

Co-designing hospital improvements for people with hidden disabilities: Recommendations for enhancing patient experience.

Authors:

Karen Roberts, Samantha Jones, Rusty Benson, Tully Zygier, Claire Nailon, Janine Standen, Muskaan Ahuja, Anne North, Kristen Lenehan and Nadeera Seedat.

AlfredHealth

speak
better health, together

 South West
Healthcare

What is the SPEAK Project?

Project aim

Aims to improve healthcare for autistic people, people with intellectual disability, and communication disability.

Run by Alfred Health and South West Healthcare with funding from the Department of Social Services (*ILC program grant*).



Why is the SPEAK Project important?

People with disabilities experience significant health inequities and poorer healthcare outcomes compared to the general population.



Five key objectives

1. Dedicated disability support service
2. Disability training and education
3. Improved consumer feedback
4. Resources and processes to improve communication
5. Enhanced disability data systems





Co-design is
elevating lived
experience
knowledge

What is co-design?

Co-design is about working with people to have a say in:

- What services are needed?
- How are services made?
- How can services be delivered?

Co-design is about making changes that matter to people with disability.

Why did we choose co-design?



People with disability and their support people have the answers.



Bridges the gap between technical knowledge (professional knowledge) and what it feels like to go to hospital (lived experience).



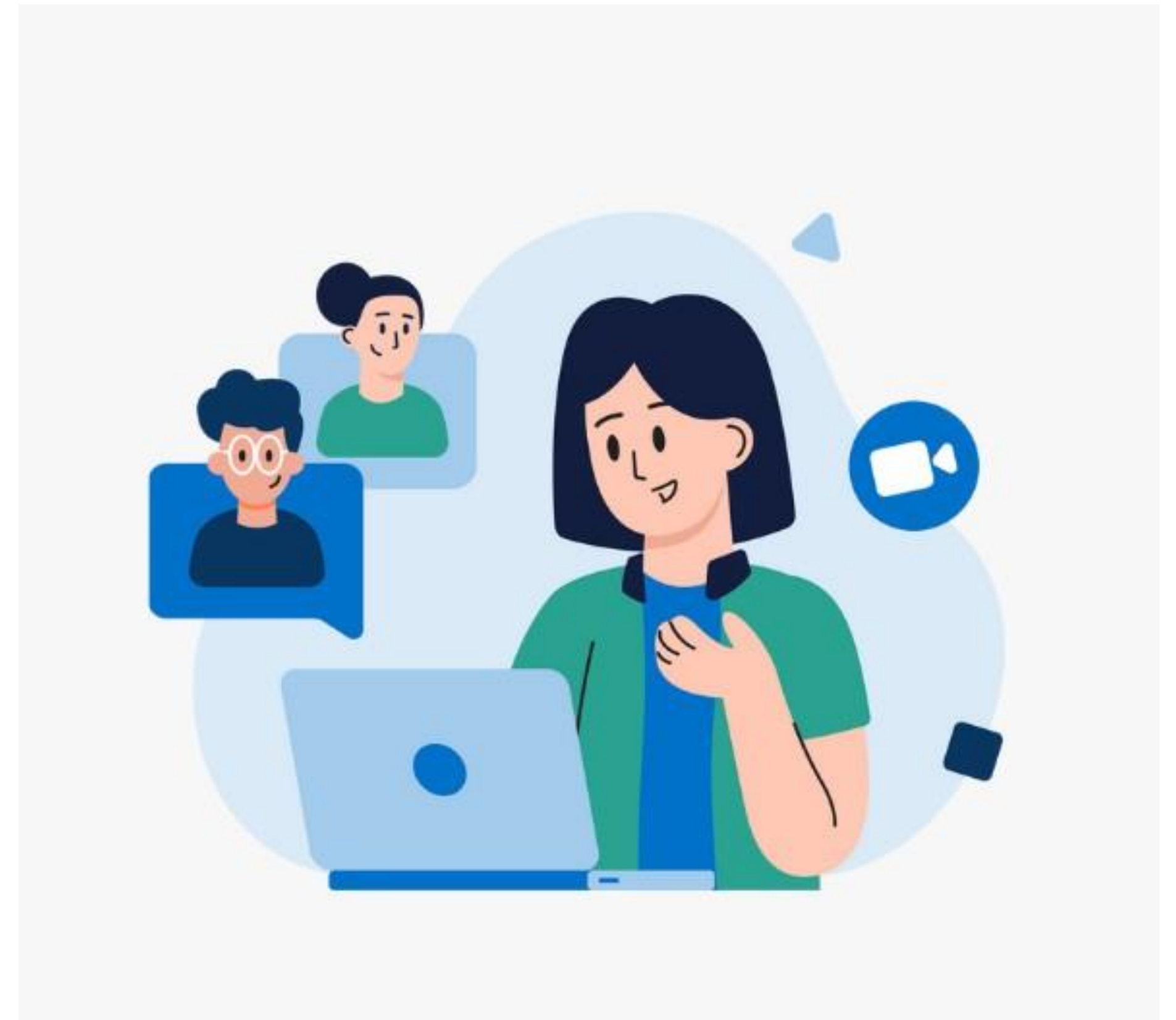
Recognises people have a right to be a part of improving services that affect them.

Who was involved?

- 41 people with disability
- 12 support people

What did we do?

- 9 online workshops with people who live in the city.
- 2 online workshops with people who live in the country.
- 1 in-person forum with Deaf-Blind Vic.
- 1 in-person workshop in Warrnambool.



Creating a safe space



Making workshops
accessible



Lived experience project
team and facilitators



Ensuring emotional
well-being

01

Treating people with respect and compassion

02

Understanding hidden disabilities

03

Challenges of the hospital environment

“You may get a nurse/doctor who has empathy and compassion—just a decent person who is nice and calm and explains things clearly ... I felt like some nurses and doctors had no time for people with disability. For example, I eat quite slowly and hate really hot food ... I remember nurses that would try and understand my situation and be patient and understanding. The others would not care. They would just try shovelling it in really fast. It made me feel inhuman.”

– **Co-designer with lived experience of an ABI, PTSD, ataxia, and dysphasia**

04

Communication that meets individual needs

05

Understanding the role of support people

06

Healthcare staff and patients working together

“It’s just small adjustments that make you feel less distressed in an unfamiliar place. For me, it’s important that staff should ask me what helps me. If I can’t tell you, ask my support person. But staff shouldn’t assume. They should ask.”

– **Co-designer with lived experience of intellectual disability**

07

Providing accessible care

08

Getting effective and safe medical treatment

09

Connected care during and after hospitalisation

“Other people around me notice my condition long before I do. The response I got from the doctor was that it must not have been that bad if you’re not feeling it. If other people notice it, but you don’t feel it, it’s not a problem.

It scares me how little health professionals don’t understand interoceptive issues in autism. I don’t know what I am feeling to then know how to communicate and describe the pain to others. It can mean serious health issues about [me as a patient] don’t get treated.”

– **Co-designer with lived experience of Autism**

Recommendations



Advocate for co-design with lived experience to improve hospital services.



Lived experience of disabilities leading or co-facilitating co-design.



Share decisions people with disabilities and support people.

When providing healthcare to PWD
it's not about people's preferences,
it's about people's needs.

For any questions about this presentation please
contact the SPEAK Project Team
speakproject@alfred.org.au



**Funded by the Australian Government Department of Social Services.
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