


# BMJ Open 'Nothing About Us Without Us': exploring benefits and challenges of peer support for people with disability in peer support organisations – protocol paper for a qualitative coproduction project

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## ABSTRACT

**Introduction** One in six people live with disability in Australia with higher levels of disability of people from diverse communities, such as those with culturally and linguistically diverse (CALD) backgrounds. In Australia, CALD refers to people from diverse ethnicity and cultures, nationalities, societal structures and religions that may or may not speak a language other than English. This study employs researchers with lived experience of disability and peer support to study the impact of peer support for people with disability, including people from CALD backgrounds, in two peer-led organisations in New South Wales (NSW) Australia.

**Methods and analysis** This study uses participatory action research and inclusive research design with researchers with lived experience, having lived experience of disability and a peer in the disability community, leading the research.

Over three years, three different groups will be recruited through Community Disability Alliance Hunter (CDAH) and Diversity and Disability Alliance (DDAlliance): (1) peers with disability, (2) peer leaders with disability and (3) researchers with lived experience of disability and peer support. Data collection and creation methods include semistructured interviews, surveys and focus groups. Qualitative data will be analysed using thematic analysis through the lens of the researchers with lived experience.

**Ethics and dissemination** Ethical approval was granted by the University of Newcastle Human Research Ethics Committee (Approval No: H-2021-0088). Dissemination includes peer-reviewed publications, presentations at local, national and international conferences and written reports for user-led organisations, disability service providers, disability agencies and people with disability.

## INTRODUCTION

Approximately 4.4 million people have disability in Australia, equating to 1 in 6 (18%) people.<sup>1</sup> Disability is diverse and unique to

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Exploring the benefits and challenges of peer support in two peer-led organisations in New South Wales, Australia led by researchers with lived experience of disability and peer support.
- ⇒ Contributing to evidence about structures that facilitate peer support for people with disability, particularly those from CALD backgrounds.
- ⇒ Situations such as COVID-19 may impact the recruitment of people with disability with experience of peer support.

each individual varying in type, complexity and experiences across the population. Some population groups may experience higher rates of disability than the general population such as First Nations people, people from culturally and linguistically diverse (CALD) backgrounds and the lesbian gay bisexual transgender queer intersex and asexual (LGBTIQ+) community.<sup>2-6</sup> In Australia, CALD refers to people from diverse cultures, ethnic backgrounds, nationalities, societal structures and religions that may or may not speak a language other than English.

In this paper, disability includes medical and social perspectives. Medically, it is characterised by a health condition or impairment, such as long-term physical, mental, intellectual or sensory impairments that makes it more difficult for a person to do certain activities. Socially, it identifies any restriction or lack of ability to perform an activity because the environment is constructed for and by the dominant or 'typical' person without disability. This may hinder a person with



disability to fully and effectively participate in society on an equal basis with others.<sup>7</sup>

Many people with disability will require support to achieve a good quality of life, and to actively participate socially and economically in society on an equal basis with others. However, barriers exist for people with disability in realising a full life despite Australia's commitment to the United Nations Convention on The Rights of Persons with Disability and laws protecting people with disability against discrimination. These barriers include social exclusion, negative attitudes, discrimination, lack of access to the environment and information, unresponsive societal systems, limited financial resources, and lack of quality services and supports that meet the demands of people with disability.<sup>8,9</sup> (please also insert ref 3 in here, beside 8 and 9)

Peer support is a practice that has been used nationally and internationally by people with disability where people who share common experiences or face similar challenges come together as equals to give and receive support based on the knowledge that comes through lived experience to bring about self-determined personal change.<sup>10-12</sup> The concept of peer support assumes that people with similar shared lived experiences can empathise, share information and skills, and provide mutual and reciprocal support.<sup>13,14</sup> A peer is someone who shares demographic or social similarities as another person and is considered as an equal.<sup>10</sup> In this research, a peer is defined as a person with disability (who has long-term physical, mental, intellectual or sensory impairments) and who has any involvement of peer support with either CDAH or DDAlliance.

The development of peer support has a historical context stemming from strong activism and social change. The term 'Nothing About Us Without Us' formed during the disability rights movement as a result of the experiences of oppression and the realisation that the needs of people with disability were not being met. Disabled people's organisation, disability rights organisations, community-based organisations, self-advocacy groups and other networks empowered people with disability to challenge the dominant perception of disability as a medical deficit to disability being understood as the result of barriers in the physical, attitudinal, communication and social environment,<sup>15</sup> better known as the social model. This gave rise to people with disability seeing themselves as people with rights, capable of claiming those rights and ability to make decisions for their own lives based on their free and informed consent as active members of society.<sup>15</sup>

Through peer support, people with disability can exercise their human and civil rights to be active members of society. This occurs through an increased sense of empowerment, decision-making power, empathy, hope and autonomy with the potential to 'lead change' across communities.<sup>13,16,17</sup>

The research partners for this study, CDAH and DDAlliance, define peer support 'as a mutual support process whereby people come together to address common issues and concerns, and share their experiences or learning'.<sup>18</sup>

This helps build an 'inclusive and just society where people with disability have voice, choice and control and full inclusion and active citizenship'.<sup>19</sup> Both organisations are peer led, run by people with disability for people with disability. As a point of difference, DDAlliance provides peer support exclusively to people with disability from CALD backgrounds including family and friends. Both organisations provide opportunities for peers to connect, learn and amplify their voices through a wide range of peer-led groups, for example, Korean-speaking peers, women peers, queer (i.e., LGBTIQ), plus other sexual orientations and genders) peers and DeafBlind peers.

Peer support for people with disability not only supplements informal support but also helps people with disability and their families to access and navigate formal support and service systems.<sup>11</sup> Despite more than nearly half of the Australian population born overseas,<sup>20</sup> there are limited studies on peer support for people with disability from CALD backgrounds or Aboriginal and Torres Strait Islander people.<sup>21</sup> Recent research evidence revealed that peer support groups run by and for people with disability from CALD backgrounds are a promising approach to culturally responsive support that meets the needs of the CALD community.<sup>22</sup>

Other challenges associated with peer support relate to how to measure the outcomes or benefits of peer support, the unintended consequences of peer support including its impact on personal identity, uneven power relationships between peers, the issue of the 'professionalisation' of peer support, the costs of peer support and ensuring access to ongoing funding for peer-led organisations to build the capacity of peers and peer support engagement.<sup>21-26</sup>

Furthermore, there have been limited studies of peer support using an inclusive research design in both Australia and internationally, particularly employing people as researchers with lived experience of disability in the evaluation process. Much disability research has historically excluded people with disability as decision-makers and thereby stigmatised in research for 'knowledge production'. This means most research studies view and treat people with disability as 'subjects' rather than people with lived experience with valuable insight leading the research. However, there is a growing movement of people with lived experience undertaking research, that improves research outcomes for people with disability and researchers.<sup>27</sup>

Research questions to be answered are: (1) What are the benefits and challenges of peer support for people with disability in peer-led support organisations? (2) In what ways can peer support for people with disability be improved? (3) In what way can support structures facilitate the development and engagement of people with disability in peer support? and (4) What are the experiences of involving lived experience researchers in the evaluation of peer support in peer support organisations?

In conducting this work, our objective is threefold: (1) To explore how peer support can broaden support

options to people with disability, (2) To provide better evidence about the structures that facilitate peer support for people with disability and (3) To explore the role of people with disability as researchers with lived experience.

This research will contribute to the evidence of broadening the scope of inclusion and participation including being culturally responsive and modelling 'Nothing About Us Without Us' by employing researchers with lived experience of disability.

## METHODS AND ANALYSIS

### Methodology

This research uses participatory action research (PAR) and inclusive research design. PAR is a research method that allows for an iterative process that is well suited to changing practice and improving outcomes throughout the research process. This happens through the cycle of collect, analyse, reflect and action. This cycle gives more flexibility of the specific needs and wants of the participants and researchers with lived experience, reflected in the research and outcomes.<sup>28 29</sup>

Inclusive research is a method that has been used to involve people with lived experience of disability in a wide range of research projects in Australia and internationally.<sup>30–32</sup> However, there are significant debates about what is inclusive research with people with disability.<sup>30–34</sup> Walmsley and Johnson contend that inclusive research with people with intellectual disability should include: commitment to social change, empowering research participants, focusing on the individual, undertaking emancipatory research with people with learning disabilities, reflexivity in the research process exploring the dilemmas and concerns about the research process for people with disability working as researchers as well as non-disabled people, and translating the research to challenge practice.<sup>34</sup> Others contend that inclusive research should not be seen as a separate strand of research but rather a process that facilitates a range of methods for inclusivity. Bigby *et al* argue that there are three broad approaches for inclusive research: advisory, leading and controlling, and collaborative group.<sup>30 33</sup> Furthermore, they assert that inclusive research can be adapted to any research paradigm and have developed a broad conceptual framework for inclusive research with people with intellectual disability.

A researcher with lived experience in this study is a researcher who has lived experience of disability, and who is also a peer in the CDAH and/or DDAlliance peer support community. They bring their own skills and experiences in research, disability and peer support. This is a multisite, longitudinal study, co-led by researchers with lived experience who provide a wide range of peer support to people with disability across NSW. Data collection and creation will be through semi-structured interviews, surveys and focus groups, repeated three times across a 2-year period, between May 2021 and April 2023.

### Patient and public involvement

This research project is a partnership between two peer-led disability organisations (CDAH and DDAlliance), the University of Newcastle and Carrie Hayter Consulting. Both peer-led organisations have a well-established history of supporting people with disability to become peer leaders in the community. Their involvement provided an opportunity to employ people with lived experience of disability and peer support to build their skills and knowledge in undertaking research in peer support. Carrie Hayter Consulting has held a long-standing partnership with DDAlliance and worked alongside people with lived experience in research, and in disability and health services. The connection with academic partner, the University of Newcastle, brings rigour to the research process and ethics approval for the research project (approval Number H-2021-0088).

Following an expression of interest process for researchers with lived experience to commence the research, the study was conceptualised together by all members of the team. Early literature review findings were reviewed by the researchers with lived experience, in addition to proposed conceptual frameworks, such as broad conceptual frameworks for inclusive research with people with intellectual disability, which could guide the conduct of the research, and proposed recruitment methods for participants, specifically in terms of accessibility of information.

### Researchers with lived experience

The research team is composed of 11 members, 8 researchers with lived experience, including 1 lived experience peer support research coordinator, and 3 researchers not identifying as living with disability, including the academic adviser.

Researchers with lived experience in this research are active participants in all parts of the research process from the design of the study, recruitment of participants, analysis of all data and the co-writing of papers. This embodies the principles and practices of PAR and inclusive research methods, and the disability rights movement concept of 'Nothing About Us Without Us'. These methods ensure that the research process is continually inclusive and accessible to people with disability from diverse backgrounds.

Researchers with lived experience are recruited via an internally advertised job description within CDAH or DDAlliance. Applicants were interviewed by a panel composed of peers, staff from both CDAH or DDAlliance and a researcher not identifying as living with disability. No formal research experience was required to join as a researcher. The level of attitude, willingness to participate, engage and learn, and the unique perspective from the lived experience of applicants was considered in the recruitment process.

This work uses the lenses of lived experience of disability and peer support, which may create ethical challenges for the researchers, in that some researchers with lived



experience may know one or more of the participants. Attempts to overcome these challenges will be addressed through researchers with lived experience interviewing peers with whom they have no existing relationship, reflective team discussions and drafting of key 'rules' for study conduct. Researchers with lived experience will also be mentored by each other and by researchers not identifying as living with disability and be provided with training and support on ethical issues in research. Weekly team meetings will explore ethical issues of sharing power and knowledge, and discussions about communicating which 'hat' people are wearing, a peer hat or a researcher hat in the analysis of data.

Researchers not identifying as living with disability will be supported by the researchers with lived experience to be inclusive in their work. Researchers with lived experience will co-chair meetings and there will be ongoing processes of reflection on how the research team is working. Researchers with lived experience will be buddied with a research team member and provided with training and mentoring to develop research skills, such as interview skills, data analysis skills and report writing skills. Opportunities for external training for researchers with lived experience will also be provided throughout the research project.

### Eligibility

This research study explores the challenges and benefits of peer support for three population groups: (1) peers with disability, (2) peer leaders with disability and (3) researchers with lived experience of disability and peer support. This can be participating in any peer event or training provided by either organisation. A peer leader is categorised as a person with disability who has had a longer-term involvement with either CDAH or DDAlliance and has a role in the planning, mentoring and/or facilitation of peer events. A researcher with lived experience of peer support is a person with disability who has experience of peer support with CDAH or DDAlliance. CDAH and DDAlliance engage with peers with disability from diverse backgrounds including CALD, gender, sexual orientation, with a range of physical, mental, intellectual or sensory impairments.

### Recruitment of participants

The three different population groups being recruited are as follows:

1. Up to 60 people with disability with experience of peer support at CDAH or DDAlliance to be interviewed about their experiences of peer support. This will include at least 10 peer leaders, and 10 people with disability from CALD backgrounds, and 3 CALD peer leaders.
2. Up to 50 participants in each round of data collection who attend any training sessions on peer support and/or mentoring provided by CDAH or DDAlliance to complete a pre-training and post-training survey. Current training provided by CDAH and DDAlliance in-

cludes 'Introduction to Peer Support', 'Introduction to Peer Facilitation' and 'Peer Mentoring'. This will include at least 10 people with disability from CALD backgrounds.

3. All eight researchers with lived experience will also be invited to be interviewed in each round of data collection to reflect on their experiences of being part of the research.

Participant recruitment is organised by the researchers with lived experience with support from each other and the researchers not identifying as living with disability. In groups of two, consisting of a lead researcher and a buddy researcher, the researchers will attend training and promotion events held by CDAH and DDAlliance to give a short presentation about the study. Peers are provided an opportunity to ask questions and request more information about the study if they wish. Peers attending the training or event will have been provided with an information sheet and the relevant consent forms beforehand. Peers who wish to participate will be provided any necessary supports to consent and participate in the study.

Language and Auslan interpreters will be used to recruit a diverse range of peers to the study and for participant interviews. Information sheets can be translated into five community languages of Arabic, Korean, Khmer, Vietnamese and Simplified Chinese where peer groups are currently operating by DDAlliance.

For recruitment and consent materials in English, please refer to online supplemental appendix 1 Easy Read Information Form, online supplemental appendix 2 Easy Read Consent Form Focus Groups, online supplemental appendix 3 Easy Read Consent Form Interviews, online supplemental appendix 4 Easy Read Consent Form R\_L\_E Interviews, online supplemental appendix 5 Easy Read Consent Form Training, online supplemental appendix 6 Easy Read Consent Form Interview Peer Leaders and online supplemental appendix 7 Easy Read Withdrawal of Consent Form. All materials have been developed by researchers with lived experience, and submitted for approval through the University of Newcastle ethics committee.

### Data collection

Research participants will be interviewed in three rounds of data collection including:

- ▶ Round 1: May 2021–December 2021.
- ▶ Round 2: March 2022–October 2022.
- ▶ Round 3: November 2022–April 2023.

The data collection for the study was completed in April 2023. Review and analysis of all study data continues through 2023.

To manage and protect pre-existing relationships between researchers with lived experience who are peers themselves and peers as participants, the researchers with lived experience from CDAH will recruit and interview participants from DDAlliance and vice versa. This is to ensure the safety and confidence of both researcher and participant.

Interviews will also be conducted with the researchers with lived experience in each round of data collection to explore their experiences in the research process and understand the involvement of researchers with lived experience in peer support research. Interviews with researchers with lived experience will be undertaken by two researchers not identifying as living with disability.

### Data analysis

Four sets of data will be analysed for this study from each round of data collection:

1. Peers with disability with experience of peer support through CDAH and DDAlliance.
2. Peer leaders with disability who lead peer events or groups through CDAH and DDAlliance.
3. Peers with disability who attended peer support training provided by CDAH and DDAlliance.
4. Researchers with lived experience who were undertaking the research.

After each round of data collection, datasets 1–3 will be deidentified, transcribed and analysed using thematic analysis. Additionally for datasets 1–3, a subset of data of peers from CALD backgrounds will be thematically analysed. For datasets 1–3, the researchers with disability will be involved in reviewing transcripts, using their lived experience lens, to identify and construct themes. Guiding questions that will be asked during the data analysis process include: ‘What main messages are you noticing? Why are you noticing this information?’ Researchers will share their data analysis together and will use Leximancer, a qualitative research tool, to explore the relationships between concepts and language. They will also use a range of online tools to collaborate and share research findings, such as Slack, Zoom and Mural, an online visual platform.

For dataset 4, two researchers not identifying as living with disability will deidentify, transcribe and analyse the data from each round using thematic analysis. They will also use Leximancer and a range of online tools to collaborate and share research findings, such as Slack, Zoom and Mural.

Identified themes and the implications for peer support for CDAH and DDAlliance will be shared and discussed after each round of data analysis. This will then inform the next round of data analysis.

### ETHICS AND DISSEMINATION

Ethical approval has been granted by the University of Newcastle Human Research Ethics Committee (approval no: H-2021-0088). The peer reviewer of the study proposal considered it an exceptionally well-designed research project, an excellent example of conducting research with population members treated as equal partners and believed it would result in highly useful results. In terms of dissemination, the study will result in peer-reviewed journal articles led by researchers with lived experience, presentation at conferences and written reports for

user-led organisations, service providers, disability agencies and people with disability.

### STUDY STRENGTHS AND LIMITATIONS

A key strength which underwrites the potency of this study is that the work is conceptualised by researchers with lived experience, using ‘Nothing About Us, Without Us’ as the principle for meaningful involvement. The two peer-led disability organisations, CDAH and DDAlliance in NSW, Australia, are well established and have built a trusted relationship within its community and with its peers, to aid recruitment efforts. However, we acknowledge this relationship may be difficult to replicate with more recently established organisations.

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**Contributors** Paid lived experience researchers conceived the study and formulated the study design (JD, SP, CW, AF, JM, SS, DZ, OB-P and FR), along with non-lived experience researchers (CH and MT). This includes the information and consent form design and content, methods for data collection and decisions surrounding population groups to recruit. DDAlliance and DDA were grant holders.

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**Competing interests** All authors have completed the ICMJE uniform disclosure at <http://www.icmje.org/disclosure-of-interest/> and declare: financial support for the submitted work from the Australian Government Department of Social Services, Information Linkages and Capacity Building Program; MT has received an honorarium from DDAlliance and CDAH for academic input; CH was a consultant contracted by DDAlliance and CDAH to be a research adviser and project manager; JD, JM, DY, CW and FR were paid a casual salary as researchers with lived experience from DDAlliance; SP, AF, SS and OB-P were paid a casual salary as researchers with lived experience from CDAH.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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