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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Acknowledgements

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, Brandt & 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 (Bjerknes & Bratteteig, 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; Basbelle 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 places the 'user' as '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).

Positioning of the researcher

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.

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[2] "(noun) extended family, 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" (Māori Dictionary, 2019).

Figure 01: Space, Safety, Boobs & Babies - Honours project,

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 & Ehm, 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.38) was a slogan for the Bauhaus modern design approach. The practice of the Bauhaus school was multidisciplinary, inspired by *Bauhütten*, 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 1980's in Scandinavia. (Bannon & Ehn, 2012).

Figure 02: Nate Robert, (2010), Bauhaus School (Dessau, Germany)

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 organised workflow by assigning workers to the requirements of the technology in the workplace. This approach was quickly criticised as workers were made to work around the technology, which did not see an increase in productivity (Bannon & Ehn, 2012, p.42). 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
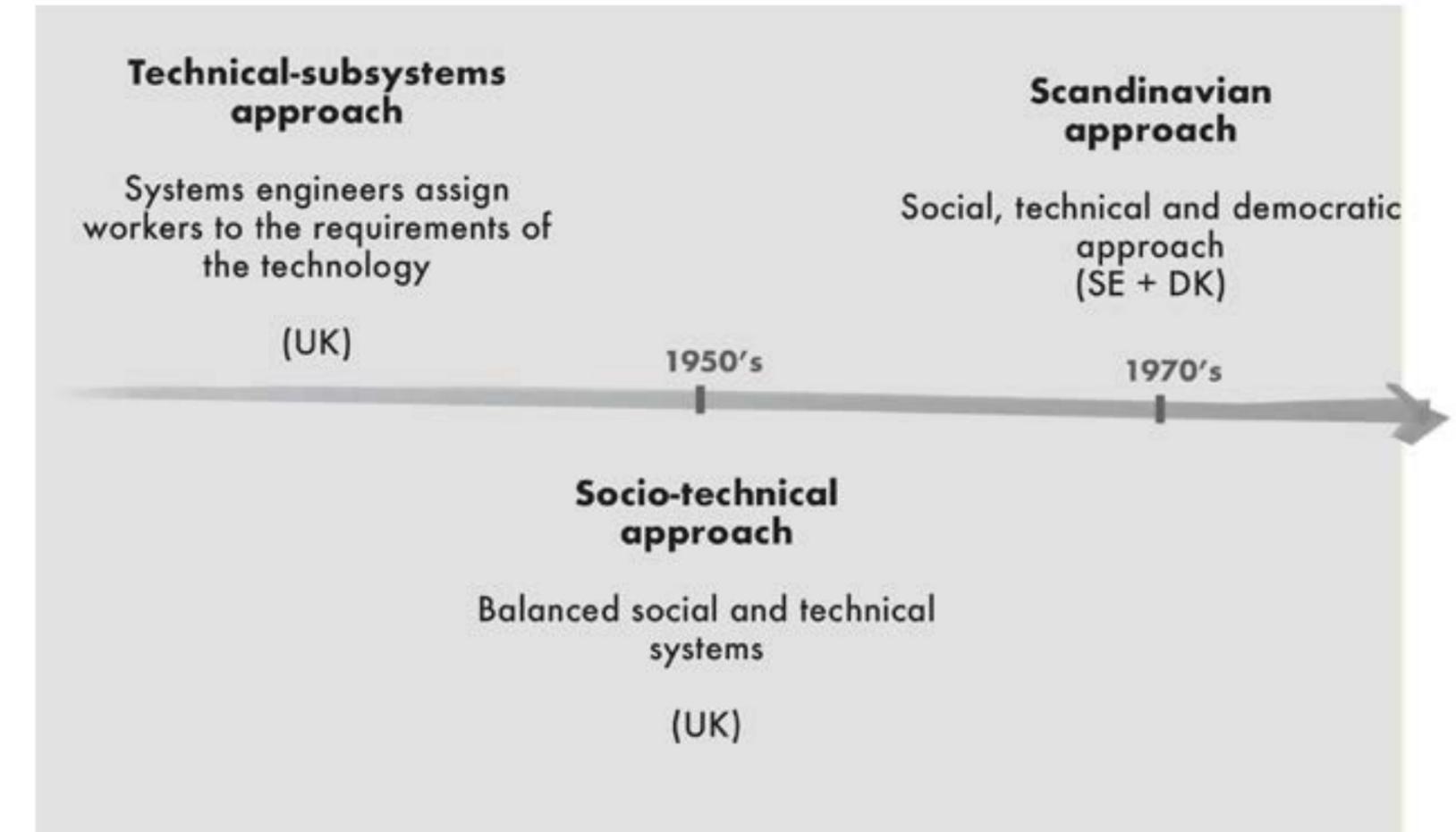
Figure 03: Diagram of Technical to Scandinavian Approach

the Norwegian Iron and Metal Workers Project, the Swedish Demos project and the Danish DDE project" (Clement & Van den Besselaar, 1993, p.30). The central idea of the projects... was the involvement of workers in the design and implementation of tools and machines they used in their work" (Basbelle et al, 2016, p.22). The Scandinavian researchers involved in these projects wanted to create an approach where engineers, designers and workers codetermined the development of systems, and information technology in these work environments. (Clement & Van den Besselaar, 1993, p.29).

One of the most notable projects was UTOPIA (1987-88), led by Swedish and Danish researchers. In this project, computer scientists, social scientists, industrial designers, and graphic designers were engaged along with the unions to design 'tools for skilled work' (Bannon & Ehn, 2012, p.39). Earlier Scandinavian Projects, such as Demos and DDE in the 1970s, encountered problems where the technologies developed had limited "the possibilities for workers to influence technological and organizational changes in the workplace" (Clement & Van den Besselaar, 1993, p.30). Therefore, the focus of UTOPIA in the 1980s was to influence the development of graphical[1] technology with users. This was the first time a participatory design project had a clear design focus (Bannon & Ehn, 2012, p.43). 'Design-by-doing' and 'design-by-playing' tools were tested and introduced into the participatory design approach at this time. These methods were previously developed during the Bauhaus Workshop era (Bannon & Ehn, 2012, p.38). At this time designers and researchers practicing participatory design began to acknowledge the variety of users and stakeholders, all of whom impacted on the design of any system. Therefore, the Scandinavian researchers and designers developed participatory design into a process that could support conflicting perspectives, and achieve partial resolution for the team of users and stakeholders (Bannon & Ehn, 2012, p.43)

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[1] Relating to visual communication or computer graphics

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.23).

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).

Figure 04: Accessible co-design in action #1.

Co-design

This sections 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 (Hartswood et al., 2002). Co-design has an ethos of empowerment (Langley et al., 2018) 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 is more than just observing and surveying participants and their interactions: "Simply asking people questions is not enough to facilitate this process" (Hagen & Rowland, 2011, para. 3). Co-design recognises that stakeholder knowledge is both explicit and tacit (Langley, Cooke and et al., 2018). A large proportion of human experience and knowledge is tacit, tucked away in our habits, unconscious beliefs and attitudes, and memories (Hagen & Rowland, 2011). This kind of knowledge can be difficult to access. However, ambiguous objects, imagery and language can help frame, draw out, express, create connections and space for people to express these thoughts, feelings and memories (Hagen & Rowland, 2011). Moreover, using our bodies and hands to make, both individually and in a group, draws out thought and meaning not easily accessed through interviewing or discussion (Hagen & Rowland, 2011). Co-design helps raise empathy and brings user experience to the forefront of the design process. Moreover, this sharing of each user's-experience is key to building trust in groups with diverse stakeholders (Langley, Wolstenholme and Cooke, 2018). This can offer, "a breakthrough in design thinking that bridges the gap between what might be defined as "good design" in a healthcare, patient-centred care model" (Carmel-Gilfilen & Portillo, 2016, p.130).

Co-design structure

Co-design researchers Sanders, Brandt, and Binder, 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 method. How methods and tools are utilised is determined by the research and design team, based on 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.

Challenge: 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 her 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

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 to just 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, 2008).

Participants may also discover a sense of creativity, or creative confidence, they were not previously aware of. In 'Convivial Toolbox', 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).

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).

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

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.S3162). 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.1). 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.1). Halskov 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.84), 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 (Bianca, Bridget et al., 2017).

Figure 07: Accessible Co-design in action #2.

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 therefore accessibility, affects around 24 percent of New Zealanders. Disability in this context is defined as a physical, sensory, learning or mental health related difficulty (Office for Disability Issues, 2017). Statistically, 1 in 4 potential participants in a co-design project could have a disability or impairment. 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 (Oliver, 1995). 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 requires 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[2]. 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.

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[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, seeing participants whose 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 there has been mistrust and problems 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, 1990, 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 codesign techniques use design representations and processes that assume effective communication skills on the part of participants" (Wilson et al., 2015, p.21).

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 'serendipity' 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 on a subject they understand better than anyone else, 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
3. Better understand best-practice dialogues in the fields of co-design and participatory design practice.

Figure 08: Accessible co-design in action #3

02. Methodology

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).

Research Project Timeline
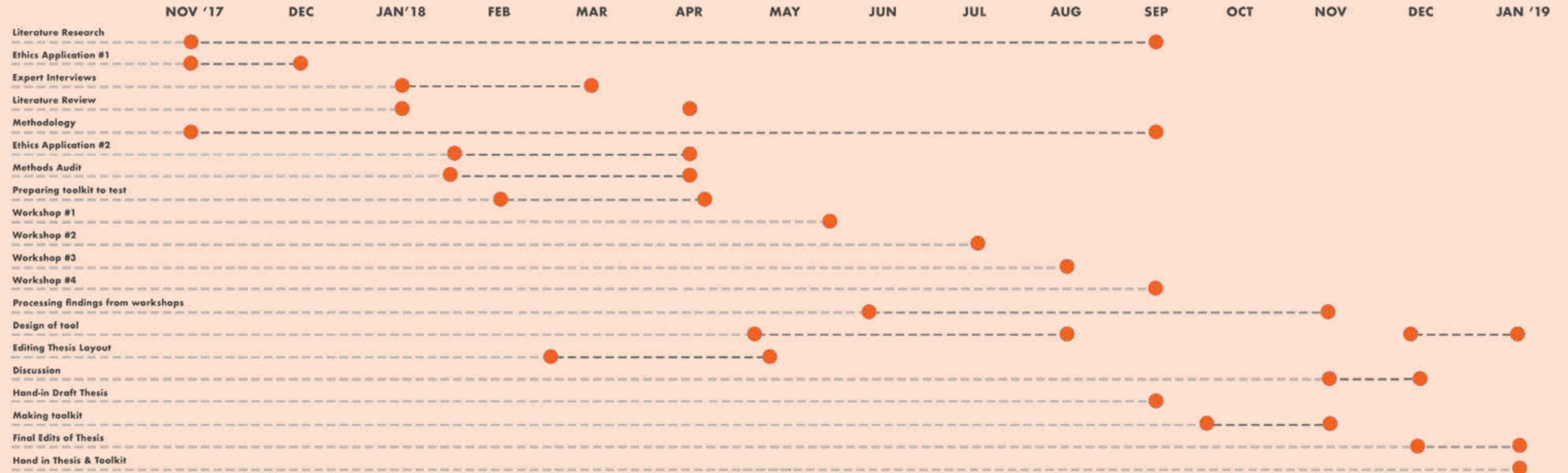
Figure 09: Research Project Timeline.

Contextual Review	Co-design Methods Audit	Expert Interviews
Method I	**Method II**	**Method III**
Co-design Workshops	Reflection	Toolkit Development
Method IIII	**Method V**	**Method VI**

Table 01: Research methods

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 persona's 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).

Persona Sue is partially deaf.

- Sue wears hearing aids to increase the volume of sound
- Sue uses a bit 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.

Figure 10: Personas for methods audit

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: 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 'toolkit'. 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
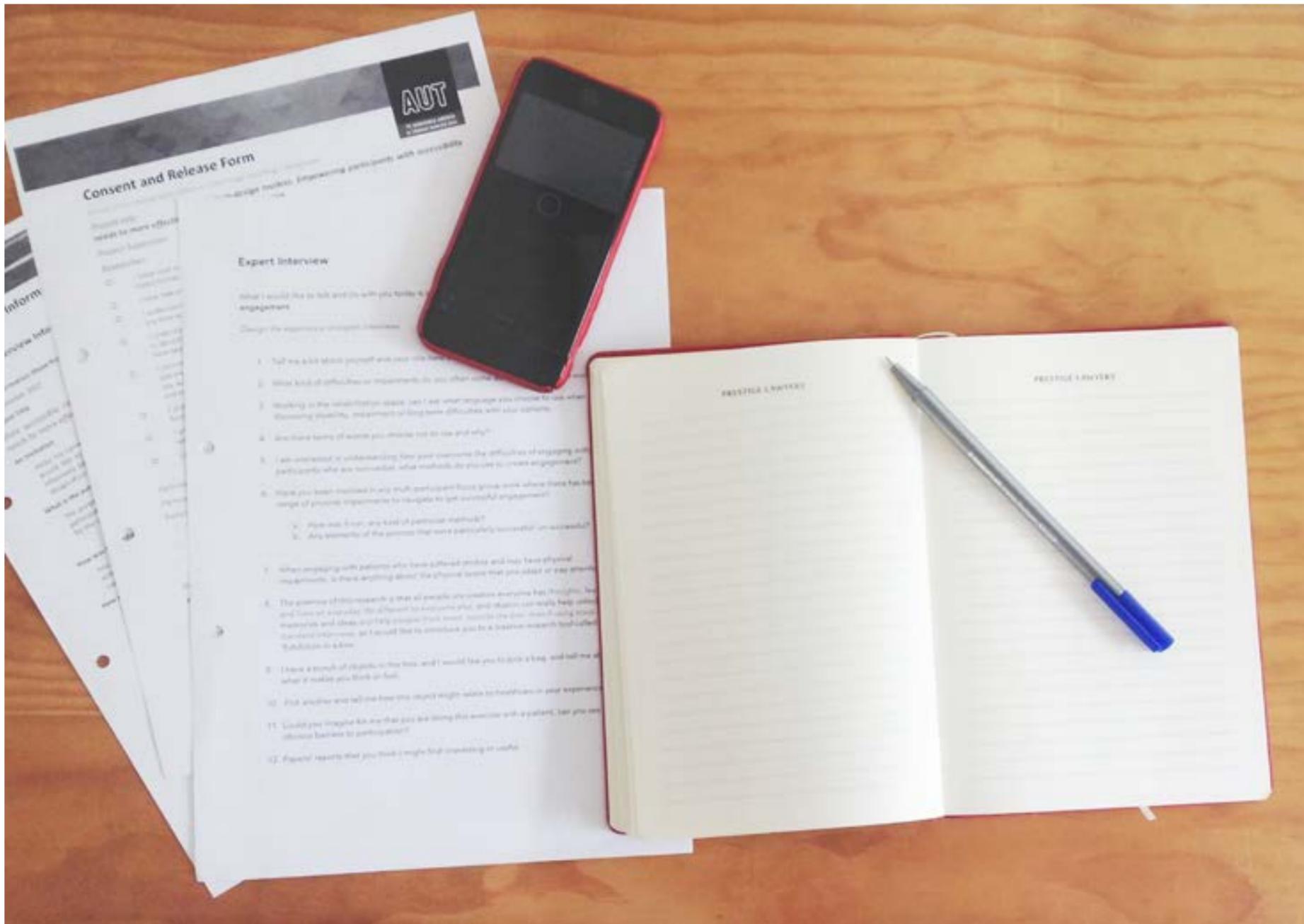
Figure 14: Expert Interviews, tools and preparation documents

Method III: Expert Interviews

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[1]. 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.

_____
[1]   Refer to appendix 02 for interview protocol

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 expert 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.

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**
> **Māori 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

Method IV: Co-design Workshops

Introduction

The co-design process involved the exploration and development of ideas, problems and solutions aligned with the following five steps of design thinking[2] as defined by the Stanford d.school, see **Figure 15.** Due to the time constraints of this research, the 'test' step will take place after this research is finished. Participants will test the idea(s) generated through this co-design process as part of a leadership programme in 2019. This section will detail the overarching process and aims of each co-design workshop. Detailed findings on the creative methods used in each workshop are presented in Chapter 03: Documentation of Research..

Workshop 1

The aim of the first workshop was to develop *empathy* between participants and develop some understanding about each person's individual experience of disability and impairment. Empathy was developed through exploring each participant's associations with the words 'disability' and 'impairment'. This indirect approach allowed the group to discuss disability language, as well as allowing participants to share (or not) their experience of disability or impairment, and gain insight into the language each participant uses when talking about disability/accessibility. Exhibition in a box (Chamberlain & Craig, 2013) was used to introduce participants to creative research. In the second part of workshop 1, participants were asked to describe their average day at AUT, and began to explore the highlights and lowlights of the student experience.

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

Workshop 2

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 (Nakarada-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 participants to dream of or ideate a better future and what they could do now 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 namely used to check that the approach of the guide was respectful in the way it discussed disability and impairment.
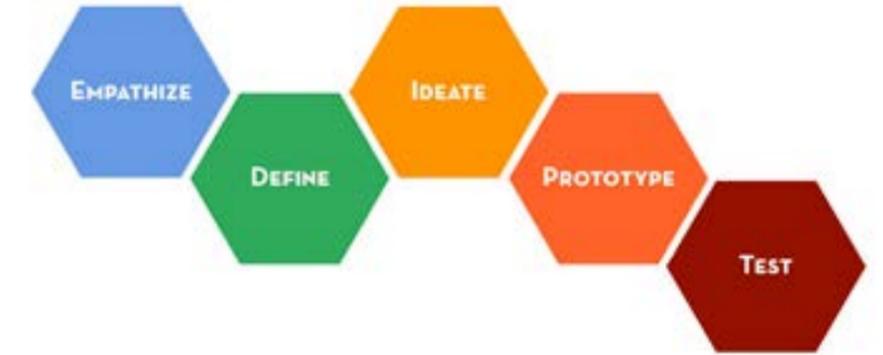
Figure 15: d.school, (2009), The five steps of design thinkingl

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[2] Five steps are: Empathize, define, ideate, prototype and test (d.school, 2009)

Recruitment

Participant recruitment is an important process whereby potential participants are approached for the research being conducted. As the research involves people who experience disability, particular care needed to be taken. Non-disability related fields lack knowledge around how to conduct research with people who experience disability (Eckhardt & Anastas, 2007). As such, research can risk disempowering and frustrating participants by increasing communication barriers and the invisibility of participants (Eckhardt & Anastas, 2007). The approach taken involved recruiting participants through a Disability Student Services (DSS) Adviser at AUT. Moreover, strict exclusion criteria were developed through consultation in the expert interviews and with the DSS Adviser. Ethics for four co-design workshops with students who access Disability Services at AUT, was formally approved by AUTEC on the seventeenth of April 2018. (AUTEC reference number 18/130), **see Appendix 01.**

In this research, the ethics process defined potential participants as 'vulnerable' due to their disability or impairment. As such recruitment also required serious consideration. The label 'vulnerable' can be used to describe anyone who identifies as living with disability, impairment or difficulty. For the formal ethical review it was argued that any 'vulnerable' person who is fully enrolled in tertiary studies, which requires a high level of intelligence, communication skills and capability, is capable of participating in a group workshop, and therefore not vulnerable as defined (or implied) by the ethical review process. One exception to this argument is explained below.

Exclusion criteria were developed to prohibit the recruitment of participants who may find the workshop experience disempowering. This exclusion was applied to students who are deaf and communicate using New Zealand Sign Language (NZSL). This exclusion was strongly recommended by three of the experts interviewed. This exclusion was established as a NZSL user would have had to access the workshop

using a third-party interpreter. It was advised by the three experts that a participant might find the experience frustrating or disempowering, due to delays for everything that is being said in the workshop to be interpreted and vice versa. This time lag would likely have contributed to their ideas and thoughts being missed out, as the pace of verbal communication might have moved faster than their ability to sign through interpretation. Furthermore, it was recommended that due to the strong culture surrounding Deaf people and Deaf research, a series of exclusive workshops would be more appropriate. However, due to the timing and costs this was outside the scope of this research.

The recruitment process consisted of the Disability Student Support Services Adviser approaching 15 students whose disabilities and needs were familiar to them. Face to face and email contact was used to invite participants, with a follow-up email containing the research information sheet and consent form (Refer to **Appendix 03**). Eight participants responded to the invitation. For workshops to be manageable the participants were put into two groups of four determined by their availability. Each workshop was run with each group twice to gather data from the two groups.

Participants were not asked to disclose their disability to the wider group. Disabilities ranged from physical to cognitive; such as cerebral palsy, traumatic brain injury, arthritis, dyslexia and aspergers. In two cases I was only aware that the disability was physical, and it was visibly obvious without having to ask for further detail how their disability would impact their engagement.

Research Method V - Reflections

Reflection played a critical role in this research. Insights and decisions were discovered, explored and reached through reflection. In 'Tensions in human-centred design' (2011) design researcher Marc 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 activities, 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 make proceeding 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.58). 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.
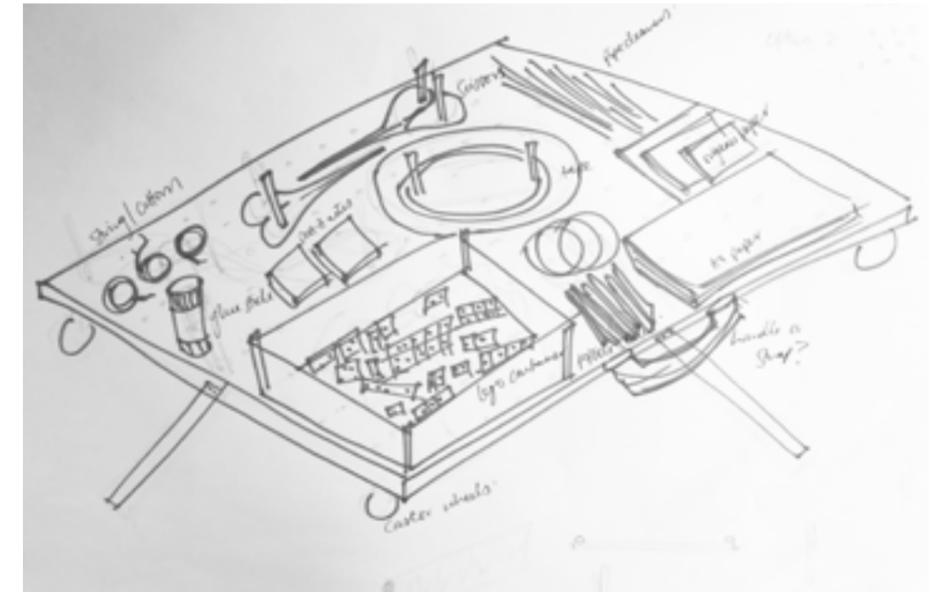
Figure 16: 'Toolbox on wheels' - first sketch

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'.

03. Documentation of Research

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.

Co-design methods 1-20	21-40	41-60	61-76
I like/I wish, what if? Statements	Resource flow	Determine what to prototype	Persona posters
Puppet play	Powers of 10	How-might-we questions	Co-creation session
Explore your hunch	Design principles	Create insight statements	Prototype for empathy
Surveys	Emoji ranking	Collage	Draw-it
Storytelling	Vision statements	How-why laddering business	Abstract sketching
2x2 matrix	Resource flow	Business canvas model	Conceptual 3D modelling
Structure & group ideas	Download your learnings	Decision making games	Rapid prototyping
Story share & capture	Bundle ideas 3x3 & 5x5	Full scale planning	Composite character profile
What? How? Why? Statements	Empathy map	Velcro modelling	Storyboard
Peers observing peers	Determine design principles	Get visual	Iterate
Critical reading checklist	Guided tours	Analogous Inspiration	Make a package
Shooting video	Card sort	Blue-sky joker cards	Small scale space planning
Self-perception triangle	Video editing	Point of view analogy	Image collaging
User-camera study	Eco-system mapping	Journey Map	Point-of-view 'want ad'
Body storming	Card sorting	Create a concept	Bundle ideas 3x3 & 5x5
Powers of 10	Find themes	Creative frameworks	
Design principles	Top Five	Mash-ups	
Emoji ranking	How might we?	Prototypes	
Vision statements	Improvisation	Prototype to test	
Download your learnings	Brainstorming	Extreme users	

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

"People can show you what they want in a new product of service by making a package for it. This method is ideal for sparking creativity and for exploring new product/service innovation" (MakeTools, p.30).

Make a package

Visually and physically impaired participants
- Could be challenging for participants who do not have fine-motor-skills, or vision to see and execute detailed arrangements of objects.

Difficult for..?

"Ask people to sort a pre-selected collection of cards into categories" (MakeTools, p.53)

Card sorting

Visually and physically impaired participants
- Combination of the need to see clearly what is on each card, as well as having to physically shuffle them.

Difficult for..?

"Images and words are selected to form a toolkit which is used by people to express their memories of the past, their feeling about the present, or their hopes and dreams for the future" (MakeTools, p.3).

Image Collaging

Visually and physically impaired participants
- Could be challenging for people with low vision and limited fine-motor-skills, due to the images and words needing to be handled.

Difficult for..?

"Video is a powerful medium for communicating ideas, insights & stories... Know what you are trying to do and be aggressive about communicating it in the frame. If it's not in the frame, it doesn't exist." (d.school, 2009, p.42)

Shooting video

Visually and physically impaired participants
- Sight and physical strength and stability is needed to shoot video.

Difficult for..?

"You can learn a lot about how people make decisions or respond to challenging scenarios by watching them play a game. The game must be designed specifically for the content domain you want to learn about" (MakeTools, p.16).

Decision making games

Visually and hearing impaired participants
- Highly visual and verbal group activity, participants who can't see or hear might struggle to take part.

Difficult for..?

"...allows us to understand a user's experience by seeing it through their eyes. It will also allow you to understand environments to which you might not normally have access" (d.school, 2009, p.8).

User-camera study

Visually impaired participants
- Sight is needed to shoot and film with a camera.

Difficult for..?

"Video is a powerful medium for communicating ideas... editing can make or break a video: the story is supported or undermined by the way a video is sequenced, paced, & scored." (d.school, 2009, p.43)

Editing video

Visually and physically impaired participants
- The sight, and fine-motor-skills necessary to edit film would make this creative method challenging for quite a few participants.

Difficult for..?

"How do your participants see themselves? The self perception triangle encourages them to prioritize their thoughts and feelings since they can place only the most salient item at the top." (MakeTools, p.56).

Exploring self-perception

Visual
- Strong reliance on visual cues to organise and represent self-perception

Difficult for..?

"People can create and visualise systems when they have an appropriate set of 2D or 3D materials to work with... ask them engage in big picture thinking and making" (MakeTools, p.20).

Ecosystem Mapping

Visually and physically impaired participants
- Difficulty could arise around the organisation of visual information and objects into a complex ecosystem.

Difficult for..?

"People can express their ideas for future spaces that they will work or live in when they are given the opportunity to make the space" (MakeTools, p.48).

Small scale space planning

Visually and physically impaired participants
- Highly visual and physical activity, which is done collectively. Participants who can't reach into the model or see it well will be left out.

Difficult for..?

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

Reflect on ideas

I like/I wish, what if? Statements ○○○

Puppet play ○○

Explore your hunch ○○○

Surveys ○○○

Get feedback ○○○

Storytelling ○○○

2x2 matrix ○○○

Structure & group ideas ○○○

Story share & capture ○○○

What? How? Why? Statements ○○○

Key
- ○ Physical mobility & fine motor skills
- ○ Partially Deaf
- ○ Legally blind

Organise ideas

Powers of 10 ○○○

Design principles ○○○

Vision statements ○○○

Resource flow ○○○

Download your learnings ○○○

Bundle ideas 3x3 & 5x5 ○○○

Empathy map ○○○

Determine design principles ○○○

Un-pack ideas

Find themes ○○○

Top Five ○○○

How might we? ○○○

Improvisation ○○○

Brainstorming ○○○

Determine what to prototype ○○○

How-might-we questions ○○○

Create insight statements ○○○

How-why laddering business ○○○

Business canvas model ○○○

Generate ideas

Full scale planning ○○○

Analogous Inspiration ○○○

Blue-sky joker cards ○○○

Point of view analogy ○○○

Journey Map ○○○

Create a concept ○○○

Creative frameworks ○○○

Mash-ups ○○○

Prototype to test ○○○

Point-of-view 'want ad' ○○○

Extreme users ○○○

Persona posters ○○○

Co-creation session ○○○

Prototype for empathy ○○○

Conceptual 3D modelling ○○

Rapid prototyping ○○○

Composite character profile ○○○

Storyboard ○○○

Iterate ○○○

Table 03: Accessible co-design methods organised by category.

Figure 20: Organising the accessible creative methods based on their function.

Reflect on ideas

Storytelling ○○○

Reflection ○○○

Group brainstorming ○○○

Get feedback ○○○

Organise ideas

Saturate & Group ○○○

Top 3-5 ideas ○○○

Un-pack ideas

Journey Mapping ○○○

Collective Visioning ○○○

Point-of-view Identification ○○○

Generate ideas

Persona Creation ○○○

Rapid Prototyping ○○○

Blue-sky joker brainstorms ○○○

Create a concept ○○○

Table 04: Final selection of accessible co-design methods for workshops

Expert Interviews

Expert interviews informed the approach of this research by highlighting important considerations for working with participants who experience disability and impairment. Important themes emerged out of the interviews which influenced the approach, design and conduct of the proceeding co-design workshops with 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 around appropriate and inappropriate language for describing disability. The responses can be separated into two groups. The first is disability language and its intersection with pride and identity, and the second is disability and person-centered language. Many disabilities and impairments are present from birth, and as such play a significant role in a disabled person's identity. Consequently they proudly identify with and use language such as 'disabled'. In a similar way, members of the Deaf community are proud to identify as Deaf, and emphasise the capitalisation of the D in Deaf. Experts reinforced this by saying that they avoid language which focuses on the ear or audiological deficit like 'hearing-impaired' or 'hard-of-hearing'.

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, 2015) disability researchers who experience also personally experience disability and impairment, point out that disability exists within the meanings attached or given to it. The meanings given or attached to disability by society are imbued whenever we think of it, speak of it, and act on it (Titchkosky & Michalko, 2014, as cited in Cameron, 2015). For this reason, the semantics of disability language are incredibly important. 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 'dis-ability'. 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, and their impairment or disability is not 'obvious', the use of language such as 'challenges and difficulties' may be used. The only instance described where they would not mirror the disabled person's language is when a person is using negative or derogatory terminology such as 'retarded' 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 disabled person shared their view that terms such as 'disabled' and 'impairment' are very Western terms and are based on deficit language ['dis-ability']. They chose instead to identify through Māori terminology like Whānau Hauā. Hickey and Wilson (2017) describe the meaning of Whānau Hauā. Whānau Hauā refers to the state in which disabled people are surrounded and supported by a family and extended community. Whānau refers to the family or network in which a disabled person is centered, the Hau in Hauā refers to the wind, or environment which surrounds the disabled person, and the final 'ā' in 'Hauā' refers to the drive or force which propels this network to create a better environment around their loved one experiencing disability (p. 86). Whānau Hauā resonates with the social model of disability 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).

Accessible methods and approaches

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 an accessible creative method functions, and to invite experts to share techniques in their repertoires for accessible research.

> The challenges for participatory design and co-design lie in the design and use of appropriate creative methods, for the context investigated

and the participants invited. The fundamental challenge of participation is communication (Chamberlain & Craig, 2013)

Having been developed with older people in mind EIB has a strong accessibility focus (Chamberlain & Craig, 2013). EIB was warmly received, and communicated clearly the aim of this research to uncover how accessible co-design can be practiced with participants who experience disability or impairment. One expert compared EIB to the poem 'Rain' by Hone Tuwhare (The Governor General, 2017), which describes how no matter if you are deaf, blind or mute you can still taste, feel and touch rain. They elaborated even further, describing EIB as positively reinforcing the capabilities that a person does have – "I might be blind, but I can still feel the dice, I might be deaf, but I can still see, and if I am learning disabled I can still contextualise 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.

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, asking 'did you mean... or do you mean something else?' Experts advised that actively creating space for participants to indicate that the researcher has not understood what a participant meant, gives them the opportunity to explain themselves again and be properly understood.

Figure 21: Accessible co-design in action #4

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. Below the experience of doing Exhibition in a box with a Deaf expert interviewee 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 a necessity, 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.

Summary

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.

Figure 22: Workshop 1A in action

Workshops 1 - 4

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 workshop. (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.19)

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.**

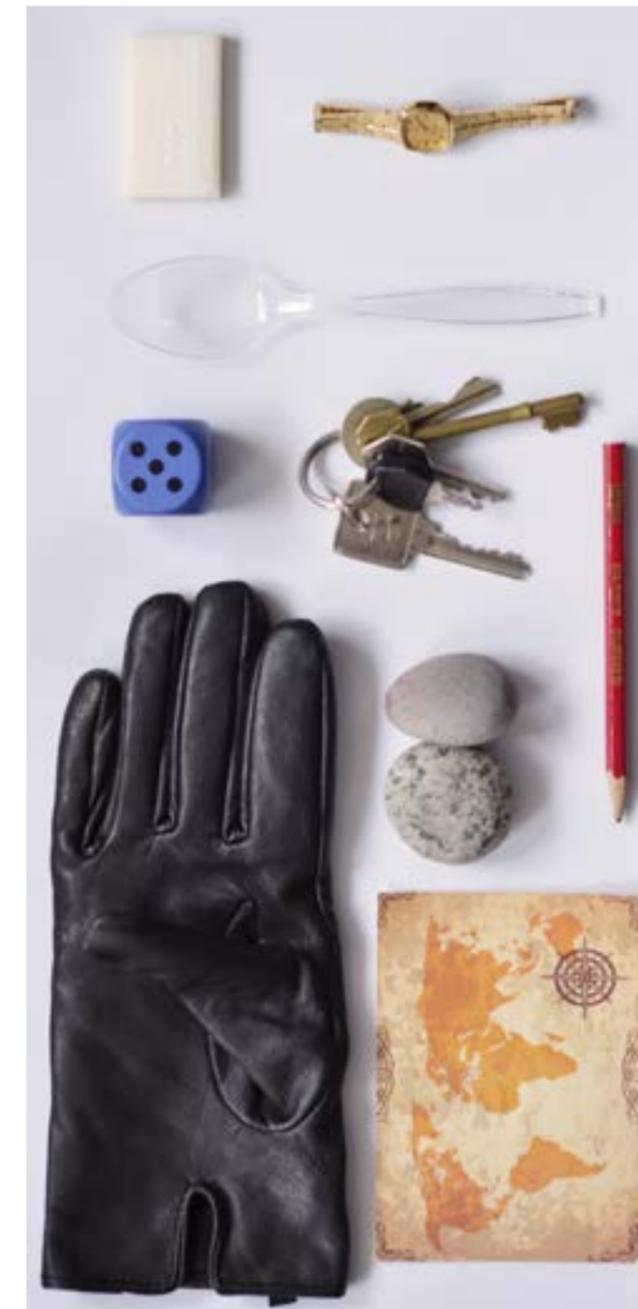**Figure 23.** Responses to associations held by participants around terms 'disability' and 'impariment'.

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 '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 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 harder 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...."

Figure 24. Exhibition in a box - responses in workshop one

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 two-fold. In the first instance, 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 have to explain why I can't do something."

A highlight of workshop one was when a solution to an accessibility problem a student faces 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 26** 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

Figure 25. 'Pain-points' of the tertiary student experience identified by participants in workshop one.
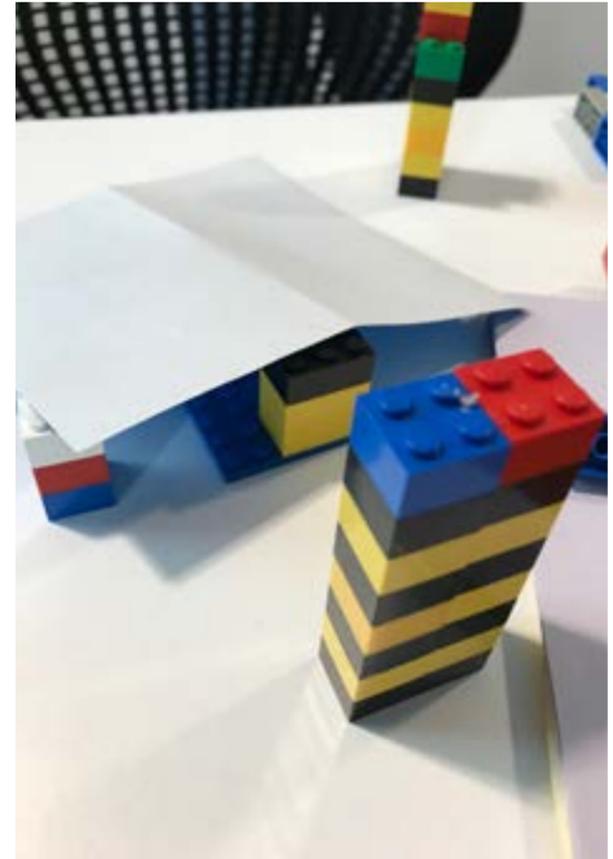
Figure 26: Participants model of building where they experience an access problem

(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 reassuring 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 don'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.

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

Figure 27: First workshop showing tools and materials being used for 'making activities'.

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 energised. 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 far, 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**).

Figure 28: Facilitators workshop template development

Figure 29: 'Toolbox on wheels' (wheels on underside of trays) prototype containing all the tools and materials offered to participants for the 'making' activities.

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
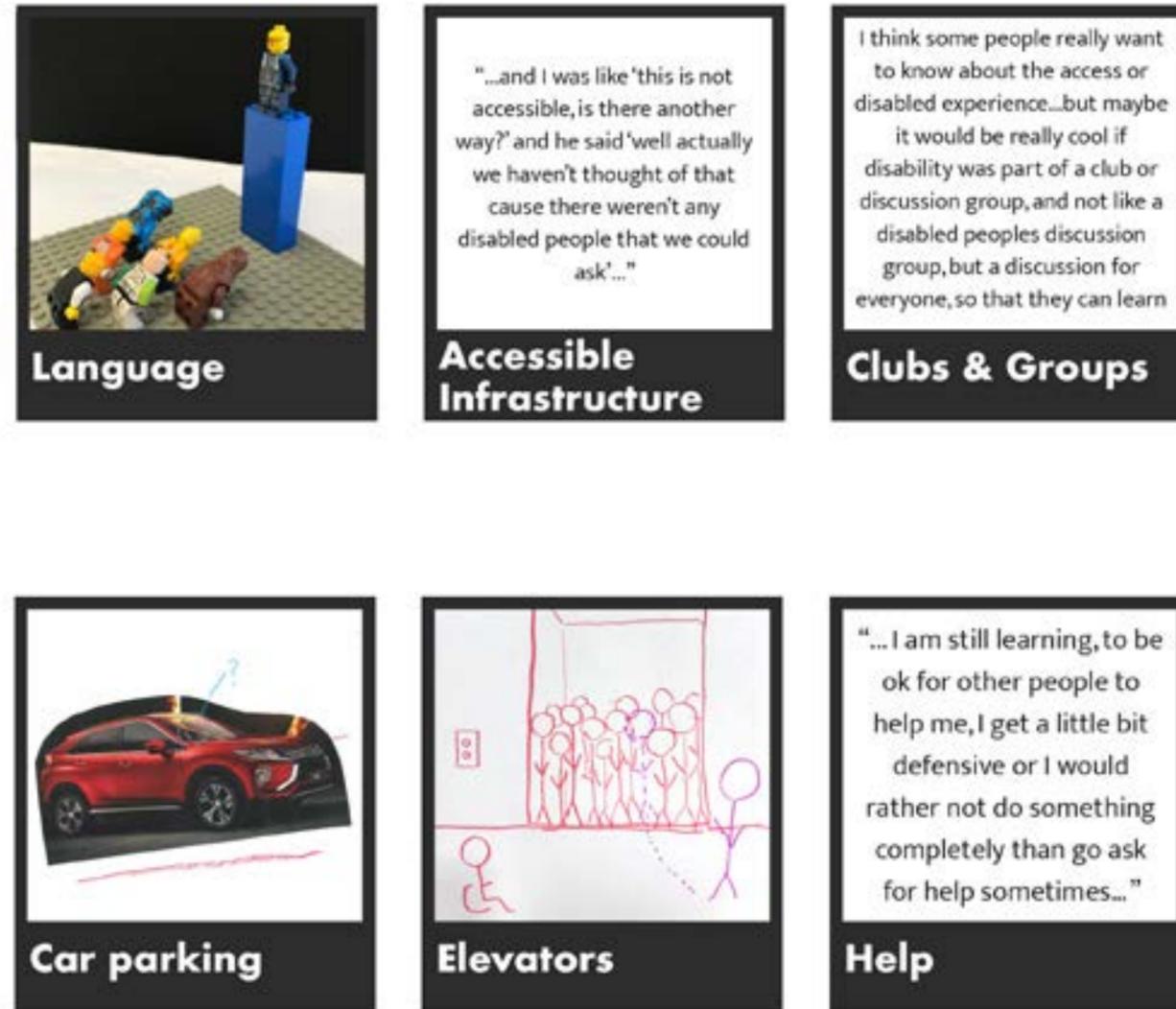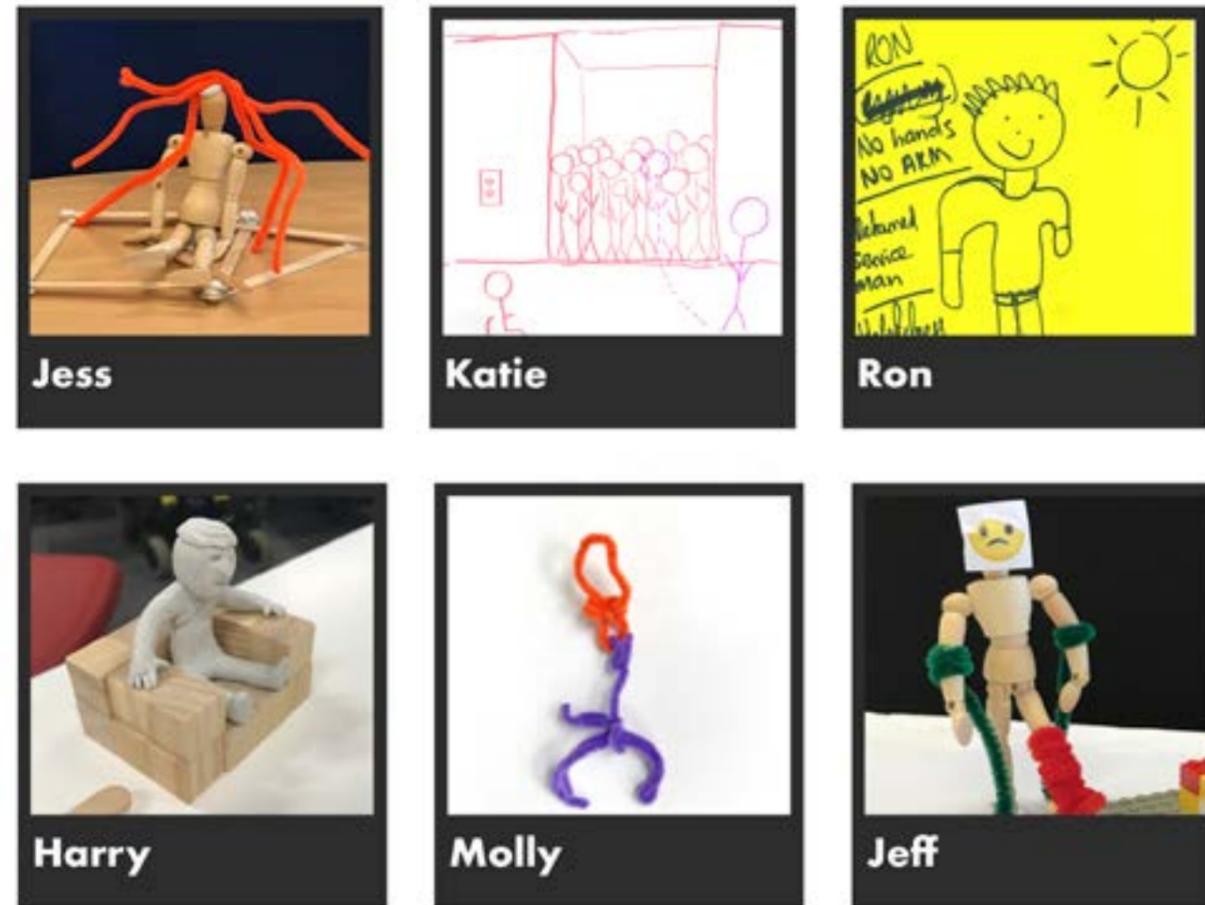
Language

"…and I was like 'this is not accessible, is there another way?' and he said 'well actually we haven't thought of that cause there weren't any disabled people that we could ask'…"

Accessible Infrastructure

I think some people really want to know about the access or disabled experience…but maybe it would be really cool if disability was part of a club or discussion group, and not like a disabled peoples discussion group, but a discussion for everyone, so that they can learn

Clubs & Groups

Car parking

Elevators

"… I am still learning, to be ok for other people to help me, I get a little bit defensive or I would rather not do something completely than go ask for help sometimes…"

Help

Figure 30: Topics selected in the second workshop for further brainstorming

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), persona 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.

"This is Jeff, he was hit by a car, and has a broken leg and is a bit fuzzy in his brain. He is at uni… 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."

Figure 31: Example of a 'persona representation', and Jeff's story.

Figure 32: The six personas created in workshop two, showing the diversity of materials and creative approaches used by participants to visually represent their personas

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

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 uninvited 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 soo much [their Lego model]", "oh my goodness Lily [name changed], you are soo 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 33: A range of brainstorming models by a less verbal participant to help them communicate meanings and associations

Figure 34: Model representing 'I am not your inspiration' by participant who had a traumatic brain injury.

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I don't really think, I will just go and do something and then make it [their artefact] into something after, not to make it a bigger thing but that is kind of how I approach my disability, I will just go do something and then figure out later how I am going to adapt it, 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
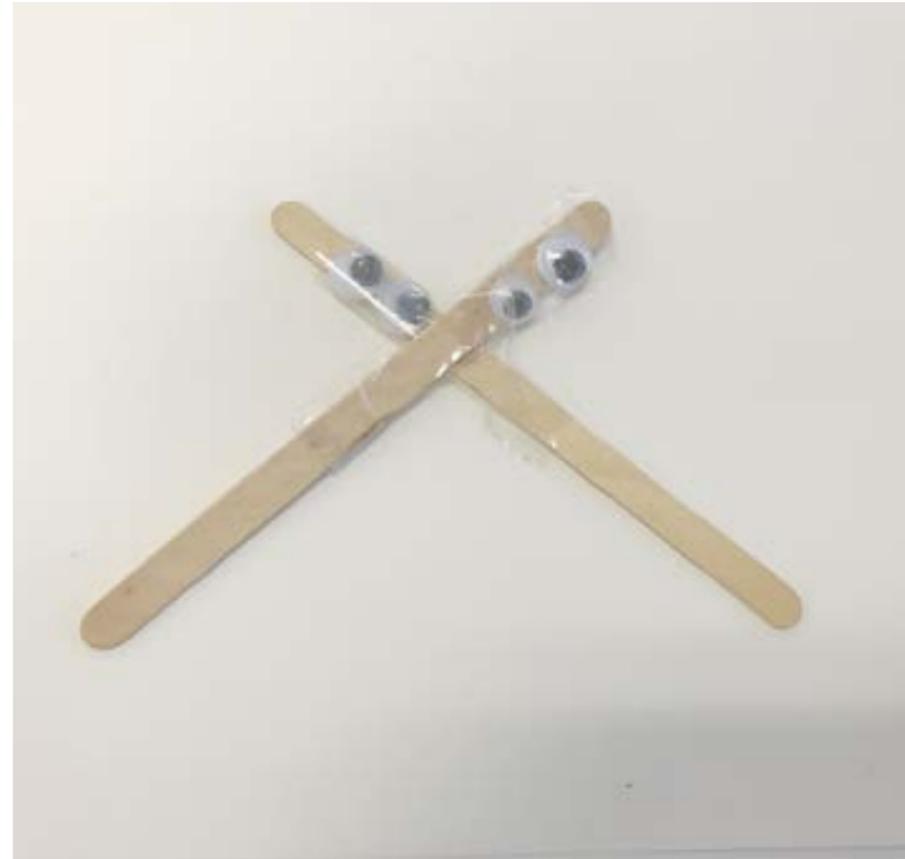
Figure 35: Model and the reflection which led to a description of how this participant approached disability

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.

Figure 36: Workshop 2A in action. Participants creating visual representations of their personas, and discussing deafness.

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, 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..."
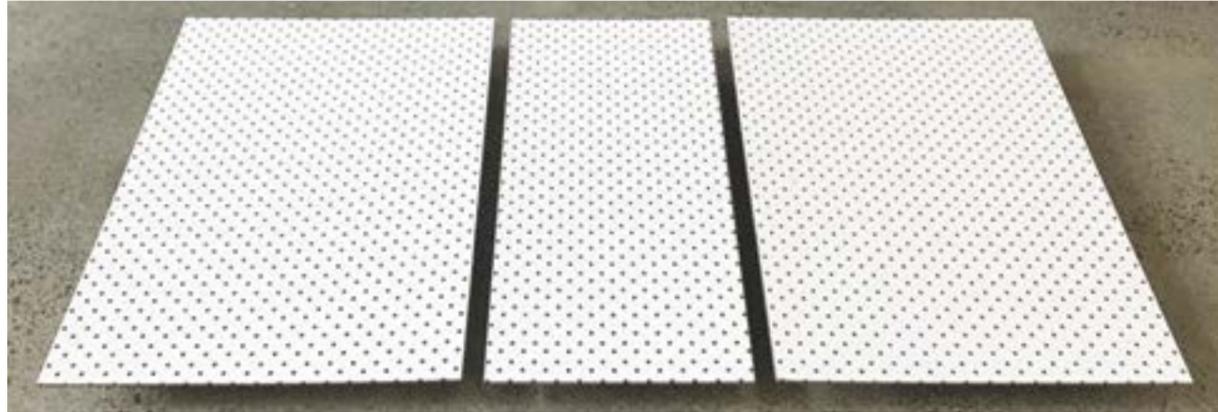
99

Figure 37: 'Toolbox on wheels' prototype being tested in workshop two.

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 38,** 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 two, 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.

Table 38: Participants' reflections on materials and tools used, as well as their experience of the co-design process.

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. 95), 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.
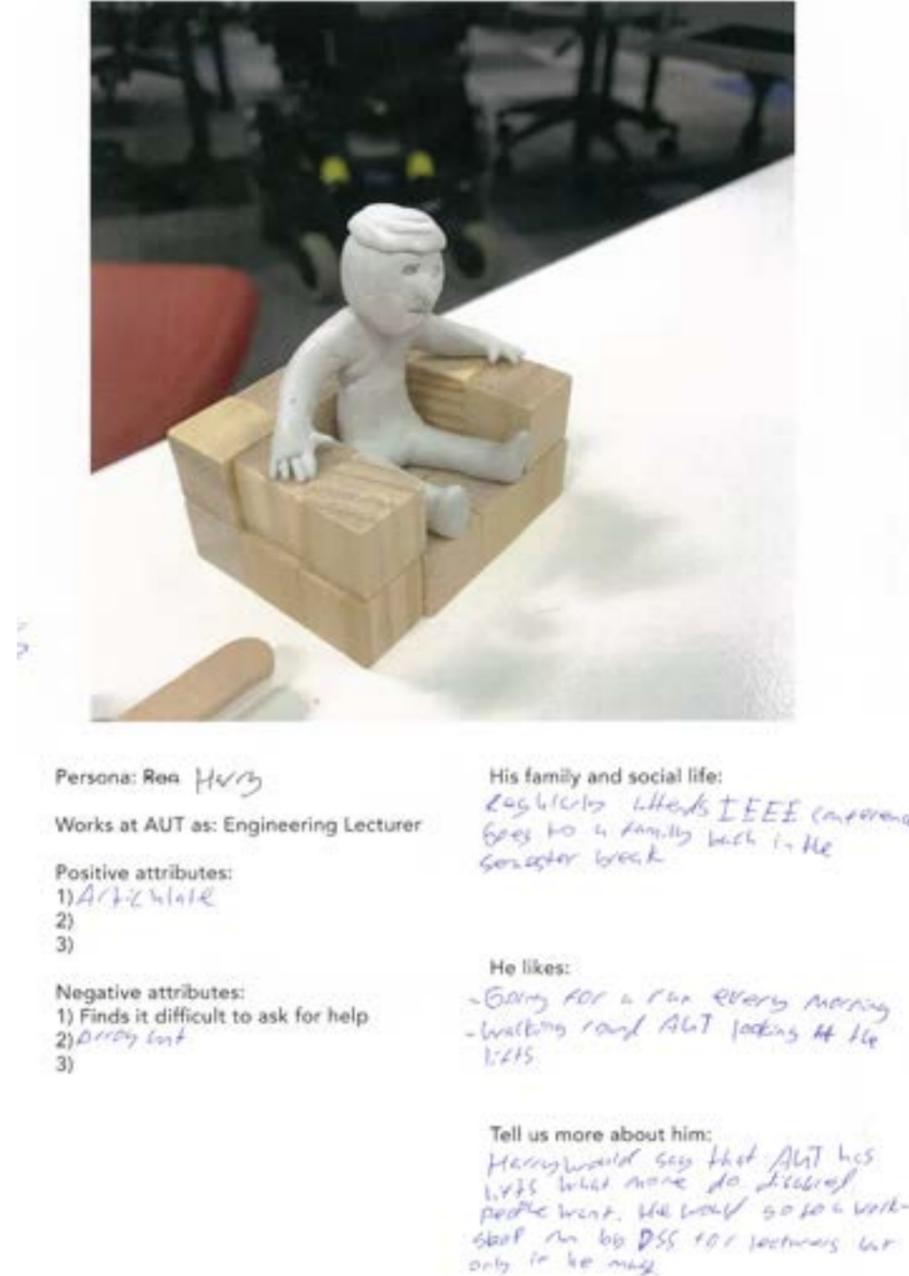
Top 5 (IDEO, 2015, p. 79) was used in this research to select the best ideas to carry over into the next activity. Top 5 helps key ideas, themes and opportunities be selected for further discussion (IDEO, 2015). In this research, Top 5 was adapted for the two workshops (3A and 3B) due to time constraints, 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 advisers'. Top 3 allowed participants to indicate those ideas or themes that struck them as the most important or emotive to design solutions for in the following activity.

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) services 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

work was repeated to further develop the persona profiles created in the previous workshop, and help give participants a platform to explore different perspectives. In workshop three, persona posters (MakeTools, p.10) (were produced in advance of the workshop), for each persona created in workshop two, using an image of the representation made by the participant of their persona in workshop two, as well as their description of the persona, a made-up role at AUT as either a student or 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 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 not 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. 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 persona at AUT.

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 or design opportunities from the previous activity. The point-of-view insights were shared at the same time as the persona posters and visual representations. The aim of this 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

Persona: Ron Harry

Works at AUT as: Engineering Lecturer

Positive attributes:
1) Articulate
2)
3)

Negative attributes:
1) Finds it difficult to ask for help
2) Arrogant
3)

His family and social life:
Regularly attends IEEE conferences
Goes to 4 family back in the semester break

He likes:
- Going for a run every morning
- Walking round AUT looking at the kats

Tell us more about him:
Harry would say that AUT has kats what more do. Disabled people want. He would go to a workshop on big DSS for lectures but only in he may

Figure 39: Example of a 'persona poster' showing 'Harry' with further detail about his personality and interests

explore how they would feel about them.

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 and signs on public transport for disabled users could be applied in elevators at AUT. The intention of the signs would be to change the elevator culture at AUT, giving wheelchair users and people who are physically impaired, priority when using the elevator. However, this method can be difficult as it involves thinking quite far outside 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.

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

In 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 by combining creative methods in activities. Further reflections were shared by participants around the importance of offering 'making' in an accessible co-design process.

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, (see **Figure 40).** From this discussion I surmise that when offering help to anyone both within a co-design process as well as in broader contexts, it is important to communicate that you believe the person is capable of what they are doing, but you are able to assist. As one participant shared, "Sometimes I only let people help if they know that I possess the ability to do it in the first place." One example of how this could be put into action is. 'Do you need a hand, or have you just about got it?'. This discussion exposed an assumption I did not realise I held. I had unconsciously assumed that people who experience disability and impairment would be fairly comfortable and confident at asking for help, and would be well practiced at doing so. This discovery of an unconscious bias was an important lesson, and it created space for reflection around how to respectfully offer help as a facilitator.

By workshop three, the impact of fatigue and concentration during a workshop was observed, it appeared that 'having fun' was the best way to keep participants engaged and energy levels high. One participant started workshop three saying. "I have been looking forward to this cause I know it's just stuff I don't usually get to do." Energy and concentration are the first functions to disappear when pain, stress, confusion or tiredness are exacerbated, which can be a daily struggle for people who experience disability and impairment. Hagen and Rowland (2011) noted that fun helps keep people's energy levels up. One participant, who struggles with fatigue and concentration said,

> Two hours went really fast... it was really good... I was like, two hours is a really long time, but then when you were like 'ok it's over', I was like 'is it?' Has it been two hours? Cause I feel like it was 45min, it went fast.

"I am still learning to be ok with people helping me, I get a bit defensive or I would rather not do something completely than ask for help sometimes."	"One day this lad that I had met the day before, saw me struggling up the hill and was like, 'do you want a hand', and that was real nice, but I said, 'oh no I can do it', and he replied, 'I know you can do it', and so in my head I was like 'ok so he knows I can do it, so I will let him do it then."	"Asking for help is alright, but I do struggle to balance asking for help and not asking for help. Sometimes it's easier to not ask, cause the only person you are inconveniencing is yourself."	"It's like super awkward having to go up to them [lecturers]... 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."
Asking for help	**Receiving help**	**Asking for help**	**Asking for help**

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

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:

"...disability comes in all shapes and sizes and more like awareness and stuff... I guess kind of people understand that disability isn't purely what you see..."

Inclusion & attitudes

"...They are disabled therefore they must have a carer that interprets the world for them."

Inclusion & attitudes

"A lot of times I think there is this fear that, people kind of see disability and they think that you probably can't verbally communicate, I guess... they assume you aren't really there."

Inclusion & attitudes

"... Just because I was walking funny, he thought he couldn't ask me what was wrong with myself, and I would prefer people asking me, particularly little kids, cause then I can tell them that it is not something to be scared of."

Inclusion & attitudes

"I always see people with disabilities around, and I know them from Attitude and documentaries...or from the wheel blacks...but other students don't know them and they just see them as that dude in the wheelchair, and it would be cool if it was more visible and proud."

Inclusion & attitudes

"...having things that involve people more with disabilities... without sort of being about targeting people with disabilities, so people can come together and understand...

Inclusion & attitudes

"...you know Uber, with all their uber people [drivers] they do sensitivity training and training how to collapse wheelchairs, if lecturers are teaching students with disabilities, or just students with differences, maybe they should learn what it means to have dyslexia..."

Inclusion & attitudes

"Maybe even workshops, like for dyslexia, so targeting people who don't have dyslexia, so people like myself aren't marginalised, so they don't think we are stupid. It's not that, we just do things differently."

Inclusion & attitudes

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.

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.

Figure 42: Workshop 3B in action, showing participants discussing ideas to improve the student experience.

Social

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.

Part 3: Reflections on co-design

Participants in workshop three made a handful of comments around their appreciation for hearing the stories and perspectives of others. Participants commented that hearing about others 'lived experience' was gratifying, regardless of whether the experiences described were similar or different to their own. One participant described, upon hearing when someone else had had the same experience at university as 'therapeutic'. We joked that co-design could also be a form of group therapy. Another participant shared that they really enjoyed the feeling when someone described something they too had experienced. It made them feel less alone in their experience of disability or impairment. Another participant shared that they were feeling 'uplifted' by the co-design process and solution-focused discussions. These reflections would not have been possible without repeatedly asking for reflection on the co-design process, what participants were learning, struggling with, and enjoying.

Reflection as a research method

In workshop two, I discovered that activities with three steps, or outputs that were described with a verbal instruction, were too challenging for participants to remember and complete. I chose to further investigate this challenge in workshop three by asking again for three outputs in a single activity, but varying the type of output required (verbal or visual), and making at least one output simple to execute with step-by-step questions to fill in. To illustrate, I asked participants to fill out the persona posters adding detail to pre-selected questions, to make a visual representation of their persona, and describe how they would respond to the Top 3 ideas. Moreover, I wrote the three outputs on the whiteboard as a reminder, "fill out the worksheet, figure out how your persona would respond to our three problems/ opportunities, and make a visual representation of your persona". Yet again, a three-part output for an activity was too challenging, at most it seems the participants are

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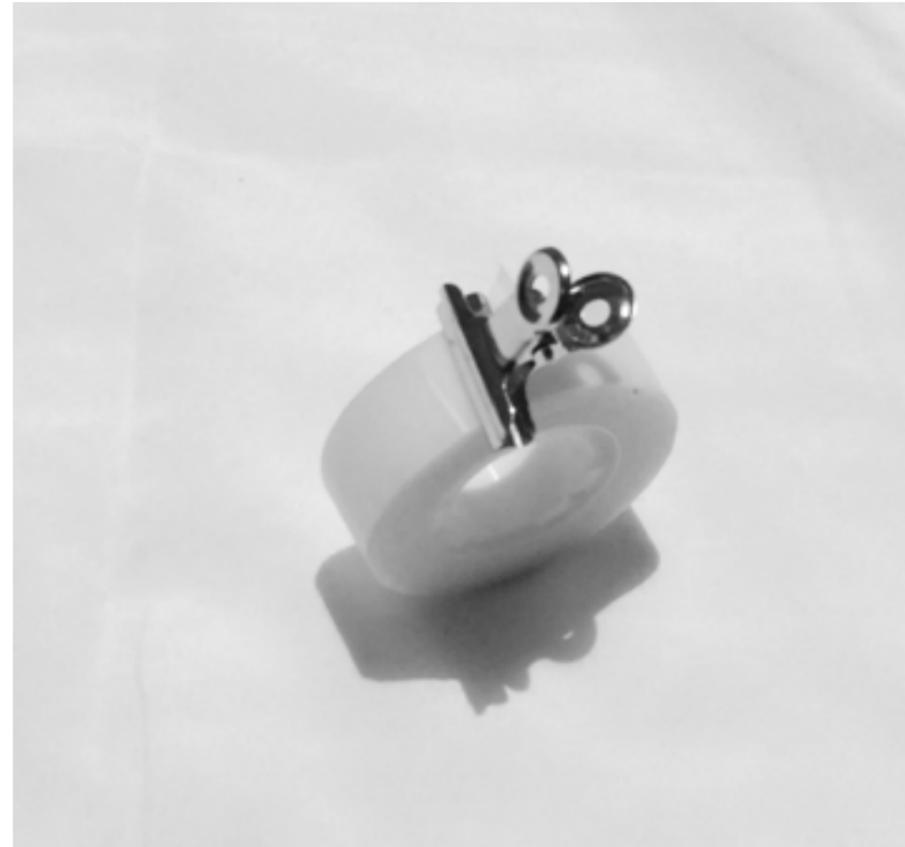
Figure 43: Bulldog clip added to the end of a roll of tape to make it easier to use.

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 experience, for students who experience disability and impairment. The final section reports on participants' final reflections on the co-design process, as well as my own final reflections on this research.

Part 1: Creative methods

Create a Concept (IDEO, 2015, p. 108) is a polished representation of the ideas and design opportunities the participants have collected together to answer their design challenge (IDEO, 2015). Participants worked together to build a 'scene' containing 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.

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.

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 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 brainstorms, 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.

Facilitator's guide for more accessible co-design

Obtaining feedback on the guide was valuable to check that the tone, language and overall message of the guide resonated with the people about whom it was written. Overall the content and approach was felt by participants to be appropriate, with participants commenting 'yeah, it's pretty good', 'it's cool, it's really good', or 'I like that, I have never thought about it like that.' Moreover, participants said the guide was more about the appropriate etiquette when working with people who experience disability or impairment, with some specific content for co-design facilitators. "It is obviously aimed at co-design facilitators, but there is a lot of general etiquette stuff in there." 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 this 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
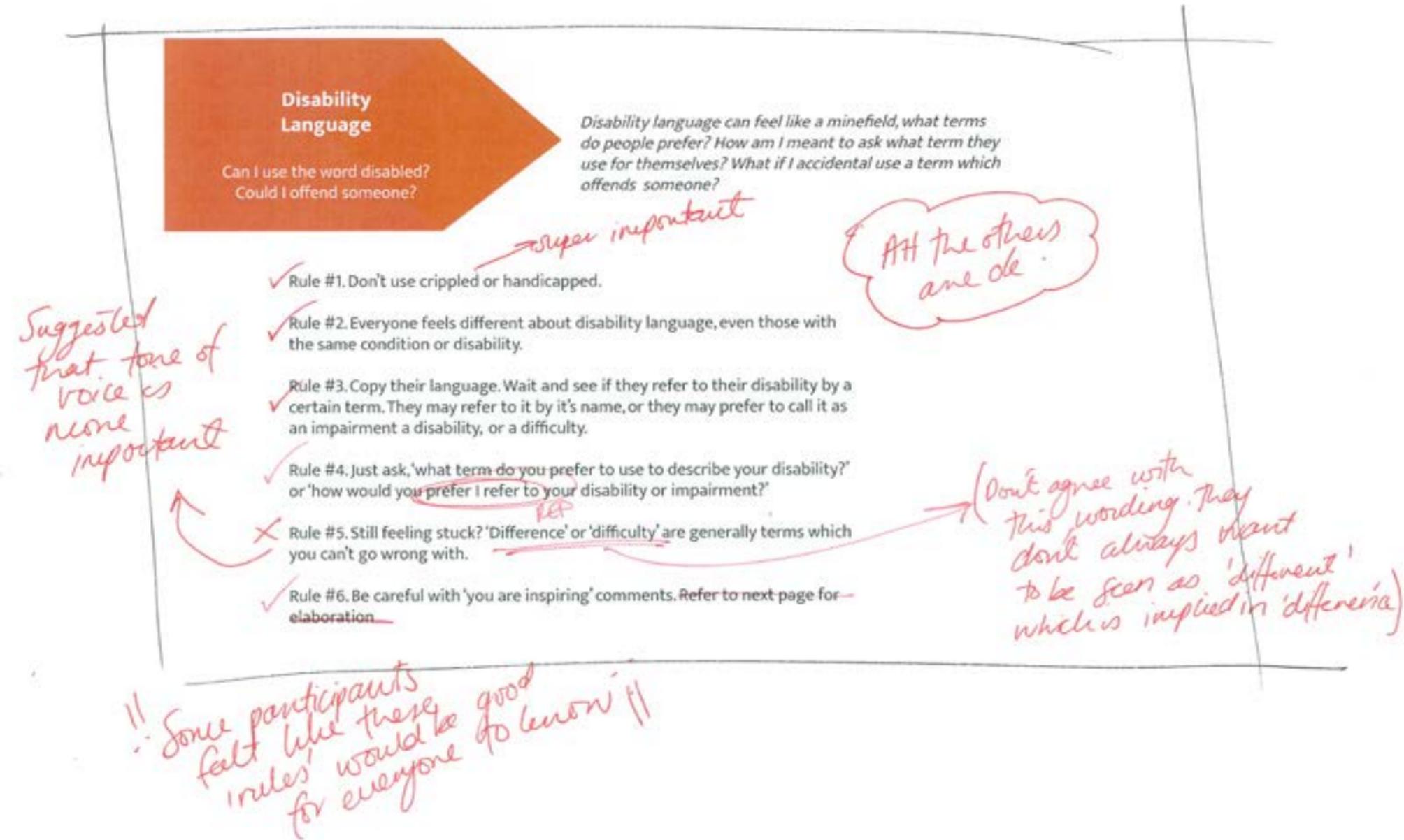
Figure 47: During critique of guide with participants in the last workshop, this page was most heavily critiqued and discussed.

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 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 them and I was like 'holy s***', like I knew these people struggle, but they were going real in depth, and I was like 'holy 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, I felt very uncomfortable.

Another participant voiced a similar experience, saying their invisible disability made them feel uncomfortable as they perceived their experience of impairment to be much less extreme:

> I felt so mediocre, I didn't want to say anything cause [my life] it's so easy compared to what they are doing... you know they were going to go through more, but just like listening to the stories, gosh, you just didn't even know what to say ...I felt the same.

These experiences raised that the perception of disability is personal, and it may be confronting to compare your experience 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 food at this workshop to encourage lecturers 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 45**) 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 redesigned 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...

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.

> There is this girl she is Deaf, and she is in one of my lectures ... I was sitting next to her in class, and I am thinking, I am a bit hesitant as well, like what is the right thing to do? Even I do not know what is the right thing to do [they are a physically disabled person], and I am like, what should I do? Should I say 'hi', should I do sign, should I mouth words, what should I do? Anyway, I got her Facebook and so we were sitting next to each other typing messages to each other on our phones while sitting next to each other. It was quite interesting and quite fun, and cause of this workshop I am starting to notice these things, notice the way she does things, or notice the way she speaks and stuff as well, it's quite different. I just realised that none of us know how to interact with each other.

The exploration and expression of 'lived experience' helped draw participants into this co-design research, and had an impact beyond the context being investigated. In a minor way it influenced participants' perceptions and attitudes of the world around them. See **Figure 48** for further examples of participants reflections about how this co-design process had changed their attitude or behaviour.

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.

"I guess I have been thinking a lot about myself and disability, and I guess other people with disability a lot more, than I would usually. You would assume I would probably think a lot about disability, but I do not really. I barely engage with that really, it's kind of an aspect of my life that 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 Hine.... I like, 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. Cause I just don't kind of sit there and think 'how did my day go today? How do I feel about this?'..."

Changed attitude or behaviour

"Everything, just this whole thing has been a learning curve, cause I have never really thought of all these things before. Then coming 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

"For me, just like opening my eyes more, like actually realising my surroundings and everyone else around me, I thought I was good before... Next time I see a special needs person coming up to an elevator, and they can't 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 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 to A and B, however just making sure that I am on time and not running late and not getting stressed or anxious 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

Table 48: Examples shared by participants about how the co-design process influenced their 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

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 code and theme was concerned with disability language and how participants feel overshadowed by this label: *disabled is a label that 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.**

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 over-shadows 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'."

Avoid the label of disability

"I would rather use impaired or disabled than crippled. I absolutely despise crippled."

Disability label is better than

"My disability is hard to explain, so it's just easier to say 'oh it's a disability'."

Happy to use the label of 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

"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 our time management"

Adapting to suit

"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"

Adapting to suit

"… 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.."

Adapting to suit

"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 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."

Adapting to suit

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

Adapting to suit

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

"I feel like the only time I remember is when someone else points it out, or you notice someone else noticing."

Person First

"I do not wake up in the morning and think 'woo I am disabled today'."

Person First

"I did a talk to a bunch of year two's in primary school and I tried to say I am not an alien from Mars, I am a child just like you. Yeah, I think the reason I object to the world 'difference' is because we are not all that different."

Person First

"...we aren't different, we just have to have a different way of going about it, that is what is different, not the actual person themselves, but how they construct their world to work for them."

Person First

"A lot of times I think there is this fear that, people kind of see disability and they think that you probably can't verbally communicate, I guess ... they assume you aren't really there."

Person First

"...I was in the mall we were going Christmas shopping and some woman walked past me and a guy come up to her and was like 'what's wrong with his legs?' and the woman was like 'I am not his mother I don't know, I have never met him in my life'. ...he thought he couldn't ask me what was wrong with myself, and I would prefer people asking me, cause then I can tell them that it is not something to be scared of."

Person First

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

day life 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 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.
'Toolbox on wheels'

Seven Principles for Accessible Co-design

1. Use appropriate language
2. Make participation accessible
3. Allow more time
4. Person first—disability second
5. Take a thoughtful approach
6. Offer, don't assume
7. Reflect continuously

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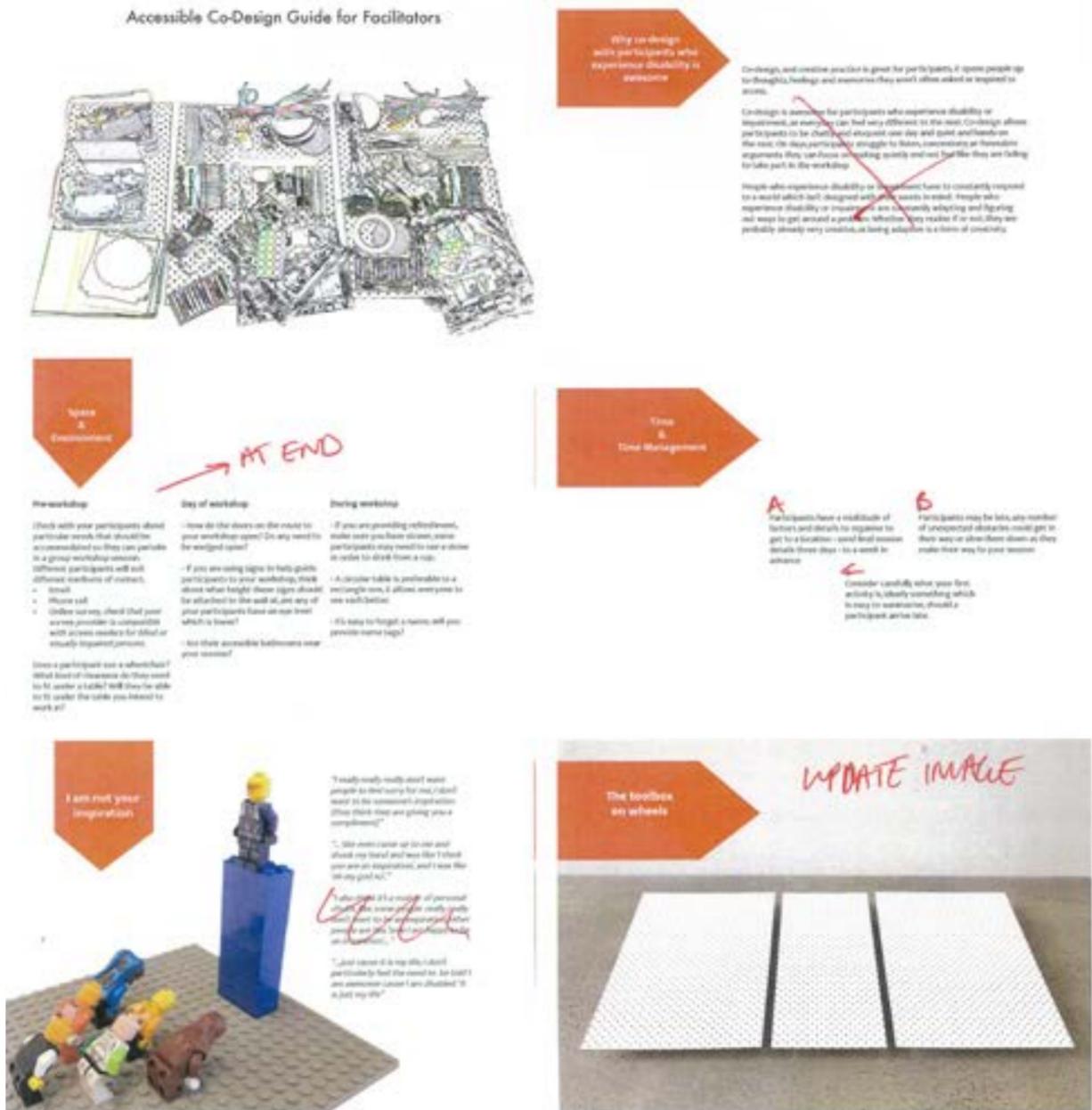
Figure 54: Selection of nine pages from first version of guide that was critiqued with participants in final workshop.

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 made 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**
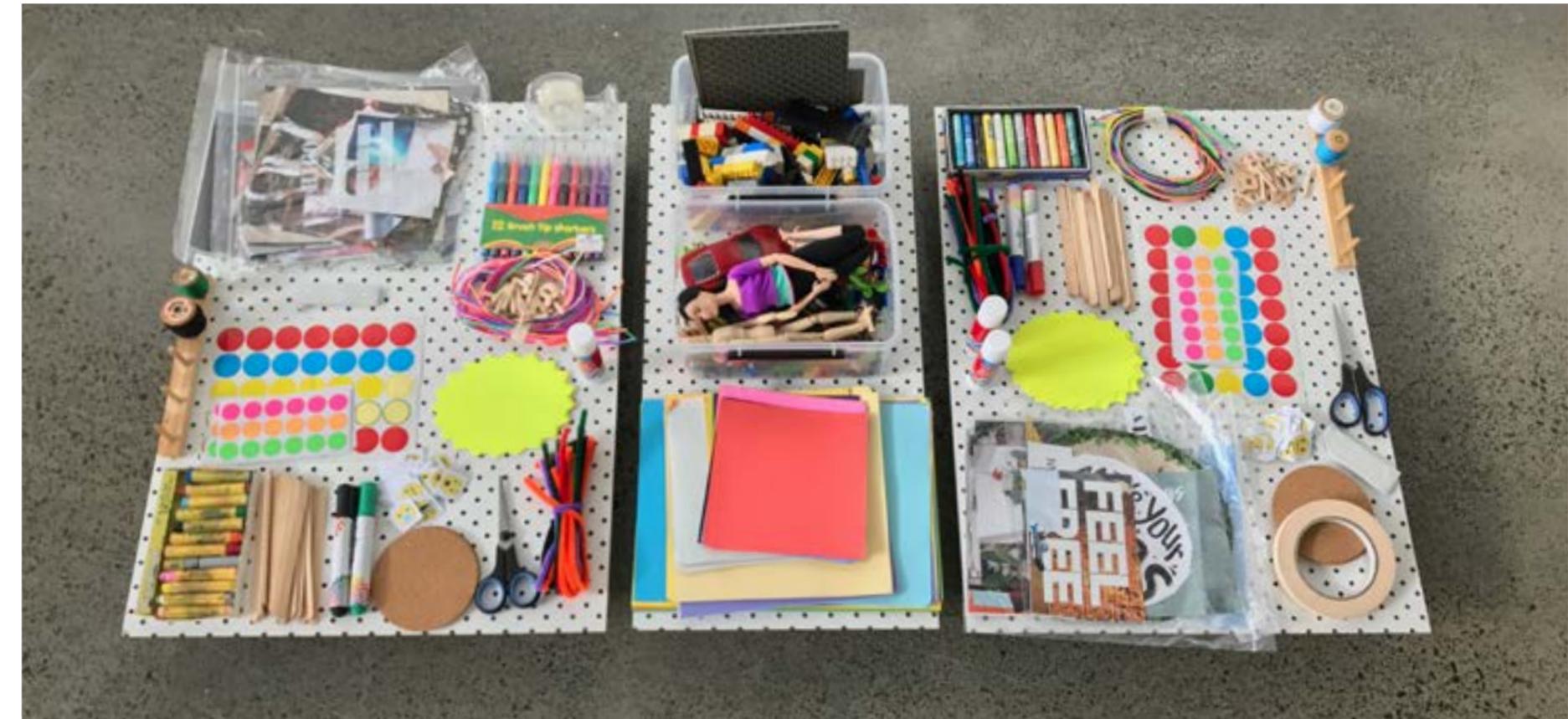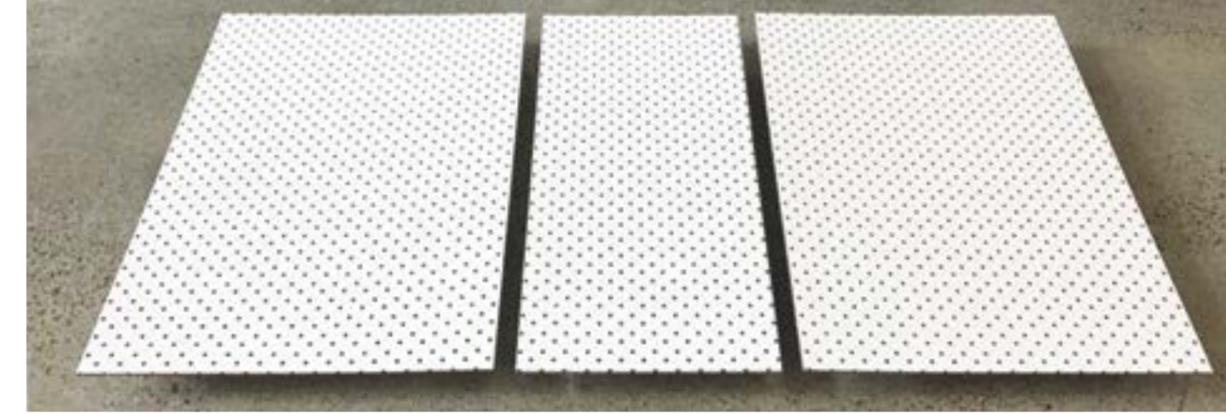
Figure 58: First prototype of 'Toolbox on wheels'

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.

Figure 63: 'Toolbox on wheels' stacked inside custome made boxes for transportation.

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 asterisks were added throughout the course of the workshops. I felt adding new tools from time to time kept the toolbox 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 ready-made objects that represent human forms, food and anything that has wheels.

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, I 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)

Tools and materials I would use again

Lego
Ready-made objects, (human forms, mini skateboards etc)
*Modeling clay
Pipe-cleaners
Scissors
Cellotape
*Googly eyes
Pre-cut collage materials, images and words cut from magazines.
Semi-circle pieces of wood
Popsicle sticks
Emoji's (pre-cut)
Blu-tack
Glue sticks
Small wooden blocks
Wooden sticks
Cork coasters
Coloured A4 paper/card
Square origami paper
Pack of felt-tip pens
Straws

Tools and materials I may use again depending on the context

Large marker pens
Crayons/pastels
Post-it-notes
*Cardboard lollipops
Circle stickers in variety of colours
Location icons

Tools and materials removed from the toolkit as they were not used

Coloured plastic string
Cotton thread
Star shaped yellow cards
A3 & A2 white and brown poster paper

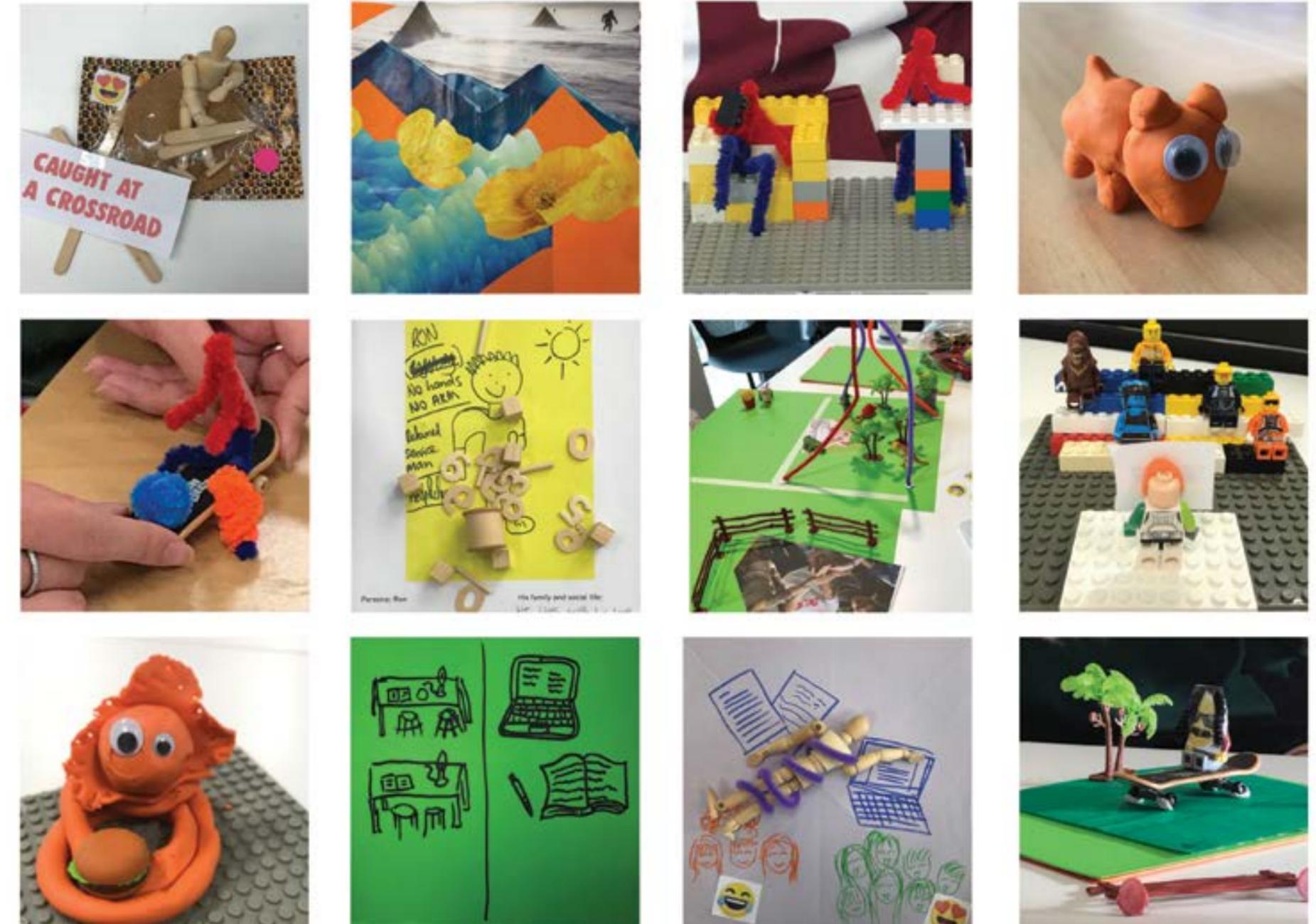**Table 05**: Most used to least used tools and materials in this research. (Asterisks notes materials or tools that were added throughout the series of workshops)

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

Discussion

Introduction

Despite the growth of co-design in recent years, co-design with participants who experience disability and impairment is still an evolving field (Hendriks et al., 2015). This 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 occurring from the physical barriers and ableist attitudes in society (Oliver, 1995). As well as Tom Shakespeare's (1996) research advocating for giving participants who experience disability "control over the [research] process, over their words and over their participation" (p.116).

The goal of participatory design activities is to include users in activities that design

future experiences (Basbelle et al., 2016). Wilson and colleagues (2015) provide an example of a co-design activity where they asked participants with reduced arm and hand dexterity, to build a tower using marshmallows and dried spaghetti. The prescriptive nature of the activity shut down opportunities for learning, was not possible for many participants and as such created poor experiences for participants. Failure to use a flexible approach can result in poor participant engagement, or disempowerment of participants.

Flexibility in codesign 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.70). 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 means 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.33).

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., 2018). 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 (2018) 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.9). Allowing disabled people to determine and manage their participation in research supports the social model of disability by reducing barriers for participation (Oliver, 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 trialled 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 still chose to interview parents/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 not dis-abled by societies attitudes or the physical space (Oliver, 1995). In 'What does participation mean? An insider perspective from people with disabilities', by Hammel and colleagues (2008), people with disabilities describe independence in research as not being defined as the ability "to perform tasks by oneself" (p.1445), but through being able "to participate freely" (p.1445). Free will and autonomy, specifically decisional autonomy, were cited as being the most important elements for independent participation, and the opportunity "to exert choice and control over how one lives and acts" (p.1445). The combination of the flexible approach in this research, combined with the adjustments made to the toolkit for more independent participation, aligns with Hummel et al.'s argument around the meaning of

independence in research for participants who experience disability and impairment.

The designers and researchers who participated in the Flemish research by Hendriks and colleagues (2015), reported that they had found it challenging to focus on capability instead of disability in their co-design practice. In this research, both a flexible approach and an accessible toolbox allowed participants to participate more independently in co-design. Consequently, they appeared to be less focused on their abilities or disabilities. Only one participant shared their desire to be able to use scissors when confronted by the adept cutting skills of another participant. "I am jealous of your cutting skills, I will never be able to cut like that, ever." Despite this comment, this participant still participated fully in their own way, using mainly Lego, modeling clay and ready-made objects.

The power of reflection

Accessible co-design can benefit from bringing a practice of regular reflection into the process, both by the participants and by the facilitator. In this research, reflection on making, on the co-design experience, and on my approach as a facilitator brought to light unexpected and valuable thoughts, experiences, and emotions. Reflection can be viewed as "both a way of learning about and as a way of changing practice" (Shutz, 2007, p.26). Moreover, reflection is an essential and valuable practice in person-centred practice (Bulman & Schutz, 2013).

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 in co-design can enable participants to externalise their thoughts and feelings, and

"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 Steen (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).

Reflecting at the end of every workshop helped me develop new techniques for facilitating, to adjust co-design methods for proceeding workshops, and to make note of interesting events in the process which I was unable to make sense of at 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.

For example, using personas can allow for the expression of personal experiences, or extreme or different opinions while protecting an individual's identity (Nakarada-Kordic et al., 2017). Moreover, Hendriks et al. (2015) discuss the challenge they (researchers) experienced when trying to understand how participants felt about disability language, (what terms participants use for themselves) as well as the researchers' insecurity around how to address impairment and disability in their interactions with participants. Hendriks and colleagues (2015) suggested that future co-design researchers should "co-design their approach with participants to navigate this challenge...to adopt a preparatory codesign approach, involving the participants with impairments..." (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.

Nakarada-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. Wilson et al. (2015) created an activity titled 'someone who isn't me', in which participants were asked to respond to an idea with their own opinion, as well as that of someone else they know who experiences 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 facilitator. 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. (2018), Hendriks et al. (2015), and Chamberlain and Craig (2013) all practice this approach. While, Shakespeare (1996), 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, in the Florence Project computer scientists (designers) and nurses (participants) 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). At first the computer scientists thought they would design a system for nurses, but after experiencing the realities of nursing, and realising 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; Bjerknes & Bratteteig, 1988).

Carroll and colleagues (2018) 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 send interview questions ahead of time so she could prepare her responses. Hendriks and colleagues (2015) 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.71). 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 participants' 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.116).

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.S3162).

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 labeled 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 experience.

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 colleagues 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.

05: Conclusion

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.

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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

Appendix 01

Ethics Approval letters from AUTEC

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

17 April 2018

Stephen Reay
Faculty of Design and Creative Technologies

Dear Stephen

Re Ethics Application: **18/130 Accessible co-design: Empowering participants with accessibility needs to more effectively participate in co-design**

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

Your ethics application has been approved for three years until 17 April 2021.

Note: Exclusion criteria apply to those persons who meet the inclusion criteria but who are excluded from the research for some other reason. In this case, the only relevant exclusion criteria are those persons who have a direct relationship with the Primary researcher, and this may be included in the Information Sheet.

Standard Conditions of Approval

1. 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.
2. 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.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: olivia.labattaglia@gmail.com; Ivana Nakarada-Kordic

AUTEC Secretariat

Auckland University of Technology
D-88, WU406 Level 4 WU Building City Campus
T: +64 9 921 9999 ext. 8316
E: ethics@aut.ac.nz
www.aut.ac.nz/researchethics

5 December 2017

Stephen Reay
Faculty of Design and Creative Technologies

Dear Stephen

Ethics Application: 17/433 **More accessible co-design toolkits: Empowering participants with accessibility needs to more effectively participate in co-design**

I wish to advise you that a subcommittee of the Auckland University of Technology Ethics Committee (AUTEC) has **approved** your ethics application **in stages**.

This approval is for three years, expiring 5 December 2020.

Full information about future stages of this research needs to be provided to and approved by AUTEC before the data collection for those stages commences.

Standard Conditions of Approval

1. 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.
2. 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.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Non-Standard Conditions of Approval

1. Removal of both the offer of counselling and the accident compensation statement in the Information Sheet.
2. Consideration of limiting the offer of confidentiality due to the small pool of potential participants who may be well known.

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by AUTEC before commencing your study.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: olivia.labattaglia@gmail.com; Ivana Nakarada-Kordic

Appendix 02

Expert Interview information sheet, consent form and indicative questions

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Participant Information Sheet

Expert Interview Information Sheet

Date Information Sheet Produced:

20 November 2017

Project Title

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

An Invitation

Hello, my name is Olivia Labattaglia. I am a Master of Philosophy student at Auckland University of Technology. I would like to interview you about your expertise in experiences of access citizens for them to be able to effectively participate in group workshopping settings. We are working towards a project concerning the re-design of co-design toolboxes and methods for greater accessibility for participants.

What is the purpose of this research?

The purpose of this research is to understand what challenges access citizens might have when attempting to participate in current 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 either living with an access need, or working within the access community. We are looking for participants who can describe experiences of group work or possibly even co-design in the access sector.

How do I agree to participate in this research?

If you would be happy to take part in this research then please get in touch with me, the researcher, Olivia Labattaglia at 021 0737315 or Olivia.labattaglia@gmail.com. I will follow up with a consent form and further information about the questions and themes we would like to discuss.

Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw from the study, then you will be offered the choice between having any data that is identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

To do this research I would like to have a face to face interview at your place of work. The interview will take between 1 – 1.5 hours. I would like to discuss your experiences of group work, and what kinds of group work you can and cannot do.

What are the discomforts and risks?

We have no intention of making you feel discomfort at any point, however you have every right to respond that you would prefer not to answer any of our questions. I will not pry.

How will these discomforts and risks be alleviated?

AUT Health Counselling and Wellbeing is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research, and are not for other general counselling needs. To access these services, you will need to:

- drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment. Appointments for South Campus can be made by calling 921 9992

Consent Form

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

Project Supervisor: **Dr Stephen Reay**

Researcher: **Olivia Labattaglia**

○   I have read and understood the information provided about this research project in the Information Sheet dated 20 November 2017.

○   I have had an opportunity to ask questions and to have them answered.

○   I understand that notes will be taken during the interviews and that they will also be audio-taped, video-taped and transcribed.

○   I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

○   I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

○   I agree to take part in this research.

○   I wish to receive a summary of the research findings (please tick one): Yes○   No○

Participant's signature: ....

Participant's name: ....

Participant's Contact Details (if appropriate):

....

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee on 05 December 2017 AUTEC Reference number 17/433

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 tell me about any focus group work or workshops you have done with participants who experience disability or impairment? What kind of style has it been done in?

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 they were run?
   b. or aspects of them that made them really successful or non-successful?

5. The premise of this research is that all people are creative everyone has thoughts, feelings, and lives an everyday life different to everyone else, and objects can really help unlock memories and ideas and help people think more 'outside the box' than if using stock-standard interviews, so I 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 I would like you to pick a bag, and then think about how this 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 with a group of participants who experience disability or impairment

8. Could you recommend any other people that I should be talking to about this project? Anyone that might be interested in what I am trying to do and might have some experiences or opinions they would be willing to share?

Appendix 03

Participant information sheet and consent form for co-design workshops

Consent and Release Form

For use when photographs, videos or other image recording is being used

Project title: **Accessible co-design toolkits: Empowering participants with accessibility needs to more effectively participate in co-design**

Project Supervisor: **Dr Stephen Reay**

Researcher: **Olivia Labottaglia**

○ I have read and understood the information provided about this research project in the Information Sheet dated 04/04/2018.

○ I have had an opportunity to ask questions and to have them answered.

○ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.

○ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.

○ I permit the researcher to use the photographs that are part of this project and/or any drawings from them and any other reproductions or adaptations from them, either complete or in part, alone or in conjunction with any wording and/or drawings solely and exclusively for (a) the researcher's thesis (b) educational exhibition and examination purposes and related design works.

○ I understand that the photographs will be used for academic purposes only and will not be published in any form outside of this project without my written permission.

○ I understand that any copyright material created by the photographic sessions is deemed to be owned by the researcher and that I do not own copyright of any of the photographs.

○ I agree to take part in this research.

Participant's signature: ....

Participant's name: ....

Participant's Contact Details (if appropriate):

....

....

....

....

Date:

Approved by the Auckland University of Technology Ethics Committee on 17.04.2018 AUTEC Reference number 18/130

Note: The Participant should retain a copy of this form

2 July 2015   page 2 of 3   This version was last edited in June 2016

CO-DESIGN WORKSHOP PARTICIPANT INFORMATION

CO-DESIGNING CO-DESIGN

Date : 08 / 05 / 2018

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.

What will happen in this research?

You are invited to take part in a series of 4 workshops, during the months of May to August. In these workshops, you will work with Olivia and Stuart, using a co-design process to discuss and interact with its methods, to help design an accessible co-design approach and toolbox.

The only requirements for participating in these workshops are, a willingness to discuss creative activities, how you might complete them, any difficulties you encounter trying to do them, and how you might adapt them in order to give them a go.

Zero artistic ability is required, just a curious mind and a willingness to try.

The 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 Tavvao-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 chose NOT to participate in this research, it will not affect your participation in the leadership programme. This research is merely 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
olivia.labattaglia@gmail.com