



Disability Rights and Robotics: co-producing futures 2019-2020

This project brought together a team of 25 co-researchers from the University of the West of England, Fairfield Farm College and Wiltshire Centre for Independent Living. The co-researchers are a diverse group including disabled people, carers, students, and academics from social work, psychology and sociology to robotics. Our research team demonstrates a wealth of experiences as some members had both lived experience of disability, in addition to being involved in teaching, learning and research.

The research question for the project was:

How can robotic technologies support disability rights?

Rights are about everyday opportunities to live life to the full, human rights that everyone is entitled to (The Convention on the Rights of Persons with Disabilities (CRPD) 2009 (Enable.un.org, 2019). In this time of rapid social change to our social and work lives, relationships and leisure, there are new technologies that might support disability rights like 'driverless cars', smart phones, social media and new robotic technologies.

The project had two aims:

- to identify priority research questions into disability rights and robotics
- to develop the co-production process for future research

Project outcomes:

- the project story – a report, a cartoon story and an article
- presentations to our organisations and wider networks interested in disability rights and robotics
- an established co-production team
- priority research questions and co-production methodology to inform a future research bid

Co-production Research

Co-production research “is undertaken *with* people rather than *on* people” to produce knowledge for socially just and relevant change (Campbell, and Vanderhoven, 2016:12). The methodology for the project was based on the Knowledge café approach developed from Brown (2001). A Knowledge Cafe entails creating a hospitable space for co-researchers to share experience, form questions together,

explore and deepen the inquiry and generate knowledge for action. The model of evaluation used was designed for public involvement research asking for feedback in four areas: flexible ways of working; many ways to be involved, having concerns heard and having a voice (Gibson et al 2017).

The co-production team

A social work academic initiated the research as a follow on from a peer research project into disabled young people's futures (Curran et al 2020) and acted as co-ordinator. To explore disability rights from experience, members of the Hub Group were invited. The Hub Group, (UWE) was set up for involvement in social work programmes with members bringing direct experience of disability, caring, and mental health. Disabled young people over 18 years old were invited from a further education college and they were supported by advocates from the Wiltshire Centre for Independent Living. To look at how robotics and social support could facilitate rights, students in social work and robotics were also invited to join. The academics in social science and robotics brought extensive experience in user involvement, public and patient involvement and public engagement. All members of the team were co-researchers. While our identities reflected membership of specific groups, it is important to note that gender, ethnicity and disability were aspects of identity that cut across the groups.

The team comprised of:

- 4 social work students (SW)
- 5 Hub Group members (HG)
- 5 young students (YS) and two advocates from the Wiltshire Centre for Independent Living.
- 4 students in robotics (RS)
- 3 social science academics (SS)
- 2 academics in robotics (AR)

A cartoonist was engaged for data capture for a graphic comic of the project story (Church and Curran 2020).



Experience based questions

In our table groups, we began conversations about robotic technologies and our experiences. We jotted down our questions on the tablecloths and then shared them in the whole group.



Figure 1 - Sharing Questions

The young students wanted to know what robots can do, how they work and if are they accessible. What can a robot learn, what is in its dictionary, how it will upgrade and how long it will last? Will it understand someone who uses an electronic assistive communication device to speak rather than voice. There were also some comments about whether it has feelings, and whether you could decorate it for it to be yours.

Hub Group members also had questions about robot functionality and potential in terms of human rights to make practical life choices viable. There were questions around the possibilities for monitoring safeguarding and concerns raised about privacy and control of personal data.

Social work students had questions about communication and accessibility, availability, cost and inequality, potential intrusion and the right to refuse a robot. There was also a concern that people would prefer a person for care especially if a robot malfunctioned.

The students in robotics were interested in how robotics could support disabled people around vision, hearing or speaking and could help disabled children to learn. They were aware of the challenge of designing robots to be intelligent enough to function while recognising public concerns around the extent of its capabilities or uses.

Sharing questions led to a discussion about language and the use of terms about disability and impairment.

‘If we could change oppression, words would not be so important’ (HG).

In the social sciences, and in the social model of disability, ‘impairment’ is about health and mental health conditions and ‘disability’ is about a positive identity and

changing the barriers disabled people can face that do not arise from impairment but from inequality and attitudes (Oliver 1991). A willingness to explain and learn from each other's points of view was voiced as a benefit of this unusual opportunity to be together as a group with diverse experiences.

Finding out

We then moved to try out Double and Pepper, the robot, for ourselves. Double, a telepresence technology, is a computer screen attached to a pole on two wheels. A person making a call on their phone from anywhere can be seen on the screen and can move Double around the room/s to talk with different people. As we tried out Double many co-researchers said how much they liked it. The young students were eager to find out how to operate it and were soon demonstrating it to others. All agreed that using Double felt much more like being in the room than using a phone or video call. With Double everyone could have more social life and learn or work from home.



Figure 3 Finding Out



Figure 2 I am a part of the café, even though I am apart from the café

Operating Double

In the shiny, echoey corridor I was alone, carefully entrusted with laptop and responsibility. Here I connected to Double. Double looks just like a tablet, on a stick, on a wheel. I had just left our knowledge café, a hubbub of noise and uncertainty where some moved uncomfortably in chairs, unfamiliar with the space, and uneasy with its inhabitants. Then, with my fingers on the keys and a smile on my face brought Double to life. My face and voice appeared, I had a robotic body, and I could move. I felt the coolness of the corridor, and yet I was in the café again. I moved around speaking with my co-researchers, some of whom were previously uneasy suddenly a buzz of energy and excitement moving close to the screen. Double was no longer a foreboding inanimate robot or an object of fear but a catalyst of curiosity. Before long, I heard the cheers of my co-researchers joining me in my lonely corridor keen to operate Double. I held the laptop steady as my teammates pushed the controls, and I felt like I was glimpsing the future. Where if even apart, we can still be a part of creating, sharing and learning together.

Pepper is a robot who can answer questions, take pre-programmed instruction and move around the room. Neither Double or Pepper can go upstairs.

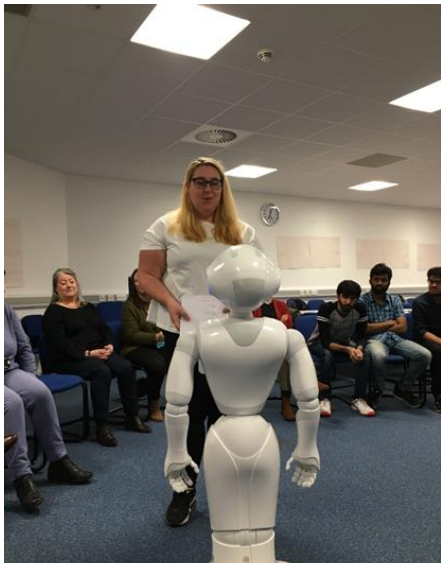


Figure 5 - Finding out about Pepper



Figure 4 - A cool buddy, or guide?

We thought Pepper the robot was cool and could do some things for us or help us do our jobs. Its appealing, its without stigma. Pepper might act as a buddy, guide or companion. Pepper was hard to work with in a room with lots of people talking. Robots can learn to understand what each of us want like a human can, but a robot could also be too much like a human and be frightening!

Seeing telepresence and the robot changed the feelings in the room as one of the social science academic said;

'We went 'whoooo' when we saw the robots, we lost our anxieties and suspicions, it was like Christmas – opening toys for grownups. We had a go, asked Pepper questions. I now saw a robot – had to see it to believe it. Everyone had a go themselves, had to touch' (SS).

Going Deeper

Back on our café tables we reviewed our questions. The young students reviewed their questions on their return journey to college.

To start with the young people said they felt scared, anxious and confused by the robots as they had not seen one before and were not sure what to expect.

'When I first saw them, I was unsure'. 'It was all new'. (YS)

After having met the robot's, views changed to a different range of feelings including happy, calm and excited.

'I feel happier now I know what to expect and its ok now' (YS)

'Looking forward to seeing the robots again now' (YS)

'The more I saw them the more it was ok' (YS)

'I liked the robots' (YS)

The young students had some suggestions about how they would use Double and Pepper:

- To give reminders to do things
- Could talk you through recipes
- Assist you with washing up and cleaning
- To help me tidy my room
- To remind me to pick up my socks
- To help me with my spellings
- To help me put my clothes away

In the social work and social science group, Double was seen to be of value to prevent social isolation. For instance, if ill and unable to attend school, they could attend with Double, and be present in the group. A person with periods of illness would be able to attend meetings and conferences overseas for work without taking the risk of travel.

'The telepresence felt like being here without being here' (SS).

The robot was seen as non-stigmatising:

'its subjective, but I would like to be seen with a robot in my home by friends – it's cool and more appealing than a carer or equipment' (SW).

For the Hub Group members there was a strong emphasis on the need for these technologies to be person centred and for robots to communicate in many different ways with age appropriate language and correct use of language (e.g. without long words or long sentences). As language is important to each person it was suggested:

'Perhaps the robot needs to ask 'how do you want me to speak to you' to avoid upset (HG).

Its role as a companion was highlighted with links made to current use of systems that respond to instructions such as SIRI and Alexa

'you could share issues and have a companion. It does not judge' (HG).

This point highlights the significance of the differences between a human and a robot, and is indicative of the power relationships that exist between people and the kind of judgements that disabled people can face in a society with inequality and excluding norms. It might have therapy potential but there was a concern voiced about attachment and the possibility of upset if it broke.

Pepper was seen to be useful for independent daily life and for emergencies if a person was unwell or had a fall, but, on the other hand, it would have difficulty in predicting harm which humans could do better. There were concerns about privacy, safety (including hacking) and potential for oppression if the person themselves did not have control or give consent.

The students in robotics discussed people's fears, expectations and wants commenting on the way robots can enable social interaction but are not themselves social or emotional;

'What is the trade-off between engineering spec and features that are actually helpful to people? People seem to desire a robot capable of fully understanding them, and at the same time they seem frightened by a robot being 'too intelligent''(RS)

Project outcomes and what next?

Knowledge for Action

Further project cafes planned to try out the driverless car and smart home space could not take place due to the COVID 19 pandemic lockdown. Themes, key messages, reflections on the co-production methodology and future research questions were identified from the analysis undertaken after the café through a series of online meetings during the COVID19 lock down. The methodology was adapted to online meetings, email communication and co-writing to co-produce the report and formulate the next steps together. The young people were not able to join this part of the research. They were sent the draft report to check and the graphic accessible version of the project story and will be involved in future impact events outlined below.

Disability Rights and Ethics

All co-researcher groups were concerned about the ethics of access, protection of personal data and being in control of technology. Making a call and being able to travel round conversations in a room was seen as inclusive participation. The use of technology for safety and safeguarding was potentially unwanted surveillance, but on the other hand, it might offer security if surveillance protects someone from risk and harm. The human involved would be key to that interpretation. Ethics was also seen to be the issue regarding access to new technology if it is to be stigma free and available and not become an out of reach luxury or 'specialist equipment' rationed through policy criteria and professionals' assessments.

Rights and Opportunities

The technology comes with standard functions and has the software to 'learn' from the person/s using it, so it can adapt its mode of communication and store favourite requests etc. This flexibility was seen as highly valuable, but the process of learning was also seen as quite problematic in terms of how much it would have to learn to be really responsive, how precise the commands need to be for it to work and how quiet the environment needs to be for the robot to register commands. Its use in providing prior programmed prompts, possibly planned by family or carers was viewed as more straightforward.

Hub Group members commented that many people are now self-monitoring their exercise or sleep without stigma and a person could control the data and make their own life adjustments. With consent, robots could share data with a person's doctor so wellbeing is monitored without the need to interrogate a person or rely on their memory. Thought would need to be given as to how a monitor can be worn as

people may be sensitive to and distressed by clothing so 'carers and disabled people must be the design and purpose in from the get go' (HG). However, it is not enough to monitor; a responsive carer wants to get to know a person very well and is always learning, curious and questioning. Having said that, Pepper might be able to be the constant when everyday life completely changes due to COVID19 and train a new carer to use pre-agreed prompts. Pepper might encourage a person to drink and eat by knowing what they like and this could avoid carers panicking and trying to over feed a person. Previous experience had shown that serving double deserts laced with food drinks only put someone off eating. Co-production and thinking about diversity in design could apply to all design.

Intimate Rights and Relationships

Pepper was seen as a potential guide or companion that would be cool to have around the house. Becoming attached was a concern if it broke or needed to be replaced. Again, the involvement and role of the human was key.

Social work students highlighted how the value of social life had become a focus in the context of the government lockdown in response to COVID19 social distancing and shielding measures. As every aspect of ordinary life changed for everyone and existing inequalities increased. If Double was available in hospitals and care settings where relatives or advocates are not able to enter, they could have that greater sense of 'being there' than if using a phone or video call. As the lockdown measures are eased, the return to pre COVID19 routines could be daunting. Double might be very useful to bridge home and college. If young people are away from school for periods, their peers can see them and not forget them and the young person can keep up connections with them more easily. Being part of the project had brought the students greater awareness of the barriers to everyday rights experienced by the young students and Hub Group members and the everyday possibilities the social work students are able to take for granted.

The potential use of Double was valued by the Hub Group carers not able to visit their adult children living in sheltered accommodation or them to visit home and be able to see home and feel present there. Using video call at set calm times and showing familiar things at home, had helped to stay in touch and keep family life going.

Students in robotics commented on how important design with communities is stressing the need to find out how people feel as 'feeling is closely linked to purpose' (RS). Whether robots generate fear or appeal will determine their value and uses or will result in unnecessary resource waste.

Key Messages

- **Disability Rights** - Co-production is working together to invest in developing the framework for understanding disability rights. Robotics engineers want to know preferred terms. Invest in careful preparation for working together
- **Driving robotics design** – "Co-design is essential – without it, it is pointless!" We want to be involved in the design of inclusive, non-stigmatising robotic technology before a prototype is developed. As many different people as possible need to be involved so robots are friendly and exciting!

- **Equal access** - We want to be able to use robotic technology in the future like everyone else; in schools, colleges, art galleries, for meetings
- **Communication** -We want robots to be ready to understand a wide range of ways we communicate as well as learning our preferences – it is frustrating if demonstrations are not accessible
- **Privacy** – it's is an entitlement and it's enshrined in law
- **Feelings** - Systems engineers want to know how people are feeling, emotion, circumstances and need dialogue – purpose links to feelings. If robots are frightening it will be off-putting, and watch out for potential to manipulate emotions and deceive.

Co-research was seen as key to design in robotics for disability rights from the initial ideas stage. The effort of the user needs to be understood as a choice. 'Do not assume a guide dog is wanted or would fix everything. Ask 'What do you want the robot to do for you?' (HG). Co-researchers recognised it is a chicken and egg situation to know what is possible, but people do know what they would like to do and what could be made easier. If technology is already designed with pre-set options, they may not be the desired functions.

'Robots are about practicality, ethics and relationships – its assumptions that are dangerous!' (HG).

Refining Co-production research

Co-researchers said they felt heard in the café, though at times it was too many people talking at once. Overall everyone expressed how much they had enjoyed the day and were looking forward to more cafés and to getting to know each other better. The preparation meetings had been important but coming to the laboratory and meeting new people and robotic was a lot to cope with at the start:

'We like to be prepared for new experiences' (YS)

The hospitable space was much appreciated and co-production needs to begin slowly for people to become familiar with the laboratory setting and the robot technology. Starting with small groups of three or four people finding out what robots can do before joining larger group was suggested, so that co-researchers can feel comfortable to think and not have too much noise to hear.

The use of the evaluation tool at the end of the café was appreciated:

'We liked to be asked about our participation – we think that it is good practice to ask us.' (HG).

The co-researcher team formation needed to generate a shared framework of understanding of disability rights and discussion of language and preferred terms. The involvement of the cartoonist who facilitates graphic illustrations could provide a bridge between the community and the engineers providing pictorial clarity. Clear word description is also vital for people to know what the technology is, and conversations about how best to share information are key.

Carers and parents, organisations and community groups could be involved to look at collective uses. Children and young people can be involved and have their own voice; they may or may not want a parent and carer with them who understands their wishes.

Questions for Future Research

The priority questions created through the project are as follows:

- **How will robots be ready to communicate in many different ways?** If a person wants to be understood when they use vocalisations, sounds, movement, or touch, can the robot respond and function accordingly?
- **How can engineers work with communities around feelings and purpose of robotics including risks and rights?**
- **How can robots add to students' learning and social experience in colleges and universities?**
- **What are the existing ethical and legal standards on robotics? Are these adequate for inclusive accessible design?**

Members of the co-researcher team have extensive networks and the team is now well placed to undertake further research into these questions. All have been awarded a certificate of achievement as co-researchers in this project.

What's next?

The academics in robotics embraced the coproduction approach and committed to sharing the use of hospitable space and the model of evaluation used with engineers so that they can learn to run a café and work with community members. The social science and robotics academics plan to joint supervise some student projects involving experts by experience with teaching around ethical co-production and rights-based research questions. Already the social science academics have been invited to contribute disability rights and co-production methodologies to a bid led by the robotics academics around disabled people accessing galleries and museums using robots towards improved wellbeing in the context of the COVID19 pandemic.

The account of the project presented in this report has been produced as a comic strip for a variety of audiences and a co-produced article is in progress for an international journal of disability and social justice. Seminars and workshops will be held as mini knowledge cafes within the organisations involved and at disability rights and robotics conferences involving the co-research team and robots.

Had the other café sessions happened, there was discussion of capturing moments from each of the café's that stood out, using an autoethnographic approach. This idea has been co-developed, and there are now plans for a website to be created. Having a space to share captured moments from time spent together co-producing knowledge, at the cafe or online, provides an opportunity for others to learn more about disability rights and robotics from our team who are at the forefront of co-design. It may also act as a space to find out how our co-research team operates, the expertise and the range of experience which contributed to the project. A small autoethnographic passage was included in this short report to reflect on the impact Double had with the co-research team from the team member who introduced Double; this acts as an example of possible blog posts for the website where conversations can continue.

Conclusion

The aims of the project have been surpassed in terms of the initiatives and relationships generated within the university to progress a disability rights focus in robotics and to embrace and develop co-production methodology. Co-production often has practical outcomes that are realisable when stakeholders come together and learn about their different contexts and further work continues beyond the life of the project (Campbell, and Vanderhoven, 2016:12). The social justice aims of co-production are reflected in the ethical commitments from the outset through to the key messages and evaluation concerning control, accessibility, equality, appeal and relevance.

‘Robotic technologies are early in design so they can be like a person, a box, taller and so on; there is no need to stick to what there is now’ (AR).

References

Brown, J. 2001. “The World Café: living knowledge through conversations that matter”. *The Systems Thinker* 12(5): 1-5. <http://www.theworldcafe.com/wp-content/uploads/2015/07/STCoverStory.pdf>

Campbell, H. and Vanderhoven, D. 2016 ESRC N8/ESRC Research Programme: Knowledge That Matters: Realising the Potential of Co- Production <https://www.n8research.org.uk/research-focus/urban-and-community-transformation/co-production/>

Church, S. and Curran, T. 2020 Knowledge Robo Café, UWE <https://people.uwe.ac.uk/Person/TillieCurran> or <http://www.samchurchillustration.com/>

Curran, T., Manns, S. and Jones, M. 2020, ‘Disabled Young People’s Hopes and Dreams in a Rapidly Changing Society: a co-production peer research study’ *Disability and Society*, 23.4.20 online <https://doi.org/10.1080/09687599.2020.1755234>

Curran, T. and Runswick-Cole- R. 2014. “Disabled Children's Childhood Studies - a distinct approach?” *Disability and Society* 29(10):1617-1630. <https://doi.org/10.1080/09687599.2014.966187>

Gibson, A., Welsman, J., and Britten, N. 2017, ‘Evaluating patient and public involvement in health research: from theoretical model to practice workshop’. *Health Expectations*, 20:826-835

Involve & NHR, 2018, Guidance on co-producing a research project, www.involve.nihr.ac.uk Patient and public involvement in research and research ethics committee review www.involve.nihr.ac.uk

Oliver, M. 1991, *The Politics of Disablement*, MacMillan

SCIE, 2013, ‘Co-production in social care: What it is and how to do it’ <https://www.scie.org.uk/publications/guides/guide51/what-is-coproduction/principles-of-coproduction.asp>

United Nations Convention on the Rights of Persons with Disabilities
2006, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> Equalityhumanrights.com

UN Convention on the Rights of Persons with Disabilities (CRPD) 2009, Enable.un.org, 2019

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