

**Peer support – a way forward driven by people with
disability, a co-production project**

**Final Report for Community Disability Alliance Hunter and
Diversity and Disability Alliance**

11 July 2023

Summary of this report

With approximately one in six people living with disability in Australia and higher rates of disability within diverse communities, the inclusion and social and economic participation of people with disability is critical to Australian society.

One way people with disability can become included in society is through peer support. Broadly defined, peer support refers to a practice 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.

In practice, peers with disability discuss issues and concerns, and offer support by sharing their experiences, knowledge or learnings with each other. Peer support has been used across the world by people with disability to empower and support each other.

Peers are connected through peer led organisations in Australia, such as CDAH and DDAlliance, which plays a key informal and formal role in supporting people with disability to navigate obstacles they encounter in society and life. It cultivates a feeling of community, fosters social inclusion, and diminishes stigma. Additionally, it enables people to assume an active role in society, develop their self-identity and enhance their general wellbeing.

While there are many known benefits of peer support, this research sought to explore some of the gaps identified in prior research of peer support, including the limited involvement of people with disability from culturally and linguistically (CALD) diverse backgrounds. Our research questions included:

1. What are the benefits and challenges of peer support for people with disability in peer led support organisations?
2. How 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?
4. What are the experiences of involving researchers with lived experience in the research of peer support in peer support organisations?

Using a participatory action research method that was led by nine researchers with lived experience of disability and peer support. The research was co-produced and led by researchers with lived experience.

A diverse range of people with disability participated in this research. A total of 43 peers (16 peer leaders, 20 peers with disability, and seven researchers with lived experience) were interviewed across two rounds of data collection between May 2021 to January 2022, and March 2022 to January 2023. There were 23 participants from a CALD background. A training survey was used to explore peer experiences of peer support training, with 13 peers completing the training survey across the two rounds.

Overall, key findings across the interview data and training survey data from peer leaders and peers with disability from CDAH and DDAlliance encompass the following:

1. Peer led peer support opportunities have supported the inclusion of people with disability in local communities such as in employment and advocacy;
2. People's lives have been transformed because of their involvement with peer support in ways that empower and value them;
3. People have an opportunity to connect with a community of people who can create shared meaning and experiences, and support each other to navigate support systems, such as the National Disability Insurance Scheme;
4. People's identity and how they see themselves as a person with disability have changed and evolved because of the opportunities to connect with other peers and learn new perspectives;
5. Peers from diverse backgrounds (such as CALD and LGBTQIA+) have unique experiences of navigating identity and peer support plays an important role in understanding the self;
6. Training provided through CDAH and DDAlliance is a pathway for people to learn about peer support. However, more flexibility in how training is delivered and providing more support to facilitators could allow diverse conversations in training to flourish;
7. Providing accessible information and training resources to people and support to use online platforms and technology was extremely important during the COVID-19 pandemic.

Peer leaders and peers with disability suggested the following improvements made for peer support:

1. Having clearer pathways and opportunities to use and further develop peer support skills, provide peer support within the community and the broader community;
2. Maintaining accessibility at all times, such as by considering the use of technology and its impact on accessibility, and access to information in a variety of formats;
3. Flexibility with the delivery of peer support and training including group size, online and face to face options, consideration of length and personal circumstances;
4. Support with promoting peer support to increase engagement of peer support within the disability community and in the broader community.

Findings also indicate the following structures facilitate the development and engagement of peer support:

1. A dedicated space to give people the opportunity to connect with others and create a comfortable knowledge support system;
2. The inclusion and strong working relationship with interpreters to engage as many people from the disability community regardless of background and disability type;
3. Funding commitment towards peer support, demonstrating the value of peer support and the diverse voices of people with disability.

Overall, key findings across the interview data with the researchers with lived experience on leading and co-producing the research included:

1. Being able to amplify the voices of researchers with lived experience of disability and peer support, including demonstrating the importance of people with disability leading and shaping research for people with disability in Australia;
2. Improved confidence and being willing and able to speak up in a range of forums and situations, bringing their lived experience of disability and peer support to public events and research;
3. Learning from each other to develop research skills, such as recruitment of participants, reviewing literature, undertaking interviews, data analysis, report writing and conference presentations, and an in depth understanding of how to do inclusive research using the principles of peer support throughout the research process.

Researchers with lived experience described how their experiences during the research project could have been improved by:

1. Involving researchers with lived experience in the initial planning and design of the research project;
2. Having more time during the research project for training and education (before the actual research commenced) and during the actual research project;
3. Ensuring there were clear boundaries about the roles of researchers with lived experience in the research process.

This research contributes to the evidence for how peer support can broaden options for inclusion and participation for people with disability. It provides further evidence of the structures that facilitate the development of peer support for people with disability, and the role of people with disability as researchers in peer support. Social reforms to increase the participation and autonomy of people with disability need to consider all experiences of people with disability if everyone is to be included and able to thrive in Australia.

The recommendations arising from our research in terms of funding of peer support, the operations of CDAH and DDAlliance, the translation of research findings into practice and future research are below:

Funding and policy for peer support

1. CDAH and DDAlliance provide a copy of this research report to representatives in relevant government agencies to highlight the benefits of peer support.
2. CDAH and DDAlliance continue to be recognised for its contributions to the informal safeguards to people with disability and be funded for peer support by the Department of Social Services.
3. CDAH and DDAlliance continue to be recognised for its contributions to the local community and be funded for peer support activities through other avenues that provide support services to the community, such as local government.

Improvements for CDAH and DDAlliance

1. CDAH and DDAlliance continue to engage with members and develop timely and transparent processes for matching peers, particularly peers involved in peer mentoring.
2. CDAH and DDAlliance provide pathways for peers to use their skills and training in a range of roles in the organisations and in community.
3. Researchers with lived experience are provided training for skill development and develop a formalised process for recruitment of researchers with lived experience to CDAH and DDAlliance. This includes exploring opportunities to build the skills of the researchers with lived experience and partnerships with research and industry organisations.
4. CDAH and DDAlliance work to ensure that all information provided to peers is accessible (including complaints processes and all training materials) and that this information is reviewed annually.

5. CDAH and DDAlliance review and revise their peer facilitation training to include: Trauma informed principles, facilitation skills on managing conflicts of lived experience of disability and allowing space for all experiences.
6. CDAH and DDAlliance should do more training and practical conversations around the social model of disability and the conflicts that can arise with different identities of disability in relation to the social and medical models of disability.
7. CDAH and DDAlliance to do more outreach to the community about the principles and model of peer support and engaging with nondisabled organisations to understand peer support.
8. CDAH and DDAlliance to have researchers with lived experience included in the planning and design of all future research work.

Translation and dissemination of research findings

1. CDAH and DDAlliance to provide funding for this final report to be written in Easy Read and that all participants who requested a copy of the study be sent a copy of the Easy Read report.
2. DDAlliance to provide funding for this research paper to be translated into the core languages used at DDAlliance.
3. CDAH and DDAlliance to host a public online forum to highlight the outcomes and findings of the research project.
4. CDAH and DDAlliance to explore options to publish two journal articles in partnership with the researchers with lived experience, the project manager and academic research adviser.

Future research

1. CDAH to provide funding for further analysis of the data focusing on queer identity and disability with the researchers with lived experience.
2. DDAlliance to provide funding for further analysis of the data focusing on culture, disability and identity with the researchers with lived experience.
3. DDAlliance to do more research on the inclusion of family and allies in peer support.