without disabled people designing, doing and writing research, how can we understand and address current and future barriers in our societies? I argue that we can't.

Tillie

Now thinking about the implications of the project and what might happen with it, I just wonder how it's left you feeling at the end of this phase of the project.

Me

Being a part of a diverse co-research team, has left me feeling proud and with a sense of belonging which is so rare. Smith (2020) talks about this move beyond tolerance to 'actively owning' a space and truly that's how it's been, which brings deep validation.

Tillie

I think you have a very particular relationship with education, so it's not just your entitlement to school, but your right to education as a form of liberation.

Me

Very much so. I think I always saw it as my way out, and not only my right to learn but being a part of that was necessary. However hard it might be. Having a right to education is not the same as being placed somewhere where you're bullied by the staff and students. It's not an acknowledgement of your needs or of your experience. I think what I have been trying to say is countering that, education can be a catalyst for liberation. Wong said 'the future is ours' and as I can be here, I intend to make more spaces for others to find ways of being here too – through innovation in robotics and technology. To drive into spaces together, to co-produce research, and co-design technology with disabled people leading the way.

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