



Storytellers with lived experience strengthening opportunities for people with disability to live independently

A co-design project

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Executive Summary

The aim of this co-design project was to create a series of tools to build the capacity of people with disability to make informed decisions about housing options. Traditionally, people with disability have been co-located in shared living environments such as group homes and residential aged care, or with family when available. In the context of acquired disabilities, discharge pathways from hospital to home can be challenging, with many people who have sustained a spinal cord injury or acquired brain injury being unable to return to their pre-injury homes, and finding themselves living in shared living environments.

In more recent years, we have seen a shift towards individualised housing options for people with disability, evidenced both globally and in Australia. While the increased availability of individualised housing options for young people with disability is welcomed, this opportunity requires many people with disability to adapt to exercising more choice and control over their lives. For some, particularly those whose lives have been institutionalised in shared housing, this shift to more independent living may not seem achievable.

By adopting a co-design approach, we sought to create capacity building tools that met the information needs of people with disability, while also challenging misconceptions and assumptions about what is possible for people with disability. This project presented a unique opportunity to use co-design to develop tools for people with disability, by people with disability, while also evaluating the co-design experience for participants.

The co-design project was conducted over a period of 12 months, facilitated by three staff and ten lived experience contributors/partners with complex acquired neurological disability. Ten capacity building tools were produced, including a four part video series about moving into independent living, a three part audio series about finding the right support and a three part podcast series about moving out of residential aged care. The tools are available on the Housing Hub website.

This project was designed with a pre-post research evaluation to gain an understanding of the co-design experience. Nine participants consented to participate in the evaluation, including three facilitators and six of the ten lived experience contributors/partners. The three facilitators are employed at the Summer Foundation and have backgrounds in allied health; one is also a stroke survivor. The lived experience partners/contributors have lived experience of moving into more independent living and brought a range of personal skills to the project with experience as an accountant, teacher, artist and disability advocate.

The tools produced were evaluated by the nine participants with use of a customised rating scale developed to evaluate i) usefulness of the tool; ii) enjoyment watching/reading the tool; and iii) satisfaction with the tool. Overall, the responses were very high in response to enjoyment, satisfaction and usefulness across all three of the tools. Usefulness of the podcast tool was rated very high with a mean rating of (4.1) and satisfaction ratings across all three tools were also high (>3.9).

In addition, 18 qualitative interviews were conducted with nine participants pre and post participation in the project. Interview transcripts were analysed using constructivist grounded theory methods, providing an in-depth understanding of the experience of the participants, capturing hopes and expectations, as well as reflections about the co-design experience. Three

main themes were developed from analysis of pre-project interview data. *Theme 1: Embracing the opportunity; Theme 2: Juggling hopes and fears; and Theme 3: Is this co-design?* An additional three themes were developed from analysis of post-project interview data. *Theme 1: Making sense of co-design; Theme 2: Being employed and contributing to society; and Theme 3: Creating meaningful tools.*

In summary, this co-design project and evaluation has produced valuable capacity building tools, while also providing new learning about the experience of participating in co-design. Indeed, the findings of this project address a gap in research evidence to guide co-design engagement with people with complex neurological disability. While further work is required to build upon these findings, a key outcome of this study will be the development of a framework to support co-design engagement for people with complex disability, especially people with cognitive and communication challenges.

Introduction

Background and context

People with disability frequently have little choice regarding where and with whom they live (Connellan., 2015; Wiesel et al., 2015). Traditionally, people with disability have been co-located in shared living environments such as group homes and residential aged care, or with family when available. In the context of acquired disabilities, discharge pathways from hospital to home can be challenging, with many people who have sustained a spinal cord injury or acquired brain injury being unable to return to their pre-injury homes, and finding themselves living in shared living environments. The Australian Institute of Health and Welfare reports that as of March 2021 there are 4,106 people under 65 years living in RAC, despite a fall of 19.7% over the previous 12 months (AIHW GEN aged care data, 2021).

While shared living suits some, evidence suggests that many people experience a lack of choice or control in such environments, with limited opportunities for meaningful occupational participation and capacity building (Oliver et al., 2020). In addition, the burden of caring for people with complex acquired neurological disabilities in the home environment is a significant and often chronic challenge for family members. This challenge is especially the case for ageing parents.

In more recent years, we have seen a shift towards more individualized housing options for people with disability, evidenced both globally and in Australia. More specifically in Victoria, with compensable schemes such as the Transport Accident Commission (TAC) and the introduction of the National Disability Insurance Scheme (NDIS) and Supported Disability Accommodation (SDA) funding, there are more opportunities for people with disability to move into individualised models of housing, upholding their human right to choose where and with whom they live (Oliver et al., 2020). According to the NDIA, as of June 2021 there are 16,033 participants receiving SDA payments (NDIA, 2021). While the increased availability of individualised housing options for young people with disability is welcomed, this opportunity requires many people with disability to adapt to exercising more choice and control over their lives. Indeed, with respect to housing choice, for some, particularly those whose lives have been institutionalised in shared housing, this shift to more independent living may not seem achievable. Therefore, as this shift occurs, impacting both people with disability and the housing sector more broadly, people with disability need support when considering housing opportunities. A critical window of opportunity currently exists to build the capacity of people with disability who would directly benefit from emerging housing options.

Compounding this need for capacity building to support enactment of choice and control in everyday life, people with disability continue to be marginalised. Adults living with complex disabilities frequently describe feeling separated or isolated from everyday community living, especially people with complex neurological disabilities with physical and/or cognitive and communication challenges. This marginalisation is evidenced in lower rates of engagement in paid employment, participation in community activities and loss of social relationships (Levack et al., 2010). Research evidence suggests that consequently, people with disability often feel disconnected and disempowered (Douglas, 2020). Indeed, young people living in aged care are one of the most marginalised and isolated groups of people in our society (Winkler et al., 2012).

Furthermore, policy and research that impacts the lives of people with disability is too often driven by people without lived experience of disability.

Adopting an expert by experience approach and using storytelling to hear the voice of people with disability is one approach to addressing the marginalisation of people with disability. The Summer Foundation, established in 2006, is a leader in supporting the voice of lived experience in the disability sector. The Summer Foundation has supported over 250 younger people in RAC or at risk of entry to tell their story and produced over 100 digital stories. The Summer Foundation seeks to change human service policies and practices related to young people (18 to 64 years old) who are living in or at risk of entering aged care. Storytelling is an accessible platform for people with disability to share their lived experience. Research evidence suggests that listening to stories of lived experience is validating for the storyteller and inspires hope for others living with disability (D’Cruz et al., 2019;2020a). Furthermore, sharing stories of lived experience to help others is recognised as meaningful occupational engagement, strengthening the validating impact of the storytelling opportunity (D’Cruz et al.,2020b).

Building upon the notion of creating opportunities for people with disability to share their insights from lived experiences and to be better heard, co-design offers much potential. Co-design is a collaborative process of knowledge sharing, problem solving and creating solutions, underpinned by lived experience (Slattery et al., 2020). While co-design is not new, in the disability and rehabilitation context, there is a more recent shift towards creating opportunities for co-design in both research and practice. Indeed, increasingly there is an expectation that research that impacts the lives of people with disability must include co-design engagement in the research design. While this is a positive shift towards valuing the lived experience of disability, there is currently limited understanding of best approaches to co-design engagement for people with complex neurological disability, especially those with cognitive and communication challenges.

This project presented a unique opportunity to use co-design to support the development of capacity building tools, while also evaluating the co-design experience for people with complex neurological disability.

Project aims

The co-design project centred around the opportunity for people with disability to create capacity building tools that demonstrate successful housing outcomes, informed by their own lived experience of moving to more independent living. The aim of the project was to share the tools produced with young people with disability currently living in residential aged care. Underpinning this project was a commitment to co-design as a suitable process to develop tools that resonate with the experiences of young people with disability living in aged care, with the potential to build their capacity to take action to move into more independent living.

Key project aims

1. Develop capacity building tools with people with complex neurological disability (inclusive of brain injury & spinal cord injury) to demonstrate independent living outcomes by people with disability.
2. Increase leadership and influencing opportunities afforded to storytellers with complex neurological disability directly involved in the project.

3. Build the capability of people with disability to be empowered consumers who have the capacity to make an informed choice about independent living options.
4. Shape the public's perception about what constitutes an ordinary life for people with disability and understand more about the benefits of people with disability residing in the community.

Research objectives

To ensure robust evaluation, a research study was wrapped around the co-design storytelling project. This study received ethics approval from La Trobe University [HEC20493]. A key objective of this study was to evaluate satisfaction with the produced capacity building tools, from the perspective of participants in the co-design storytelling project. In addition, given the lack of available research evidence to guide the use of co-design with people with complex neurological disability, we sought to develop a more in-depth understanding of the experience of co-design engagement, exploring enablers and barriers. We also sought to identify potential benefits of co-design engagement such as developing peer social connections and building new skills/capacity. New insights into ways to build peer connections are particularly relevant given the negative impacts of social isolation and reduced productive and meaningful occupational engagement opportunities for people with complex disabilities.

Key research objectives

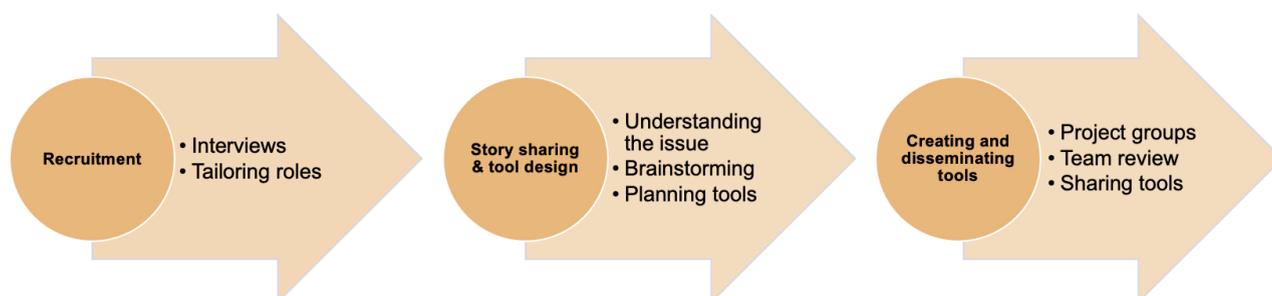
1. Evaluate satisfaction with the capacity building tools from the perspective of project participants
2. Understand the experience of co-design engagement from the perspective of participants
3. Identify potential enablers & barriers
4. Identify potential capacity building benefits
5. Identify potential peer connection benefits

Method

Project procedure

The co-design storytelling project was conducted over 12 months (including planning & recruitment to the project), led by Monique de Costa from the Project Implementation Team at the Summer Foundation. The project was designed with three main phases: Phase 1: Recruitment; Phase 2: Story sharing and tool design; and Phase 3: Creating and disseminating tools.

Figure 1 – Project phases



Phase 1: Participant recruitment

Participants were recruited to this project by advertising and interviewing short-term contract positions for people with lived experience of disability. The co-design positions were advertised on Seek and Ethical Jobs, as well as disseminated through Summer Foundation networks. Given the context of Covid-19 restrictions in Melbourne, recruitment interviews were conducted on zoom, by staff at the Summer Foundation experienced in working with people with disabilities. Interviews were adapted to the needs of participants with cognitive and communication challenges such as provision of written and verbal information, use of plain language, and rest breaks as needed. Participants were also given encouragement and positive feedback throughout the process given that for some people, this was their first experience of a job interview. The process was intended to be a strengths-based, capacity building experience for each of the participants. Following the interviews, positions for participation in the co-design project were tailored to the skills and needs of the participants. While the intention was to offer only paid positions, given the personal circumstances of some, there was a need to offer paid (Lived Experience Partner) and unpaid (Lived Experience Contributor) positions. Lived Experience Partners were employed on a short-term contract position for the duration of the project. Lived Experience Contributors provided input at different timepoints throughout the project and were offered gift vouchers for their involvement. In total ten lived experience contributors/partners were engaged for this project.

Phase 2: Story sharing and tool design

Phase two involved five key workshop activity sessions conducted online. These sessions were planned prior to the commencement of the project, but were sufficiently flexible to be adapted to the needs of the group throughout the project. Each session was scheduled for a maximum of two hours, occurring on a weekly basis over a period of eight weeks. The sessions were facilitated by three staff from the Summer Foundation; all with professional backgrounds in allied health, one of whom is a stroke survivor.

These sessions included the three facilitators and lived experience partners and focused initially on story sharing and the formation of trust and connection between the team. Each of the lived experience partners had previous experience of moving from shared living such as residential aged care or group homes to more independent living. As the project progressed, smaller working groups were formed, centred around the three types of capacity building tools created. Some of the work of the lived experience partners and contributors involved working as a team via zoom, and other tasks were completed between project sessions, involving a combination of reading and written work. The facilitators supported the lived experience partners/contributors both within and outside of the sessions as required.

Activity 1: Understanding your experience and aims of project

Activity 2: Understanding the problem we are trying to solve

Activity 3: Defining the problem and scope of tools

Activity 4: Brainstorming ideas and content for tools

Activity 5: Confirming content for tools and delegating roles

Phase 3: Creating and disseminating tools

Phase three involved the creation and dissemination of the capacity building tools. This process primarily occurred in the smaller groups and involved script writing, filming, audio recording and editing. Lived experience contributors supported the process, providing feedback and consultation on the process and tools as they were developed. This phase concluded with sharing and review of the tools across the larger group and development of a broader dissemination plan.

Activity 6: Developing tools

Activity 7: Reviewing and editing tools

Activity 8: Finalising tools and developing engagement plan

Research procedure

Qualitative research methodology was chosen for this research given the focus on understanding the subjective experience of co-design engagement. Qualitative research stems from the epistemological paradigm of constructivism and interpretivism, in which the experiences of individuals are understood as constructed and interpreted from the influence of the social world in which the experiences exist (Charmaz., 2014). We utilised constructivist grounded theory to guide all stages of the research. Constructivist grounded theory is situated within the symbolic interactionist methodological framework and emphasises the co-construction of a theoretical understanding of the data by both the participants and the researcher.

Participants of the co-design storytelling project (lived experience partners/contributors & facilitators), who met the inclusion criteria outlined below, were invited to participate in this study. Prior to participation in the study, consent was provided by all participants. Semi-structured in-depth interviews were the primary method of data collection. [See appendix A for an example of the interview guide]. Interviews were conducted pre and post participation in the co-design project. Consistent with Covid-19 restrictions in Melbourne at the time of the project, all interviews were conducted individually via zoom. Interviews were audio recorded and transcribed, with a

pseudonym allocated to each participant to ensure anonymity. Consistent with grounded theory methods, data collection and analysis occurred concurrently.

Co-design participants: Lived experience partners/contributors

Inclusion criteria:

- Adults between 18-65 years living in Victoria
- People with experience of physical, sensory and/or cognitive disability such as neurological disorders (brain injury, spinal cord injury, progressive disorders).
- Have experience of moving into more independent housing
- Have a device to participate in online activities, e.g. computer, laptop, ipad
- Can independently provide consent
- Have adequate communication skills to participate in an online interview

Co-design participants: Facilitators

Inclusion criteria:

- Employed by the Summer Foundation and facilitating the co-design project

Data collection also included evaluation of the capacity building tools that were produced. A customised rating scale was developed to evaluate i) usefulness of the tool; ii) enjoyment watching/reading the tool; and iii) satisfaction with the tool. A 5-point response format (1 very low to 5 very high) was used for each of the scales. All participants (lived experience partners/contributors & facilitators) were invited to complete the rating scale via email and were also invited to discuss their responses in the follow-up interview. The rating scale was purposefully developed for this project and included the following questions. See example of rating scale questions below.

How **useful** do you think these tools are in demonstrating successful housing and support outcomes to help people with disability to take steps toward moving out of nursing homes. Please rate from 1-5.

1. Very low
2. Low
3. Medium
4. High
5. Very high

How **enjoyable** was it to watch or read these tools? Please rate from 1-5.

1. Very low
2. Low
3. Medium

4. High
5. Very high

How **satisfied** are you with the end product of these tools? Please rate from 1-5.

1. Very low
2. Low
3. Medium
4. High
5. Very high

Research data analysis

The first author (KD) analysed all 18 interview transcripts, drawing upon constructivist grounded theory methods (Charmaz., 2014). Charmaz describes constructivist grounded theory data analysis as involving two main phases: initial coding and focused coding, with axial and theoretical coding as secondary processes. Initial coding involved line by line coding of the data, while focused coding followed a process of refining the codes. The most frequent codes were systematically compared, while exploring relationships between the codes, resulting in emergent categories drawn from the initial codes. Axial coding brought the analysed data back to a more coherent whole to produce the final themes and sub-themes. This process was supported by regular discussions with co-author (JD), along with memo writing and critical reflective writing, contributing to the trustworthiness of the study.

Results

Participants

In total nine people consented to participate in this study: six lived experience partners/contributors and three facilitators.

Lived experience partners/contributors who participated in the interviews are aged from their 30's to their 60's and have lived experience of moving from shared living into more independent living. Each of the lived experience participants either currently live in an SDA apartment (5) or are waiting to move into an SDA apartment (1). Prior to this move they came from a range of previous living situations, such as residential aged care, group homes and living with family. Main disability types included stroke (2), traumatic brain injury (1), muscular dystrophy (1) and multiple sclerosis (2). Lived experience partners/contributors brought a range of previous skills and experience to the project including accountant, teacher, artist and disability advocate. Lived experience partners had a paid position in the storytelling project, while the lived experience contributors had a volunteer role.

Facilitators who participated in this study are employed at the Summer Foundation and have backgrounds in allied health. They are aged in their 30's to their 40's with a range of experience facilitating storytelling and/or co-design work with people with disabilities. One of the facilitators is a stroke survivor.

Project outcomes: Capacity building tools

Ten capacity building tools were created from this project and are available on the Summer Foundation and Housing Hub websites. The tools include:

Three part podcast series: [*A conversation about moving out of a nursing home*](#)

Part 1: Grief, loss and mental health

Part 2: Fears about moving and challenging others' perspectives.

Part 3: The hardest and the best things about SDA, the day to day reality and having hope

Four part video series: [*What it was like leaving a nursing home and moving into a new apartment*](#)

Part 1: Challenges and barriers to moving

Part 2: What supported you to move?

Part 3: Coordinating my daily support

Part 4: What is life like now?

Three part audio and written series: [*Where to find the right support for your move*](#)

Part 1: Where to find support?

Part 2: Who is in a support team?

Part 3: How to choose good support?

Table 1 – Key aims of the project and key outcomes

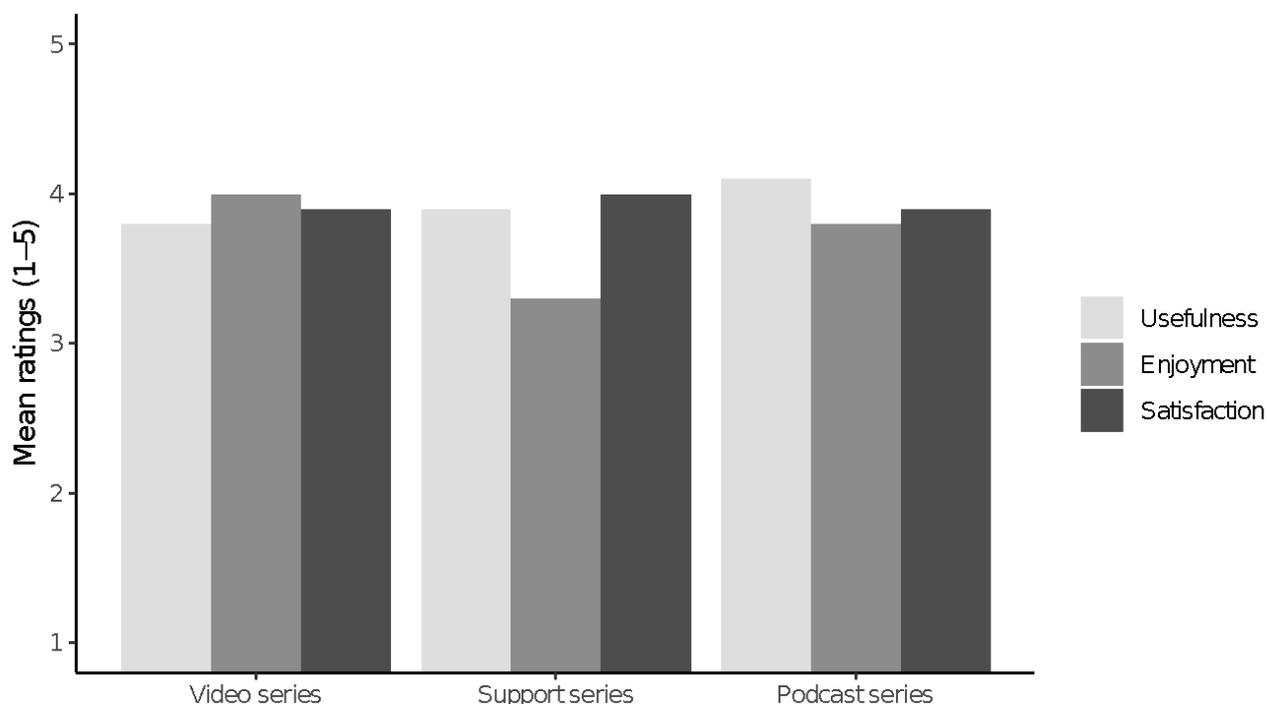
Aims	Outcomes
<p>Develop capacity building tools with people with ABI &/or SCI to demonstrate independent living outcomes by PWD.</p>	<p>10 capacity building tools created:</p> <ul style="list-style-type: none"> ● Three-part podcast series about moving out of residential aged care ● Three-part audio & written series about support (where to find support, who makes a support team, how to choose support) ● Four-part video series about moving out of residential aged care (RAC) to supported disability accommodation (SDA)
<p>Increase leadership and influencing opportunities afforded to storytellers with ABI &/or SCI directly involved in the project.</p>	<ul style="list-style-type: none"> ● Research interviews demonstrated that lived experience partners/contributors gained skills and confidence in co-design collaboration and work readiness. ● One of the lived experience partners co-presented at a co-design public forum as part of the 6th Pacific Rim Conference in Melbourne, 2021. ● Lived experience partners/contributors created a short video about the meaning of co-design.
<p>Build the capability of PWD to be empowered consumers who have the capacity to make an informed choice about independent living options.</p>	<ul style="list-style-type: none"> ● Capacity building tools are available on the Housing Hub webpage as a resource for people with disability and supporters when looking to move into more independent housing. ● Links to the capacity building tools were shared with the audience (100+) people with and without disability who attended the co-design public forum (Melbourne, 2021). ● Links to the capacity building tools were shared with the audience (40+) people with and without disability who attended a presentation of the project/study at the Living with Disability Research Centre seminar series (La Trobe University, 2021) ● Links to the capacity building tools have been shared on social media platforms. ● Links to capacity building tools are shared at workshops facilitated by the Housing Hub and Summer Foundation targeting an audience of health

	<p>professionals and/or people with disability and close others.</p> <ul style="list-style-type: none"> • Capacity building tools have been profiled on the Staying Connected page on the Summer Foundation website
<p>Shape the public's perception about what constitutes an ordinary life for people with disability and understand more about the benefits of people with ABI &/or SCI residing in the community.</p>	<ul style="list-style-type: none"> • Links to the capacity building tools were shared with the audience (100+) people with and without disability who attended the co-design public forum (Melbourne, 2021). • Links to the capacity building tools have been shared on social media platforms. • Links to capacity building tools are shared at workshops facilitated by the Housing Hub and Summer Foundation targeting an audience of health professionals and/or people with disability and close others.

Capacity building tools: Evaluation

All nine participants completed the rating scale that evaluates the tools produced. Mean usefulness, enjoyment and satisfaction ratings across all three tools are shown in figure 1. Average ratings were all at the high end of the scale (>3.8) except for the enjoyment of the support tool (M 3.3, R 2-4). Usefulness of the podcast tool was rated very high with a mean rating of (4.1) while enjoyment of the video series and satisfaction with the support series were also rated very high with mean scores of (4). There was no notable difference between scoring by lived experience contributors/partners and facilitators across each of the tools. Overwhelmingly the responses were very positive in response to enjoyment, satisfaction, and usefulness across all three of the tools produced.

Figure 2 – Tool evaluation



Co-design experience: Qualitative findings

In total 18 interviews were conducted with nine participants. The interviews were conducted prior to participation in the co-design storytelling project and after the conclusion of the project. Analysis of the interview transcripts provide an in-depth understanding of the experience of the participants, capturing hopes and expectations for the project, as well as reflections about the experience of participating in the project. While the interviews were conducted across three participant groups (lived experience partners/contributors and facilitators) there was consistency in experiences.

Pre-project: Hopes and expectations

Three main themes were developed from analysis of pre-project interview data. *Theme 1: Embracing the opportunity*; *Theme 2: Juggling hopes and fears*; and *Theme 3: Is this co-design?* These themes capture the hopes and expectations of the project participants, centred around the opportunity to do things differently through co-design, as well as the opportunity to be employed in a meaningful role by contributing to the lives of others. The following quote from Ingrid, a lived experience partner, captures the overall sentiment of the project participants, “*I have always wanted to work like this but felt that it was out of reach.*”

Embracing the opportunity

All of the participants, including lived experience partners/contributors and facilitators expressed excitement about this project, and the opportunity for people with lived experience of disability to

be involved in shaping the outcomes of the project. As shared by Frankie, one of the facilitators, *“Lived experience partners have so much more to give than what we have given them the opportunity to do.”* More specifically, this project was seen as a chance for participants with lived experience to not only draw upon their lived experience knowledge, but to complement this by bringing other personal skills and experience and to be actively involved with idea generation and problem solving. Holly, one of the lived experience partners described this opportunity as, *“Moving on from the storytelling a bit to making a difference.”* While the opportunity to do things differently, afforded by co-design, was appealing to the lived experience partners/contributors, they also valued the opportunity to contribute to the aim of the project to help people currently living in residential aged care. They recognised that they had the knowledge and experience, from their own lived experience of moving from residential aged care, to help others. Christine, one of the lived experience contributors, said that upon viewing the advertisement she felt, *“Wow- this is me”*. She then shared how the project resonated with her saying, *“I want everyone to have the same experience [moving out of aged care, as I have had]”*

Juggling hopes and fears

Each of the participants expressed hopes and fears about the co-design project, with some differences noted between those with lived experience and the facilitators.

The participants with lived experience of disability (partners/contributors) were particularly hopeful that the co-design nature of the project would enable them to be more fully engaged in the project. *“It will be fantastic to give my opinions and suggestions and have them listened to”* (Christine). While some participants were skeptical about the potential of co-design to be different, they noted that the opportunity to be employed in a paid position for the project instilled confidence in the authenticity of the project. The participants were also very excited about the opportunity to test out their work capacity through this supported work role. Deidre shared, *“My main goal is to see whether or not I can do it.”* Many reflected concerns about the potential impact of their communication difficulties, fatigue and access to sufficient support for work tasks such as reading and typing. For example, Gabby said, *“I’m a bit worried about other people understanding me and my speech and communication.”* While cautious, participants were also looking forward to the potential of meeting new people and building relationships with fellow project participants. Ingrid shared, *“Looking forward to working with others who have a similar life to mine.”*

The facilitators were particularly hopeful about achieving a genuine co-design experience. They expressed a vision for co-design in which lived experience participants were more than participants or consultants but rather were in a collaborative partnership with the facilitators. While the facilitators had faith in the capacity of the participants, they recognised potential challenges associated with achieving the right balance between empowering and supporting lived experience participants. The facilitators talked about trusting the process and tightening and loosening the structure as needed. The facilitators were also hopeful about creating a positive experience for the lived experience partners/contributors in which they created meaningful tools, while also experiencing a meaningful co-design process, supporting personal growth and capacity building. Erin, one of the facilitators, shared, *“I really hope that the tools that are produced are something different to what we have done before, given that they will be delivered by a co-design process.”* Frankie, another of the facilitators, shared her concerns about having enough time to make the process different. She said, *“Having more time to invest in each other and process but will it be enough?”* Facilitators were also keen to learn more about what lived experience participants were

seeking from the co-design opportunity, especially in relation to being employed. *“What value are people looking for? Employment or being paid? What does this look like for people?”*

Is this co-design?

Across all the participants, prior to the commencement of the project, there were many questions and reflections about the meaning of co-design. The lived experience participants, while having heard about co-design, were mostly not particularly informed or confident about their understanding. One lived experience contributor, Christine, shared her thoughts about co-design, focusing on the strengths-based solution focused nature of the project. She said, *“As a concept [co-design] sounds fantastic. It is a great movement on. When I have provided my lived experiences... I haven't really looked at, not so much a more positive thing.”* Others saw it mostly as a collaborative opportunity as described by Deidre: *“Team effort of coming together, people from [Summer, Foundation] people with disabilities coming together collaboratively working to design their tools.”* Other lived experience partners who were more familiar with co-design shared scepticism about whether this project will actually be co-design or whether it will be like other projects that fall short of the mark. One of the facilitators also shared reflections about the possibility of missing the mark, while reflecting upon the potential learning about finding the right balance for co-design engagement with people with complex disability. She raised the question, *“Is this what we can do and how we can do it? Is it OK if it isn't co-design?”*

Post-project: Reflections about the co-design experience

Three main themes were developed from analysis of post-project interview data. *Theme 1: Making sense of co-design; Theme 2: Being employed and contributing to society; and Theme 3: Creating meaningful tools.* These themes capture the reflections of the project participants, centred around new learning about co-design and work capacity. Overall the participants found the experience to be positive, expressing pride in the tools produced, while recognising areas for improvement in the co-design process. The following quote from Ingrid, a lived experience partner, captures the overall sentiment of the project participants, *“This is better but not fully there.”*

Making sense of co-design

Each of the participants, including lived experience partners/contributors and facilitators, reflected positively on their experience of the project. Central to the experience was the development of trusting and respectful relationships across the lived experience partners/contributors and facilitators. In particular, the lived experience participants described feeling well supported and valued throughout the project. They described feeling comfortable and safe to share their experiences, offer opinions and suggestions, ask questions and discuss potential solutions. As shared by Deidre, *“I think I definitely felt involved. I felt that my voice was heard. It was a teamwork project in order to make the tools.”* Consistent with this experience, participants also reflected that their initial concerns about their communication difficulties proved not to be a concern. *“I felt like everyone was very understanding [of communication] and I felt quite comfortable.”* (Gabby). From the perspective of the facilitators, Frankie had previously worked with some of the lived experience participants, and reflected that this established relationship was helpful throughout the project. She shared, *“This work is relational. I think having a relationship is helpful because otherwise we have to do that work at the start of this project to build that relationship.”* For the other facilitators who did not have a pre-existing relationship, the recruitment interviews prior to the project served as an important tool for building trust and familiarity with the lived experience partners/contributors early in the project. Each of the facilitators also reflected upon the importance of respectful

communication throughout the project to create a safe and trusting environment for co-design to thrive. Erin shared, *“I was really conscious of doing everything with respect, carefully listening and very aware of using inclusive language and being sensitive in my communication.”*

The participants also reflected about the meaning of co-design following participation in the project. Billie described good co-design as, *“Providing opportunities and building the skills of people.”* Deidre described it as, *“A more synergistic approach to make a fit for purpose resource”*, and Gabby shared, *“I thought it was a good way for people to share their experiences and their skills.”* A few of the lived experience participants questioned the need to define it as co-design, with Ingrid suggesting the use of the term *‘design’* as she felt that there should be an inherent understanding that all work for people with disabilities involves the input of people with disabilities.

While the participants found the project a positive experience, lived experience partners/contributors and facilitators shared reflections on areas for future improvement. Most of the participants felt that a clearer description of roles and an outline of the project project would have been helpful in increasing their understanding of project expectations. Consistent with this feedback was a view that co-design with people with cognitive and communication challenges benefits from facilitator leadership. Indeed, some participants reflected that in this project there was at times too much focus on equal partnership and the participants would have preferred more direction from the facilitators. Billie, one of the lived experience partners shared:

In equal partnership was the definition [of co-design] before [project commenced]. I think it confused our expectations about the project. [At the end of the project] We had a good conversation that we don't have the skills to project manage. Our skills are valued to make this product work [drawing upon lived experience knowledge].

Consistent with this reflection from the lived experience partners/contributors, were reflections from the facilitators about navigating decision making points in the process such as when to *‘step-in and lead’* to keep the project moving forward. *“This is me making the decision which is problematic but I don't know how else to move things along.”* (Frankie). While the facilitators described feeling dishonest at times when making decisions on behalf of the team, at the conclusion of the project, it was agreed by the majority of participants that given the fast pace of the project and the skills/needs of the lived experience participants, active facilitation and direction was required. Central to the success of this strategy is being transparent with the whole project team about the functionality of this leadership. As shared by Billie:

And the other thing that was mentioned in this was coming up with an agreed process map with key timeframes and who is involved. Important to map out the project and this is when we are going to make this decision and there are the key decision making points.

While there was support for an active facilitation role in a project management sense, the lived experience partners/contributors and facilitators emphasised the importance of opportunities for lived experience participants to make decisions and show leadership at key points in the design process. Indeed one of the lived experience participants, Ingrid, suggested that she would have liked to have had a bigger role in the project with more time and more responsibility. Frankie, one of the facilitators summed up the perspective of the facilitators:

Our intentions were more around supporting people to make decisions and whether this is a decision that we [facilitators] would make or not, I didn't really care about. We are saying to people, 'Yes you can make decisions about this'.

Participants also reflected that a mentor role would have been useful in supporting the lived experience partners to fulfill their role obligations. This potential mentor role was particularly noted in relation to the pace of the project, with participants reporting that they would have liked more time to reflect throughout the project and to process the content and emotions associated with sharing their lived experience. In the context of this project, one of the facilitators who is also a stroke survivor, reflected that perhaps her role in the project could have been more impactful if she had taken on a peer mentor role, checking-in with participants throughout the project. *"Being that person that they could vent to or clarify things, to be a reflection point and an extra support"* (Alex). Ingrid, one of the lived experience participants felt that having this support and space for reflection would have assisted with managing the time frame of the project and getting the message right for maximum impact. Without this space, Ingrid felt, *"I was editing myself too much"*.

Being employed and contributing to society

As indicated in the pre-project interviews, the lived experience participants highly valued the opportunity afforded through this project to participate in meaningful work. Deidre captures the sentiments of the lived experience participants with the following quote:

When you have a disability you feel that you have to resign to just having to focus on your disability and nothing else and to not work and to be a pensioner. It is nice to feel that [with this opportunity] you can contribute to society.

For some of the lived experience participants, this project provided the ideal opportunity to test out their work readiness. As shared by Deidre, *"It was a great way to reintroduce myself to the field of work and employment which is a huge deal for me."* For some it was about having the opportunity to be involved in problem solving solutions, while for others it was the opportunity to work on the development and write up of the tools. Gabby talked about the opportunity of testing out the development of professional working relationships. Fortunately for those participants who explored their work readiness, the project was a positive experience in which their work capacity was affirmed, contributing to an increased confidence in future work opportunities. For example, Deidre shared, *"When I started the project, I was unsure of whether I could meet all the requests, but I discovered that I could...I would love to continue to be involved with casual work. I think I can manage it. Definitely gave me confidence."* Indeed, three of the lived experience participants were offered a six month extension of their contracts for future co-design work. It is important to acknowledge that the lived experience partners/contributors in this project were closely supported by the facilitators, with roles tailored to their strengths and specific needs accommodated with flexible work tasks and hours. And for some, the work demands remained a little too fast, with suggestions for further flexibility in the pace of the work. *"I thought week to week it was a bit too fast to complete the tasks between team meetings"* (Gabby).

In addition to engaging in meaningful work and contributing to the lives of others, lived experience participants valued the opportunity of being employed. For some, this was about being paid, but for others it was about belonging to an organisation and the way in which this experience contributed to a positive sense of self. As shared by Deidre: *"Being part of an organisation is important. Paid and unpaid work." Not just being a drain on the system.* While not all participants were focussed

on the financial reward, they shared reflections about being able to treat themselves to a little purchase that they would not ordinarily be able to afford in their everyday life. Others were unable to accept a paid position and therefore took a volunteer role as a contributor due to concerns about the potential impact upon government payments/pensions. All the lived experience participants valued the opportunity to connect with others, coming together with a shared purpose in the co-design work. While they valued this opportunity, given Covid-19 restrictions at the time of the project, all co-design work was conducted online, impacting the social-relational opportunities for participants.

Creating meaningful tools

The final theme that emerged from analysis of the interview transcripts captures reflections about the experience of participating in the design and creation of meaningful and potentially impactful tools. The participants were proud of the tools produced and shared reflections about both the end products as well as the process of collaborating with others. Christine said, *“I think the project is great and they are fantastic tools...A voice that is actually part of a whole that people have some part of together.”* And Deidre shared, *“I very much enjoyed working on this project and seeing the end results.”* The participants also felt strongly that the tools reflected their experiences of moving out of shared living, and therefore were better tools to support the needs of others thinking of making the step toward more independent living. Deidre commented, *“Definitely showed through, people’s opinions showed through on the final product and I think that is a good thing.”* The facilitators also reflected that the tools *“achieved what we set out to achieve”*(Alex) in terms of co-design engagement and recognised the effort taken to ensure that the tools captured the voice of the lived experience participants. The facilitators also valued the ‘voice’ of the co-design lived experience contributors/partners in the tools produced and reflected upon the time and effort required to ensure the integrity of the co-design process and therefore achievement of this outcome.

The facilitators also talked about the important next step of dissemination of the tools being critical to achieving the aims of co-design. Erin shared, *“Getting these tools to people with disability, and getting them to people around them [close others] is going to be really key and how we do that is something that we have to think about carefully.”* Another facilitator, Alex, reflected that receiving feedback about the impact of the tools following dissemination will be important for the lived experience participants who have invested in the project and generously shared their experiences.

Discussion

This report outlines the outcomes of a capacity building co-design project as well as the research findings of a qualitative evaluation of the experience of participating in co-design. The findings of the evaluation provide valuable new learning to guide future co-design work. In particular, this study addresses a gap in research evidence, in how best to engage in co-design with people with complex neurological disability, including those with cognitive and communication difficulties.

The tools produced from this project have the potential to support people with disability who are currently living in residential aged care, group homes or living with family, and looking to move to more independent living. By engaging in co-design these resources have been informed by lived experience and are therefore targeted to meet the information needs of people with disability and their close others. Indeed these tools promote choice by being responsive to the lack of information currently available to people with disability to make an informed choice about appropriate housing and support options. Currently, many people with complex neurological disability have to make housing choices while still in hospital or rehabilitation settings, or in an institutionalised setting such as residential aged care. It can be difficult for people with disability to exercise choice in these settings, either due to having limited lived experience of a recently acquired disability, or longer term experiences of disempowerment in an institutionalised environment. The capacity building tools developed through this project are a resource to assist people with disability to make a more informed and empowered choice about where they live, who they live with and what modifications, equipment and supports will be required.

Overwhelmingly, this co-design project successfully met the aim of producing capacity building tools that are developed by and for people with disabilities. The lived experience participants are proud of the tools produced, demonstrating confidence that the contribution of their lived experience adds to the value of the tools to build the capacity of others looking to move to more independent living. While this report evaluated the tools with a rating scale, reporting high levels of satisfaction, this evaluation has only been conducted from the perspective of those who were involved in the co-design project. A future next step of this project will be to evaluate the usefulness of the tools from the perspective of other people with disability who have moved from shared living such as residential aged care, people with disability currently residing in residential aged care, close others and others such as support workers and health professionals.

While the explicit intent of this project was to create meaningful and impactful tools to help others, by engaging with people with disability in the co-design of the tools, the project itself demonstrates innovation in the disability sector. This innovation is evidenced in a number of ways including i) sharing the stories of people with disability and illuminating how people with disability can successfully move into appropriate housing of their choice; ii) creating an opportunity for people with disability to engage in meaningful occupational engagement that enables capacity building; and iii) demonstrating the work readiness of people with disability and the value of their contribution to the workplace.

Furthermore, by conducting a qualitative evaluation of the experience of participating in co-design, we are better positioned to understand the impact of this experience from the perspective of people with disability. As indicated in the thematic findings, the lived experience participants expressed that through co-design participation they felt heard and their experiences valued. Indeed, having

the opportunity to not just share their story of lived experience but to problem solve and create solutions, was a particularly valued experience. And while the participants recognised the important contribution of the facilitators to oversee the project and to keep it on track, they also recognised the important contribution of their own lived experience, in shaping and creating tools. Both the co-design process and the tools produced demonstrate a strengths-based perspective of disability. Furthermore, the lived experience participants affirmed the importance of having the opportunity to test out their work readiness and to be engaged in meaningful employment. Consistent with the findings of previous studies into the storytelling work of the Summer Foundation (D’Cruz et al., 2020), the participants affirmed the value that they placed on having the opportunity to help other people with disability. However, in the context of this co-design project, being employed (paid or unpaid) was additionally meaningful to the lived experience participants, contributing to their sense of belonging to the work of the Summer Foundation, as well as contributing more generally to society.

By seeking the subjective experience of participants (lived experience partners/contributors & facilitators) through interviews conducted pre and post participation in co-design, we have also gained valuable insights into the process of co-design. The findings suggest that while co-design is a valued and effective approach to designing tools informed by the lived experience of people with disability, when working with people with complex neurological disability, the role of the facilitator remains important to the process. While a couple of lived experience participants expressed an interest in developing facilitation skills and experience, others reflected that they would have appreciated more clearly defined roles and a project outline that included points of leadership in which the designated facilitators took more responsibility for project management decisions. It was felt that this style of facilitation might better enable the lived experience participants to engage in key problem solving and decisions throughout the project. Central to the success of such an approach would be transparent communication between the facilitators and participants about this division of roles. In line with this learning, a secondary outcome of the project will be the development of a framework for co-design engagement with people with complex neurological disability, informed by the research findings.

Furthermore, reflections from the lived experience partners/contributors and facilitators identified the potential value of a mentor to support the engagement of lived experience participants in co-design. Lived experience participants, in particular, felt that a lived experience mentor could provide opportunities for check-in conversations throughout the co-design process to support reflective thinking and making sense of experiences/actions. While peer mentoring is an emerging area of practice in disability, this finding warrants further exploration to better understand how mentoring might positively impact co-design engagement and how it could be best implemented, considering both efficacy and efficiency. One possible area for future research might include action research methodology to implement and evaluate a mentor role embedded within co-design, tailoring facilitation to best meet the needs of co-design participants.

Conclusion

In summary, this co-design project has produced valuable capacity building tools, while the qualitative evaluation has provided helpful new learning to guide future co-design work with people with disability. The findings of this project address a gap in research evidence to guide co-design with people with complex neurological disability and the findings of this study will be further disseminated at conferences and in research publications. A key next step of this project is the dissemination of the capacity building tools. The tools are currently available on the Housing Hub website, and while the tools are freely accessible, support and education is key to successful use of the tools. Therefore the dissemination and translation plan includes sharing the tools with people with disability and their close others, as well as people who work with people with disability such as health professionals, support coordinators and support workers, through education programs provided by the Summer Foundation and the Housing Hub. The tools will also be distributed via professional networks and established points of connection with people with disability and their close others, such as the 'Staying Connected' page on the Summer Foundation website. In addition to dissemination of the tools, further work is required to build upon the evaluation findings, to inform future co-design engagement with people with disability. A key outcome of this study will be the development and piloting of a framework to support co-design engagement for people with complex disability and cognitive and communication challenges.

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Appendix A

Co-design participants: Pre-project interview guide

1. Can you tell me a little about you and what interested you in this co-design workshop opportunity?
2. What do you know about the co-design workshops?
3. What do you think you will offer or contribute to the workshops?
 - Skills/ideas
 - Experience
4. Have you done anything like this before?
 - If so, can you tell me about your experience?
5. How are you feeling about this opportunity?
 - What are you most looking forward to?
 - What do you think might be challenging for you?
 - Do you have any specific support needs?
6. Do you have any hopes or goals that you would like to achieve?
 - If so, what are they?
7. Do you know any of the other workshop participants?
 - If so, how do you feel about working together as a co-design team?
8. Is there anything else you would like to share?

Co-design participants: Post project interview guide

1. Can you tell me about your experience of the co-design workshops?
 - Was the experience like you expected?
 - If you could choose 3 words to describe the experience, what would these words be?
 - What was your experience of working with the facilitators? What did you find most helpful/unhelpful?
2. Can you tell me the tools you developed?
 - Do you think the tools capture your experience?
 - Who is your target audience?
 - How do you think they should be used?

- Would you like to be involved in the delivery of these tools?
3. What was the co-design process like?
 - What did you most enjoy and why?
 - What do you think you contributed?
 - What did you find most challenging?
 4. Would you like to do something like this again?
 - If so, why and do you have any suggestions for improvements?
 - If not, why not?
 5. Did you learn or develop any new skills from the co-design process?
 - If so, can you tell me about this?
 6. What was it like working as a group?
 - Did you create any new friendships?
 - Do you think you might keep in touch with some of the other participants?
 - If so, what might support these friendships or connections?
 7. Let's look back at the hopes or goals you identified in the first interview. Did you achieve these?
 - If not, why?
 - If yes, how does that feel?
 - Do you have any new hopes or goals? And how might you achieve this?
 8. Any final comments or suggestions for future co-design work?
 9. Anything else you would like to share?

Facilitators: Pre-project interview guide

1. Can you tell me a little about the co-design workshops?
2. How would you describe your role and what will you contribute to the workshops?
 - Skills/ideas
 - Experience
3. Have you done anything like this before?
 - If so, can you tell me about your experience?
4. How are you feeling about this opportunity?
 - What are you most looking forward to?

- What are some of the potential challenges?
 - How have the workshops been designed to meet the needs of the participants?
5. What are you hoping to achieve with the workshops?
- For the participants?
 - For future learning?
6. Is there anything else you would like to share?

Facilitators: Post project interview guide

1. Can you tell me about your experience of the co-design workshops?
 - Was the experience like you expected?
 - If you could choose 3 words to describe the experience, what would these words be?
 - What was your experience of working with the other facilitators? What did you find most helpful/unhelpful?
 - What was your experience of working with the other participants? What did you find most helpful/unhelpful?
2. What was the co-design process like?
 - What did you most enjoy and why? What do you think you most contributed?
 - What do you think worked well?
 - What did you find most challenging?
 - What did you learn from the process?
3. Any thoughts on the experience of the co-design participants?
 - Do you think the experience contributed to capacity building of participants?
 - Do you think the participants built peer connections?
 - Can you tell me about what you observed and learnt for future workshops?
4. Can you tell me about the tools that were developed?
 - Do you think the tools captured the lived experience of the co-design participants?
 - Who is the target audience?
 - How do you think they should be implemented?
5. Let's look back at the hopes or goals you identified in the first interview. Did you achieve these?
 - If not, why?
 - If yes, how does that feel?

- Do you have any new hopes or goals? And how might you achieve this?
6. Any final comments or suggestions for future co-design work?
 7. Anything else you would like to share?