

## Prevention in Practice Example

### Experts in Our Health by Women with Disabilities Victoria (WDV)

#### What is the project?

The Experts in Our Health Project was undertaken by Women with Disabilities Victoria from 2021 to 2024 and funded by the Department of Social Services.

The Experts in Our Health Project centres lived experience of women with disabilities through co-design of resources, peer-led workshops, and training for health workforces across Victoria. The Experts in Our Health Project promotes the empowerment of women with disabilities through self-advocacy and urges organisations to include lived experience perspectives and accessible practices in their work.

The project aims to equip service providers in the health and community services sectors with the knowledge to make health services accessible. Workforce training and professional resources focus on rights-based practice that involves women with disabilities in decision-making and respects lived experience as an expertise.

In developing the Experts in Our Health resources, WDV recruited diverse women with disabilities, training them in advocacy, resource design and facilitation. The co-design and co-facilitation model supports organisational change, in that it foregrounds women with disabilities as leaders and experts in their health. The evaluation of Phase 1 of the Experts in Our Health Project can be accessed on the WDV website [www.wdv.org.au](http://www.wdv.org.au).

#### What is the context?

In the area of health and wellbeing, significant disparities exist between disabled and non-disabled people in Australia.<sup>1</sup> People with disability experience many health inequities often due to barriers to access and participation.<sup>2</sup> For example:

- Women with disabilities experience higher levels of socio-economic disadvantage than other groups in the community.<sup>3</sup> The cost of medical treatment is a barrier to access for many women with disabilities.
- Rural women often experience a scarcity of specialist services, and inaccessible transport is a significant barrier to care.<sup>4</sup>
- Lack of disability knowledge among service providers and inaccessible health information are commonly experienced barriers to health access.<sup>5</sup> When interacting with health professionals, women with disabilities often face inappropriate assumptions and must advocate to have their health concerns investigated.<sup>6</sup>



- Ableism and gendered discrimination can also intersect, which means that women with disabilities experience multiple forms of disadvantage at the same time.<sup>7</sup> Women with disabilities may also identify with other marginalised communities who face discrimination, including LGBTIQ+, culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities.

Alarming, only 24% of people with disability in Australia describe their health as very good, compared with 65% of Australians without disability.<sup>8</sup>

The right of people with disability to equal healthcare is described in Section 25 of the United Nations Convention on the Rights of Persons with Disabilities<sup>9</sup> and is reiterated in the Australian Charter of Healthcare Rights.<sup>10</sup> Intersectional disadvantage must be addressed for health rights to be upheld.<sup>11</sup>

Areas that relate to the **National Preventive Health Strategy (2021-2030)** include:

- **Social and structural determinants of health:** The Experts in Our Health Project addresses the wider determinants and root causes of health including service provision, systemic attitudes and practices, health literacy, working conditions, and social support and participation.
- **Priority populations:** The Experts in Our Health Project is designed for people with disability, a priority population in the National Preventive Health Strategy. It also employs an inclusive and intersectional approach for women from diverse backgrounds and populations.
- **Partnerships and community engagement** The Experts in Our Health project centres the voices of Australians with lived experience, which is important to address the health needs of priority populations including women with disabilities.
- **Research and evaluation** The Experts in Our Health project evaluation utilised many types of expertise and drew on strong partnerships with multiple stakeholders, which is critical to effective preventive health research and evaluation.
- **Health Information and Literacy** Women with disabilities experience barriers to accessing information about how to manage their health and wellbeing. The experts in Our Health Project provided high-quality accessible health information.
- **Principles:** The Experts in Our Health Project aligns with several principles from the National Preventive Health Strategy including:
  - Improving health equity
  - empowering and supporting Australians
  - enabling the workforce
  - multi-sector collaboration
  - community partnership and collaboration



## How was it developed?

The project was implemented and evaluated using a participatory and inclusive approach<sup>12 13</sup>, with a focus on qualitative evaluation in order to centre the voices of women with disabilities. A best practice, accessible, end-to-end co-design process was adopted to develop the content and design resources and training.

**Co-design** is when service users are involved in the design process from the beginning and have time to share their experiences and collaborate with organisations.<sup>14</sup> Co-design makes service users equal partners in the development of products, resources and services. When done well, co-design produces quality services and resources and enables change in the ways service providers and communities relate to each other.<sup>15</sup>

WDV recognised the expertise of women with disabilities and placed this expertise at the centre of the design and content of the resource package. The resources were co-designed by a group of women with diverse backgrounds and experiences, and they communicate key messages identified by the lived experience team members.

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To remove barriers to engagement, the resources were created in a range of accessible formats. Creating safe and accessible spaces, both in person and online, was also a priority for the project team.

## What were the results?

- 12 women with disabilities were employed as lived experience Health Experts.
- 135 women with disabilities attended Experts in Our Health workshops.
- 17 organisations hosted Experts in Our Health Workforce training.
- Experts in Our Health resources were disseminated to 1,100 workforce contacts in the disability, health, family violence and university sectors as well as government agencies.

The Health Experts were involved in all phases of planning, design and development of the training materials for the health workforces. A train-the-trainer co-facilitation model provided opportunities for the Health Experts to develop facilitation skills and confidence. The participation of the Health Experts in the learning program, co-design process, and train-the-trainer program resulted in the group becoming confident advocates.



**Increased leadership, advocacy and facilitation skills and enhancing opportunities for women with disabilities were key outcomes of this project.**

The success of this project was its inclusive co-design process and the Health Experts group have reported pursuing opportunities for employment, advocacy and leadership as a direct result of their project participation. Members of the Health Experts group have also engaged in consumer advisory roles and public discussion panels and have hosted podcasts promoting women's health.

The Health Experts developed 5 key messages drawn from their diverse lived expertise:

1. Women with disabilities are experts in their own health.
2. Women with disabilities should be listened to.
3. Accessibility is everyone's business.
4. Women with disabilities should be partners in decision-making.
5. The voices of women with disabilities should be valued.

**Feedback from Health Experts, training attendees and workshop participants**

*'The information shared today not only made me feel valuable and knowledgeable, it gave me a strong sense of being able to develop my existing skills to be a great trainer and advocate.'*

-Health Expert

*'I appreciated and found it helpful when the presenters shared some of their lived experiences with what was being presented. I find this helps me to understand the context of the information presented. I have trouble retaining dry information/statements: lived experience enables me to connect it to something so it's meaningful and I can retain it.'*

-Workshop attendee

*'It was not just listening to women with disabilities share their stories and or identity, this project was more than that. It was drawing attention to the systems and barriers – politicising – centring lived experience stories.'*

-Project Advisory Group Member

*'I have had job opportunities and have increased my roles and responsibilities in other work. I have had the chance to speak at advocacy events and feel my influence is growing in Women's Health.'*

-Health Expert

*'It was valuable for a few reasons. First, hearing from women with lived experience provided a lot of insight into experiences and barriers in a human way, rather than from research or other ways. Understanding the intersections of discrimination was explained really clearly. Finally, the model explaining that accessibility is everyone's business, valuing voices, partnerships and listening and treating people as individuals was great.'*

-Health Workforce Attendee



## What actions would support prevention across the health system?

Prevention is supported by accessible health services that are low-cost or free, physically accessible, and have knowledgeable staff who take a holistic view of the health of women with disabilities.<sup>18</sup> Health information that is readily available and accessible for women with disabilities is key to achieving quality care and improved outcomes.<sup>19</sup>

The Health Experts project strengthens preventive health action and a stronger prevention system by addressing gendered barriers to accessing health care and gender-based health discrimination.

### Recommendations to support access to healthcare and inform future decision making

1. Support healthcare access for women with disabilities from diverse backgrounds through the production of accessible co-designed resources.
2. Collaborate with disability self-advocacy organisations, support co-design, and embed practices that increase health access for women with disabilities.
3. Engage women with disabilities in meaningful co-design and develop resources that empower women with disabilities to make informed decisions about their healthcare, promoting respect, dignity, choice, and control.
4. Support access by women with disabilities to peer learning and support programs such as Communities of Practice that are co-designed and facilitated by lived experience advocates.
5. Identify access for women with disabilities as a priority in strategic planning and resource initiatives that increase access, including co-design programs.
6. Collaborate with disability advocacy organisations to embed lived experience perspectives into the education of health and community services professionals.
7. Increase the participation and employment of women with disabilities in the design and delivery of services. Collaborate with disability self-advocacy organisations to create inclusive co-design processes.
8. Support health workforces to engage in ongoing professional learning, such as Communities of Practice that focus on disability access and centre lived experience.

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## References

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<sup>1</sup> Australian Institute of Health and Welfare (AIHW), *Health and welfare of people with a disability*, Australian Government, 2022.

<sup>2</sup> Z Aitken, GM Bishop, G Disney, E Emerson and AM Kavanagh, 'Disability-related inequalities in health and well-being are mediated by barriers to participation faced by people with disability. A causal mediation analysis', *Social Science & Medicine*, 2022, 315:115500, doi: <https://doi.org/10.1016/j.socscimed.2022.115500>.



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<sup>3</sup> S Petrony, P Horsley and A Kavanagh, [Access to health services for women with disabilities](#), Women with Disabilities Victoria, 2010.

<sup>4</sup> C Brophy, [Brief submission to the special rapporteur on the rights of persons with disabilities on the right of persons with disabilities to the highest attainable standard of health](#), Women With Disabilities Australia, 2018.

<sup>5</sup> S Petrony et al., [Access to health services for women with disabilities](#).

<sup>6</sup> C Brophy, [Brief Submission to the special rapporteur](#).

<sup>7</sup> Women with Disabilities Victoria, [Understanding Disability Guide: Gender and Disability Workforce Development Program](#), Women with Disabilities Victoria, 2022.

<sup>8</sup> AIHW, [Health and welfare of people with a disability](#).

<sup>9</sup> United Nations Department of Economic and Social Affairs, [Convention on the rights of persons with disabilities](#), United Nations 2006.

<sup>10</sup> Australian Commission on Safety and Quality in Healthcare, [Australian Charter of Healthcare Rights](#), Australian Government, 2020.

<sup>11</sup> S Petrony et al., [Access to health services for women with disabilities](#).

<sup>12</sup> JB Cousins and E Whitmore, 'Framing participatory evaluation,' *New Directions for Evaluation*, 1998, 10.1002/ev.1114.

<sup>13</sup> S Robinson, K Fisher and R Strike, 'Participatory and inclusive approaches to disability program evaluation', *Australian Social Work*, 2014, 67(4), pp 495-508, doi: <http://dx.doi.org/10.1080/0312407X.2014.902979>.

<sup>14</sup> Agency for Clinical Innovation, [A Guide to Build Co-design Capability](#), NSW Government, 2019.

<sup>15</sup> KA McKercher, *Beyond Sticky Notes: Doing co-design for real: mindsets, methods and movements*, Beyond Sticky Notes, 2020.

<sup>16</sup> Agency for Clinical Innovation, [A Guide to Build Co-design Capability](#), NSW Government, 2019.

<sup>17</sup> KA McKercher, *Beyond Sticky Notes: Doing co-design for real: mindsets, methods and movements*, Beyond Sticky Notes, 2020.

<sup>18</sup> S Petrony et al., [Access to health services for women with disabilities](#).

<sup>19</sup> C Brophy, [Brief Submission to the special rapporteur](#).