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To cite this article: Olivia Labattaglia, Stephen Reay & Ivana Nakarada-Kordic (10 Oct 2023): Co-designing accessible co-design, Design for Health, DOI: [10.1080/24735132.2023.2265239](https://doi.org/10.1080/24735132.2023.2265239)

To link to this article: <https://doi.org/10.1080/24735132.2023.2265239>



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Published online: 10 Oct 2023.



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Co-designing accessible co-design

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ABSTRACT

Participant empowerment is a core function of co-design. However, some participants might find co-design sessions disempowering if they cannot engage in activities or undertake tasks. Consequently, researchers and designers need to ensure that co-design is used in a way that is accessible to all participants regardless of impairment or disability. In this case study, we report on the accessibility of a co-design process through a series of co-design workshops with university students who experienced disabilities. While the co-design sessions explored the topic of an 'accessible university', participant reflections on the co-design experience brought to life the meaning of 'accessibility' in the context of how best to involve them in a co-design process. A flexible and negotiated approach and adapted tools improved the experience for those with accessibility challenges. Five key insights are presented to support others who wish to facilitate accessible codesign sessions.

ARTICLE HISTORY



Received 26 October 2022
Accepted 12 June 2023

KEYWORDS

Co-design; accessibility;
creative design methods

Introduction

Participatory design (and the contemporary co-design), are approaches that attempt to involve non-designers in a design process (Sanders, Brandt, and Binder 2010). Participatory design aims to bring the voices of relevant stakeholders into the final outcome of the design process (Visser et al. 2005). Co-design is a practice whereby designers and non-designers engage in various creative activities to aid the articulation of participant knowledge and experience of the context being explored (Sanders and Stappers 2008). A primary aim of co-design is to co-create solutions to problems using the knowledge and expertise of those with an authentic experience of the issue being investigated. Co-design has an ethos of empowerment (Langley, Wolstenholme,

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and Cooke 2018) and advocates for the user as an expert of their lived experience (Kidd et al. 2021). As such, users should be actively involved in the design of anything that impacts their life (Kidd et al. 2021). In this capacity, the boundaries between designers and end-users in traditional user-centred design are blurred (Wilson et al. 2015).

Co-design with participants who experience impairment is a relatively new and consequently, somewhat fragmented field (Hendriks, Slegers, and Duysburgh 2015). In theory, co-design is aligned with the motivations and aims of underserved groups leading demand for change (Wilson et al. 2015). Moreover, co-design is consistent with the shift in attitudes over the last 30 years towards the social model of disability, which sees disability arising not from medical impairment, but from disabling barriers and attitudes within society (Oliver 1996). Critically, the social model of disability casts people with disabilities into a new role - 'rather than being passive recipients of care ... they are experts who are leading the demand for change' (Wilson et al. 2015, 22). This resonates strongly with co-design attitudes of designing with, not for users of future services, products, or experiences. Co-design is often used in disability research due to its potential to create design solutions that can transform the lives of their users (Wilson et al. 2015). However, there are still gaps in research about the practice of co-design with participants who may not fit the able-bodied stereotype (Wilson et al. 2015), with many co-design toolkits appearing to assume participants are able-bodied (e.g. Carroll et al. 2018; Hendriks, Slegers, and Duysburgh 2015). Simply put, participants unable to easily engage in activities or undertake tasks will likely find co-design disempowering. Consequently, the aim of this research was to better understand how participants who experience disability or impairment can be enabled to more effectively participate in co-design.

Methods

A series of co-design workshops was undertaken with university students who experience disabilities to explore the meaning of 'accessibility' in the context of a co-design process. To effectively examine what co-design methods, tools and activities were (or were not) accessible, an exploratory co-design project was used to explore, and sought to develop, solutions to improve accessibility at a university campus. While not documented in detail in this research, the findings of the co-design workshops were subsequently shared with staff in the university's disability service as potential inputs to be used in ongoing improvements for students.

Fifteen students with a range of disabilities were identified and invited to participate in the research through a Disability Student Support Services Adviser (whose disabilities and needs were familiar to them). Face to face and email contact was used to invite participants, with a follow-up email containing

the research information sheet and consent form. Eight participants responded to the invitation. For the workshops to be more manageable, participants were put into two groups of four determined by their availability. Between the first and second workshop, two participants (one from each group) decided to leave the research. The participants' disabilities ranged from physical to cognitive (e.g. cerebral palsy, traumatic brain injury, arthritis, dyslexia and Asperger's). Students who were deaf and communicated using New Zealand Sign Language (NZSL) were excluded from participating in the research. It was advised that a deaf participant might find the experience frustrating or disempowering, due to delays associated with the use of a translator. Furthermore, it was recommended that due to the strong culture surrounding Deaf people and Deaf research, a series of exclusive workshops would be more appropriate. However, due to the timing and costs this was outside the scope of this research. Ethical approval was obtained for the research (AUTEC reference number 18/130).

The co-design process followed a five-step design thinking structure - empathize, define, ideate, prototype and test (as described by d.school 2009) to explore and develop ideas, problems and solutions over a series of four 2-hour workshops as follows:

Workshop 1 - empathize

The first workshop aimed to develop empathy between participants through exploring each participant's associations with the words 'disability' and 'impairment'. This enabled the group to discuss (initially in pairs) disability language, as well as supporting participants to share (or not) their experiences of disability or impairment. Three creative co-design methods were then tested alongside a warm-up activity and questions asking participants to reflect on the co-design process. First, Exhibition in a box (Chamberlain and Craig 2013) was used as 'a tangible prompt to scaffold conversations' (26) and helped to show the power of creative methods (Figure 1). Using Exhibition in a box, participants were asked to relate to an object in the box to their experiences of disability and impairment. Their stories highlighted the complexity of being disabled or impaired in an ableist world. Second, using a range of materials (Figure 2), participants were asked to visually describe and share a normal day on campus with the group. This journey mapping activity aimed to begin interrogating the participants' experiences at university and to deepen familiarity about what it meant to be a student with different experiences of disability. Finally, using these journey maps participants were asked to describe and represent examples where they experience 'pain', defined as 'a moment when being a student is a challenge'. The intention of this pain-point identification (d.school 2009, 19) was two-fold - to continue to develop empathy and familiarity amongst the group, and to identify shared difficulties.

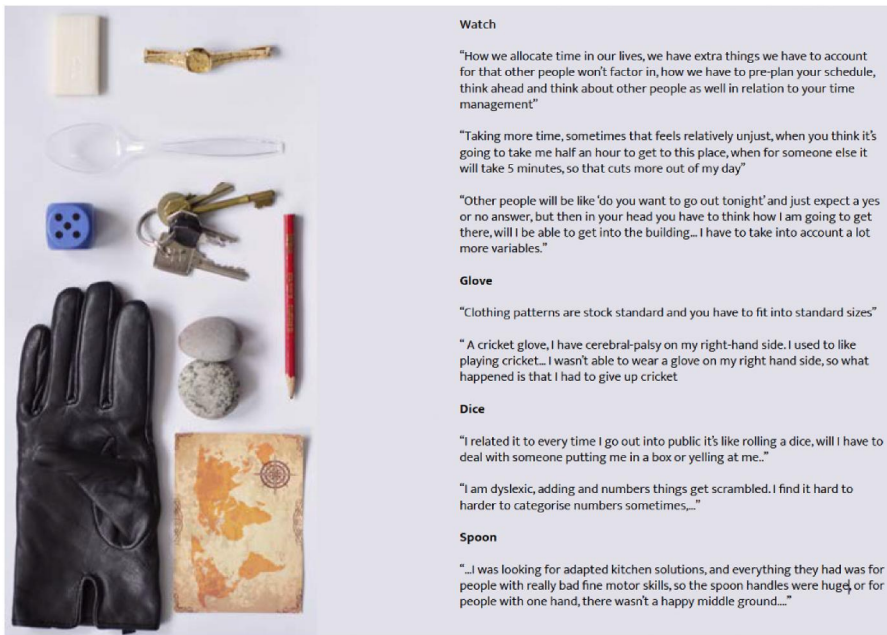


Figure 1. Objects used in exhibition in a box, with some of the responses elicited by participants summarized.

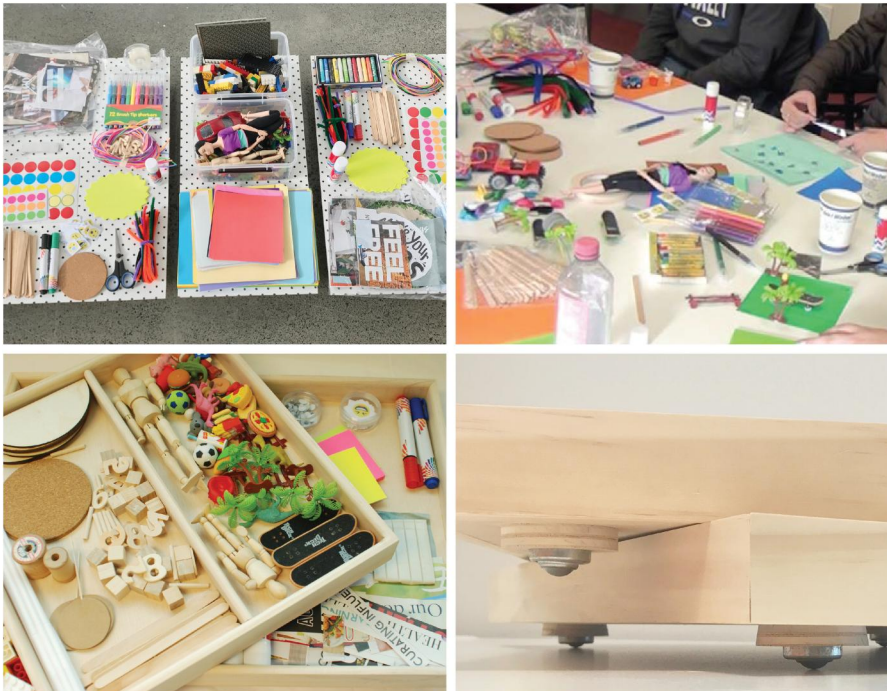


Figure 2. A variety of materials were used throughout the workshops to visualize ideas and experiences and, later, a mobile toolkit (on wheels) for added accessibility was developed during the research in response to feedback from users.

Workshop 2 - define

In the second workshop, the warm-up activity was a group discussion around the meaning of 'accessibility'. Participants were asked to reflect on their meaning of 'accessibility' in everyday life and their campus experience. This discussion highlighted the diverse ways 'accessibility' can be interpreted and applied in very different contexts. Storytelling was used as a quick-fire method to generate memories, feelings and stories. Participants were invited to tell three stories (preferably based on personal experience), and make a visual representation for each story, based on (but not exclusive to) the topics that were discussed in workshop one. Overall, 25 stories were shared, along with eight visual representations. At the end of this activity, participants were asked to select three topics to explore further in the next activity - a 'persona representation' to capture these experiences. Participants were asked to give their persona a name, a disability or impairment, a degree they are studying towards, and to tell a story about a time this persona experienced one of the three topics the group had chosen (Figure 3). Storytelling using a persona allows participants to share their own experiences, thoughts and feelings by projecting these onto a fictional character without drawing direct attention to the storyteller (Nakarada-Kordic et al. 2017). Following on from personas, 'How Might We' questions were used to turn a challenge into an opportunity to inspire solution ideation and brainstorming.

Workshop 3 - ideate

Workshop 3 was focused on identifying and exploring solutions to improve the student experience for those who experience disability and impairment. Participants started by discussing 'What could this group do together to improve student experiences at Auckland University of Technology (AUT)?', and 'If you could change one thing at AUT to improve your experience, what would it be?' The persona profiles created in the previous workshop were further developed to help give participants a platform to explore different perspectives. Following this, a few ideas were voted on to carry forward for solution generation before these were tested from the perspectives of different stakeholders (e.g. academic staff, students and professional staff), to ensure solutions were considered from a range of perspectives (Figures 4 and 5). In the final activity participants brainstormed how their solutions might be implemented.

Workshop 4 - prototype

In the fourth and final workshop the focus was on prototyping. Participants were asked to prototype their solutions from the previous workshop into a model communicating their desired student experience. It was also the first instance of participants working together to make something. The intention of this activity was to make the participants negotiate the final elements of

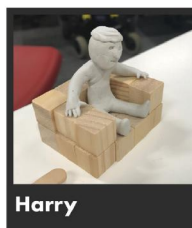


Figure 3. Examples of personas develop in workshop 2 showing the diversity of materials and creative approaches used by participants to visually represent their personas. ‘by allowing participants to project their thoughts, feelings and experiences onto a fictional character, any sense of direct attention or pressure on a specific individual was dramatically reduced ...’ (Nakarada-Kordic et al. 2017, 234).



Figure 4. Participants making during the workshops.

their solution, leaving some ideas on the ‘cutting room floor’, and selecting the most important elements to bring into the final design. Participants worked together to build a ‘scene’ containing the ideas and solutions they had developed over the previous workshops (Figure 6). The final scenes portray the kind of student experience these participants believe would improve their time studying at AUT, and how they would like to engage with Disability Student Support Services. After negotiating the ideas to be included or discarded for the final model, each participant took charge of an aspect of the design that they were passionate about and convened with

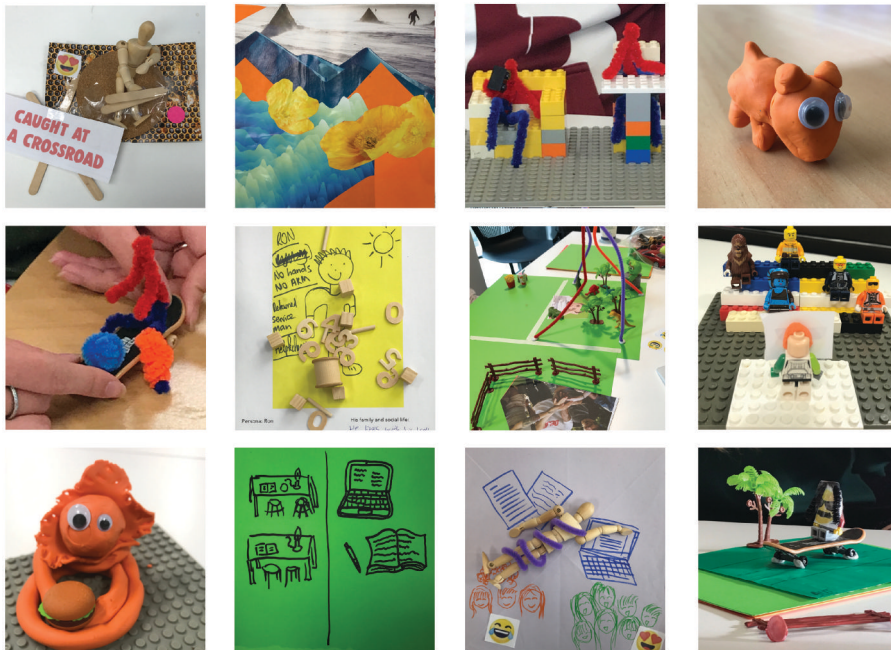


Figure 5. Selection of models, visual representations and artefacts made by participants in this research.

the others about how to bring all the elements together into the final concept. Collective visioning (Sanders and Stappers 2013) was implemented after the group model was built to generate a verbal description of the solutions the participants had included in their final model.

Data analysis

Each workshop was recorded using video, photo and audio equipment. After each workshop, discussions and quotes were transcribed. Transcripts were read and re-read and emerging themes were highlighted. Thematic analysis was used as the basis for the identification and organization of themes discussed either implicitly or explicitly (Braun, Clarke, and Terry 2014). Salient quotes were highlighted that either (a) clearly communicated an opinion that was individual or shared by many, (b) clearly described why a participant did something a certain way, (c) highlighted strengths or weaknesses of co-design identified by participants, or (d) raised an ambiguous, but pertinent action done by a participant. Ambiguous actions refer to habits demonstrated by participants that required further investigation or analysis.

Results

Four main themes relevant to the co-design process were identified.



Figure 6. Final concept models the two groups showing their solutions for improved student experience. Both models described an orientation event where students and teachers engage in accessibility-focused orientation sessions. Accessible campus tours, free food and a chance to meet other students who experience disability, and a session for lecturers to better understand how to support students experiencing disability were discussed as useful for those experiencing disability.

Social accessibility

Accessibility was loosely defined by all participants as, ‘having access to things’. However, these ‘things’ were varied. Participants with physical impairments discussed ‘accessibility’ regarding the spatial and built environment,

such as steps, ramps, and entrance spaces. Other participants referred to the level of accessibility that they have to lecturers at university (e.g. talking after class or one-on-one). 'Social accessibility' was also discussed, and described as, 'Being able to socialize on equal ground is just as important as being able to move around on equal ground.' Half of the participants shared the opinion that being a student with a disability takes more time compared to non-disabled students. Participants described many instances where others did not consider their needs, for example 'there is a lot of face-saving, it very much hurts me to walk all the time, but I don't want every second person knowing that. I absolutely don't share that ... I would rather come across as slack or lazy by not going than have to explain why I can't do something.' Regarding the use of language relating to disability, one participant contested the use of 'different' or 'difficulty'. They shared that some people who experience disability or impairment might not agree with being explicitly labelled as 'different'. They argued that we are all different, regardless of disability and impairment, and what makes us genuinely different, is our individual approach to managing and achieving all the areas and aspects of our lives. Participants felt that the tone of voice was more important than the words used. This was illustrated by '... people notice if you are trying to say it in a mean way, it's context, even like a normal word, if you say it in a nasty way it can be nasty.'

Creative activities can exclude

Participants were asked to reflect on their experience of co-design. Two out of the eight participants expressed a lack of confidence or willingness to be creative. One participant commented on another participant's cutting skills. 'I am super super jealous of [other participant's] cutting skills, I will never ever be able to cut like that, cause I don't have the dexterity. So for me, something like the larger blocks made it [the making activities] easier...' highlighting the potential for participants to be confronted by their own limitations. The majority of participants expressed the desire to use tools and materials that were familiar to them. One participant was an exception and had wanted to use the 'emoji faces', but with only one hand, they could not cut them up themselves, highlighting the importance of pre-cutting all materials to make them more accessible. Asking for help was described as important, with participants sharing a multitude of stories describing how 'help' is a complex social interaction. It was observed that when offering help within a co-design process (and more broadly), it was important to communicate that you believe the person is capable of what they are doing, but you are able to assist. As one participant shared, 'Sometimes I only let people help if they know that I possess the ability to do it in the first place.'

Fatigue and a lack of concentration were also observed. In particular, tiredness appeared to trouble participants in one workshop held after a long day of lectures. Ensuring participants could enjoy the co-design process and have fun was critical, as it helped participants remain engaged during the sessions and enjoy the experience. One participant stated, 'I have been looking forward to this 'cause I know it's just stuff I don't usually get to do.' Another participant, who struggles with fatigue and concentration said, 'Two hours went really fast ... it was really good ... I was like, two hours is a really long time, but then when you were like 'ok it's over', I was like 'is it?' Has it been two hours? Cause I feel like it was 45 min, it went fast.'

Participating by making or talking

Participants seemed to prefer either verbal communication or 'hands-on' participation. Both kinds of contributions were equally valued and celebrated by other participants. For example, one participant, who had a traumatic brain injury, contributed to the workshop by making models of the discussions around them. Another participant said they enjoyed 'crafting' as they found following a discussion and contributing verbally difficult. The other participants responded with comments like 'I like this so much [their Lego model]', 'oh my goodness Lily, you are so good [at making]'. Another less verbal participant expressed how they were feeling through artefact creation. They shared having a '... bad hearing day ...', with a blu-tack model of a cat stating that, '...when I am having a bad hearing day is like herding cats'. Encouraging a flexible, open, accommodating, and individual enactment of co-design was identified as the most appropriate approach for enabling participation. When asked to reflect on their making, one participant highlighted that being flexible allowed them to represent themselves creatively in the most natural way.

Asking participants to reflect on their representations was valuable to learn more about the participants and their co-design experiences. For example, one participant described how they threw a few things together for the task and subsequently figured out the meaning. They reflected that this was how they approached their disability - 'I don't really think, I will just go and do something and then make it [their artefact] into something after, not to make it a bigger thing but that is kind of how I approach my disability, I will just go do something and then figure out later how I am going to adapt it...'. Another participant expressed their difficulty in associating stories and memories with objects. When asked to reflect on storytelling and object making they realized that their memory was more effectively triggered by smell and sound. During idea generation activities, those participants with physical (handwriting) and cognitive (spelling) challenges were

less able to quickly make notes and contribute to discussions. This was resolved by the facilitator documenting the participants' ideas and contributions using post-it notes.

Sharing experiences to gain empathy

Participants commented that hearing about others 'lived experiences' was gratifying and therapeutic', regardless of whether the experiences described were similar or different to their own. It was joked that co-design was a form of group therapy. Another participant shared that they enjoyed it when someone described something they had also experienced. Many participants reflected that through the co-design process they gained greater empathy for and felt more engaged with members of the campus disability community. For example, some participants said they would behave differently when they saw someone who experiences a physical disability. Participants also felt more confident when reaching out to others who also experienced disability or impairment. For example, one participant shared that they had been hesitant to engage with a Deaf student whom they often sat next to in one of their lectures. Between the third and fourth workshop they found the courage to try '... cause of this workshop I am starting to notice these things, notice the way she does things, or notice the way she speaks and stuff as well, it's quite different. I just realized that none of us know how to interact with each other.'

Participants articulated perceptions of hierarchy in and around the experience of disability. Perceptions of disability were described as personal, and that it could be confronting to compare 'your' experience to those of others. Two participants felt hierarchy was noticeable when describing 'lived experiences', and may make people feel uncomfortable if their experience was more or less extreme than others. Two participants (one with an 'invisible' disability and one with a non-physical disability) described feeling awkward as they perceived their experience of disability as being far less extreme.

Discussion

Participating in co-design was found to be empowering. In this research, we viewed empowerment as supporting individuals or groups with the authority, skills, and resources needed to take control of their situation and make decisions that affect them. This was most apparent when supporting participants to engage flexibly and independently, by allowing participants to self-manage between challenging and less challenging creative tasks, set their own limits, define their participation and maintain their engagement in the co-design process. While participants struggled with confidence in the first workshop, as the workshop tools and processes developed in response to their feedback, they found the workshops to be more 'fun' and enjoyed learning from their peers.

They responded positively to the stories shared by their peers and found these to be gratifying or therapeutic (when others described experiences similar to their own - it was joked that codesign itself could have been described as therapeutic), and they felt more engaged with the disabled community at the university. The five stages followed through the workshops effectively scaffolded learning as the codesign process unfolded. The key learnings from this research are discussed below.

A flexible approach

Accessible co-design accommodates and encourages multiple modes of communication and participation. Allowing participants to engage with a co-design method or activity in any way or style, using whatever materials or tools, was found to be the most accessible way to approach co-design. A flexible approach is supported by the social model of disability, which sees disability as occurring from the physical barriers and ableist attitudes in society (Oliver 1996). Shakespeare (1996) advocates giving participants who experience disability 'control over the [research] process, over their words and over their participation' (116). Flexibility in codesign is not novel. Hendriks, Slegers, and Duysburgh (2015), Wilson et al. (2015), Carroll et al. (2018) and Nakarada-Kordic et al. (2017) made similar observations when researching with disabled populations. A flexible approach was developed in this research when it became apparent that the co-design methods, techniques or activities were unlikely to be accessible to all participants in this research. While attempts have been made to develop generalized approaches to conducting co-design with participants who experience disability or impairment, both Hendriks, Slegers, and Duysburgh (2015) and Wilson et al. (2015) concluded that developing guidelines for conducting co-design with participants who experience disability or cognitive impairment could not be made. Consequently, researchers advocate for an individualized approach for participants involved in a co-design process, and that a large part of this individualization should happen 'in-situ' by the participants and researchers (Hendriks, Slegers, and Duysburgh 2015; Wilson et al. 2015; Nakarada-Kordic et al. 2017; Carroll et al. 2018). Wilson et al. (2015) further suggest that 'one key to success is a clear focus on tangible design language, customized for specific design activities ...' (33). A flexible approach negotiated 'in-situ' also means that incorrect assumptions regarding a person's capabilities or preferences on the basis of a diagnosis may be avoided (Carroll et al. 2018).

The importance of independence

A key learning from this research was the importance of supporting independent engagement in the co-design process. This was achieved through

the flexible approach, using a movable toolbox on wheels, as well as providing pre-cut materials and adapted tools. Consequently, participants very rarely had to ask for help. Independent engagement is important in disability research, and when coupled with a flexible approach supports the social model of disability (Oliver 1996). Hammel et al. (2008), suggest people with disabilities describe independence in research as not being defined as the ability 'to perform tasks by oneself' (1445), but through being able 'to participate freely' (1445). The combination of the flexible approach in this research and the adjustments throughout made for more independent participation (Hammel et al. 2008). It can be challenging to focus on capability instead of disability in co-design practice (e.g. Hendriks, Slegers, and Duysburgh (2015)). In this research, both a flexible approach and an accessible toolbox helped participants to participate more independently. Consequently, participants appeared to be less focused on their abilities or disabilities.

The value of an indirect approach

Indirect approaches for broaching and discussing complex and emotive topics can be useful in co-design. For example, group discussions that focus on people's associations with words can help them more effectively navigate discussions of complex issues. In this way, personas can express personal experiences, or extreme or different opinions while protecting an individual's identity (Nakarada-Kordic et al. 2017). Hendriks, Slegers, and Duysburgh (2015) discuss the challenges researchers experienced when trying to understand how participants felt about disability language and the researchers' insecurity around how to address impairment and disability in their interactions with participants. They suggested co-design researchers should 'co-design their approach with participants to navigate this challenge... to adopt a preparatory codesign approach, involving the participants with impairments ...' (74). This approach was taken in this research and was advanced by using indirect questioning techniques around sensitive subjects, to gain insight into individuals' vocabularies to describe their experiences. Similar approaches (e.g. the use of personas (Nakarada-Kordic et al. 2017), 'someone who isn't me' (Wilson et al. 2015)) allow participants to 'project' their own personal experiences, feelings and thoughts without having to feel like they were being put on the spot. These approaches allow participants to express an alternative view and give researchers a broader range of opinions.

The power of reflection

Accessible co-design can benefit from bringing a practice of regular reflection into the process, both by the participants and by the facilitator. In this

research, reflection on making, on the co-design experience, and on the facilitator's approach brought to light unexpected and valuable thoughts, experiences, and emotions. Reflection can be viewed as 'both a way of learning about and as a way of changing practice' (Schutz 2007, 26). Moreover, reflection is an essential and valuable practice in person-centred practice (Bulman and Schutz 2013). A practice of reflection in co-design can help participants further develop their understanding of their experiences, opinions and selves. Langley, Wolstenholme, and Cooke (2018) describe making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit. In this research, the act of making helped enable participants to externalize their thoughts and feelings, and 'use the making as an opportunity to reflect and to initiate a conversation with themselves' (Langley, Wolstenholme, and Cooke 2018, 5). By reflecting at the end of every workshop supported the development of new techniques for facilitating, to adjust co-design methods for proceeding workshops, and making notes of interesting events in the process.

Disability and impairment affect each individual in different ways and to different degrees. This research sought to understand how to adapt co-design to enable participants who experience disability and impairment and who study at a university and as such the findings may not be universally applicable. This research was also limited by its predominant use of visual and haptic tools and materials. While people often use a mix of visual, auditory, and kinaesthetic learning styles, more accessible co-design would likely benefit from research around the stimulation of a more diverse range of senses by tools and materials. Consequently, this research provides only a glimpse into some important factors for an accessible co-design process, but presents some important learnings that may be used to support other researchers. We aspire for this research to serve as a springboard for exploring how co-design workshops may be designed and guided in a way inclusive of individuals with varying physical and cognitive abilities. Our ideal vision for the future would be one in which the participants' specific attributes do not limit workshop design.

Acknowledgements

The authors would like to thank all participants who gave them time and expertise during this research.

Disclosure statement

No potential conflict of interest was reported by the authors.

Notes on contributors

Olivia Labattaglia is a User Experience Designer and Researcher in software. In her work, Olivia enjoys the user research and problem-discovery phases. Working with customers to understand how software products have the potential to change the way people work, and designing flexible solutions that are can be utilized by people regardless of context or sector.

Stephen Reay is a Professor, School of Art and Design and Director of Good Health Design at University of Technology (AUT) – a design studio that has been initiated to more effectively explore how to bring together the fields of design and health and to help students better understand how they can engage with design processes in the area of health and wellbeing.

Ivana Nakarada-Kordic is a design for health researcher at Good Health Design, Auckland University of Technology (AUT). Her current research focuses on the potential of human-centred design to support and enhance health and wellbeing, including developing and applying creative and empathetic human-centred approaches and methodologies for researching complex experience problems and facilitating the sharing of knowledge between designers and non-designers.

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