“I have always wanted to do work like this but felt it was out of reach”: Hopes and expectations of participating in a co-design storytelling project

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Aim: To design and create tools to build the capacity of people with disability to take action to move out of aged care into inclusive housing

Lived Experience Partners (5), Lived Experience Contributors (5), Co-design Facilitators (3)
Produced tools

Three-part podcast series: A conversation about disability and leaving a nursing home
Three-part audio series: Choosing and managing your own support
Four short videos: The experience of moving out of a nursing home into my own apartment

Aim: To explore the experience of participating in a co-design project from the perspective of partners/contributors and facilitators with and without lived experience of disability

- Enablers & barriers to co-design engagement
- Potential capacity building benefits
- Potential peer connection benefits
Methodology

• Qualitative study utilising constructivist grounded theory methodology (Charmaz, 2013)

• In-depth interviews conducted with lived experience partners, contributors & co-design facilitators

• Reflective journals completed by co-design facilitators

• Constant comparative process of data analysis; open & focused coding
Research participants

**Three co-design facilitators**
Skills/experience: physiotherapy, occupational therapy, stroke

**Six lived experience partners / contributors**
Skills/experience: accountant, teacher, artist, acquired brain injury, muscular dystrophy, MS, stroke, dystonia

**Inclusion criteria for lived experience partners/contributors**
Lived experience of disability
Lived experience of moving out of aged care
Findings

Hopes & expectations

- Embracing the opportunity
- Juggling hopes & fears
- Is this co-design?
Embracing the opportunity

Helping others

*I want everyone to have the same experience [moving out of aged care]* (Christine)

Being employed

*Wow- this is me* (Christine)

Contributing in a new way

*Moving on from the storytelling a bit to making a difference* (Holly)

- Idea generation & problem solving
- Drawing upon lived experience and other skills/experiences

*Lived experience partners have so much more to give* than what we have given them the opportunity to do
### Contributing & having impact

It will be fantastic to give my opinions and suggestions and have them listened to (Christine)

- Is the project worthy of personal investment?

### Testing work capacity

My main goal is to see whether or not I can do it (Deidre)

- Fatigue
- Availability of support
- Work tasks

### Building social connections

Looking forward to working with others who have a similar life to mine (Ingrid)

- Hopeful but cautious

### Worried about communication

I’m a bit worried about other people understanding me and my speech and communication (Gabby)
Juggling hopes and fears (Co-design facilitators)

Doing co-design well

- More than consultation
- Shift or change in power relationships
- Trusting the process - tightening & loosening the structure

Being true partners also means contributing to the process - Feeling comfortable to share knowledge (co-design facilitator)

Enabling growth & capacity building

Having more time to invest in each other and process but will it be enough?

- Role of facilitator with lived experience of disability?

Creating meaningful process & tools

If the lived experience partners are the decision makers then the tools will be great (co-design facilitator)

What value are people looking for? Employment or being paid? What does this look like for people?
Is this really co-design?

Is this what we can do and how we can do it? **Is it OK if it isn’t co-design?**

I just really like the opportunity to **work with other people** (Gabby)

**Bringing skepticism** about the co-design process (Billie)

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 (Christine)

Team effort of coming together, people from Summer, people with disabilities coming together **collaboratively working** to design their tools (Deidre)
Co-design was identified as a strengths-based opportunity to contribute.

Excited to use lived experience knowledge in addition to other skills such as listening, discussing and problem solving.

Appreciative of and motivated by the opportunity to be employed; payment does not suit everyone.

Hoping to build new connections.

Worried about the impact of communication difficulties.
Thank you

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