Accessible Co-Design.
Attestation of Authorship

“I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree, diploma or a university or other institution of higher learning.”

Date: 25/01/2019
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Accessible Co-design

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Abstract

Co-design involves working creatively with, rather than for, people throughout the design process. Increasing attention is being paid to the power and value of applying design thinking to improve public services. However, while still in its infancy the application of co-design for healthcare is relatively fragmented and underdeveloped. There is a considerable gap in the research literature and practice concerned with accessible co-design methods and approaches. This research explores how an accessible approach to co-design may produce a more empowering experience for participants who experience disability and impairment. In New Zealand, according to the most recent disability survey, 24 percent of the population were identified as disabled. Since persons with disabilities are often more vulnerable to secondary and co-morbid conditions, they tend to seek more healthcare than people without disabilities.

In this research, principles for conducting co-design with participants who experience disability and impairment were explored, contextualised and analysed through a series of co-design workshops. The focus of each workshop was two-fold, the university experience for students who experience disability and impairment was explored, and the co-design process was assessed for accessibility. Participants’ reflections on the co-design experience brought to life the meaning of ‘accessibility’ in this context.

The resulting outputs of this research include an accessible co-design toolkit produced for designers and researchers. The toolkit consists of a guide which explores principles for conducting accessible co-design to help other researchers establish more accessibility-friendly environments and experiences. A toolbox on wheels, to support more independent making in group situations, was developed, along with suggested materials and tools to use in a co-design process.

If co-design continues to be applied in healthcare and wellbeing fields, co-design should acknowledge, respect and accommodate the variability of physical and cognitive function in the population. Participant empowerment is a core function of co-design. Consequently, researchers and designers need to ensure that co-design is used in a way that is accessible to all participants regardless of their impairment or disability.
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Introduction to the research

Universal design, inclusive design and accessible design are all design ideals that seek to remove barriers for use. They design to accommodate the diversity of people in our population and create solutions that can be used by a wide audience of people (Fletcher, 2006). Human-centred design on the other hand describes an approach used by designers and researchers to work with and learn from potential and future users of a product or service (Steen, 2011). The aim of human-centred design is to design and develop products and services that reflect users needs, routines, practices and preferences (Steen, 2011). Human-centred design can be located within a web of other design practices, such as participatory design which all emphasise the importance of the user's voice.

Participatory design (and the contemporary approach of co-design) are emerging design approaches which attempt to involve non-designers in a design process (Sanders, Bransch & Binder, 2010). The aim of participatory design is to bring the voices of relevant stakeholders into the final outcome of the design process (Visser et al., 2005). Participatory design has been utilised in healthcare design projects since the 1980s (Bjernres & Brattereg, 1988). However, there may still be nuances that should be explored around how co-design is utilised with participants who do not fit the able-bodied archetype. Research around co-design for disability and healthcare is fragmented, and appears to be more focused on the outcomes or solutions produced, rather than the methods used to achieve them (Hendriks et al., 2015; Beadle et al., 2015). It is this gap in the literature that is explored in this research.

The main aim of co-design is to co-create solutions to problems using the knowledge and expertise of those who have authentic experience of the issue or need being investigated. Co-design proposes that the ‘user’ is ‘an expert of their experiences’ (Visser et al., 2005) at the center of the enquiry and creative process. In this capacity, the boundaries between designers and end-users in traditional user-centred design are blurred (Wilson et al., 2015). I propose the next step for the field of co-design is to become more aware of the physical and cognitive variance possible in any participant, and develop strategies to accommodate these strengths and weaknesses, through adapted methods and accessible approaches. In doing so participants would ideally experience a more enabling and active co-design experience. Moreover, a greater range of participants may be approachable in the future.

The research shows that guidance for designers and researchers in the disability and health space is desired, in order to understand how to work more appropriately and respectfully with research participants including patients. Participatory design approaches such as co-design attempt to bring the worlds of designers and users together, and through mutual learning show participants how to work more creatively with designers and vice versa (Steen, 2011), co-design is one approach that can be used to bridge the gap between able-bodied researchers and disabled research participants (Steen, 2011).
The link between patients in healthcare and people who experience disability, and who are engaged in this research, lies in the data that demonstrates that, “People with disabilities report seeking more health care than people without disabilities and have greater unmet needs” (World Health Organisation, 2018). While some disabilities and impairments can result in poor health and considerably more healthcare needs, all people with disabilities have the same universal needs for healthcare (World Health Organisation, 2018). As our most vulnerable users of healthcare I argue it is important to effectively engage with these users to find solutions for their health, lifestyle and futures. As such these users are an appropriate user-group for improving the accessibility of co-design for healthcare and wellbeing fields.

The intention of this research is to better understand the subtleties of respectfully working with participants who experience disability and impairment when engaged in co-design processes. Moreover, discovering how to better enable and empower these participants in a co-design process, so that they are invited and able to bring their voice and experience to the research being conducted, is necessary so that they can influence matters which will affect their futures. The outputs of this research should prove helpful for designers and researchers wishing to work with participants who experience disability and impairment, or who wish to use a more accessible approach in any co-design process.

I have been engaged in design for healthcare since 2015. During my undergraduate degree in Spatial Design, a brief was offered investigating the re-design of the entrances and arrival experience at Auckland City Hospital through the Design for Health and Wellbeing Lab (DHW Lab) (2014-2017). The DHW Lab was a design studio co-led by AUT and the Auckland District Health Board (ADHB) located at Auckland City Hospital (Reay et al., 2017). Over the summer of 2015-2016 I interned at the DHW Lab for 10 weeks doing a variety of design and research projects, and in 2016 I undertook a year-long honours research project with the DHW Lab, investigating the spatial experience of public breastfeeding in waiting spaces at Auckland City Hospital (see Figure 01).

This time with the DHW Lab opened my eyes to the potential of designing for healthcare environments, their patients, their families (whānau)1, and staff, as well as the broader experience of giving or receiving medical care. As a designer, the opportunity to study research and design in a context where the best and worst of life can take place simultaneously is engaging and complex work.

In 2017, I broadened my design for healthcare horizons and organised a six-week internship at Stanford Hospital in California. I worked with the Patient Experience, Product and Service Integration team, investigating solutions for better patient experience in the Emergency and Orthopedic Departments. This time at Stanford informed my Masters research. Time and time again the patients I engaged with were generous with their enthusiasm to feedback on ideas and designs. However, I became aware of my lack of understanding around how to design with those who are temporarily or chronically sick or injured. I never seemed to have information printed out at the right size, or the right kind of pen for a patient to use. I reflected that designers are not trained to work with patients, despite the potentially harmful consequences of not being properly prepared, for both the patient and the designer.

In my design practice, I am interested in how design, creative practice and research can be used with patients, their families (whānau), medical staff, and non-medical staff to improve healthcare experiences. In order to do this, I need to develop my approach, including the appropriate communication tools and methods to support the expression of thought, feeling and memory. This research has benefited my ability to facilitate design workshops with non-designers. Especially participants who experience diverse physical and cognitive function, which could be perceived as more challenging for designers and researchers wishing to use a co-design process to improve a service or experience.

1 "(noun) extended family, group, a familiar term of address to a number of people - the primary economic unit of traditional Māori society. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members” (Dekker Dictionary, 2016).
01. Contextual Review
History of Participatory Design

Introduction

Co-design with participants who experience impairment is relatively new, as a consequence, it is a somewhat fragmented field (Hendriks et al., 2015). As such there are gaps in the literature and research about the practice of co-design with participants who do not fit the able-bodied stereotype (Wilson et al., 2015). This contextual review will first explore the history of participatory design, showing the evolution of participatory design into the more contemporary approach of co-design. Secondly, an investigation of the application of co-design in healthcare, and the strengths and weaknesses of this approach, will be explored alongside a review of the accessibility of current co-design ‘toolkits’. Finally, literature where co-design has been used with participants who experience disability or impairment will be described, alongside the challenges and gaps highlighted by these papers for the emerging field of accessible co-design.

Origins of Participatory Design: Bauhaus & modern design

Participatory design emerged from the Bauhaus design school and theory of modern design in Germany following the Great War (1919), see Figure 02 (Bannon & Ehn, 2012). At this time in history design emerged as its own complex, more mature field, merging art, craft, architecture, technology, science—both social and natural—and engineering (Bannon & Ehn, 2012). “Art and Technology – a new Unity” (Bannon & Ehn, 2012, p.34) was a slogan for the Bauhaus modern design approach. The practice of the Bauhaus school was multidisciplinary, inspired by the medieval organisation of craftspeople who collaboratively built cathedrals (Bannon & Ehn, 2012). Engineers and artists were educated side by side in the Bauhaus design school. ‘Design-by-doing’ and ‘design-by-playing’ methods were developed during the Bauhaus Workshop era and were introduced into participatory design in the 1980s in Scandinavia (Bannon & Ehn, 2012).
Chapter 01: Contextual Review

Section 04: History of Participatory Design

From the Socio-technical to the Scandinavian Approach

In the United Kingdom, socio-technical systems research emerged after World War II in the 1950s. The socio-technical approach developed from a preceding focus on the design of technical systems (Bannon & Ehn, 2012, p.42). During this period of technical systems design, systems engineers organized workflow by assigning workers to the requirements of the technology in the workplace. This approach was quickly criticized as workers were made to work around the technology, which did not see an increase in productivity (Bannon & Ehn, 2012, p.43). In response, the socio-technical approach focused equally on the social subsystem (the workers) and the technical subsystem (the machinery) in workplaces, creating a more balanced system. Figure 03 shows the transition from the technical to the Scandinavian approach. Researchers at the Tavistock Institute in London developed a socio-technical approach through their research with coal miners in the 1950s (Trist & Bamworth, 1951). These same researchers later argued for greater industrial democracy for workers, encouraging workers to participate in workplace strategy. By the 1970s socio-technical ideas pushed the boundaries both geographically and technically in Scandinavia; factory workers were involved in the design of the technologies being introduced into their workplaces. It was under these conditions that participatory design began to emerge in Europe.

Participatory design in Scandinavia

Participatory design (also known as the Scandinavian approach or cooperative design), emerged in Scandinavia in the early 1970s as a political critique of the socio-technical approach in the United Kingdom (Bannon & Ehn, 2012, p.43). “PD [participatory design]... originates in the Scandinavian Labour model that focused on empowering trade unions and workers. Pioneering projects were known as the Scandinavian projects and were conducted in manufacturing and office work, such as...
Participatory design in healthcare

In 1987, Norwegian researchers Tone Bratteteig and Gro Bjerknes brought participatory design into a healthcare context with the Florence Project (Clement & Van den Besselaar, 1993). The aim was twofold: first to design a system that provided daily information to patients without increasing paperwork for staff, and secondly, to create strategies and tools to help nurses work more effectively with newly acquired computer technology. The participatory design approach used in the Florence Project was based on notions of ‘mutual learning’, or working with users, in this case the nursing team. During the phase of mutual learning the nurses were shown how they might use computers in their daily tasks. Once nurses had sufficient knowledge about computer technologies, they were able to make informed decisions around customising a computer system for their working needs. Through mutual learning, both parties in the design process were able to find where skills, ideas and priorities overlapped, and could be exploited to create a more effective solution for all.

The computer scientists involved in the Florence Project came to see the nurses as ‘expert users’ in this context. The computer scientists identified early on that building a computer system for nurses was unlikely to lead to a successful outcome. They learned that in participatory design the ‘designer’ of a system or product cannot insist or default to developing a computer system for users, that the user must in turn adjust to suit their needs and habits. Therefore, to create a system suitable for the nursing staff, “the nurses had to find it… The Work Paper System in the Florence Project is based on an idea originating from the nurses” (Bjerknes & Bratteteig, 1988, p.261). The computer scientists learned that they must work with users, because “people are superior to the computer system” (Bjerknes & Bratteteig, 1988, p.263).

Diversification of participatory design

By 1993, participatory design was being used in contexts outside of the factories and manufacturing workplaces. From the 1980s onwards participatory design was beginning to be used in offices and service industries. Basbelle and colleagues (2016), outlined this shift as:

...the larger agenda of emancipation and democracy has been abandoned in favor of a narrower one of improving systems for users. Starting as a political grassroots movement to empower workers and enable them to represent their interests in technological change at the shop floor, PD [participatory design] now is more and more a tool to improve the design and implementation of information for technology, for users and management (p.22).

This transformation underlines the potential of participatory design, with its flexibility to diversify into new domains. Participatory design is today increasingly being used around the world and in previously unexplored contexts, such as in developing countries and healthcare (Drain, Shekar & Grig, 2018) and healthcare (Bate & Robert, 2006).

1 Relating to visual communication or computer graphics
Co-design

This section discusses how co-design emerged out of participatory design. Following this, the strengths and weaknesses of co-design with reference to existing co-design toolkits are explored. Following on, co-design in healthcare and wellbeing fields is unpacked, with particular reference to co-design that has been used with participants who experience disability and impairment.

Co-design extends from the practice of participatory design (Hartwood et al., 2002). Co-design has an ethos of empowerment (Lungley et al., 2010) and advocates for the user as an expert of their lived experience (Hagen & Rowland, 2011). As such, users should be actively involved in the design of anything that impacts their life (Hagen & Rowland, 2011). Co-design is a practice whereby designers and non-designers engage in various creative activities in order to aid the articulation of participant knowledge and experience of the context being explored (Sanders & Stappers, 2008). This does not mean users are asked to be designers. Instead, they are guided through ways of accessing and expressing their experience of the context being investigated, using creative and making-focused techniques (Hagen & Rowland, 2011). As an emerging participatory design approach, co-design does not have an officially recognised definition. However, Elizabeth Sanders and Pieter Jan Stappers, two contemporary experts in the field, have coined the following description: “We use co-design in a broader sense to refer to the creativity of designers and people not trained in design working together in the design development process” (Sanders & Stapper, 2008, p.6).
The changing role of the designer

The evolution of design from user-centred to co-design is affecting the roles of the researcher, designer and user (Sanders & Stappers, 2008). The role of the designer or researcher in co-design is to assist participants through a series of creative methods that help access participants’ thoughts, feelings, ideas and experiences in doing so. Participants begin to access feelings and experiences that they are not often asked to reflect on (Hagen & Rowland, 2011). Co-design researchers Sanders, Brandt, and Binder (2010) describe and define each aspect of the co-design structure in ‘A Framework for Organizing the Tools and Techniques of Participatory Design’ (2010). In this, tools, techniques and methods are strategically organised into an approach whereby the entire experience of the co-design process is designed to prime and prepare participants for a series of design activities (Sanders et al., 2010). The overall structure of this co-design framework consists of tools, a toolkit, techniques and a set of methods and tools are utilised to facilitate the desired aims and outcomes of the research (Sanders et al., 2010). These co-design structures are defined in Figure 05 and are used in the research.

Challenges: Creative confidence

Most people see creativity as “a rare gift only handed out to a select group of individuals” (Sanders & Stappers, 2012, p.38). Boden (1990) differentiates between two diverse forms of creativity - ‘H-creative’ and ‘P-creative’. In his work, “H-creative refers to historically creative” someone who is historically creative would come up with an idea, product, or invention that no one has ever imagined before. P-creative refers to being psychologically creative, whereby someone takes an idea from one domain and re-applies it in another. This form of creativity can also be known as ‘everyday creativity’ (Sanders & Stappers, 2012). Co-design participants can be expected to show a reluctance to take on the role of designer or creator if this role is not familiar to them. “It is also difficult for many people to believe that they are creative and behave accordingly” (Sanders & Strappers, 2008, p.9). Therefore, the role of designer is to help show participants that through making-focused materials and tools they can express ideas and thoughts differently, and articulate knowledge that may not be easy to put into words. ‘Making’ in this sense becomes a creative act where meaning is constructed.

Co-design structure

Co-design researchers Sanders, Brandt, and Binder (2010) co-design and define each aspect of the co-design structure in their framework for Organizing the Tools and Techniques of Participatory Design (2010). In this, tools, techniques and methods are strategically organised into an approach whereby the entire experience of the co-design process is designed to prime and prepare participants for a series of design activities. The overall structure of this co-design framework consists of tools, a toolkit, techniques, and a set of methods and tools are utilised to facilitate the desired aims and outcomes of the research. These co-design structures are defined in Figure 05 and are used in the research.

Challenging Creative confidence

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Figure 05: Co-design definitions for accessible co-design, as defined by Sanders, Brandt and Binder (2010).
and transformed, “prototypes confront the world; because the theory is not hidden in abstraction” (Sanders & Stappers, 2014, p.6). As such, the role of participants is not just to design or create the solution, but journey through a creative process offering their experience as inspiration and direction, and in doing so contribute to the design (Sanders & Stappers, 2010).

Participants may also discover a sense of creativity, or creative confidence, they were not previously aware of. Sanders and Stappers (2012) discuss how participants’ creative confidence can be a challenge for designers to manage. Sanders and Stappers (2012) offer a framework to understand and manage participants with differing levels of creative confidence (see Figure 06). They encourage designers to understand that participants will be at different levels on this creative scale, and that pushing people beyond their level of creativity and confidence is not best practice (Sanders & Stappers, 2012). Facilitators need to be prepared to guide and support each participant in a way that encourages their individual expression of creativity. Participants who are at the ‘doing’ level will need to be led to use materials. Participants who are at the ‘adopting’ stage might need some guidance around what to use and how to assemble and embellish. Participants at the ‘making’ stage might just need a few suggestions and gentle direction, while participants at the ‘creating’ level might just need encouragement and a clean slate to bring their ideas to fruition (Sanders & Stappers, 2012).

Figure 06: Sanders & Stappers table of ‘levels of creative confidence’.

Weakness: Accessibility

Co-design as it is more often approached and practiced today, emerged from a practice that was developed in largely industrial and corporate sectors (Halskov & Hansen, 2015). Consequently, approaches like participatory design and co-design are facing some challenges when they move beyond the workplace context into wider areas of use (Halskov & Hansen, 2015). Cunningham (2017) argues that design-led methods, while successful in commercial contexts, run the risk of creating more harm and diminishing trust in social contexts if they do not acknowledge and accommodate the variety and depth of lived experience. This is an emerging issue for co-design in healthcare and wellbeing contexts (Wilson et al., 2015).
Co-design in healthcare

Accessibility of co-design toolkits

When used in healthcare and wellbeing fields, co-design should acknowledge the "considerable diversity in mental and physical capability both across the population and over the length of the life-course" (Bianchin & Heylighen, 2017, p.316). Co-design in the healthcare and wellbeing fields needs to adapt to accommodate physical and cognitive diversity. Inviting participants to a co-design workshop that has not considered and accommodated their physical and cognitive capabilities may create a disempowering experience. Current co-design toolkits do not acknowledge in any great detail how co-design should be approached with participants who experience disability or impairment (Hendriks et al., 2015). Notions of able-bodiedness are implicit in current co-design toolkits (Wilson et al., 2015). This could lead to the disempowerment of participants if a customised approach is not well planned by designers and researchers.

During the initial literature review, ten participatory or co-design toolkits, from a range of well-known international organisations, and less well-known local organisations, were researched to uncover where and how accessibility has been previously considered in co-design. Accessibility, or the accommodation of disability and impairment, was not explicitly referenced in any of these ten toolkits. At best, two of the ten toolkits acknowledged that participants will have diverse strengths and weaknesses, and so some consideration should be made for these. Sanders (2002) describes the need for appropriate tools for successful participant expression when she states, "It is the belief that all people have something to offer to the design process and that they can be both articulate and creative when given appropriate tools with which to express themselves" (para.5). Hagen (2013), a New Zealand participatory design facilitator, acknowledges in her guide, 'Practical Tips for Designing a Co-design Workshop,' that people have different strengths and therefore, "Diverse methods will help to cater for the different strengths and communication styles of attendees" (p.5). Halpin and Hansen (2015) share the opinion that when participatory design shifts into new cultures of use and move "beyond the workplace to wider areas of use" (p.44), these voyages into the unknown generate new areas of research.

Changing roles: experts and service providers in healthcare

This shift towards user-centred design has changed the role of 'expert' and the provider of 'service' in design and innovation projects (Burkett, 2014, p.8). In a healthcare context, it represents a shift of 'expertise' into the hands of users, patients and their families. 'Providers of service' are now in the hands of designers and researchers. In 'Patients and staff as co-designers of healthcare services', Robert and colleagues (2015) action for greater patient involvement in "identifying, implementing and evaluating improvements to healthcare services" (Robert et al., 2015, para. 2). Historically patients have only held passive roles, while staff members have been the decision makers (Robert et al., 2015). Robert and colleagues share that patients bring value to healthcare service design as, "patients provide insight, wisdom, and ideas, and we urgently need to include them more creatively as partners in change" (Robert et al., 2015, para. 13). This shift in the recognition of the value of patients in healthcare service design encourages a more collaborative relationship between patients, their families, hospital staff and the design team (Blancia, Bridget et al., 2017).
Co-design and disability research

Disability

The diversity of mental and cognitive capabilities across society due to disability and impairment affects a large proportion of society. Disability and accessibility affects around 24 percent of New Zealanders. Disability, and therefore accessibility, affects around 1 in 4 potential participants in a co-design project. Simply put, participants might find co-design disempowering if they are not able to engage in activities or undertake tasks. The deeper implications of co-design being inaccessible is that it contradicts the politics of participatory design approaches, which seek to empower individuals to influence the design and implementation of tools and machinery they themselves use (Basbelle et al., 2016; Sanders & Stappers, 2008).

Disability Research

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). Disabled persons are recognised as an underprivileged group (Tringo, 1970). Moreover, co-design is consistent with the shift in attitudes over the last 30 years toward the social model of disability. The social model of disability sees disability arising not from medical impairment, but from disabling barriers and attitudes within society (Oliver, 1995). Critically, the social model of disability also 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, p.22). This resonates strongly with co-design attitudes of designing with, not for users of future services, products, or experiences. In 'Research with Deaf People: Issues and Conflicts' Baker-Shenk and Kyle (1990), describe how:

Unlike in previous research, the new interest required research with deaf people, rather than on deaf people... For the first time deaf people have had to join research groups and are treated as experts in the comprehension of language, through assistants in the planning and conduct of research itself (p. 67).

In theory, co-design is aligned with the motivations and aims of underprivileged groups leading the demand for change (Wilson et al., 2015). However, due to the origins of participatory design, current co-design toolkits appear to assume participants are able-bodied. The following examples explore how co-design has been used in disability research, why it was used and the insights that emerged.

In a New Zealand/Aotearoa study with young people who experience disability (Carroll et al., 2018), a flexible mixed-methods ‘tool box’ approach was used to work respectfully and effectively with participants (Carroll et al., 2018). This study sought to bring to life the ‘life worlds’ of disabled young people and their experiences in the wider community, as well as voicing the needs of young disabled people in an urban planning context (Carroll et al., 2018). Despite this study not having a strict co-design approach, it enabled a high level of participation by adapting methods to suit different impairments and ages of participants:

As we engaged with the disability sector and disabled young people themselves it became evident that a flexible research process, a toolbox of research methods and a readiness to adapt research methods in response to individual capabilities/impairments, was essential... (Carroll et al., 2018, p.8)

In doing so, the research team found they were able to work respectfully and effectively with participants. Flexibility was necessary, with methods and protocols being adapted to suit participants’ time, energy and availability.

Co-design and disability research

Co-design methods for people living with cognitive or sensory impairments is an emerging research field (Hendriks et al., 2015). Hendriks and colleagues (2015) co-design researchers based in Belgium, sought to develop a generalised co-design approach with participants who have cognitive or sensory impairments. In their literature review they discussed the lack of method description, or discussion about adaptations made to co-design by researchers working with participants who experience cognitive or sensory impairments. The focus of the academic papers reviewed by Hendriks and colleagues was mostly on the outputs of the research - the artefacts, designs or services produced. There was very little reflection on the methods used, and how they were determined and adapted for the cognitive abilities of the participants in the research that was reviewed. Consequently, it was difficult to make generalisations around how co-design techniques may have been adapted for participants with cognitive and sensory impairments so that this could be replicated in other studies.

2 Types of sensory or cognitive impairments included, visual impairments, dementia, autism spectrum, aphasia, intellectual disabilities, learning problems, hearing impairments and cerebral palsy (Hendriks et al., 2015, p.72)
Hendriks et al. (2015) conducted a workshop with 42 researchers and designers who, in the previous three years had participated in co-design projects with individuals who experience cognitive or sensory challenges. They discussed their experiences with how researchers and designers adjust common co-design techniques to derive general principles for co-designing with participants who have cognitive or sensory impairments. From these workshops, the Flemish researchers raised the following three points (explored further below) for other designers and researchers to consider for the practice of co-design with participants who experience disability and impairment.

1. Compensating for lack of ability

Researchers and designers who contributed to Hendriks and colleagues’ (2015) research, commented on being conscious of focusing on participants’ abilities. A wide variety of tools and materials for expression were provided, and yet the researchers still found themselves feeling like they were “compensating for disability rather than starting from the abilities of their participants” (Hendriks et al., 2015).

2. Talking about disability

Another challenge noted by researchers and designers was concerned with insecurities around how to address impairments and disabilities in interactions with participants (Hendriks et al., 2015). Language which describes disability has evolved with society, and certain subtleties in and around this language are not always fully understood by someone new to the disability field. As such, researchers and designers may not feel that they have enough knowledge and experience with this language to use it comfortably at first.

3. Participants’ confrontation of own limitations

In cases where participants who have a similar condition are brought together for a co-design session, there is the potential for participants to be confronted by their own limitations, or those of others. Moreover, if an impairment is progressive or degenerative, this condition is further advanced could be distressing (Hendriks et al., 2015).

The second point, concerned with the participant/researcher relationship also resonates with research concerned with the inclusion of disabled participants in research. Beasley, Moore and Benzie (1997) commented on the unease that can exist between disabled and non-disabled people brought together through research: “The disabled/non-disabled divide is one we experience as blurred and indeterminate and is a source of vulnerability and unease” (p.152). Moreover, Baker-Shenk and Kyle, suggest that “involving participants in the deaf research space between hearing researchers and non-hearing participants. These problems stem from a lack of appropriate training and sensitivity on part of the researcher” (Baker-Shenk & Kyle, 1996, p.65).

Co-design has also been adapted and used with participants who experience aphasia to develop computer-based aphasia therapy tools. Aphasia is a communication impairment causing difficulty with spoken and written language, and in most cases, it results from a stroke (Wilson et al., 2015). Aphasia does not affect thought or memory, and people with aphasia can construct opinions, solve problems and develop detailed knowledge (Wilson et al., 2015). However, Wilson and Roper commented that, “many co-design techniques use design representations and processes that assume effective communication skills on the part of participants” (Wilson et al., 2015, p.24). Hendriks and colleagues (2015) further comment that researchers conducting co-design with participants who experience disability, around how methods are adapted, or how co-design is approached would add value to the co-design literature. For example, Wilson et al. (2015) detailed how their research developed two computer-based aphasia therapy tools, however they gave little commentary on how their methods were adapted for people who experience disability. From the authors’ description, it appears probable that they did not have a clear idea of how best to approach facilitation, as they described that their approach emerged largely through ‘instinct’ and experience (p.26).

In summary, literature in the fields of participatory design, and co-design for healthcare and disability shows that many existing co-design toolkits use creative methods and approaches that assume able-bodiedness on part of the participants. This may either result in certain participants being excluded, despite the value of their expert experience and understanding, or that their experience of co-design is disempowering which conflicts with the core principle of participatory design practice which is participant empowerment. Consequently, this research explored what enables co-design to be more accessible for participants who experience disability and impairment.
The research question is: What enables co-design to be more accessible for participants who experience disability and impairment?

The aims of the research were to:

1. Better understand how participants who experience disability or impairment can be enabled to more effectively participate in co-design.
2. Explore the perspectives of disability language in the context of a co-design process.
Co-design as a methodological approach

Introduction

As described earlier, co-design as a methodological approach is concerned with the co-creation of solutions with participants who are experts of the problem or opportunity being explored (Sanders & Stappers, 2012, p. 25). The answers I sought through this research were more likely to be found in the lived experience of a diverse range of people. Thoughts, feelings, and memories make up what is called ‘lived experience’ (Hagen & Rowland, 2011). Co-design focuses on the uncovering and expression of ‘lived experience’. The expression of lived experience takes place through group discussion and the act of making with our bodies (Hagen & Rowland, 2011).

Understanding and probing participants to share lived experience as creative inspiration for design is complex. Simply asking people questions about their lived experience is not enough (Hagen & Rowland, 2011). Lived experiences are often tacit, innate, or embedded in our everyday habits or memory (Hagen & Rowland, 2011; Langley et al., 2018). Therefore, in order for participants to engage in co-design they must be encouraged to access their imagination and memory, and explore and express emotion, experience, and expectations (Hagen & Rowland, 2011). Moreover, a successful co-design process creates a space where collaboration, discussion, brainstorming, connections, and interpretations can be shared between participants and the research and design team.

In this research, the question of ‘what enables co-design to be more accessible for participants who experience disability and impairment?’ uses co-design to test and develop-in-situ what accessibility means and how it can be achieved with participants. When working with open-ended questions researchers should not generally have any preconceived ideas of the solution (Sanders & Stappers, 2012). Researchers should find the solution with the participants, and not attempt to fit their preconceived ideas into the findings.

Individual or group making is important to help develop and externalise thought, making it tangible and encouraging discussion and idea generation (Hagen & Rowland, 2011). In this research, the physical and cognitive challenge of ‘making’ for participants who experience disability or impairment may appear a challenging activity to encourage. However, through co-designing with people who experience disability and impairment, the act of making with a disability or impairment can be openly discussed and explored. Creative methods in this context, need to be adapted to the individual in order to be accessible and have meaning. Handing over the control of a creative method to the participants allows them to develop ideas and solutions that actually mean something to them.

Lastly, to help reduce confusion around the repeated use of the word ‘methods’ throughout this research, the term ‘research methods’ refers to the methods used to obtain theoretical knowledge about accessible co-design. Creative methods refer to co-design methods, activities or techniques chosen by the researcher to investigate and co-create principles for accessibility in a co-design context (Jury, 2015).
## Chapter 02: Methodology

### Section: Introduction

![Research Project Timeline](image)

**Figure 09: Research Project Timeline.**

<table>
<thead>
<tr>
<th>Event</th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Literature Research</td>
<td>Nov '17</td>
</tr>
<tr>
<td>Ethics Application #1</td>
<td>Dec '17</td>
</tr>
<tr>
<td>Export Interviews</td>
<td>Jan '18</td>
</tr>
<tr>
<td>Literature Review</td>
<td>Feb '18</td>
</tr>
<tr>
<td>Methodology</td>
<td>Mar '18</td>
</tr>
<tr>
<td>Ethics Application #2</td>
<td>Apr '18</td>
</tr>
<tr>
<td>Methods Audit</td>
<td>May '18</td>
</tr>
<tr>
<td>Preparing toolkit for audit</td>
<td>Jun '18</td>
</tr>
<tr>
<td>Workshop #1</td>
<td>Jul '18</td>
</tr>
<tr>
<td>Workshop #2</td>
<td>Aug '18</td>
</tr>
<tr>
<td>Workshop #3</td>
<td>Sep '18</td>
</tr>
<tr>
<td>Workshop #4</td>
<td>Oct '18</td>
</tr>
<tr>
<td>Processing findings from workshops</td>
<td>Nov '18</td>
</tr>
<tr>
<td>Design of tool</td>
<td>Dec '18</td>
</tr>
<tr>
<td>Editing Thesis layout</td>
<td>Jan '19</td>
</tr>
<tr>
<td>Discussion</td>
<td>Feb '19</td>
</tr>
<tr>
<td>Hand-in Draft Thesis</td>
<td>Mar '19</td>
</tr>
<tr>
<td>Making toolkit</td>
<td>Apr '19</td>
</tr>
<tr>
<td>Final Edit of Thesis</td>
<td>May '19</td>
</tr>
<tr>
<td>Hand-in Thesis &amp; Toolkit</td>
<td>Jun '19</td>
</tr>
</tbody>
</table>
Method I: Contextual Review

Accessible co-design as a creative research field is in its academic infancy (Hendriks et al., 2015). Therefore the review was a process of combining relevant content from different fields into a judicious and academically robust argument. The contextual review (see Chapter 01) developed my knowledge of the participatory design field, co-design and how it has been applied in healthcare, wellbeing and disability contexts in the past, raised questions around language for describing disability, and was used to confirm the existence of a gap in the literature around accessible co-design approaches.
Research Method II - Accessible co-design methods review

A review or audit of existing co-design creative methods, activities and techniques, was conducted to assess the accessibility of existing co-design practice, and to determine a selection of creative methods and activities to use in the co-design workshops. An audit is a “methodical examination and review” (Merriam-Webster, 2018). The review of creative co-design methods for accessibility was undertaken in two stages. In part A, each creative method, technique or activity found in the three selected toolkits were read, written down on a post-it note and awarded coloured dots. The coloured dots relate to three personas that had been developed specifically for this audit exercise, to help assess how accessible each creative method could be for a range of physical and cognitive impairments. If the creative method appeared to be accessible to the persona then it was awarded the corresponding coloured dot. See Figure 10 for further detail about each persona, what colour they are represented by and their impairment. Any creative methods which were assessed as inaccessible for two or more personas were discarded from the audit. See Figure 11 for an image of the methods that were assessed and past stage one of the review. In the second stage, the remaining creative methods were organised based on whether they reflected, organised, unpacked or generated ideas. From this data, a range of accessible co-design methods were selected for the proceeding workshops. (See Figure 12 for an image of the methods being organised in the second stage of the audit).

Figure 10: Personas for methods audit

Persona Sue is partially deaf.
- Sue wears hearing aids to increase the volume of sound
- Sue uses a lot of lip-reading to assist in communicating, and can speak English quite confidently.
- Where possible, Sue prefers information to be shared visually rather than verbally, but copes well in verbal situations.

Persona Mike is legally blind.
- Mike sees colour and light/shadow but little definition.
- Mike prefers for information to be shared verbally and discussed as a group.

Persona Pip has Cerebral Palsy.
- Pip cannot confidently use her hands for tasks that require precision.
- Pip used an electric wheelchair.

Figure 11: Methods that were assessed and past stage one of the review.

Figure 12: Methods being organised in the second stage of the audit.
Figure 11: Auditing creative methods for accessibility.

Figure 12: Co-design methods assessed for accessibility and categorised by their creative function.
Co-design methods and activities were chosen from the following three toolkits.

- MakeTools - Generative Design Method Cards (MakeTools, 1999)
- The Field Guide to Human-Centered Design by IDEO (IDEO.org, 2015)
- Bootleg Bootcamp by the d.School (d.school, 2009)

These toolkits were selected due to the variety of methods offered, as well as the level of detail each method was described in. Moreover, each toolkit was designed with a different co-design context in mind. The IDEO Field Guide (2015) was designed to be used in third-world countries where language barriers may exist. MakeTools - Generative Design Method Cards (1999) is a generalised co-design approach, that has been used by Sanders in the healthcare and wellbeing contexts. Finally, the d.School Bootleg Bootcamp (2009) was written for an entrepreneurial context.

Exhibition in a box (EIB) (Chamberlain & Craig, 2013) was also used in this research as an accessible co-design ‘toolbox’. EIB was audited in the expert interviews. EIB encourages creative discussion and engagement through everyday objects. EIB was created by design for health academics working with older persons. It was inspired by Duchamp’s ‘boîte en valise’ [box in a suitcase], which holds a monograph containing 69 reproductions of Duchamp’s work. Exhibition in a box brings the exhibition to older people and transforms “the home into a discursive research arena, providing individuals with a tangible prompt to scaffold conversation” (Sheffield Hallam University, 2018, para. 1). As a creative method EIB asks users to either hold and/or look at an object and contextualise the object’s meaning. EIB was used as a warm-up creative method in the first workshop to generate creative discussion. See Figure 13 for the objects included in Exhibition in a box.

Figure 13: Everyday objects used to generate conversation in Exhibition in a box.
Method III: Expert Interviews

Introduction

The findings of these interviews are discussed in Chapter 03: Documentation of Research. The learnings gained from the expert interviews informed the approach and content of the co-design workshops, including the exclusion of certain participant groups.

Recruitment

Experts for this research were considered professionals or academics who work in the disability sector, in both health practice and research roles, and included individuals who personally experience disability or impairment. Experts were approached through recommendations by my research network, as well as through snowballing (Statistics How To, 2014), where one expert interviewee would suggest other experts to approach. An email invitation was sent to potential expert participants inviting them to participate, if their response was positive a participant information sheet and consent form was attached with arrangements for the time and place of the interview. See Appendix 02 for participant information sheet and consent form.

Introduction

The aim of the expert interviews was to gain guidance and advice around organising and executing creative workshops with participants who experience disability or impairment. Findings from the six expert interviews are arranged and analysed under three main headings; disability language, accessible methods and space & sessions. Ethics for the recruitment and interviewing of experts in the fields of disability and person-centered design, was applied for, and formally approved by AUTEC on the fifth of December, 2017 (AUTEC reference number 17/433). Refer to Appendix 01.

Expert Interviews

An expert is defined as someone who has or displays “special skills or knowledge derived from training or experience” (Merriam-Webster Dictionary, 2018). Expert interviews in the initial or exploratory stages of research is an efficient and concentrated mode of data collection (Bogner, Littig & Menz, 2009). Each interview lasted between 30-60 minutes, with the exception of one interview with a New Zealand Sign Language Interpreter which was 10 minutes long and more informal. A similar series of questions was asked of each expert, focusing on their approach to ‘best practice’, environmental factors they adapt when working with people who experience disability or impairment, opinions around the syntax of disability language, and their thoughts on the accessibility of ‘Exhibition in a box’ as an example of an accessible creative method.

Experts were approached from a range of fields that encompass living, working with or researching disability, impairment and difficulty. The following six experts were consulted. Experts who are bolded also personally experience disability:

- Disability Student Advisor
- Health Researcher
- Speech and Language Therapist and researcher
- Senior Lecturer of Clinical Sciences and Centre for Person Centered Research
- Lecturer in New Zealand Sign Language and Deaf Studies who is deaf
- New Zealand Sign Language Interpreter

1 Refer to appendix 02 for interview protocol

Chapter 02: Methodology
Method III: Expert Interviews

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New Zealand Sign Language Interpreter

1 Refer to appendix 02 for interview protocol
**Method IV: Co-design Workshops**

These stories led to initial explorations into the participants’ lived experience.

**Workshop 1**

The focus of workshop 2 was on defining the participants’ student experience at AUT. Participants were asked to discuss associations with the word ‘accessibility’ in order to understand how this word is defined, or seen by people who have accessibility needs. Continuing on from the last workshop, participants delved deeper into the stories they told about their student experience, and defined aspects of their student experience that were negative. They explored these negative experiences through a representation of an imaginary persona, describing how their persona thinks and feels about their experience. The use of a persona helped participants to indirectly share their thoughts and feelings. Indirect techniques like this help participants to draw inspiration from their own lived experience without having to be put on the spot, or made to feel uncomfortable sharing personal information (Kallanda-Kordic et al., 2017). Finally, the group brainstormed some simple solutions, in preparation for the next workshop where they would focus on solution creation.

**Workshop 3**

Workshop 3 was focused on ideating solutions that may improve the student experience for those who experience disability and impairment. Participants started by discussing how the group could work together to make a difference at AUT, and what that difference could be. The intention of this activity was to inspire the participants to dream of or ideate a better future and what they could do to make that future possible. From this activity, a handful of ideas were selected via a vote to carry forward into the proceeding activity. The following making activity had the participants generate solutions, and test them from the perspectives of different people at AUT. For example, academic staff, students and non-academic staff. The point of this activity was to check that they had considered their solutions from a range of perspectives, and that their solutions were unlikely to cause harm to others. In the final activity participants were asked to brainstorm how they would implement their solutions at AUT. The intention of this activity was to encourage the participants to think about how any student learns about new initiatives or services at AUT, and how they should market their solutions.

**Workshop 4**

In workshop 4, the focus was on prototyping. Prototyping was tackled from two different angles. In the first part of the workshop, the participants were asked to prototype their solutions from the previous workshop into a model which communicated their desired future 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 their solution, leaving some ideas on the ‘cutting room floor’, and selecting the most important elements to bring into the final design. Moreover, it was an opportunity to see how participants worked together.

Throughout the research, an ‘Accessible Co-design Guide’ was developed for facilitators. The intention of the guide was to help facilitators conduct co-design with participants who may experience disability or impairment. This guide was developed alongside the workshops. I sought feedback on the ideas I had developed about doing co-design with participants like themselves. Their critique was mainly used to check that the approach of the guide was respectful in the way it discussed disability and impairment.
Research Method V - Reflections

Reflection played a critical role in this research. Insights and decisions were discovered, explored and refined through reflection. In ‘Tensions in human-centred design’ (2011) design researcher Mari Steen advocates for reflection by Human-Centred Design practitioners (HCD) (Steen includes co-design in this text). Designers participate with users and others in a design process and as such must critically reflect on their methods and ways of working. Reflection on action in a co-design process is important as designers do not own the process, yet often determine its outcome. Design research is a series of decisions, made by people privileged by knowledge. As such, reflecting on the knowledge gained and decisions made will improve the design researcher’s practice (Steen, 2011).

Reflection was practiced in two ways. Firstly, I asked participants to reflect repeatedly throughout the workshops on their actions and decisions in co-design activities. Moreover, I also asked for reflections at the end of each workshop to test and explore my assumptions about their experience of the co-design process. At the end of a set of creative methods, I would ask participants to describe how they felt about the activity, for example, why they made what they made, and why they had chosen the materials they used. Moreover, at the beginning and end of each workshop, participants were asked if they had any comments or thoughts to share with the group.

Secondly, I used reflection in two more ways: to inform the decision-making process of the workshop plans, and in the search for insights which could inform the accessible toolkit. After each workshop I would reflect on what had gone well and not so well in the workshop. These reflections allowed me to adjust my approach in the upcoming workshops. Moreover, I would reflect more deeply on participants’ responses or questions, and search for insights or assumptions that might help me proceed co-design workshops more accessible. To further develop an insight I would build it into the next workshop. Reflection allowed me to iterate the workshop plans, and make sure I was exploring underdeveloped insights or assumptions.
Research Method VI - Toolkit development and testing

Toolkit development and testing

The accessible co-design toolkit was developed using an iterative process throughout the co-design process. This was done using an ongoing iterative process that allowed for the construction and transformation of meaning (Sanders & Stappers, 2014). A large portion of the co-design toolkit was developed and tested with participants during the workshop process. The remainder was developed at the end of the co-design process through the thematic analysis of the transcriptions of the workshops. The following section describes how the toolkit was developed and tested.

In tandem with the workshops, aspects of the toolkit were designed and tested with participants. Reflection during and after each workshops shed light on minor elements of the co-design process that could improve the accessibility of the process and approach. As these elements for change arose they were interrogated, designed for, and reintroduced into the workshops to test if they would increase accessibility.

Two substantial tests were carried out to critique the guide. The first was in workshop four, and again two months after the previous revisions had been addressed, see Figures 17 and 18. Participants were asked to respond to the rules, advice, syntax and conclusions offered in the guide. The critique made by the participants is described in Chapter 03: Documentation of Research.

Thematic analysis of transcriptions

The toolkit was further developed at the conclusion of the co-design workshops using a thematic analysis of the transcriptions made. Thematic analysis of qualitative data is a method for systematically identifying, organizing, and offering insight into patterns of meaning (themes) across a data set (Braun & Clarke, 2014, p.57). Braun and Clarke (2014) also describe that thematic analysis “has a lot of potential for use within participatory design research projects” (p.56). For the purpose of this research, I was interested in identifying themes and important insights, which could form the basis of ‘principles’ for conducting co-design with participants who experience disability or impairment. Thematic analysis allowed for the identification and organisation of themes discussed either implicitly or explicitly (Braun & Clarke, 2014). Moreover, thematic analysis allows the researcher to highlight “the obvious or semantic meanings in the data” (Braun & Clarke, 2014, p.58), or explore the latent meanings of what is said or done by participants in research.

Each workshop was recorded using video and audio equipment. Photographs of artefacts were taken during the workshops to document the making. After the workshops, discussions and quotes were transcribed by the design researcher. Transcripts were read and re-read and emerging themes were highlighted. 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. Once quotes and photos of artefacts made by participants were organised, key themes began to emerge. Principles for accessible co-design were developed from the key themes, as well as from personal reflections on the co-design experience. I wrote the text for the guide and sought the skills of a graphic designer, to support the visual communication of the content.
Chapter 02: Methodology

Method 6/6: Toolkit Development

Figure 17: Final feedback from participants on the ‘Accessible Co-design Guide’.

Figure 18: Close up of post-it-notes critiquing ‘Accessible Co-design Guide’.
Co-design Methods

Findings

The aim of the co-design creative methods review was to find a selection of accessible creative methods to use in a co-design process with participants who experience disability or impairment. A two stage review was undertaken, stage one assessed a wide range of methods for accessibility, while stage two selected a refined list of methods to use in this research. Two key findings, discussed below, emerged from the review of co-design creative methods for accessibility.

The first review identified a long list of creative co-design methods that were suitable for use with participants who experience disability and impairment. Accessibility was determined through the use of three personas who experience physical impairments, as demonstrated by Figure 10. A key finding of the first review was that it was the expression or description of the method in each toolkit, and not the method itself, which made it accessible or inaccessible. Toolkits that described precisely how a creative method was to be executed appeared inaccessible, as the approach of the toolkit did not encourage or consider a flexible approach for participants who have diverse capabilities. Toolkits which described in vaguer terms how a creative method should be enacted were seen as more accessible, as they appeared more flexible and open to personalisation.

Table 02 lists all the creative co-design methods assessed for accessibility. From this first review, eleven creative methods were considered inaccessible and excluded from further review. These creative methods, and the reasons why they were deemed inaccessible are described in detail in Figure 19. At the end of the first review, 64 methods were considered accessible.

The second review sought to categorise in some manner the 64 accessible creative methods, and select a handful for use in this research. It became clear that while some methods are used to generate ideas or designs, other methods are used to organise ideas or reflect upon them. Literature confirmed this framework for organising creative methods (Sanders & Stappers, 2012). In the second review creative methods were organised based on whether they generate, un-pack, organise or reflect on ideas, as demonstrated in Figure 20 and Table 03. This was a valuable insight as a mix of methods are needed throughout a co-design process. The final selection of methods was made by choosing two to four creative methods from the four aforementioned categories, which are shown in Table 04. It was decided that accessible creative methods which are repeatedly used across different co-design toolkits would be selected. Using ‘popular’ co-design creative methods was one way to demonstrate how an accessible approach can be applied in any co-design project.

Table 02: Master list of co-design creative methods to assess for accessibility. (MakeTools, n.d.) (bootcamp bootleg, 2009) & (IDEO, 2015)

Table 03: Co-design methods

<table>
<thead>
<tr>
<th>1-20</th>
<th>21-40</th>
<th>41-60</th>
</tr>
</thead>
<tbody>
<tr>
<td>I/life/what, what/it Statements</td>
<td>Resource flow</td>
<td>Determine what to prototype</td>
</tr>
<tr>
<td>Puppet play</td>
<td>Powers of 10</td>
<td>How might we questions</td>
</tr>
<tr>
<td>Explore your hunch</td>
<td>Design principles</td>
<td>Create insights statements</td>
</tr>
<tr>
<td>Surveys</td>
<td>Emory ranking</td>
<td>College</td>
</tr>
<tr>
<td>Storytelling</td>
<td>Vision statements</td>
<td>Visualising adding business</td>
</tr>
<tr>
<td>360 web</td>
<td>Resource flow</td>
<td>Business canvas model</td>
</tr>
<tr>
<td>Structure &amp; group ideas</td>
<td>Download your learnings</td>
<td>Decision making games</td>
</tr>
<tr>
<td>Story share &amp; capture</td>
<td>Card sort</td>
<td>Full scale planning</td>
</tr>
<tr>
<td>What’s in the bag?</td>
<td>Video editing</td>
<td>Voice modelling</td>
</tr>
<tr>
<td>Statement 2</td>
<td>Ecosystem mapping</td>
<td>Get visual</td>
</tr>
<tr>
<td>Peers observing peers</td>
<td>Card sorting</td>
<td>Analogous inspiration</td>
</tr>
<tr>
<td>Critical feedback chat</td>
<td>Storytelling</td>
<td>Blue sky thinking</td>
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<tr>
<td>Shooting video</td>
<td>User experience</td>
<td>Heart of user journey mapping</td>
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<tr>
<td>Self perception on triangle</td>
<td>Card sorting</td>
<td>Creative concept</td>
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<tr>
<td>User camera study</td>
<td>Storytelling</td>
<td>Creative frameworks</td>
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<tr>
<td>Body storming</td>
<td>How might we?</td>
<td>Storyboards</td>
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<td>Powers of 10</td>
<td>How might we?</td>
<td>Storiesboard</td>
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<td>Design principles</td>
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<td>Email ranking</td>
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<td>Extreme users</td>
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<tr>
<td>Vision statements</td>
<td>Download your learnings</td>
<td>Bundles ideas 3x4 &amp; 5x5</td>
</tr>
</tbody>
</table>
Make a package

Card sorting

Image Collaging

Shooting video

Decision making games

User-camera study

Make a package

"Images and icons are selected from a toolkit which is used to create a collage that resembles the memories of the person. It’s about the person’s hopes and dreams for the future.”

[Diagram]

Card sorting

"They were given the opportunity to generate ideas about the story's purpose and organize them into cards, then review and refine them before presenting to the group.”

[Diagram]

Image Collaging

"Students are asked to create a collage using images and words that represent their personal goals and aspirations.”

[Diagram]

Shooting video

"You are responsible for the creative team. It is in your hands to decide on the storyline and the layout of the video.”

[Diagram]

Decision making games

"Participants are asked to make decisions based on the visual and textual information provided.”

[Diagram]

User-camera study

"The user-camera study allows the participant to experience and evaluate their own interaction with the environment.”

[Diagram]

Chapter 02: Documentation of Research
Part 1/7: Co-design methods review

Figure 19: List of co-design methods which were declared inaccessible and corresponding explanation (continued over two pages).
Expert Interviews

Person-centered language

Language, and person-centered language, is very important for disability and the people who experience it. Titchkosky and Michalko (2014, as cited in Cameron, 2017) state that often words that people use to describe disability to others are not appropriate for people who experience disability and impairment. Point out that disability exists within the meanings attached or given to it. The meanings of disability are complex, the accessibility of Exhibition in a box (Chamberlain & Craig, 2013) as a creative method, the exclusion of Deaf participants from this research, and finally, recommendations for making the space and facilitation approach accommodating and empowering for participants who experience disability and impairment. The themes encompassed disability language and its complexity, the accessibility of Exhibition in a box (Chamberlain & Craig, 2013) as a creative method, the exclusion of Deaf participants from this research, and finally, recommendations for making the space and facilitation approach accommodating and empowering for participants who experience disability and impairment. 

Disability language, pride and identity

An interesting and diverse range of perspectives were shared in response to interview questions about appropriate and inappropriate language for describing disability. Importantly, experts shared that ‘person experiencing disability’ and ‘disabled person’ are appropriate terminology, while ‘person with disability’ is not. ‘Person experiencing disability’ acknowledges that the person and their disability are separate entities, and the person experiences disability as an individual. Alternatively, ‘disabled person’ reflects the social model of disability where emphasis is put on the societal factors that ‘disable’ a person (Hickey & Wilson, 2017). ‘Person with disability’ refers to disability as being a part of the person, and that person being abnormal, limited, or restricted by the disability. Moreover, ‘person with disabilities’ reinforces the traditional medical model of disability, where impairments are seen as deficits and need to be fixed (Hickey & Wilson, 2017).

Experts agreed that the best approach was to mirror the language used by the person. Moreover, when someone is not forthcoming with describing or labeling their condition, their impairment or disability is not obvious. The use of language such as ‘person with disabilities’ may be useful. The only instance described where they would not mirror the disabled person’s language is when the person is using negative or derogatory terminology such as ‘invalid’ or ‘handicapped’. They stated they would politely inform the person that that language is no longer appropriate and should not be used (in New Zealand). They also pointed out that for people who acquired a disability or their disability was the result of an accident (such as a spinal cord injury), other language options like ‘access citizen’ may be preferred as this language can feel less stigmatizing and confronting as they adjust to a changed identity (it was also suggested to be aware and sensitive of this).

In another example of person-centered language, a Māori health researcher and disability researcher in the Pacific described their research approach as ‘person-centered research’ because terms such as ‘disabled person/impairment’ are very Western terms and are based on deficit language (disability). They chose instead to identify through Māori terminology like Whakau Haua, Hickey and Wilson (2017) describe the meaning of Whakau Haua Whakau Haua. Moreover, when someone is not forthcoming with describing or labeling their condition, the final ‘ā’ in ‘Haua’ refers to the drive or force which propels this network to create a better environment around their loved one experiencing disability (p. 86). Whanau Haua refers to the family or network of disability of which does not see the barriers to living and thriving in society as originating from the disabled person, but as something perpetrated by society (Hickey & Wilson, 2017).

Experts described how multimodal communication is important when conducting research with participants who experience disability and impairment. Multimodal communication can aid in clearer communication. When speaking, researchers can write down key words and draw simple images, point to written words and images when referencing them, and use body gestures whenever possible. The importance of checking in with participants regularly was also stressed, confirming with participants that the researcher has understood their meaning, using their words. For example: “Do you still want to participate? Are you still happy to continue with this research?”. Experts also recommended checking in with participants regularly was also stressed, confirming with participants that the researcher has understood their meaning, using their words.

Exhibition in a box

Exhibition in a box (EIB) (Chamberlain & Craig, 2013) was used with experts as it was thought that some of the experts may not have had any design or co-design experience. Exhibition in a box was used to introduce this kind of creative approach, demonstrating how accessible creative methods function, and to invite experts to share techniques in their repertoires for accessible research. Having been developed with older people in mind EIB has a strong accessibility focus – it is easy to transport, easily set up and can be properly understood. It is also thought that the researcher has understood their meaning, using their words. For example: “Did you mean ‘do you mean something else’? Experts advised that asking questions around appropriate and inappropriate language for describing disability, or their disability was the result of an accident (such as a spinal cord injury), experts would politely inform the person that that language is no longer appropriate and should not be used (in New Zealand). They also pointed out that for people who acquired a disability or their disability was the result of an accident (such as a spinal cord injury), other language options like ‘access citizen’ may be preferred as this language can feel less stigmatizing and confronting as they adjust to a changed identity (it was also suggested to be aware and sensitive of this).

Other examples of person-centered language include ‘person with disabilities’ and ‘disabled person’ being used instead of ‘disabled person’ and ‘impairment’. Experts agreed that the best approach was to mirror the language used by the person. Moreover, when someone is not forthcoming with describing or labeling their condition, their impairment or disability is not obvious. The use of language such as ‘person with disabilities’ may be useful. The only instance described where they would not mirror the disabled person’s language is when a person does have – “I might be blind, but I can still feel the dice, I might be deaf, but I can still use sign language, I might be mute, but I can still communicate in my own way.” Another expert raised the possibility of asking participants to respond to the EIB objects with a composition, story, or another 3D object, to vary the use of spoken English.

Accessible methods and approaches

Experts described how multimodal communication is important when conducting research with participants who experience disability and impairment. Multimodal communication can aid in clearer communication. When speaking, researchers can write down key words and draw simple images, point to written words and images when referencing them, and use body gestures whenever possible. The importance of checking in with participants regularly was also stressed, confirming with participants that the researcher has understood their meaning, using their words. For example: “Did you mean ‘do you mean something else’? Experts advised that asking questions around appropriate and inappropriate language for describing disability, or their disability was the result of an accident (such as a spinal cord injury), other language options like ‘access citizen’ may be preferred as this language can feel less stigmatizing and confronting as they adjust to a changed identity (it was also suggested to be aware and sensitive of this).

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Research with Deaf participants

Expert interviews brought to light assumptions held about New Zealand Sign Language (NZSL) and the frustration of spoken language-based research for Deaf participants. Before the experience of doing Exhibition in a box with a Deaf expert interviewer is described, alongside the advice from experts to not include Deaf participants in this research.

Exhibition in a box was a successful but a considerably different experience with the Lecturer in NZSL and Deaf Studies who is Deaf. As a creative method it proved itself to be accessible for Deaf participants, but there was noticeably more difficulty for this expert in comprehending EIB questions. This was due to my previously held assumptions of NZSL, and failure to consider in advance how best to phrase EIB questions so that they could be translated from spoken language to NZSL succinctly and clearly. Like with all languages, meaning changes, and can even be lost in translation and interpretation. Using EIB in this interview highlighted the reality of interpretation and translation between languages. Before the expert interviews I had assumed that New Zealand Sign Language (NZSL) is an ‘embodied’ direct translation of spoken English. It became very clear that NZSL is its own language and requires complex interpretation.

Moreover, experts with experience in and around the Deaf Community encouraged me to not include New Zealand Sign Language (NZSL) users in this research if they were to be a minority in the participant group. Three experts, the Lecturer in NZSL and Deaf Studies who is Deaf, the NZSL Interpreter, and the Clinical Sciences researcher, all expressed the opinion that research with NZSL users should be done in environments where their mode of expression is the norm and they are the majority. For NZSL users, communication with verbal English users involves a frustrating time lag. Conversations move on before they have the opportunity to sign their thoughts and have them translated, which is never an empowering and fluent experience for Deaf people. Due to the complexities described above, the decision was made not to include individuals who are Deaf and communicate through NZSL in the co-design workshop process.

Space & sessions

Environmental factors can be important for people who experience disability and impairment. As described by the social model of disability, people who experience disability and impairment are disabled by ill-considered, inadequate or nonexistent access to public spaces and environments where everyday life is conducted (Cameron, 2015). Inviting participants to a workshop entails asking them to navigate a physical environment that may be unknown to them. Experts discussed ways to respect, accommodate, and empower research participants through the physical environment. Accessible bathrooms are necessary as well as signage placed at a variety of heights to suit varying visual eye-height ranges. For example, some wheelchair users may operate at a lower eye level, therefore signage placed at an appropriate height is perceived as more respectful. Experts also discussed the use of highly flexible environments and approaches. Light, both natural and artificial, can enhance or disable a person’s ability to participate, therefore using spaces where natural and artificial light can be adjusted was recommended. Moreover, each day can be different for someone who experiences disability and impairment. What works one day might not work the next, so it is important to acknowledge this and be flexible and dynamic with interactions and breaks. Breaks every forty-five minutes, at a minimum were advised.
In summary, the expert interviews identified four main themes or areas important to this research. In the first instance, the complexity that surrounds language that describes disability was explored and remained unsolved, indicating the necessity for further discussion. Secondly, Exhibition in a box was confirmed as being appropriate as an accessible creative method for a range of disabilities and impairments, and encouraged experts to discuss their accessible approaches to research. Thirdly, the discussions around Deaf participation encouraged an ‘unexpected’ exclusion criteria, and challenged my assumptions around NZSL and the research experience for Deaf participants. Finally, the aim of this research was validated by the experts as an important and valid research topic to explore.
Workshop 1 Findings

Introduction

In the first workshop, three creative co-design methods were tested alongside a warm-up activity and questions asking participants to reflect on the co-design process. The aim of the first workshop was to develop empathy and familiarity amongst the participants and myself. Empathy, the first step in the d.school co-design process (d.school, 2009), was interpreted to mean ‘build empathy amongst the participants and the design researcher about each persons experience of disability or impairment, and being a student’. This section is presented in three parts. The first describes the creative methods, how they were used, and why they were used at this stage in the co-design process. The second part of this documentation presents the findings around the student experience and the co-design activities. The final section reports on the reflections shared by participants about their workshop experience, as well as my own reflections on the research approach and adaptations I made for the proceeding workshops. Each workshop was repeated twice as the eight participants were divided into two groups of four based on their availability.

Part 1: Creative Methods

Introduction

The workshop started with a discussion in pairs to warm-up and build familiarity, followed by the first creative activity, Exhibition in a box (Chamberlain & Craig, 2013). The second creative method was a Journey Map (d.school, 2009, p.19), and finally pain point identification (d.school, 2009, p.18).

The warm-up activity was a discussion in pairs around the associations held by each participant about the words ‘disability’ and ‘impairment’. Responses were fed back and shared with the whole group. The initial discussion was an opportunity for participants to get to know each other, and share opinions about disability and disability language. Moreover, if comfortable, participants had the opportunity to share any disability or impairment they experience and the language they use to describe their impairment. This technique quickly gave everyone an insight into each participant’s experience of disability and impairment and their attitudes towards it.

The perspectives shared were thoughtful and personal, and aligned with perspectives shared in the expert interviews about the complexity of disability language. (See Figure 23).

The first creative method was Exhibition in a box. As previously described, Exhibition in a box provides “a tangible prompt to scaffold conversations” (Chamberlain & Craig, 2013, p.26) and helps show the power of creative methods. In the same pairs participants were asked to take an object and describe how they relate that object to their everyday life. Their responses were shared with the group. This method was repeated two further times, and participants were asked to relate the object to their lives and their experiences of disability and impairment. The stories and answers shared highlighted the complex experience it is to be disabled or impaired in an ableist world. EIB helped participants access deeper thoughts which was evidenced in the richness of the answers compared to the opinions shared in the warm-up brainstorm. Responses are described in Figure 24.
“...I do not use [disability] to describe myself, so I don’t like other people using it to describe me...”

“I feel like impairment is less visible than disability.”

“I think it [impairment] is a more mild extra challenge. A disability is a bit more extreme.”

“I think the word [impairment] generally has negative connotations.”

“(Disability) doesn’t describe my personal experience, so I don’t feel comfortable using it for me.”

“My disability is hard to explain, so it’s just easier to say ‘oh, it’s a disability.’”

“...I was looking for adapted kitchen solutions, and everything they had was for people with really bad fine motor skills, so the spoon handles were huge, or for people with one hand, there wasn’t a happy middle ground....”

Watch

“How we allocate time in our lives, we have extra things we have to account for that other people won’t factor in, how we have to pre-plan your schedule, think ahead and think about other people as well in relation to your time management”

“Taking more time, sometimes that feels relatively unjust, when you think it’s going to take me half an hour to get to this place, when for someone else it will take 5 minutes, so that cuts more out of my day.”

“Other people will be like ‘you want to go out tonight and just expect a yes or no answer, but then in your head you have to think how I am going to get there, will I be able to get into the building, I have to take into account a lot more variables.”

Glove

“Clothing patterns are stock standard and you have to fit into standard sizes.”

“A cricket glove, I have cerebral palsy on my right-hand side. I used to like playing cricket... I wasn’t able to wear a glove on my right-hand side, so what happened is that I had to give up cricket”

Dice

“I related it to every time I go out into public it’s like rolling a dice, will I have to deal with someone putting me in a box or yelling at me.”

“I am dyslexic, adding and numbers things get scrambled. I find it hard to categorise numbers sometimes...”

Spoon

...I was looking for adapted kitchen solutions, and everything they had was for people with really bad fine motor skills, so the spoon handles were huge, or for people with one-hand, there wasn’t a happy middle ground...”
The second creative method was a Journey Map (d.school, 2009. p.19). The participants were asked to describe and represent, using all the making tools and materials on offer, an average day at AUT, and to share with the group. The aim of the Journey Map activity was to begin interrogating the participants’ student experiences, and deepen empathy and familiarity amongst the participants about what it means to be a student with different experiences of disability.

The third creative method was pain-point identification (d.school, 2009. p.19), a method used within the Journey Map method. In this research it was extracted and used as a stand-alone method. Participants were asked to describe and represent examples in their average day, or week, where they experience pain. Pain was described to participants as meaning ‘a moment when being a student is a challenge’. Participants were asked to describe their experience and create a representation using the materials on offer, and share their pain-points with the group. The intention of pain-point identification (d.school, 2009. p.19) was to continue to develop empathy and familiarity amongst the group, and secondly to discover if there were any shared difficulties experienced by the participants which could be resolved through this co-design process. The pain-points identified by the participants are described in Figure 25.

Part 2: Exploring the accessibility of co-design to better understand the student experience

The three creative methods and warm-up activity helped participants explore and share their lived experience of disability. Personal stories were shared, insights about the experience of being disabled or impaired were described, disabilities and impairments were disclosed and a rapport between the participants was quickly developed. Most participants stated that AUT was very accessible and a great place to be a student, when compared to their experiences at high school. However, many stories were compared around the various difficulties participants face as disabled students. Over half of the participants shared the opinion that being a student with a disability takes more time compared to non-disabled students. For example, transport, moving between classrooms, study and waiting for the only accessible bathroom to be free, absorbs more out of their day compared to non-disabled students. Some participants even mentioned times when other students had expressed jealousy over their disabled parking permits, after-hours security card for the elevators or extra time in exams. Participants also compared stories when their needs had not been considered by lecturers or other students. One participant explained that when instances like this occur, she prefers to look lazy and leave the class than struggle along. “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 to have to explain why I can’t do something.”

A highlight of workshop one was when a solution to an accessibility problem a student faced was found. One participant described an access issue they experience in one campus building where they cannot access the elevators after 6pm. It is a challenge with their physical disability to use the stairs, especially after a long day of lectures. (The Disability Student Services (DSS) Adviser was able to fix this problem, and organise an ‘after-hours swipe card’, see Figure 25 for the model this participant built to describe this challenge).

Participants were asked to reflect on their experience of co-design halfway through and at the end of workshop one. Two out of the eight participants expressed a lack of confidence or willingness to be creative. Initial reluctance or hesitance to share or engage in using creative methods is common as discussed by Sanders and Stappers.
I had assumed that participants would want to use all the materials on offer, and as such the issue of how to make all the materials and tools accessible was at the forefront of this research. Interestingly, the majority of participants expressed the desire to use tools and materials that were familiar to them. “Because I didn’t know what to do with them [the other materials] so I just went with something I know…” “...I just kind of choose what I am familiar with, and so just drew.” “Probably seeing something familiar.” Participants used a wide range of tools and materials, however most individuals chose materials that were familiar to them. (See Figure 27 for the tools and materials offered in the first workshop).

Lastly, the co-design process allowed participants to take control of the experience, their words, and their contribution. This approach is encouraged by Tom Shakespeare (1996) and meant rapport developed quickly between participants during the ‘making’. Participants were able to ‘chit-chat’ while they were busy making. These periods of making allowed participants to control the conversation and mood. Moreover, when explaining the significance of their visual representations or artefacts nearly all the participants divulged their disability or impairment, and shared stories about experiences of being disabled or living with impairment. From a facilitation perspective, this meant I did not have to directly ask participants to disclose their disability or impairment. This indirect approach for discussing disability and impairment gave the participants further control over their contribution.

Part 3: Reflections on the co-design activities

After each workshop, reflection was utilised as a research method to capture what had been learnt about the accessibility of co-design, and ideas to test in the next workshops. Moreover, aspects of the experience which I noticed but were unsure of (2012). One participant repeatedly expressed, “I am not naturally an abstract thinker”, throughout and resistance to creative activities was shared by another, “Like I said, I am not very creative, I try to hide when creativity comes along” As described by Sanders and Stappers (2012) this is a normal reaction. As a facilitator I found it was most effective when I responded to these comments by focusing on and questioning participants about the materials and tools they might enjoy working with and measuring them to just be themselves.

Hendriks and colleagues (2015) highlighted the concern that for some participants being confronted by their own limitations in comparison to other participants could lead to a disempowering participatory design experience. One participant commented on another participant’s cutting skills, “I am super super jealous of [other participant’s] cutting skills, I will never ever ever be able to cut like that, cause I didn’t have the dexterity. So for me, something like the larger blocks made it [the making activities] easier.” Hendriks and colleagues (2015) raised this issue in connection with participants who have the same or similar conditions. Neither Hendriks et al., (2015) nor I had considered that participants may compare themselves to other participants whose range of strengths and weaknesses could be vastly different. Despite this, the participant who shared this view was confident in using other tools and materials to construct their representations.

With respect to the toolkit and approach, two interesting lessons were learned. Seven out of the eight participants were able to use all the tools and materials they desired. One participant had wanted to use the ‘emoji faces’, however they were not individually cut-out, and as they only have the use of one hand, they were unable to cut them-up themselves. “I think if the stickers [emojis] were cut, I would use them, because it’s harder to hold with my right hand, so I choose not to use them.” This highlighted the importance of pre-cutting all materials to make them more accessible. The second insight was concerned with the choice of materials made by participants.
their significance were recorded for future reflection. For workshop two, I reflected that there might be value in asking participants at the beginning of each workshop if they had any feedback or comments to share after the last workshop. Creating space for reflection at the beginning of the workshop allowed participants to share any thoughts they had had between workshops. Moreover, I did not discuss participants’ associations with the word ‘accessibility,’ an important discussion to include in the second workshop. Lastly, I did not expect the workshops to be so much fun, or to finish still feeling fresh and energized. I assumed I might be quite exhausted after leading a workshop for two hours, but that was not the case. Participants also commented that the time had flown, and they couldn’t believe it two hours had passed.

After the first workshop, two physical aspects of the toolkit needed revision. My workshop plan had been difficult for me to follow, and minor activities and questions were skipped over. I reflected that I needed to design a template for the workshop plan that was more engaging, and which communicated at a glance the workshop process step-by-step. (Refer to Figure 28 for the template that was produced after workshop one). Secondly, I was unsure about the manner in which the tools and materials had been strewn all over the table. I considered the possibility that some participants may have restricted themselves to tools which they could reach, if they physically could not reach or bend for or if they did not feel comfortable asking someone to pass them a tool or material. (Refer back to Figure 27, showing how materials while being used, were spread all over the table, making access difficult for some participants. Based on this observation, I developed a prototype ‘toolbox on wheels.’ This toolbox attempted to make the co-design session more accessible by allowing each participant to pull the tray on wheels towards them to access with all the available materials and tools. (Refer to Figure 29).
Workshop 2 Findings

Introduction

In the second workshop, three creative co-design methods were tested alongside a warm-up activity and reflections on the co-design process. The aim of workshop two was to define the student experience participants wanted to have. Define, the second step in the d.school co-design process (d.school, 2009) was interpreted to mean ‘define your student experience and describe aspects of the experience which are challenging or difficult.’ This section is presented in three parts. The first describes the creative methods, how they were used, and why they were used at this stage in the co-design process. The second part of this documentation presents the findings around the student experience and the co-design activities. The final section reports on the reflections shared by participants about their workshop experience, as well as my own reflections on the research approach and adaptations I made for the proceeding workshop.

Part 1: Creative methods

The warm-up activity was a group discussion around the meaning of ‘accessibility’. Participants were asked to reflect on their meaning of ‘accessibility’ in reference to their everyday life, as well as their experience at AUT. This discussion highlighted the diverse ways ‘accessibility’ can be interpreted and applied in very different contexts. Responses ranged from the accessibility of spaces and places, to the accessibility of people and resources, as well as notions of social accessibility.

The first creative method was ‘storytelling’ (d.school, 2009, p. 44). Storytelling is an effective way to share ideas that focus on underlying emotions and meanings. Storytelling affects the listener and teller both intellectually and emotionally (d.school, 2009, p.44). Storytelling was used as a quick-fire method to generate memories, feelings and stories. It is effective for idea generation as it is a familiar and well-practiced form of sharing amongst verbal language speakers (d.school, 2009, p. 44). Participants were asked to tell three stories, and make a visual representation for each story based on the nine topics that were discussed in workshop one. (Refer to Figure 25, on page 83). Participants were invited to add a topic that they felt was missing. One participant asked to include ‘when people are overbearingly helpful’. This addition encouraged stories from participants where they had experienced people trying to be helpful, but the participants perceived their approach as being rude or offensive. For example, one participant described strangers coming up behind people who use wheelchairs and pushing them, without first asking if their help is wanted. Participants were encouraged to base their stories on personal experience. Overall, 25 stories were shared, along with eight visual representations. At the end of this activity, participants were asked to select three topics that had generated stories, and which the participants were interested in exploring further in the next activity. (Refer to Figure 30 the topics chosen in workshops 2A and 2B). Between the two groups different and similar themes were discussed however the topics selected were different, with the exception of accessible infrastructures which encompassed elevators.

The second creative method used in workshop two was ‘persona posters’ (MakeTools, p.10). Persona posters were reframed to ‘persona representations’ for this accessible approach. Participants were asked to create a persona and make a visual representation of them (using all the tools and materials on offer), giving them a name, a disability or impairment, a degree they are studying toward at AUT, and to tell a story about a time this persona experienced one of the topics that the group had
Figure 30: Topics selected in the second workshop for further brainstorming

Figure 31: Example of a ‘persona representation’ and Jeff’s story.

Figure 32: Images of the six personas created by participants.

chosen to explore further. An example of a ‘persona representation’ and their story is presented in Figure 31. While being imaginative and creative can be challenging for some people (Sanders & Stappers, 2012), personas creation lends itself to all levels of creativity doing, adopting, making and creating (Sanders & Stappers, 2012), as participants can adapt (adopt) a persona using themselves as inspiration, make a persona based on someone they know, or create a completely new persona using their imagination. Moreover, personas can indirectly ask participants to share more about themselves (Sanders, 1999). “People often tell you a lot about themselves when they are asked to describe others” (MakeTools, p.10). Personas were also used by Nakarada-Kordic and colleagues (2017) in their research with young people experiencing psychosis, to allow participants to project their thoughts and feelings onto the persona they created. “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, p.234). (Refer to Figure 32 for images of the six personas created by participants).

The third creative method used in workshop two were “How Might We” questions (IDEO, 2015, p.85). How might we questions or statements turns a challenge into an opportunity, and suggests that there are many possible solutions (IDEO, 2015). “How Might We” questions were formed after each participant described their persona and the difficulty they experience at AUT. As a group, participants were asked questions such as, “How might we design a solution for Katie?”, or “How might we inspire people to take the initiative when they see wheelchair users waiting for an elevator?” “How Might We” questions were used to inspire solution ideation and brainstorming in preparation for the subsequent workshop, which would focus on ideation. The use of “How Might We” questions helped to clearly frame the problems that needed brainstorming without indicating in any way how it could be resolved, thus supporting participants to be creative in their search for imaginative solutions.

“...and I was like this is not accessible in these other way...” and she said “well actually we haven’t thought of that cause there weren’t any disabled people that we could ask...”

“I think some people really want to know about the access to disabled regulations, maybe it would be really cool if disability was just part of a culture discussion group and not a disabled people discussion group but inclusion for everyone, so that they can learn...”

“...and I am still learning to be ok for other people to bully me, I get a little bit defensive at I would rather not do something completely than go ask for help sometimes...”

Car parking
Elevators
Help

Language
Accessible Infrastructure
Clubs & Groups

“This is Jeff, he was hit by a car and has a broken leg and is a bit fuzzy in his brain. He is not... he can’t get up the stairs to go to his class, all the elevators are taken, and one was broken down so he can’t get to his class on time, and then he misses his class, so he is not happy... he was the best player in his team but now he can’t play soccer so everyone is really angry at him and this is the soccer ball and he got kicked out of the soccer team cause he can’t play...”
In workshop two, ‘accessibility’ and its meaning in the context of participants’ lives was discussed. Overall, ‘accessibility’ was loosely defined by all participants as, “having access to things.” However, the kinds of ‘things’ that participants described needing access to were varied. Participants with physical impairments discussed ‘accessibility’ in terms of 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, for example being able to talk to them after class or make an appointment to see them one-on-one. ‘Social accessibility’ was also discussed, and described quite eloquently by a participant as, “Being able to socialise on equal ground is just as important as being able to move around on equal ground.” This participant referenced times when they felt unwelcome or were even unwelcomed to social gatherings as their presence restricted the kinds of activities that could be undertaken. Overall, ‘accessibility’ was described by the participants to mean access to physical environments and to certain people and resources, as well as access to tertiary education and social gatherings. ‘Accessibility’, according to the participants in this research encompasses a combined physical and social ethos. ‘Sociophysiology’ is the “interplay between society and physical functioning” (Freund, 1988, p.86).

If you think of the co-design experience, the process and the people involved, as representing ‘society’, then this discovery highlights that accessibility in the context of this co-design research, is one where participants feel welcome, involved, engaged, and supported physically to take part or contribute independently.

In workshop two, participants’ strengths and challenges become more discernible. Of particular interest was the way some participants relied on their verbal communication to participate, while other participants focused on ‘hands-on’ participation. What was encouraging was that both kinds of contributions were...
equally valued and celebrated by other participants. Two out of the six participants in workshop two were considerably non-verbal and contributed to the workshop through their ‘hands-on making’. One of these two participants, who had a traumatic brain injury, contributed to the workshop by making models of the discussions taking place around them (see Figure 34). This participant described that they enjoyed ‘crafting’ as following a discussion and contributing verbally was difficult. The other participants celebrated this participant’s contributions with comments like, “I like this so much [their Lego model], oh my goodness Lily [name changed], you are so good at making”.

Another less verbal participant expressed how they were feeling through artefact creation. They shared that they were having a “bad hearing day...”, with a blu-tack model of a cat stating that, “I have made a model of a cat out of blu-tack to represent that talking to me when I am having a bad hearing day is like herding cats”. This participant focused on quietly making in this session, and went on to produce three times more artefacts than the other participants, (see Figure 33). As the facilitator, this participant’s use of making to suggest that I should not expect as much verbal input from them in the session illustrates how co-design makes it possible for participants to communicate their thoughts and feelings in many different ways. In both examples, these participants contributed to the workshop through mainly non-verbal ‘hands-on’ techniques, demonstrating that accessible co-design should accommodate and encourage multiple modes of contribution.

Asking participants to reflect on the representations they made proved valuable for learning more about the participants, as well as their co-design experience. For example, one participant responded to the question ‘why did you make your representation the way you did?’ Stating that they “throw a few things together and then figure out its meaning after” (see Figure 34). However, they finished this explanation by describing that they approach their disability in the same manner:

Figure 34: Model representing ‘I am not your inspiration’ by participant who had a traumatic brain injury.
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 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, whereas some people figure out how they are going to adapt it first, which is sometimes a better way of going about it, cause it saves you potential hurt or whatever, so yeah I just went and did it.

A simple question around why a participant used popsicle sticks and ‘googly’ eyes led to a reflection around how this person approaches their disability. During reflection, another participant expressed their difficulty in associating stories and memories with objects. They were asked to reflect on storytelling and object making and they realised that their memory is more effectively triggered by smell and sound:

I feel like that game with the bags [Exhibition in a box] I can’t, I don’t associate memories and things with objects, I associate more things with sound and music… like with a melody, I think of times when I would listen to the song and what that felt like and it would lead to different avenues, whereas objects… don’t open my mind up as well… It just clicked, in that last exercise… I am very good at talking about random stuff, but [with] objects there was nothing there.

This reflection provides valuable insight for accessible co-design, and raises the possibility of considering the use of other senses. Co-design was approached in this research with a focus on visual and haptic tools and materials. The use of tools and materials that have a smell or sound element in co-design toolkits could help non-visual thinkers engage more successfully with creative methods. This idea is further discussed in Chapter 04.

Elevators or lifts was a topic which participants kept returning to. The main issues around elevator use were concerned with buttons that are too high to reach for some wheelchair users, or people with reduced limb strength or range. Moreover, in peak elevator-traffic periods wheelchair users were left waiting for an elevator with less people in it in order to fit themselves and their chair in. The frustration expressed was around able-bodied people not thinking about giving up their place in the elevator for someone who cannot take the stairs. In response a range of solutions were considered for these challenges. One was an elevator app that allows users to select the floor on their phone when they are standing in the elevator. Participants also related this experience to catching the bus, and considered that the well-known protocol on public transport of giving up your seat for the elderly, disabled or pregnant could be introduced into elevator culture at AUT.

NZSL and the Deaf community

Participants discussed and compared the experience of different disabilities. The experience of disability for the Deaf community was explored, with participants questioning if Deafness should even be considered a disability, and how the greater disability community could better support the Deaf community. A participant questioned the categorisation of Deafness as a disability, comparing it to a tourist who visits a country where they do not speak the language.

I think it’s an interesting point because NZSL is a non-verbal, non-auditory language is considered a disability, but if you come over from Brazil where they speak Portuguese, and you come to a country that speaks English, you aren’t disabled, you just have a language problem.
This discussion lead to further reflection on the intersection of the Deaf community in the disabled community. A participant who is a leader in the disabled community shared their desire to learn NZSL, so that they could introduce themselves in spoken English and sign language, in the same way many New Zealanders introduce themselves in Te Reo Māori and English.

Don’t you think it would be awesome, for speeches and stuff... how some people open in Te Reo? As a disabled person, it would be very cool for me to open in sign, cause I identify with that more than Te Reo (cause I don’t have in background in that identity) but I do have some in the disability community, so that would be really cool for me, I would really like that.

Finally, another participant questioned why NZSL is not taught in high schools in the same way Japanese, French and Te Reo Māori are: “In high school they make you choose a language like Japanese or something, why wasn’t sign an option? Cause that would have been my first choice, I really want to learn it and fluently do it.” It was interesting to note that participants were interested in making the disability community more accessible to the Deaf community. Following workshop two, one participant decided to study a paper in New Zealand Sign Language and Deaf Cultural Studies at AUT. This participant attested this discussion to their decision to choose this paper.

Part 3: Reflection on co-design

Participants continued to reflect on the co-design experience and encourage its improvement. The iterations I made to the toolkit in workshop one and the changes implemented in workshop two are described, as well as new reflections from workshop two for the improvement of workshop three.

Participants reflections of workshop one

At the beginning of the session participants shared reflections about how they felt about the first workshop, and what they were getting out of it. It was valuable to hear that the participants were having fun, that they were learning more about the disabled experience from their peers, and that one participant had felt comfortable enough to express that they had struggled a little in the first workshop due to a headache.

Accessibility of co-design tools & approach

The accessibility of co-design was further tested with the addition of the ‘toolbox on wheels’ prototype (see Figure 37). Participants responded very positively to the addition of the wheels. One participant responded, “Great idea, excellent idea, a lot easier than last time when you were just kind of reaching over people, or couldn’t reach, or you had to ask people to grab things for you, it’s a lot easier...” In the other workshop the reflection was phrased differently, and participants were asked why the toolbox on wheels prototype had been made, to which one participant responded: “To make it easier to access all the materials and tools.” Participant feedback demonstrated that the aim of the ‘toolbox on wheels’ had translated into the desired experience for the participants. Straws were identified as a necessary tool to be included in all co-design toolkits for participants who experience disability and impairment. Moreover, straws may be needed for some participants if you are serving refreshments during the workshop. Including straws in the toolbox of tools and materials will mean a straw is always on hand. No other materials or tools were identified in workshop two as inaccessible or difficult to use. When asked to reflect on the experience of making, participants expressed positive feelings, such as, “I think it’s pretty good, everything is pretty easy to use, nothing is too complicated, like the boards, you can move them around...”
As a consequence of the opening reflection, the focus of this research started to shift in workshop two. It became more apparent that the focus during the preparation phase of this research, to figure out how to make all the tools and materials accessible and usable for every participant and their range of physical strengths, was not the most important factor for accessible co-design. It became clearer through participant reflections that participants chose to work with tools and materials they were familiar with, and had enjoyed using in the past. As such they were not interested in tools and materials that they would have found more difficult to use. Figure 36, details participants’ reflections around their choice of materials and tools in workshop one and two. The discovery of specific elements, for the toolbox, that are necessary for accessible co-design, such as straws, pre-cut materials and trays on wheels was an important step in this research. However, it appeared it was the approach of engaging in co-design, and not the physical instruments for doing co-design, that were more important for an accessible experience.

The approach of this research began to shift from the tools, materials and creative methods, to re-focus on encouraging a flexible, individual approach by participants in a co-design process. In workshop two, the spectrum of participation by participants, from non-verbal hands-on making, to entirely verbal with little making, was uncovered. Therefore, I felt this research needed to further encourage this spectrum of participation, to create a workshop experience where everyone felt like they were participating equally, and being celebrated and appreciate for their form of participation. When asked to reflect on their making, one participant highlighted that the flexible approach being used was not restricting participants, but allowing them to represent themselves creatively in the way most natural to them. “...we are all different people, how we see things, how we represent things is all different, so it gives us the freedom to do what we want, not restricting us.” Encouraging a flexible, open, accommodating, and individual enactment of co-design began to emerge as the appropriate approach for enabling participation in co-design by participants who experience disability and impairment.

Reflecting on workshop one and two, the testing of creative methods was focused on the accessibility of each method, testing one method at a time. Having discovered that the participants were more than capable of achieving each creative method or activity, it appeared possible to challenge the participants further in workshop three, I attempted to push the participants by asking for a greater volume of outputs during the storytelling method. They were asked to come up with three stories, each story encompassing one topic, as well as a visual representation for each story. Only one participant created more than one visual representation, the rest shared two to three stories and one visual representation. Upon reflection, I think the long verbal instruction given was too much for participants to take in, remember and complete. In workshop three, I decided to challenge the participants again to create a greater number of outputs in a single activity, while figuring out the best approach for giving this instruction, in an accessible and memorable way.

Lastly, between the first and second workshop, two participants (one from each group) decided to leave the research. One participant cited being over-committed, while the other was struggling at university and needed to focus on their studies.
Workshop 3 Findings

Introduction

Workshop three was focused on delving deeper into the student experience at AUT, to help inspire the ideation of solutions to improve the student experience. In the third workshop, five creative co-design methods were used (and tested for accessibility). They were Brainstorm (IDEO, 2015, p. 95), Top 5 (IDEO, 2015, p. 79), persona posters (MakeTools, 1999, p. 10), point of view insights (d.school, 2009, p. 21) and Analogous Inspiration (IDEO, 2015, p. 53). This section is presented in three parts. The first describes the creative methods, how they were used, and why they were used at this stage in the co-design process. The second part of this documentation presents the findings around the student experience and the co-design activities. The final section reports on the reflections shared by participants about their workshop experience, as well as my own reflections on the research approach and adaptations I made for the proceeding workshop.

Part 1: Creative methods

Brainstorm (IDEO, 2015, p. 105) and Top 5 (IDEO, 2015, p. 79) are two creative methods that generate and synthesise ideas. Brainstorming encourages the open and fruitful sharing of ideas, no matter their level of feasibility (IDEO, 2015, p. 95). The group brainstorm was focused on the following two questions: ‘What could this group do together to improve student experience at AUT?’ and ‘If you could change one thing at AUT to improve your experience, what would it be?’ These questions quickly generated a mass of ideas and stories or solutions. IDEO encourages ideas to be visualised on post-it notes. However in this research with physical (handwriting) and cognitive (spelling) challenges experienced by some participants, I was not comfortable suggesting participants write ideas down on post-it notes. This issue was resolved when I chose, as the facilitator, to be the scribe and write the participants’ ideas down on post-it notes.

Top 5 (IDEO, 2015, p. 79) was used in this research to select the best ideas to carry over into the next activity. Top 5 helps ideas, themes and opportunities be selected for further discussion (IDEO, 2015). In this research, Top 5 was adapted for the two workshops (3A and 3B) due to time constraints, and participants were instead asked to decide on the Top 3 ideas. Top 3 was used as it helped organise ideas or stories under themes. For example, accessible desks, handrails on stairs, and automatic doors were combined under the theme ‘AUT’s built environment and student accessibility’.

Both groups agreed that orientation, and in particular, the accessible tours during orientation, should be led by students who experience disability and impairment. Both groups agreed that clarifying what services Disability Student Support (DSS) offers students, and what that means for lecturers, was an important idea to brainstorm solutions for. One group chose the idea of creating student accessibility advisors for the built environment at AUT. While the other group wanted to implement monthly meetings or peer mentoring for students who experience disability or impairment.

Persona representations (an adapted form of ‘persona posters’ (MakeTools, p. 10)) were used in workshop two to push participants creatively. In workshop three, persona representations were used to help participants creatively. In workshop three, persona representations were used to help participants.

Chapter 03: Documentation of Research
Section 5/7: Workshop three
work was repeated to further develop the persona profiles created in the previous workshop, and help participants to explore different perspectives. In workshop three, persona posters (MakeTools, p.10) (were produced in advance of the workshop, and help give participants a platform to explore different perspectives. The aim of the method was to encourage participants to think about all the people at AUT who might be impacted by their ideas and design opportunities, and to help them to understand the perspectives of these people.

The fourth creative method in workshop three was ‘point-of-view’ insights, (an adapted method from the d.school bootcamp bootleg). Point-of-view insights, asks participants to imagine the point-of-view of their persona’s, about the Top 3 ideas their representation made by the participant of their persona in workshop two, as well as the intention of the signs. The persona based this method was to encourage participants to think about all the people at AUT. In preparation for the following creative method of ‘point-of-view’ insights, participants repeated this method twice, completing a poster of a student and staff member, and blank fields which needed to be completed to further develop the character of the persona. The blank fields asked for further detail about the persona’s strengths and weaknesses, their social life and family, things they like, and any further detail participants wanted to add. In one instance the image of the visual representation made by the student was not used in the corresponding poster, as their representation did not support their very detailed verbal description of the persona. The blank fields asked for further detail about the persona that was based on an ‘online influencer’. Instead a photo of the person who inspired this persona was used. An example of how a persona from workshop two was turned into a persona poster for workshop three is shown in Figure 39. Participants were asked to take the poster of the persona they had created in the previous workshop. The purpose of the activity was to encourage participants to think and imagine the life, feelings and opinions of another person who works or studies at AUT. Whether their representation made by the participant of their persona in workshop two, as well as the intention of the signs was used, or turned into a persona poster for workshop three. The purpose of the activity was to encourage participants to think and imagine the life, feelings and opinions of another person who works or studies at AUT. Whether their representation made by the participant of their persona in workshop two, as well as the intention of the signs was used, or turned into a persona poster for workshop three.

The intention of the signs was to encourage participants to think about all the people at AUT who might be impacted by their ideas and design opportunities, and to help them to understand the perspectives of these people.

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The final creative method in workshop three was ‘Analogous Inspiration’ (IDEO, 2015, p.53). Analogous inspiration refreshes one’s thinking by comparing their problem to a similar problem, and the ways that problem has been solved (IDEO, 2015). For example, in workshop two, participants identified that the solution of reserved seats to a similar problem, and the ways that problem has been solved (IDEO, 2015) for wheelchair users and people who are physically impaired, priority when using the box. It was intentionally chosen to challenge the participants, to see just how creative they could be. This method turned into a brainstorm and discussion around how to solve the problems and opportunities identified, and how participants might implement their solutions at AUT. Some ‘analogous inspiration’ was identified, such as the importance of food to attract people to your presentation or workshop, as well as the use of video and visual communication strategies to catch people’s attention and communicate your message.

Asking for help is an experience familiar to most people, both in the act of offering help and asking for it. Asking for help emerged as an important theme in this workshop, with participants sharing a multitude of stories describing how ‘help’ is a complex social interaction. One participant shared, ‘Sometimes I only let people help if they know that I possess the ability to do it in the first place.” One participant shared, ‘Sometimes I only let people help if they know that I possess the ability to do it in the first place.”

Workshop three, greater focus was placed on the student experience, and the ideation of solutions. Moreover, aspects concerned with the accessibility of co-design were discovered, they were the angst of asking for help, the importance of having fun for fatigue and concentration levels, and the results of challenging participants to be fairly comfortable and confident at asking for help, and would be well practiced at doing so.

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As a facilitator I was concerned about managing participants’ fatigue and concentration, especially as I did not wish to exhaust the participants before lectures or study sessions. Tiredness only troubled participants in one of the eight workshops. However, this was put down to the workshop being held from 3-5pm, after a long day of lectures for most participants. Ensuring participants could enjoy the co-design process and have fun was critical for this research, as it helped participants remain engaged during the sessions and enjoy the experience.

One way to make sure participants could more easily engage and enjoy the co-design sessions was through the hands-on making. The importance of offering accessible hands-on making, as discovered in workshop two, was further reinforced by a participant in their reflection in workshop three. As mentioned previously, the importance of allowing participants to manage their own engagement, creates a more accessible approach for participants who experience disability and impairment. Accessible co-design was reinforced in workshop three as being achievable through flexibility, variety and independence. Supporting participants to engage flexibly and independently allowed participants to self-manage between challenging and less challenging creative tasks, allowing participants to independently set their own limits, define their participation and maintain engagement in the process.

Workshop three focused on ideating ways to improve the student experience, for tertiary students who experience disability and impairment. Problems and their respective ideas are discussed below, and are thematically organised based on whether they improve mental, physical or social aspects of the student experience.

**Mental**

Participants discussed the desire to see disability acknowledged, represented and discussed more openly at the university for two reasons. First, disability in all its visible and invisible forms affects nearly a quarter of the population, yet it is not openly discussed, celebrated and in some cases even understood. Participants with invisible impairments, such as dyslexia, advocated for lunchtime lectures or online resources for people who would like to understand what dyslexia is. These participants wanted to work on removing stigmas, for example, that people with dyslexia are ‘dumb’, from people’s associations with this impairment. Secondly, some participants shared that they know of disabled students who have achieved national success or recognition in sports teams like the wheel-blacks, or in documentaries for overcoming challenges, and yet they are perceived as being only as ‘that dude in a wheelchair’. Figure 41 describes the range of stigmas or experiences they would like to see challenged about disability.

All participants shared their experiences of engaging with lecturers about the necessary arrangements that allow these students to partake in exams and assessments. Most stories expressed the difficulty, confusion and frustration that was felt by students, lecturers and DSS Advisers when making the necessary arrangements. In particular, the students reflected that they could understand that lecturers may find organising the necessary arrangements annoying or confusing. As such, the students brainstormed ways lecturers could be shown how to make these arrangements, in an interesting and engaging way.

On a similar topic, participants also discussed where engaging with lecturers for support is particularly awkward, and could be improved by an online chat system. Participants most often seek out their lecturers for support right after a lecture, as it does not require making an appointment to see them, which sometimes means a wait of a week or more. However this often means that students have to share personal information with their lecturer with tens to hundreds of students in close proximity, as evidenced by the following quotation:

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Table 40: Examples from participants about their experience of asking and receiving help.

<table>
<thead>
<tr>
<th>Asking for help</th>
<th>Receiving help</th>
</tr>
</thead>
<tbody>
<tr>
<td>“One day it’s this. I had met the day before, you was stepping up the hill and was like, ‘Do you want a hand?’ and it was real nice. But I said: ‘No, I can do it, and if I did, you know I can do it’. And so in my head was like ‘so he knew I can do it, so I will let him do it then.’”</td>
<td></td>
</tr>
<tr>
<td>“Asking for help is alright, but I struggle to balance asking for help and not asking for help. Sometimes it’s easier to not ask, cause the only person you are accommodating is yourself.”</td>
<td></td>
</tr>
<tr>
<td>“It’s like super awkward having to go up to them [lecturers] when are basically there are people trying to walk around you, and you are trying to explain something that is quite serious, it’s just super awkward.”</td>
<td></td>
</tr>
</tbody>
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Chapter 03: Documentation of Research
Section 5/7: Workshop three
Figure 41: Range of examples shared by participants around the attitudes they would like to see changed, and inclusive behaviours they would like to see more of.

Chapter 02: Documentation of Research
Section 5/7: Workshop three

It’s like super awkward having to go up to them and being like, ‘can I just have five minutes of your time?’ And when awkwardly there are people trying to walk around you, and you are trying to explain something that is quite serious, it’s just super awkward.

Lastly, participants spoke of how a guide could help students understand the support they can receive from Disability Student Services. Some participants described learning about support options that could help them through other students, “… a lot of the time you hear about it [support options] and then you go and ask for it... If I don’t know about it and it isn’t put in front of me how am I meant to know about it?”

Physical

Participants with physical disabilities mentioned areas of the built environment that reduce physical accessibility. One pertinent example shared described where handrails on staircases finish before the last steps, leaving some people with physical disabilities stranded, with nothing to hold onto to maintain balance and finish their descent.

Additionally, electronic doors without sensors that do not suit the slower pace someone might take to walk or wheel themselves through a doorway, can cause alarm when they close on the person.

Automatic doors are kind of scary, they are really big and heavy and sometimes the time they are open is like not long enough and it doesn’t have a sensor and open back so they hit you... even with my chair between me and the doors I still get scared of being hit.

Students suggested creating an ‘accessibility working group’ of students who experience disability and impairment, that AUT could consult when building or fixing buildings on campus.
All participants in the third workshops, felt that the accessible tours run during orientation at AUT, should be led by students who experience disability and impairment. Currently the ‘Accessible Orientation Tour’ is led by student ambassadors who do not necessarily experience disability or impairment. Participants felt that the Accessible Tour should match new students with current students who have a similar disability and let the tour be a chance for current students to pass on advice and tips for getting around the campus. For example, there should be a ‘rolling tour’ for wheelchair users, where difficult to find entrances or ramps and hidden elevators can be pointed out to new students.

Lastly, some participants felt monthly DSS meetings for students to network, talk about challenges they are facing, and check-in about how their studies are going, would be beneficial for the emotional and social aspects of the student experience. Moreover, faculty based peer support for students who access DSS services was even discussed, as a way for students further along in their studies to help newer students.

In summary, between the two workshop groups, three ideas to improve the student experience were the same. They were helping lecturers understand how to organise support for students, helping students understand the support they can receive from DSS at AUT, and current students engaged with the disability community at AUT guiding the accessible tour at orientation. Both groups had one different idea. One group wanted monthly meetings for DSS students to catch up, check-in and discuss how everything is going. While the other group focused on the establishment of student accessibility advisors, who could work alongside any new AUT building projects or refurbishments, to iron out physical environmental accessibility issues.

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able to complete two outputs within one activity. This investigation has demonstrated that two outputs per activity was achievable.

On reflection, as the facilitator I made an error in judgment when I pre-assigned the six personas as either a student or lecturing staff at AUT, when preparing the persona posters for the third workshop. The breadth of perspectives discussed was not broad enough, and did not explore a diverse and appropriate range of perspectives. In retrospect, there should have been a brainstorm to choose the six personas who would be affected by our problems/ideas. For example, one of the personas should have been a Disability Student Services Adviser. Facilitators arguably hold agency and power in co-design, and should be careful to not make decisions that steer the process away from the direction the participants are taking it in, or make decisions that limit the thinking or imagination of the participants (Steen, 2011).

In workshop three, I observed a participant struggling with tape. I reflected that the addition of a guitar pick or bulldog clip to the end of the roll might make finding the end and pulling the tape off the roll easier, refer to Figure 43.

Lastly, at the end of workshop three I briefly described to the participants the plan for the fourth workshop. The participants indicated that they would like to see the ‘Accessible Co-design Guide’ in advance of the workshop, so that those with cognitive impairments in particular, could review the guide at their own pace and come prepared with feedback. This highlights the importance of giving participants control over their participation (Shakespeare, 1996). Moreover, by informing participants of the proceeding steps in the co-design process, space was created for participants to let the facilitator know how they would like to engage in the co-design process.

Figure 43: Bulldog clip added to the end of a roll of tape to make it easier to use.

Figure 44: Workshop 3B in action, participants making visual representations.
Workshop 4 Findings

Introduction

The fourth and final workshop of the co-design process was divided into two parts. In the first half, participants were challenged to create a group model of their solutions to improve the student experience at AUT. In the second half, participants were asked to evaluate the draft guide for accessible co-design, that I had been developing throughout the series of co-design workshops. Three co-design creative methods were utilised and tested in workshop four. The first was Create a Concept (IDEO, 2015, p.108) the second was Collective visioning (MakeTools, p.8), and the final was Get Feedback (IDEO, 2015, p.126). This section is presented in three parts. The first describes the creative methods, how they were used, and why they were used at this stage in the co-design process. The second part of this documentation presents final findings about accessible co-design, as well as the final models for improved 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 the others about how to bring all the elements together into the final concept. 'Create a concept' was tested in this final workshop to assess how accessible group work could be for these participants.

Collective visioning (MakeTools, p.8) can help facilitate the description of a group’s ideas, and their vision for the future experience they are designing for (MakeTools). Collective visioning was implemented after the group model was built, to generate a verbal description of the solutions the participants had included in their final model. It was specifically used to give the Disability Student Service Advisor a clear statement to describe the final models. Refer to Figures 45 and 46 for the two models made by participants in workshops 4A and 4B.

Part 1: Creative methods

Create a Concept (IDEO, 2015, p.108) is a polished representation of the ideas and solutions they had developed over the previous workshops. 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 the others about how to bring all the elements together into the final concept. ‘Create a concept’ was tested in this final workshop to assess how accessible group work could be for these participants.

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Part 2: Exploring the accessibility of co-design to better understand the student experience

‘Create a concept’ was the first hands-on group activity in previous workshops, group work only went as far as discussions and brainstorming, which was intentional as I was unsure about the accessibility of hands-on group work, due to the limited fine motor skills of some participants, and the cognitive ability of others to listen, negotiate and plan with others. The decision to use group work later in the co-design process was based on the assumption that it would be easier for the participants to work together once they were familiar with each other’s strengths and styles. This assumption proved correct, and the participants demonstrated that they could plan and divide up the work based on who would be best at completing each element. I would advise using group work in the later stages of co-design processes, with participants who have a range of physical and cognitive strengths and limitations.

Soliciting critique on a prototype is the backbone of any good project, as it keeps the people who are being designed for at the core of your design (IDEO, 2015). It also helps give a project momentum (IDEO, 2015). As the workshops proceeded, I developed and tested concepts that could help enhance more accessible co-design. At the appropriate time these concepts were introduced into the workshops for critique. In the final workshop the guide was critiqued. Participants were asked to critique the tone, language, message and overall approach advocated by the guide. The feedback received confirmed that the guide was communicating the appropriate message. A handful of minor details were critiqued, and the appropriate changes were made to the guide.

Part 4: Introducing the final workshop

As such it could be a useful guide for others. When asked who could benefit from reading this guide? The answers ranged from lecturers and classmates, to high school teachers and just about anyone. In particular one participant responded,
Figure 45: Final concept model for improved student experience by participants in the final workshop.

Figure 46: Final concept model for improved student experience by participants in the final workshop.
Pretty much anyone and everyone...at the beginning there is more design stuff, but towards the end it’s kind of seems like something I just want to give out as a brochure to people that I meet, like ‘read this and understand please’.

During feedback, participants contested and discussed three aspects of the guide which they felt should be reworked: the choice of language, tone of voice, and awareness around the types of disabilities and impairments that are brought together in a co-design session.

Language
A participant contested the use of ‘different’ or ‘difficulty’ in ‘Disability Language’ under “Rule #5. Still feeling stuck? ‘Difference’ or ‘difficulty’ are generally terms which you cannot go wrong with”. They shared that some people who experience disability or impairment might not agree with being explicitly labeled as ‘different’. It uses language that reinforces the dichotomy of able-bodied/non able-bodied. “I would be careful about saying that ‘difference’ is a safe word … if you say ‘difference’ you are explicitly saying someone is different, whereas people might not want to be labeled as explicitly 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. Another participant backed up this argument by saying:

People just assume you will be different cause you have a disability, but we are just the same, we aren’t another species… we might have some challenges that you might not experience, but most of the things are the same, we experience the same things, we feel the same way.

They recommended replacing Rule #5 with a prompt to ask someone how they like to refer to their disability or impairment. Refer to Figure 47 for this page of guide critiqued by participants.

Tone of voice
Participants in both workshops were of the opinion in their discussion of the ‘Disability Language’ page (see Figure 47). They agreed that the tone of voice was more important than the words used. A participant illustrated this point by saying,

I always feel like, you won’t really offend someone … if you aren’t using it [disability language] in a mean way, nobody is going to tell you off. 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.

This was echoed by another participant in the other workshop who shared that, …it’s all about the way you say things, like crippled or handicapped, if you use it in a sentence and it’s meant to hurt someone … but if you say it in a sentence like ‘oh he is crippled’, it is all down to how you interpret it too.

Combinations of participants
The final piece of feedback was concerned with the perception of hierarchy in and around the experience of disability. For example, the hierarchy between physical and cognitive impairments, and more extreme versus less extreme experiences of disability. Two participants in particular felt that in a workshop where the focus is on describing ‘lived experience’, this hierarchy is noticeable and could make people feel excluded.

During critique of guide with participants in the last workshop, this page was most heavily critiqued and discussed.
feel uncomfortable if their experience is more or less extreme than others. One participant described how awkward they felt in workshop one as the only participant who did not have a physical disability, and how they perceived their experience of disability as being far less extreme than the other participants:

*“...in the first session that we had I felt very out of place, just due to the fact that everyone else had a physical disability and that first session that we had I was like, I didn’t know what I could say and couldn’t say, I was almost too afraid to open my mouth, cause these guys were talking about disability and what it meant for me and I was like ‘no’... I like knew these people struggled, but they were going real in depth, and I was like ‘oh crap’ and then when it came around to me, I was like ‘I don’t want to say anything’, I am never afraid to speak my mind, but just in that setting I felt it was very, very felt very uncomfortable.”*

Another participant voiced a similar experience, saying their invisible disability made disability as being far less extreme than the other participants:

*“...Another participant voiced a similar experience, saying their invisible disability made...”*

Participants in this research also described feeling a greater sense of community with other people who experience disability or impairment, and found themselves feeling more confident reaching out to others. One participant shared that they had been hesitant to engage with a Deaf student who they had sat next to many times in one of their lectures. However, between the third and fourth workshop they found the courage to try.

*“...Participants in this research also described feeling a greater sense of community with other people who experience disability or impairment, and found themselves feeling more confident reaching out to others.”*

**Disability Services Orientation**

The final concept models in workshop four described the solutions for better student experience developed by the participants. Both groups situated their suggested improvements within week zero of the academic calendar, which corresponds with orientation at the beginning of each semester. Both concept models included a workshop for lecturers to learn about the support Disability Student Services (DSS) provides to students, and how to engage with DSS to organise support for their students. The participants felt it was crucial to provide feedback at this workshop to encourage lectures to attend. One group (see Figure 46) focused on monthly meetings for students who access DSS services, and peer mentoring for new students in their first year. In comparison, the other workshop group (see Figure 47) focused on designing a ‘How to Survive Semester 1’ booklet for new students who will access DSS services, with all the services that are provided clearly explained, as well as other campus and student life related advice. Lastly, this group reorganized the accessible orientation tour at AUT for new students who will access DSS services, with tour guides who experience disability and impairment who can offer first hand advice on moving around the campus, and an additional one-on-one tour for new students who would like to have someone take them through their timetable, showing them all their classrooms before classes start.

**Part 3: Reflections on co-design**

In the final reflection of workshop four, many participants reflected that through this co-design process they felt more engaged with the disabled community at AUT. In particular, the struggle that wheelchair users can experience using elevators during peak traffic times at AUT. Some participants said they would behave different when they see someone who experiences a physical disability, particularly a wheelchair user, waiting for a lift.

*“...Next time I see a special needs person coming up to an elevator, and they cannot fit and are going to be late for this class, I will be like ‘come on guys, let’s get out, we can take the fricken stairs, it’s only two floors up, let’s go.’ So that they aren’t late for their class...”*

The majority of participants read the guide in advance and had prepared comments to share. This shows the value of communicating next steps with participants and the value of reflection. In conclusion, the entire series of workshops went better than expected. The approach to accessible co-design shifted throughout the process, which was a valuable discovery. Moreover the workshops were more enjoyable than anticipated. The participants gave generously with their time, thoughts, and reflections about the process as well as of themselves.
Table 48: Examples shared by participants about how the co-design process influenced their attitude or behaviour.

"I guess I have been thinking a lot about myself and disability, and other people with disability a lot more. I think I would usually. You would assume I would probably think a lot about disability, but I don't really think much about that. You say 'Isaac' just think in itself. I think that's a weird aspect of my life. I do not really connect with it, even though it's a really big part of my life."  

Changed attitude or behaviour

"I agree with the idea... I think reflecting this has given me a chance to reflect on bits of my life that I do not usually get to reflect on, which is what you said. And I just don't think about it, but think 'how did my day go today? How do I feel about that?'"  

Changed attitude or behaviour

"For me, just like opening my eyes more, like actually realizing my surroundings and everyone else around me. I thought I was good, but I saw a special needs person coming in an elevator, and they didn't fit and I was about to be late for the idea. I felt like come on guys, let's get out, we can take the stairs, it's only two floors up, let's go!"  

Changed attitude or behaviour

"...I am not in a wheelchair and don't have problems walking. And I do, however, just making sure that we are on time and not running late and not getting dressed or anything like that, everything is planned out for me and it's cool seeing that we are similar, even though we are not physically similar, we are working in similar ways."

Changed attitude or behaviour

"Everything just this whole thing has been a learning curve, cause I have never even thought of all these things before. Then sitting together with all these people, and... I am like 'wow I never thought of that.' So that has been really good. Literally everything, everyone's experiences are interesting and different, and good to learn and be aware of!"

Changed attitude or behaviour

Figure 49: Participants building their final model of solutions for improved student experience for students like themselves who experience disability and impairment.
Design of the toolkit

Thematic Analysis

The thematic analysis of the six expert interviews and eight co-design workshop transcriptions highlighted three core themes for designing more accessible co-design. These themes highlight ‘high level’ aspects of the disabled or impaired experience. The first theme reflects the ‘minefield’ that is language which describes disability. The code developed for this theme is: there are no rules when it comes to disability language. The second core theme was concerned with participants’ experiences of accommodating others and the world around them, while not always receiving the same in return. The code for this theme was: How I accommodate the world, but the world doesn’t accommodate me. The third theme was concerned with disability language and how participants feel overshadowed by this label: disabled is a label which overshadows who I am as a person. Out of these three core themes, seven principles were developed to help guide an accessible co-design approach, as described in the following section.

Theme #1: There are no rules when it comes to disability language

Disability language is a complex web of stigma, attitudes, and preference. It is complex and varies with context and individual. The range of responses from the experts in their interviews, and participants during the workshops, highlighted the vast spectrum of opinions around what word or label is appropriate for every individual and the disability or impairment they co-exist with. A selection of these responses are listed in Figure 50. Participants described and shared the many ways in which they adapt and accommodate the able-bodied centric world in which we live, and the frustration of not receiving equally accommodating treatment in return. Figure 51 presents a variety of examples that participants shared. Interactions with participants, both direct and indirect, uncovered ways of accommodating a wide range of needs in a positive and empowering manner. Accessible co-design should aim to accommodate participants through a flexible and understanding co-design process. The facilitator should encourage participants to determine their own engagement, adapting it where they see fit. Finally the facilitator can support participants’ weaknesses with adapted or pre-prepared tools and materials, such as tape with clips on the end, pre-cut materials, having straws on hand and loosening marker pen lids.

Theme #2: How I accommodate the world, but the world doesn’t accommodate me

Participants described and shared the many ways in which they adapt and accommodate the able-bodied centric world in which we live, and the frustration of not receiving equally accommodating treatment in return. Figure 51 presents a variety of examples that participants shared. Interactions with participants, both direct and indirect, uncovered ways of accommodating a wide range of needs in a positive and empowering manner. Accessible co-design should aim to accommodate participants through a flexible and understanding co-design process. The facilitator should encourage participants to determine their own engagement, adapting it where they see fit. Finally the facilitator can support participants’ weaknesses with adapted or pre-prepared tools and materials, such as tape with clips on the end, pre-cut materials, having straws on hand and loosening marker pen lids.

Theme #3: Disabled is a label which overshadows who I am as a person

The final theme that emerged from the transcribed data was concerned with the impact of the ‘disabled’ label, and how participants perceive and experience their identity through the eyes of the public. One participant described this experience when they said: “I feel like the only time I remember [that they are disabled] is when someone else points it out, or you notice someone else noticing.” Other examples are described in Figure 52. Participants emphasised the importance of seeing them first and foremost as a person who thinks and feels in exactly the same way as an able-bodied person, with only their approach to achieving the same tasks in their day to
Table 50: Participants diverse feelings about language which describes disability

- "...I do not use (disability) to describe myself, so I do not like other people using it to describe me... I do not wake up and go 'I am not able-bodied today'"
- "I would rather use impaired or disabled than crippled. I absolutely despise crippled."
- "My disability is hard to explain, so it’s just easier to say ‘oh it’s a disability’.
- "I only use the word (disabled) in a very clinical setting... I do not use it in any other context."

Avoid the label of disability

Disability label is better than

Happy to use the label of disability

Avoid the label of disability

Figure 51: Examples shared by participants about instances where they have to adapt to suit the able-bodied world.

"How we allocate time in our lives. We have extra things we have to take into account, which other people won’t factor in, like how we have to pre-plan our schedule, think ahead and think about other people as well in relation to the time management."

"Taking more time, sometimes that feels relatively unjust, when you think it’s going to take me half an hour to get to this place, whereas someone else will take 5 minutes, so that cuts more out of my day."

"... every time I go out into public it’s like yelling at me, I will have to deal with someone putting me in a box or yelling at me."

"Other people will be like ‘do you want to go out tonight’ and just expect a yes or no answer, but then in your head you have to think how am I going to get there, will I be able to get into the building... I have to take into account a lot more variables."

"Clothing patterns are stock standard and you have to fit into standard sizes."

Adapting to suit

Adapting to suit

Adapting to suit
Chapter 03: Documentation of Research
Section 7/7: Design of the toolkit

Table 52: Participants examples of times when they feel their disability overshadows them as people.

Table 52: Participants examples of times when they feel their disability overshadows them as people.

Daylife making them different. This theme became abundantly clear when it came to the hands-on making tasks in the co-design process. At the beginning of the research I was concerned with making the tools, materials, and methods ‘accessible’ in the first workshops. However it was discovered that participants did not show interest in any tool or material that they would not be able to use comfortably.

These three core themes encompass and describe the experience of disability and impairment that emerged through participants conversations around their ‘lived experience’. Intertwined with those conversations were further discussions and reflections about the co-design process, as well as my own reflections on what I was seeing, hearing, and experiencing as the facilitator. Seven principles emerged from these discussions and reflections, (see Figure 53), which informed the framework of the ‘Accessible Co-design Guide’
The seven principles

One of the outcomes of this research was to produce a ‘toolkit’ for more accessible co-design. The elements of the ‘toolkit’ were unknown at the beginning of the research; however, it emerged early in the process that a guide for facilitators would likely be an important element of the toolkit. The aim of the guide was to support facilitators to approach co-design with an accessible and accommodating mindset, to structure and organise their process appropriately, and to suggest tools they could use. In developing the guide, seven principles emerged. These principles are described below grouped by the core theme from which they emerged.

Theme #1: There are no rules when it comes to disability language

Principle 1 - Use appropriate language, emerged from the first theme concerned with understanding how to approach language for disability. Discussed previously was the reflection that time spent in and around the disability field can help co-design facilitators understand what language is appropriate with certain individuals and what language may be most appropriate in certain situations. However, for those who find themselves working in the disability field for the first time, some form of guidance is warranted to avoid embarrassment and unintentional offence. As such, the ‘Guide for Accessible Co-design’ starts with its first principle around how to approach disability language. The series of suggestions offered in the guide were written with the support and review of participants in the last workshop, and in a following session six weeks later.

Theme #2: How I accommodate the world, but the world doesn’t accommodate me

Accommodating the strengths and talents of participants, in the co-design process, was central to this research for understanding the meaning of accessibility in a co-design space. Interactions with participants, both verbal and non-verbal, uncovered ways of accommodating a wide range of creative needs in a positive and empowering manner. Four out of the seven principles were developed from this theme: Principle 2 – Make participation accessible, Principle 3 – Allow more time, Principle 5 – Take a thoughtful approach, and Principle 6 – Offer, don’t assume. All four of these principles focus on accommodating participants, describing ways of approaching co-design with participants who experience disability and impairment, and which elements of co-design must be adapted to offer an accessible co-design experience.

Theme #3: Disabled is a label which over-shadows who I am as a person

The final theme, ‘Disability is a label which over-shadows who I am as a person’, highlighted the need for the following two principles, which describe how the person must always be seen first and their disability second, once the co-design process is underway. Principle 4 – Person first, disability second illustrates that participants are people first, with experiences, memories, and preferences around creative tools and materials, which will influence their participation. Preference trumped ability when it came to participant choice over what tools and materials to work with, and the modes of creativity they used to engage with the co-design creative methods/activities. This insight would not have been possible without asking participants to reflect on their co-design experience and why they used the materials they used, or engaged in the way they did. This inspired Principle 7 – Reflect continuously. Verbal reflection and questioning allowed for deeper insight into the lived experiences of the participants, that then shaped the course and outcomes of this research. See Figures 54, 55, 56 and 57, to see how the ‘Accessible Co-design Guide’ was influenced by participant feedback, and how it developed graphically.

Figure: The seven principles that frame the ‘Accessible Co-design Guide’.
Figure 54: Selection of nine pages from first version of guide that was critiqued with participants in final workshop.

Figure 55: Third version of the guide, critiquing colour scheme and layout.
Figure 56: Selection of nine pages from the fifth version of the guide, language and layout being critiqued and updated.

Figure 57: Final ‘Accessible Co-design Guide’. Selection of nine pages to show the graphic style.
The ‘toolbox on wheels’ catered for participants who could not reach forwards or around others easily to access materials and tools on the table, while also reducing the need to ask others for help. The first prototype was developed from the idea of pegboard (Figure 58). The initial concept consisted of using peg-board with wooden dowels inserted into the holes to organise and hold the tools and materials in place. The addition of wheels meant it could roll around the surface of a table. This prototype was developed and tested in workshop two to four and further revisions were made which are described below.

Concept refinement

Three major refinements were made to the prototype, and included removing the wooden dowels, which did not hold all the tools and materials securely on the tray, and applying a border to the edges of the tray to stop tools and materials rolling off the sides. Once the dowels were removed and a border was applied, pegboard was no longer the best material to work with. As such, the pegboard was replaced with 4mm plywood and the small castor wheels were replaced with ball bearings, (see Figure 58). The height of the castor wheels meant participants could not easily see each other’s work, so replacing the wheels with smaller ball bearings reduced the overall height profile of the trays.

The final concept used 4mm plywood with a pine veneer and a solid plain border to contain all the tools and materials. The use of ball bearings gave the trays moveable over a flat surface. Tools and materials were divided over two trays determined loosely by whether they create 2D or 3D objects. Refer to Figures 59 - 63.

Tools and materials
Figure 59: "Toolbox on wheels" close up.

Figure 60: Ball bearings used as wheels on underside of trays.
Figure 61: “Toolbox on wheels”, trays are designed to be stacked for easy transportation.

Figure 62: “Toolbox on wheels” showing some of the materials.
During the research, some tools and materials were more frequently used. Tools listed in the blue column were used the most, tools and materials which were used a fair amount are listed under the green column, and tools and materials which were hardly touched, or even removed from the toolkit as they weren’t used, are listed in the grey column (see Table 05). Materials or tools marked with an asterisk were added throughout the course of the workshops. I felt adding new tools from time to time kept the toolkit interesting for participants, that it might encourage participants to look more closely at what was on offer; or try something new. I comment below on the tools and materials used, and any opinions shared by the participants.

Most popular tools and materials

The top five materials and tools used were Lego, ready-made objects, modelling clay, pipe-cleaners, and coloured card. See Figure 64 for all tools and materials that were included in the final toolkit.

Lego

The Lego was an excellent tool for many reasons: It is fast to work with, it can represent something complex easily, and it provided some familiarity for participants who needed to build some confidence around being creative. Moreover, participants commented that you cannot make a mess with it, and it can handle being dropped, especially by participants who have reduced fine-motor-skills.

Ready-made objects

Ready-made objects are small figurines and toys, and were fantastic for representing an idea quickly. Moreover, participants who struggled with creativity could put a few figurines or toys together and describe what they represent (I suggest including

modelling clay

The modelling clay was not added until the third workshop; previously participants had used blu-tack to make small figurines. The modelling clay was instantly liked and used repeatedly by most participants. Participants commented, “I like the clay, the clay is fun, cause you can pretty much make anything and you can’t make mistakes.” Moreover, some people enjoy the soft tactile nature of the material to roll through their hands while talking. “…I tried to do it in clay, cause it was tactile and fun” am enjoying rolling it through my fingers at the moment.”

Googly eyes

The googly eyes were used in a multitude of ways. They were used literally as human and animal eyes, in an abstract way to signify surveillance and point of view, and creatively as the white and black hexagons on a soccer ball.

Small wooden objects

The wooden blocks, sticks, semicircles and cork coasters were excellent building blocks and were used to represent a multitude of everyday objects such as tables or chairs, and as a solid base for other artefacts. (See Figure 65 for a selection of visual representations/artefacts made by participants in this research)
Table 05: Most used to least used tools and materials in this research. (Asterisks notes materials or tools that were added throughout the series of workshops)

<table>
<thead>
<tr>
<th>Tools and materials I would use again</th>
<th>Tools and materials I may use again depending on the context</th>
<th>Tools and materials removed from the toolkit as they were not used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logo</td>
<td>Large marker pens</td>
<td>Coloured plastic string</td>
</tr>
<tr>
<td>Ready-made objects, (human forms, mini scenes, wardrobe...)</td>
<td>Crayons/paints/inks</td>
<td>Cotton thread</td>
</tr>
<tr>
<td>Modeling clay</td>
<td>Point-tip markers</td>
<td>Star shaped yellow cards</td>
</tr>
<tr>
<td>Pipe-cleaners</td>
<td>Corkboard/lollipop</td>
<td>A3 &amp; A2 white and brown poster paper</td>
</tr>
<tr>
<td>Scissors</td>
<td>Circle stickers in variety of colours</td>
<td></td>
</tr>
<tr>
<td>Cellotape</td>
<td>Locations signs</td>
<td></td>
</tr>
<tr>
<td>*Google’s eyes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Print-out collage materials, images and words cut from magazines</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi-circle pieces of wood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Push-pull sticks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Erasable pencil</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blue/tack</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glue sticks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small wooden blocks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wooden sticks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cork coasters</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coloured A4 paper/card</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Square origami paper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pack of felt-tip pens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Straws</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 65: Selection of models, visual representations and artefacts made by participants in this research.
Suggested Tools & Materials

Figure 64: Suggested tools and materials (continued over two pages)
04. Discussion
The goal of participatory design activities is to include users in activities that design their participation (p.116). Research found synergy with what was previously reported, as well as generating new knowledge for the field of co-design, specifically co-design for healthcare and disability. The five key lessons of this research are discussed with reference to previous research, and finally, the limitations of this research and recommendations for future research are discussed.

A flexible approach

Accessible co-design accommodates and encourages multiple modes of communication and participation. Allowing participants to engage with the 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. The flexible approach was developed from two key texts. The social model of disability, which sees disability to be the most accessible way to approach co-design. The flexible approach was method or activity in any way or style, using whatever materials or tools, was found to result in poor participant engagement, or disempowerment of participants.

Flexibility in co-design is not novel. Hendriks et al. (2015), Wilson et al. (2015), Carroll et al. (2018) and Nakarada-Kordic et al. (2017) all reach similar conclusions in their research with disabled populations. The flexible approach developed in this research emerged from the realisation that co-design methods, techniques or activities were unlikely to be accessible for each participant in this research. A similar path has been travelled many times before by co-design researchers. For example, researchers have tried to develop generalised approaches to conducting co-design with participants who experience disability or impairment (Hendriks et al., 2015; Wilson et al., 2015). In both cases, the focus was on developing guidelines for co-design method adaptation. Both concluded that developing guidelines for conducting co-design with participants who experience disability or cognitive impairment cannot be made. “We aimed to understand how researchers and designers adjust common codesign techniques [methods and activities] and to derive general principles from those adjustments... however, it became clear that formulating such guidelines was too an ambitious goal...” (Hendriks et al., 2015, p.73). Wilson et al. (2015) further described that developing generalisations for cognitive and physical impairments is not possible due to the variety of difficulties experienced by different cognitive impairments. However, differences between diagnoses mean that generalisations cannot be assumed. For example, the SWIM technique would be challenging for people with autism, who struggle to reflect on the thoughts and feelings of others; and people with dementia might be confused if asked to trial several alternative prototypes (p.13).

Consequently, researchers advocate for an individualised approach for participants involved in a co-design process, and that a large part of this individualisation should happen “in-situ” by the participants and researchers (Hendriks et al., 2015; Wilson et al., 2015; Nakarada-Kordic et al., 2017; Carroll et al., 2015). Wilson and colleagues (2015) further argue that “one key to success is a clear focus on tangible design language, customised for specific design activities...” (p.33).

Carroll and colleagues (2015) further illustrate the importance of a flexible approach negotiated “in-situ” through the example of “Elena” – Elena shared her opinion that “disabled young people regularly encounter others who are ‘set’ in their thinking of what disability looks like’ and ‘who wrongly believe that they know a person’s capabilities and preferences on the basis of a diagnosis or initial meeting” (p.8). Allowing disabled people to determine and manage their participation in research supports the social model of disability by reducing barriers for participation (Silver, 1995).

Although Hendriks and colleagues (2015) provided a wide range of tools and materials for participant expression, they still felt that they were “compensating for disability rather than starting from the abilities of their participants” (p.74). This was not the case in the current research. To understand why this was the case would require further detail on Hendriks and colleagues (2015) research. However, as discussed above, it can be challenging to know in advance of co-design sessions what a participant’s abilities might be. As such, it is important to design methods that focus on ability, instead of disability. However, I can speculate that the flexible approach trialed in this research meant participants found a way to make the method accessible, and were able to participate and express themselves successfully using the tools and materials provided.
The importance of independence

The second key lesson is the importance of supporting independent engagement in the co-design process for participants. In this research, this was achieved through the flexible approach, the movable toolbox on wheels, as well as through providing pre-cut materials and adapted tools. The result was that participants very rarely had to ask for help.

Carroll et al. (2018) noted that in previous research, information about the experiences of disabled young people were not gathered directly from them, instead, parents and caregivers served as their proxies. In their research with disabled young people, Carroll and colleagues chose to interview participants/caregivers; however, they respected the wishes of older participants who asked that their parents were not interviewed, and participants who agreed to let their parents/caregivers be interviewed as long as they too were present (Carroll et al., 2018).

Independent engagement is important in disability research, and when coupled with a flexible approach it supports the social model of disability. The social model of disability encourages experiences for disabled people where they are enabled instead of dis-abled by societies attitudes or the physical space (Oliver, 1995). In ‘What of disability encourages experiences for disabled people where they are enabled with a flexible approach it supports the social model of disability. The social model of disability encourages experiences for disabled people where they are enabled instead of dis-abled by societies attitudes or the physical space (Oliver, 1995). In ‘What of disability encourages experiences for disabled people where they are enabled instead of dis-abled by societies attitudes or the physical space (Oliver, 1995).’

The power of reflection

Accessible co-design can benefit from bringing a practice of regular reflection into the process, both for disabled participants and the facilitator in this research, so as to make sense of the time, but whose meaning was clear in hindsight. Reflection on practice is also an opportunity for a practitioner to be examined and criticised by contemporaries (Dewey, 1933), which I would argue creates a richer discourse for the development of co-design in healthcare and wellbeing fields.

The value of an indirect approach

Indirect approaches for broaching and discussing complex and emotive topics can be useful in co-design. Group discussions that focus on people’s associations with words can help them more effectively navigate the discussion of complex issues. Indirect approaches for broaching and discussing complex and emotive topics can be useful in co-design. Group discussions that focus on people’s associations with words can help them more effectively navigate the discussion of complex issues.

The designers and researchers who participated in the Flemish research by Hendriks and colleagues reported that they had found it challenging to focus on making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit. The act of making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit. The act of making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit.

A practice of reflection in co-design can help participants further develop their understanding of their experiences, opinions and selves. Langley et al. (2018) describe making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit. The act of making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit. The act of making as being an inherently reflective process, capable of uncovering and communicating memory and knowledge both explicit and tacit.

"use the making as an opportunity to reflect and to initiate a conversation with themselves" (Langley et al., 2018, p.5). In this research one participant reflected that their approach to making their visual representations in a co-design activity was like their approach to navigating their disability. They just "throw a few things together and figure it out" as they go.

Reflecting on my approach was undertaken to help me improve as a facilitator. Marc Sten (2011), advocates for designers and researchers in human-centered design (HCD) to reflect on their influence in a design-process: HCD practitioners can tend to privilege their own ideas and experiences over users’ ideas and experiences. One possible way for HCD practitioners to cope with these tensions is by critically reflecting on their own methods, their own roles - their usage of power, their agency - in their projects (p.54).

Accordingly, a practice of reflection in co-design can enable participants to externalise their thoughts and feelings, and...
how they might approach a task in a way that supports their capabilities. Negotiating facilitator. The intention of this principle is to create space for participants to discuss Accessible co-design invites participants to negotiate the co-design process with the importance of negotiating the process with participants...to adopt a preparatory codesign approach, involving the participants...with impairments...” (p.74). In this research, this approach was taken and advanced by the use of indirect questioning techniques around sensitive subjects, to gain insight into the vocabulary each participant used to describe their experience of disability or impairment.

Kordic et al. (2017) in co-designing with young people experiencing psychosis, their persona (Jack) was used to allow participants to ‘project’ their own personal experiences, feelings and thoughts without having to feel like they were being put on the spot. When et al. (2012) created an activity called someone who isn't me”, in which participants were asked to respond to an idea with their own, as well as that of someone else who know they experience aphasia. This approach allowed the participants to express an alternative view and gave researchers a broader range of opinions.

The importance of negotiating the process with participants Accessible co-design invites participants to negotiate the co-design process with the facilitation. The intention of this principle is to create space for participants to discuss how they might approach a task in a way that supports their capabilities. Negotiating the process with participants is not new to participatory design, as described by the Florence Project which was conducted in the 1980’s (Bjerknes & Bratteteig, 1987). Carroll et al. (2010) and Hendriks et al. (2013) and Chamberlain and Craig (2015) offer practice this approach. (Shakespeare, 1986) describes the techniques he chooses not to use in research with participants who experience disability and impairment.

The active co-operation between participants and designers is fundamental in participatory design (Bjerknes & Bratteteig, 1987). Discussed in Chapter 01, the Florence Project participants and co-designers worked together, negotiating the inquiry and design process. For example, computer scientists spent time in and around the hospital wards, observing and understanding the role and work of the nursing staff (Bjerknes & Bratteteig, 1987). As first the computer scientists thought they would design a system for nurses, but after experiencing the realities of nursing, and realizing that they could not possibly understand what nurses do and why they do it, the computer scientists understood they would have to design and build a system with the nurses (Bjerknes & Bratteteig, 1987). 

Carroll and colleagues (2010) implemented a highly flexible research approach to make participation possible for their participants. In the case of one participant who uses an Augmentative and Alternative Communication (ACC) device, it was agreed to seed interview questions ahead of time so she could prepare her responses. Hendriks and colleagues (2010) reflect on the social model of disability, stating that with this view in mind “…one should involve people living with impairments in the design process...” (p.77). Chamberlain and Craig (2016) take this argument further by pointing out that, in some research contexts, some individuals will not be able to verbally articulate and express their ideas” (p.10). In these instances, it is necessary to assume that participants may not be able to adapt and engage with the methods and activities the researcher has set out, and to be ready to focus and build on participant everyday experiences (Chamberlain & Craig, 2016). Tom Shakespeare (1996) states that in research with participants who experience disability or impairment he would not use research techniques that “obscure the voice of the participants...for example formal structured interviews or questionnaires” (p.19).

Summary

This research set out to co-design an accessible co-design approach for participants who experience disability and impairment. The contextual review found that existing co-design toolkits do not adequately consider accessibility, or an accessible approach for participants who would not fit the able-bodied mould in the context of co-design for health and wellbeing fields, where there will be greater representation of non-able-bodied users, due to temporary or chronic illness and disability. Co-design for healthcare and wellbeing fields should acknowledge the “considerable diversity in mental and physical capability both across the population and over the length of the life-course” (Bianchin & Heylighen, 2017, p.316).

The flexible, and at times indirect and negotiated approach, combined with adapted tools provided on trays with wheels, used in this research has shown that accessible co-design is not a challenge to implement and conduct. Disability and impairment is not only physical, but also encompasses sensory, learning or mental health related difficulties. (Office for Disability Issues, 2017). These ‘invisible’ disabilities and impairments are labelled as such, as they are hard to see and be aware of. Therefore, an accessible co-design is more accommodating for the 24 percent of the New Zealand population who experience disability and impairment. As Cunningham (2017) argues, design-led methods run the risk of creating more harm and diminishing trust in social contexts, like in health and wellbeing, if they do not accommodate the variety and depth of lived experiences.
The resulting ‘Accessible Co-design Guide’ discusses how to organise, approach and execute accessible co-design. High-level top-tips, seven principles with detailed steps for managing each principle, and advice around what tools and materials to provide in a manner which enhances independence, is offered in this toolkit.

Limitations of the research
Disability and impairment affects 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 tertiary level. Consequently, this research, while advocating an accessible approach with participants who experience disability or impairment, cannot represent the full range of disabilities and impairments, nor can it claim to cater to every age group. As such, this research provides only a glimpse into some important factors for an accessible co-design process. For example, the Deaf community which was not included in this study, based on the findings from expert interviews, would need to have their co-design needs studied within their own silo.

This research may have been limited by its predominant use of visual and haptic tools and materials. As one participant pointed out that they had struggled to associate thoughts and memory with objects using just their sense of touch and sight. They raised the idea of introducing objects and materials which stimulate auditory or olfactory senses. Most people are a mix of visual, auditory, and kinesthetic learners (Sebora, 2008), as such, co-design would greatly benefit from research around the stimulation of a more diverse range of senses by tools and materials. This is an area for future research to build on.

Recommendations for further study
The toolkit, including the toolbox on wheels, the tools and materials recommended, as well as the guide and its approach, would benefit from further testing with a wide range of users (participants and facilitators). Future research is needed to build on this research by exploring the principles and usefulness of the proposed guide and toolkit in the context of a wider range of disabilities and impairments, age groups, and participants outside the tertiary study context. Ideally, such exploration would lead to an updated, more comprehensive set of principles, guidelines, and tools for making accessible co-design possible.

I undertook this research to discover a more accessible approach for facilitators, designers and researchers to take in a co-design process with people who are experiencing sickness or disability in healthcare and wellbeing fields. It would be valuable to know how this accessible toolkit increases a facilitator’s sense of confidence in their approach.

Lastly, accessible co-design is not only for participants who experience permanent disability and impairment. Temporary disability, impairment and chronic illness can affect anyone at any time. It would be interesting to compare this ‘accessible approach’ with more commonly used co-design approaches that don’t prioritise accessibility, to assess whether an accessible approach offers an improved experience for the general population.

Ongoing steps
The toolkit and guide in particular will be shared in the initial months of 2019 with a range of collaborators and contacts who have expressed an interest in the research. Meetings with five local and international experts in community engagement and healthcare fields are planned.
Conclusion

In conclusion, this research has investigated co-design and proposed an approach which emphasises flexibility, independence and negotiation. The resulting guide and toolkit encourages and describes for co-design researchers, designers and facilitators how to accommodate, respect and empower participants. The key lessons that steered this research to its final outcomes will be highlighted to draw this thesis to a close.

First and foremost, the quest by designers and researchers to understand how to adapt co-design methods and activities for accessibility plays a smaller role than what might be expected. A more promising approach lies in how these tools and techniques are offered up for engagement and enactment. A flexible approach allows participants to control their engagement and accommodates participants’ strengths and weaknesses. Moreover, reflection, indirect approaches and negotiating the process with participants, further enables a facilitator to adapt and subtly co-design the co-design experience with their participants in situ.

Three core themes emerged out of the workshops with tertiary students who experience disability and impairment. These themes brought to life the stigma embedded in disability language, the many ways in which people who experience disability and impairment are not accommodated by society, and how the label of disability and impairment can overshadow personality and identity. These themes informed the seven principles of the ‘Accessible Co-design Guide’. It is hoped that the guide will give co-design researchers, designers and facilitators more confidence to embark on co-design processes with participants who experience disability and impairment. However, an accessible co-design approach does not need to be restricted to groups of participants where disabilities and impairments are known, or the fields of healthcare and wellbeing. Statistically 1 in 4 potential co-design participants will have some form of disability or impairment (Office for Disability Issues, 2017). Adopting an accessible approach has the potential to improve the co-design experience in any co-design process or context.

In the words of Elizabeth Sanders (2002),

"Participatory experience is not simply a method or set of methodologies, it is a mindset and an attitude about people. It is the belief that all people have something to offer to the design process and that they can be both articulate and creative when given appropriate tools with which to express themselves."
Reference List


Appendices

Appendix 1: Ethics Applications, approval letters
Appendix 2: Expert Interview questionnaire, participant information sheet & consent form
Appendix 3: Workshop research information sheet & consent form
Dear Stephen,

Re Ethics Application:

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

I wish to advise you that a subcommittee of the Auckland University of Technology Ethics Committee (AUTEC) has granted ethical approval. Your ethics application has been approved on the following terms:

1. This approval is for three years, expiring 5 December 2020.
2. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
3. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
4. Your research must be conducted in accordance with the provisions of the approved protocol. Non-standard conditions must be completed before commencing your study.
5. Consideration of limiting the offer of confidentiality due to the small pool of potential participants who may be well known.
6. Removal of both the offer of counselling and the accident compensation statement in the Information Sheet.
7. Consideration of offering participants access to independent expert consultation outside the University following their participation.
8. Consideration of offering to provide participants with resources or assistance to effectively participate in co-design.

This approval is subject to the conditions of approval that must be observed by all researchers. The conditions are as follows:

1. Ethics Approval letters from AUTEC

Appendix 01

Ethics Approval letters from AUTEC

17 April 2018

Stephen Reay

Faculty of Design and Creative Technologies

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Appendix 02
Expert Interview information sheet, consent form and indicative questions

Expert Interview Information Sheet

Date Information Sheet Prepared: 26 November 2017

Project Title: More accessible co-design toolkits: Empowering participants with accessibility needs to more effectively participate in co-design.

Annexure:

In the context of the research, I am a PhD candidate in Philosophy, Minor in Educational Technology. I would like to interview you because your experiences of co-design may help to solve existing inequalities in co-design. This interview is voluntary but essential to completing my research. There will be no adverse consequences for refusing to participate.

What is the purpose of this interview?

The main purpose of this interview is for you to share your experiences of co-design methodologies. This research will count towards a Master of Philosophy degree for the researcher, this will involve a written dissertation.

How was I identified and why am I being invited to participate in this research?

You have been identified as an expert and as someone who would be willing to share your expert experience of experiences of group work with access citizens. This interview is voluntary and can be ended at any time.

How do I agree to participate in this research?

If you would like to participate in this research then please fill in the consent form and sign. This interview is voluntary and can be ended at any time.

Participant’s name: .....................................................

Participant’s Contact Details (if appropriate): .....................................................

Participant’s Signature: .....................................................

Date: .....................................................

Note: The Participant should retain a copy of this form.

Indicative questions for expert interviews

What I would like to talk and do with you today is some person-centred, creative ways of engagement.

1. Tell me a bit about yourself and your role.
2. Can I ask you about your go to phrases for describing disability? And which do you avoid?
3. Can you recall a real or fake group work or workshop you have done with participants who experience disability or impairment? What kind of topic did it focus on then?
4. Have you been involved in workshops with access citizens where there was a problem to solve or ideas to generate?
   a. Can you describe how these were run?
   b. or aspects of them that made them really successful or unsuccessful?
5. The premise of this research is that all people are creative, everyone has faith, feelings, and lives or experiences differently to one another, and objects can really help which remember us and ideas and help people think outside the box. But if using stock-standard interviews, we would like to introduce you to a creative research tool called Exhibition in a box.
6. I have a bunch of objects in this box, and would you like you to pick a bag, and then think about how the object relates to your life and tell me a bit about what it makes you think or feel.
7. How have you felt about this game? How feasible do you think a game like this would be in practice?
Appendix 03

Participant information sheet and consent form for co-design workshops

Hello, my name is Olivia Labattaglia and I am a design researcher in the healthcare and wellbeing fields. I’m interested in improving how we practice co-design.

Co-design is an exciting and fun approach to designing with people instead of designing for them. Current co-design methods assume participants are able-bodied. This is often not the case, and can create a disempowering experience for those involved in the co-design process.

Co-design workshops will be held at AUT’s City Campus, in a central location with accessible amenities. The workshops will last two hours, with a break in the middle for refreshments.

Why are we doing this? What are the benefits?
This research seeks to discover an accessible co-design approach for participants who have a diverse range of physical or mild cognitive difficulties.

I, the researcher, will benefit from this research by using the insights, learnings and design outcomes to complete my qualification. I will also benefit from the practice and experience of running a project like this.

Stuart Taavao-Matau and Disability Services will benefit from getting to know you better, and learning about how you think and feel about the student experience at AUT.

I hope that you will benefit from the opportunity to discuss and contribute your thoughts towards a more accessible co-design approach, and have a positive experience working with your peers in an interactive design process.

Why am I being invited to participate in this research?
You have been invited to participate in this research as Stuart Taavao-Matau has approached you to be involved in a leadership programme with Disability Services. If you choose NOT to participate in this research, it will not affect your participation in the leadership programme. This research is entirely an extra opportunity we would like to offer you, but it is not compulsory.
The End....

Get in touch if you have any questions or comments
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