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

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Acknowledgement of Country

The research team acknowledges Australia's First Nations peoples as the Traditional Custodians of the lands, seas and waters of Australia, and pays respect to First Nations Elders past and present.

Content warnings

This report contains information that may be distressing to some readers.

It includes stories of peer support, belonging, identity, some experiences of discrimination and challenges of living with disability.

Support services

If you need support to deal with difficult feelings after reading this report, there are free services available to help you.

If you are deaf and/or find it hard hearing or speaking with people on a phone, you can call the National Relay Service on 133 677 and give the number you want to call.

If you need an interpreter in another language, you can call the free Translating and Interpreting Service on 131 450 and give the number you want to call.

Peer support

Community Disability Alliance Hunter (CDAH) and Diversity Disability Alliance (DDAlliance) have two peer support officers who worked on this research project who are available to provide peer support. You can get support by contacting:

- Shaylie Pryer at CDAH via email at shaylie@cdah.org.au
- Catherine Walsh at DDAlliance via email at catherine@ddalliance.org.au

Blue Knot Foundation

Blue Knot provides information and support for anyone who is affected by complex trauma. Complex trauma is repeated, ongoing, and often extreme interpersonal trauma (between people), violence, abuse, neglect or exploitation experienced as a child, young person and/or adult.

Blue Knot's National Disability Counselling and Referral Service is free. People can connect by telephone on 1800 421 468 and webchat between 9 am and 6 pm AEST from Monday to Friday, and 9 am to 5 pm AEST on weekends and public holidays. For information refer to: www.blueknot.org.au/

Beyond Blue Support

Beyond Blue provides information and support for anxiety, depression and suicide prevention for everyone in Australia.

Beyond Blue services are free. People can connect by telephone on 1300 224 636 and webchat 24 hours, 7 days a week. For information refer to: https://www.beyondblue.org.au/

Lifeline Crisis Support

Lifeline provides compassionate confidential support for people in crisis when you are feeling overwhelmed, having difficulty coping or thinking about suicide.

Lifeline services are free. People can connect by telephone on 13 11 14, SMS on 0477 13 11 14 and webchat 24 hours, 7 days a week. For information: https://www.lifeline.org.au/

QLife

QLife provides Australia-wide anonymous, LGBTIQ+ (Lesbian, Gay, Biexual, Transgender, Intersex, Queer, plus other sexual orientations and genders) peer support and referral for people wanting to talk about a range of issues including sexuality, identity, gender, bodies, feelings or relationships.

QLife services are free and include both telephone and webchat support, delivered by trained LGBTIQ+ community members across the country. Services are for LGBTIQ+ individuals, their friends and families, and health professionals in Australia.

People can connect by telephone on 1800 184 527 and webchat from 3pm – midnight every day. For information: https://qlife.org.au/

1800RESPECT

1800RESPECT is a national sexual assault, family and domestic violence counselling line for any Australian who has experienced, or is at risk of, family and domestic violence and/or sexual assault.

1800RESPECT services are free. People can connect by telephone on 1800 737 732 or webchat 24 hours, 7 days a week. For information: https://1800respect.org.au/

Other resources

The Black Dog Institute provides mental health resources and support tools. For more information: https://www.blackdoginstitute.org.au/resources-support/

Suggested Citation

Acknowledgements

About the research team

This research project is a partnership between two peer led disability organisations, Community Disability Alliance Hunter (CDAH) and Diversity Disability Alliance (DDAlliance); Carrie Hayter Consulting; and Dr Meredith Tavener from the University of Newcastle.

CDAH and DDAlliance have a well-established history of supporting people with disability to become peer leaders in the community. CDAH and DDAlliance have provided the opportunity to employ people with lived experience of disability and peer support to build their skills and knowledge by undertaking this research in peer support as researchers with lived experience.

Our researchers with lived experience are from diverse backgrounds including culturally and linguistically diverse (CALD), gender, sexual orientation, and people who have different experiences of disability and peer support.

Carrie Hayter from Carrie Hayter Consulting has held a longstanding partnership with DDAlliance and working alongside people with lived experience in research, disability, and health services. Carrie was the project manager and one of the research advisers to the research project.

Dr Meredith Tavener, from the University of Newcastle, is a qualitative health researcher and was the academic research adviser to the research project. This research had ethics approval through the University of Newcastle (approval Number H-2021-0088).

This final research report was written by the research team comprising of nine researchers with lived experience of disability and peer support, two of which had additional roles as peer support research coordinators, and the two research advisers.

About the organisations

Community Disability Alliance Hunter (www.cdah.org.au)

Established in 2012, Community Disability Alliance Hunter (CDAH) is one of the first peer led organisations established in the Hunter region of New South Wales. CDAH is an independent, collective voice committed to full inclusion and active citizenship. CDAH is the first peer-led organisation established to prepare people for the National Disability Insurance Scheme (NDIS).

CDAH works to build the capacity of peers to develop, organise and lead peer groups to enable people to share their experiences and learn together. CDAH believes that peers have the right to genuine and meaningful inclusion in the social, economic, cultural and political life of the communities. CDAH's values are:

- Peer led
- Accountability for ourselves and others
- Diversity and inclusion
- Paying it forward
- Humility

Diversity and Disability Alliance (www.ddalliance.org.au)

Diversity and Disability Alliance (DDAlliance) is a peer-led organisation, run by people with disability from diverse backgrounds with the support of families and allies. Established in 2014, DDAlliance's mission is to support people to live the lives they choose. DDAlliance strives for an inclusive, diverse and just society where people with disability have voice, choice and control over their lives.

DDAlliance aims to:

- Maximise the knowledge, skills, and capacity of people with disability, their families and allies from diverse backgrounds;
- Build the capacity of all communities to include people with disability; and
- Share collective lived experiences and knowledge.

DDAlliance believes that each person with disability has the right to:

- Genuine voice, choice, and control of their lives;
- Genuine and meaningful inclusion in the social, economic, cultural and political life of the communities they choose to belong to;
- Have a collective voice which promotes our common experiences, and recognises and values the diversity of our communities; and
- To live in line with the principles and articles of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Language used in this report

The way language is used can be powerful. The use of inappropriate words and language to describe people with disability and their experiences can harm them and silence their voices. Respectful language choices promote awareness, inclusion, empowerment and a rights-based approach to our work.

This report generally uses person-first language. This means we refer to individuals as people first, rather than putting a disability, impairment, condition or diagnosis first. For example, we refer to 'people with disability', not 'disabled people'.

However, people with disability are the experts when it comes to language in this area. We recognise that people with disability have different preferences about language and that language is changing. Some people with disability and their representative groups may have different preferences about how they describe themselves and their disability. Some individuals and groups prefer identity-first language, which reflects the belief that disability is a core part of a person's identity. For example, a person may prefer to be referred to as an 'autistic person' rather than a 'person with autism'. Some individuals and groups may also prefer to use 'disabled person' rather than 'person with disability', reflecting their understanding of disability as arising from social barriers. In deciding on the language for this report, we have been guided by our researchers with lived experience of disability.

Key terms and definitions

The following definitions are words we may use in the report or that our team considers important within our community. Please note this comes from the teams' understanding of what these terms mean for the context of the report. There may be other definitions that exist.

Ableism – A set of beliefs or practices that devalue and discriminate against people with disability. It assumes that people with disability need to be 'fixed' and are less than people without disability. **Internalised ableism** is the way that people with disability absorbs and applies the beliefs of the dominant ableist culture, at an individual subconscious level.

Autism – A neurodevelopmental disability that is complex. It presents differently for each individual. It can be characterised by differences in social and communication skills, executive functioning, ways of learning, and behaviour. It can also be referred to as neurodivergency.

Autistic person (identity first language) – A person who self identifies as having autism or being neurodiverse.

Attitudinal barriers – The way people negatively think and act towards people with disability. This is based on false assumptions about people with disability where they only see the impairment and not the person.

Cisgender – A term used to describe people whose gender is the same as that assigned to them at birth (male or female). 'Cis' is a Latin term meaning 'on the same side as'.

Co-production – A process where people with lived experience are employed as co-researchers who share decision-making power throughout all stages of the research process.

Communication barriers – The inaccessibility of communicating because people who have disabilities that affect hearing, speaking, reading, writing, and/or understanding use different ways to communicate than people who do not have disability.

Culturally and linguistically diverse (CALD) – People from diverse cultures, ethnic backgrounds, nationalities, societal structures, and religions, that may or may not speak a language other than English. This also includes people who are Deaf or Deafblind that may identify as being culturally and linguistically diverse. Internationally, people sometimes use the terms People of Colour (PoC), Black Asian Minority and Ethnic (BAME), or Black Indigenous and People of Colour (BIPOC).

Disability/(Dis)ability/Dis/ability – Medically characterised by a health condition or impairment (such as, long-term physical, mental, intellectual or sensory impairments) that makes it more difficult for the person to do certain activities. Socially it identifies any restriction or lack of ability to perform an activity within the range considered 'typical' for a human being within environments that are constructed for and by the dominant or 'typical' person. This may hinder a person with disability to fully and effectively participate in society on an equal basis with others.

Disabled person (identity first language) – People with lived experience of disability, describing who they are, and their disability as part of their identity and understanding of who they are.

Discrimination – The unfair, less favourable treatment of people and groups based on their characteristics such as race, gender, age, or sexual orientation, or disability.

Environmental barriers – Inaccessible environments, natural or built, that create challenges of access for people with disability.

Institutional barriers – The laws, policies, practices, or strategies that discriminate against people with disability.

Intersectionality – A theoretical concept that describes how people may experience overlapping forms of discrimination or disadvantage based on attributes such as Aboriginality, age, disability, ethnicity, gender identity, race, religion, and sexual orientation.

LGBTQIA+ – An acronym and an umbrella term that is used to describe lesbian, gay, transgender, queer, intersex, asexual, plus other sexual orientations and genders.

Natural safeguard – The protective features which are part of people's day today lives, such as having people around you that you trust, being part of a community or having a job. These are actions, structures or supports that protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising choice and control over one's life.

Non-binary – Genders that sit within or outside of only male and female. A person might identify solely as non-binary or relate to non-binary as an umbrella term and consider themselves genderfluid, genderqueer, trans masculine, trans feminine, agender, bigender, or something else different from their assigned gender at birth (male or female).

Participatory action research – A way of doing research that involving doing research 'with' rather than 'for' people. People with lived experience of the research subject are actively involved in doing the research in every stage.

Peer – A person who shares lived experiences and other characteristics, and who is seen as an equal. In this research, peers are people with disability who attend or have attended any peer event run by CDAH and DDAlliance.

Peer support – A practice of shared support where peers come together to discuss issues or concerns, share experience and knowledge, and learn from each other.

Peer leader – Anyone within CDAH or DDAlliance who are in leadership positions. They can be facilitators that provide training for peer support or lead specific projects or peer groups.

Peer led – People with disability running and leading organisations and activities, with outcomes determined by fellow peers.

Researcher with lived experience – A researcher that has shared lived experience of disability, and who is also a peer in the peer support community.

Trans and gender diverse – These are umbrella terms that describe people whose gender is not the same as that assigned to them at birth (male or female). Trans people may position 'being trans' as a history or experience, rather than an identity, and consider their gender identity as simply being female, male or a nonbinary identity.

Self-advocacy – Advocating and speaking up for oneself and their own needs, using one's own voice to be empowered.

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.

1. Introduction

1.1 Disability in Australia

Disability is diverse and unique to each individual as it varies in type and complexity across the population. There are many experiences of disability. Some result from accidents, illness or genetic disorders, while others have no known cause. Approximately 4.4 million or one in six (18%) people have disability in Australia,(1) with the rate of disability increasing with age.(2) This means the longer people live, the more likely they are going to experience some form of disability. Disability is part of the human condition. Almost everyone will either experience a temporary or permanent disability at some point in life or know or support someone with a disability.

However, disability can be seen negatively. Negative perspectives on disability means that people with disability are viewed as 'abnormal' in line with the medical model of disability. Historically in Australia, like many other countries, this meant people with disability have received an institutional response from society such as placing people in asylums, hospitals and other institutions. In other words, people with disability are seen as 'others', as a homogeneous group or that need charity, rather than equal peers in line with the social model of disability.

Responses like these have changed since the 1970s due to the rise of the disability rights movement where activists and scholars developed new ways of thinking about disability to support demand for social change. This is known as the shift from the medical model to the social model of disability. It means seeing disability through the lens of equality and rights and therefore understanding societal changes are needed.

The United Nations Convention on The Rights of Persons with Disability (CRPD) emphasises that 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'.(3) The CRPD sees people with disability as subjects of rights and active members of society, not as objects of charity and medical treatment.(4,5) Defining disability this way means that disability is not a problem of the person and progress can be made in society by addressing the barriers which prevent people with disability in their day-to-day lives succeed.

In 2008, Australia committed to improving the lives of people with disability by signing the CRPD. Various commitments from national, state and territory governments has focused on promoting fundamental changes in societal attitudes and structures, and removing barriers so people with disability can participate and contribute to society. Examples include the National Disability Insurance Scheme (NDIS), the National Disability Strategy 2010-2020 and more recently Australia's Disability Strategy 2021-2031.(6)

Despite Australia's ongoing reforms and commitment to uphold the CRPD, people with disability still experience barriers preventing people from fully participating in society as equal members. This can be especially challenging for people from particular groups, such as First Nations people, people from Culturally and Linguistically Diverse (CALD) backgrounds, and people from the LGBTQIA+ community, as they experience higher rates of disability, multiple disadvantages and different types of disadvantages which can make large-scale government response ineffective.

1.2 Disability rates across different groups

Some population groups may experience higher rates of disability than the general population such as First Nations people, people from CALD backgrounds, and the LGBTQIA+ community.

The proportion of Aboriginal and Torres Strait Islander people with disability is considerably higher than the amount of people with disability in the general population. The Australian Bureau of Statistics (ABS) National Aboriginal and Torres Strait Islander Health Survey in 2018–19 suggests that almost four in ten (38%) people reported they had a disability. The proportion of people with disability was about the same for males (39%) and females (37%),(7) and children accounted for almost one-quarter (25%) of all Aboriginal and Torres Strait Islander people with disability.(8)

Whilst data of people with disability from CALD backgrounds are reported similar to the general population of Australia, the number of people with disability who identify as CALD is likely higher than reported due to the limited way 'cultural and linguistic diversity' is defined. This makes it difficult to accurately measure how many people from a culturally and linguistically diverse background have a disability. In 2011, the Federation of Ethnic Communities Councils of Australia suggests people with disability from CALD backgrounds represent almost 20% of the Australians who experience disability and that they have a greater rate of profound and severe disability and a higher level of need for assistance with core activities.(9,10)

The Australian LGBTQIA+ community also has a high reported percentage of its population having a disability at 38%.(11) The percentage of disability changes between specific groups within the LGBTQIA+ community, such as trans people having a higher percent within the LGBTQIA+ community.(12)

1.3 Barriers in society

Many people with disability will require support to achieve a good quality of life and to actively participate in society on an equal basis with others. However, many barriers exist for people with disability to do this despite laws protecting people with disability against discrimination. There are also specific issues and barriers unique to certain groups of people based on their background.

Areas where barriers are commonly experienced by people with disability include:

- Social exclusion, negative attitudes and discrimination across all areas of life such as health, employment, justice, education and recreation.(13) This can stem from ableist attitudes towards people with disability grounded by stereotypes and misconceptions held by businesses communities, governments and individuals.(14)
- An individual's self-confidence to make decisions and be involved due to discouragement, lack of expectations or low expectations from other people, or lack of power and involvement in decision making.(13)
- Lack of access to the environment and information affecting participation and communication in the community and understanding of and exercising one's basic rights.(14) This can be more disabling in certain environments such as employment and education.(13)
- Lack of capacity and response in the systems to meet the needs of people with disability, such as the education system. This can affect their ability to develop socially, emotionally and establish a sense of identity.(14)
- Poor employment outcomes and experiences driven by ableism, misconceptions and lack of supports.(13) People with disability are therefore less likely to be employed, live in poverty and rely on the Disability Support Pension (DSP).(14)
- Limited financial resources not only for people with disability but also within the public sector who fundamentally serves to look after Australians. This can lead to eliminating 'unnecessary' and 'costly' welfare policies affecting people with disability in addition to their already lowered socioeconomic position to begin with.(13)
- Lack of services and supports where services are unavailable, unaffordable, poor quality, unable to meet demand and often not built to the needs of people with disability.(14)

These types of barriers can have an overwhelming effect on people with disability such as lowered participation in education and employment including poorer experiences, social isolation, and higher rates of poverty compared to people without disability. For example: (1)

- People with disability make up 38% of the population living in poverty and are more than twice as likely to be in financial stress, compared with 18% without disability.

- 21% of people with disability left school before the age of 15, compared to 8.9% without disability. Similarly, only 34% of people with disability completed year 12, compared to 66% without disability. Only around 17% of people with disability have a bachelor's degree compared to 35% without disability.
- 48% of people with disability are employed, compared to 80% without disability.
- One in five (22%) people aged 15 and over with disability experienced some form of discrimination (including disability discrimination), compared with one in seven (15%) without disability.
- 42% of people with disability experienced fair or poor health, compared to 7% without disability, and 32% of people with disability also experienced high or very high levels of mental health distress.
- Almost one in three (33.1%) people with disability avoided situations because of their disability.

Many of these barriers also affect the lifespan of a person with disability and have a flow on impact on their opportunities in life. This is common in access to education which can be pivotal in someone's life to increase their skills and knowledge to gain employment. However, university students with disability can face barriers that make it more difficult for them to access and complete their studies.(15) For example, policies imposed by the university limiting resources and access to education for people with disability such as ending remote education and requiring that students must attend in person.

Barriers can also impact self-worth and self-esteem.(15) Even more concerning is the increased risk of people with disability experiencing violence, abuse, neglect and exploitation because of barriers and its associated impact.(16) Barriers and impact can be heightened for people with disability from particular backgrounds.

Aboriginal and Torres Strait Islander people with disability face further barriers within society that can impact on their social and emotional wellbeing. Factors such as stress, social exclusion, inequality and racism can worsen disability.(17) It has also been documented that Aboriginal and Torres Strait Islander people with disability experience higher rates of discrimination than non-Aboriginal and Torres Strait Islander people with disability.(18) These factors can contribute to increased exposure to health risks, contact with the criminal justice system and reduced access to services and support.(17) Aboriginal and Torres Strait Islander people with disability also face higher rates of unemployment and poverty, with over half (50%) not being in employment compared to just under a quarter (25%) of Aboriginal and Torres Strait Islander people without disability.(19) Whilst Aboriginal and Torres Strait Islander people with disability could live in institutions that meet their support needs it also means being disconnected from their country, culture and family.(20)

Besides the issue of a limited understanding of what CALD should consist of, there are also various definitions of what people from CALD backgrounds consider as disability which also

impacts the way they view disability. As a result, people with disability from CALD backgrounds may experience high rates of stigma and underdiagnosis of disability.(21) Negative attitudes towards disability within their own community can lead to adverse outcomes such as differential treatment, isolation and exclusion, and increased risk of harm.(21) Discrimination is also prevalent on many levels based on disability, ethnicity, race, language and culture. This can drive the lack of access to critical supports and services and accessible information from government and community based programs.(10) Furthermore the combination of disability, cultural diversity and low English proficiency can heighten social and economic exclusion within a western system of government services and supports.(22)

As of 30 June 2019, people with disability from Aboriginal or Torres Strait Islander backgrounds made up 5.7% of all NDIS participants,(23) and people with disability from CALD backgrounds made up 8.4%,(24) despite both community groups having higher rates of disability within the community. This demonstrates the ineffectiveness of services and systems reaching people with disability that needs it the most, and the systemic barriers they face in equitable access. This is especially reflected in the impact of colonisation where for many Aboriginal or Torres Strait Islander people, the category of disability can be seen as 'another marginalising identity,' and a relationship with stigmatisation and violence.(25) Therefore, there is a resistance to accepting the westernised ideals of disability and the social model.

People with disability in the LGBTQIA+ community face barriers in society such as higher levels of harassment and bullying than non-disabled youths. Barriers can also relate to issues with identity and acceptance. For example, people with disability in the LGBTQIA+ community feel invisible in both communities with LGBTQIA+ events or facilities not being accessible such as Pride Month events, despite the importance of Pride Month to the LGBTQIA+ community.(26) People with disability in the LGBTQIA+ community also express that they experience lower levels of support and acceptance when accessing health or support services,(11) and higher rates of poverty and unemployment.(12)

These experiences reflect the diversity of people with disability in Australia and their unique experiences and barriers that reduce their social and economic participation. Similarly, it represents the challenge of large-scale governmental response to improving the lives of people with disability when disability is experienced diversely and differently by not only individuals but certain groups of people with disability. Many of these initiatives led by government do not respond to the cultural needs of people with disability in a safe or appropriate manner and therefore are ineffective at facilitating inclusion and participation in society.

Many studies have found that the perceived autonomy of people with disability generates feelings of optimism and self-confidence, which could become a personal resource for the person with disability.(13) Furthermore, disability identity has been shown to be more

positively formed when people with disability are seen as equal, with full participation in society, including having voice and control around connection to community, access to supports, and leadership on issues that impact them.

This research study proposes that one way people with disability are increasing their social and economic participation in Australia is through peer support, which can help people with disability build autonomy to navigate and reduce barriers. Peer support can also be considered to help people with disability, empower and protect themselves and therefore act as a natural safeguard to reduce the risk of harm and promote quality.

2. Peer support

Peer support has been extensively studied around the world for many years leading to the recognition of different forms of peer support that has demonstrated a range of positive impact. It is a practice that has been used nationally and internationally by people with disability to empower and support each other. More recently it has received attention in that it actively involves people as individuals and collectively to address their specific needs and improve outcomes that matter to them.

At times, peer support can overlap with other types of support, such as advocacy and self-advocacy,(27) although it is generally considered distinct in the research and practice literature.

2.1 What is 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 to bring about self-determined personal change.(28–30) Peer support can provide a safe space for people to connect and share lived experience in dealing with different types of social circumstances, emotional challenges or health issues.(28,31)

A view in practice

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'.(32) This helps build an 'inclusive and just society where people with disability have voice, choice and control and full inclusion and active citizenship'.(33)

Generally, peer support is commonly delivered in-person, in-group sessions or through online peer support - a relatively new option that has become particularly prominent during the COVID-19 pandemic.(34) It is used by people with disability and also by family members of people with disability such as parents and siblings.(35)

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.(36,37) This is done by peers. A peer is someone who shares demographic or social similarities as another person and is considered as an equal.(28) This notion of shared social experience and status, whether relating to disability, age, ethnicity, sexuality or gender is considered integral to the application of any peer support program.(38) It differs from other types of support because it is delivered by a person with lived experience and with deep understanding of the relevant issues.(30,39) When people find affiliation with others similar to them, they feel a connection. This enables peers to work in partnership and allow for social connection, mutual understanding, learning and growth.

2.2 Peer support as a means of participation

The history of peer support in the disability context can be linked to the strong activism and social change during the disability rights movement in the late 1960s. The term "Nothing About Us Without Us" focuses on the active involvement of people with disability in the planning of strategies and policies that affect their lives.(40) It relies on the principle of participation and has been part of the global movement to achieve the full participation for, by and with people with disability.(40) Its formation stemmed from the experiences of exclusion of people with disability 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,(41) better known as the social model. This helped people with disability see themselves as people with rights, capable of claiming those rights, and able to make decisions for their own lives based on their free and informed consent as active members of society.(41) People with disability could reclaim their power by having a strong collective identity and formed communities to address issues of active participation in society including policy and research(42) and advocating for improvement.(43)

Disability identity has been shown to be more positively formed when people with disability are seen as equal, with full participation in society, including having voice and control and connection to community, access to supports, and leadership on issues that impact them.(44) However, it is common for people with disability to hide their disability and therefore reject disability identity because they may perceive danger, social prejudice, or a social cost if they disclose their disability.(45)

Through peer support, people with disability can exercise their human and civil rights to be active members of society. For example, the shared experiences of paternalism, prejudice, and vulnerability grounded disability identity and peer support can enable political motives and power. Although peer support emerged in a political environment, it is also an

interpersonal process with the goal of promoting acceptance and growth in the context of community.(46) This occurs through an increased sense of empowerment, decision-making power, empathy, hope, and autonomy with the potential to 'lead change' across communities.(36,42,47)

2.3 Key values of peer support

Social relationships and reciprocal sharing of experiences are at the centre of peer support. In a systematic review of peer support, all 79 studies stressed the importance of reciprocity.(48) This is reflected in Mead's definition of peer support as 'a system of giving and receiving help founded on key principles of respect, shared responsibility and mutual agreement of what is helpful'.(46)

Empathy (being able to understand and share the feelings of another person), congruence (being able to relate to others as equals) and acceptance (being non-judgemental) are other important elements to the success of peer work.(49) These core elements are also seen as important principles and values in the delivery of peer support.

A view in practice

CDAH and DDAlliance have developed peer support training and induction reflecting the key values in a culturally responsive way as:

- Be humble - as equals with respect for differences.
- Be accountable - to build trust and regard for responsibility.
- Pay it forward- give first to be able to receive.

These three key values are embedded in the practice of peer support in the two organisations.

Connections built on mutual experience and understanding as equals gives people the space to 'be' with each other without the limitations of traditional relationships found in experts and patient or client relationships. This can help members of the peer community to try new behaviours and experiences with each other and move beyond one's self perspective built on disability or diagnosis.(46)

2.4 Models of peer support

Peer support has emerged out of different theoretical models. One is an empowerment model and the other one is a behavioural change model. There are also various models of practice.

In the empowerment model, people are empowered through their connections and relationships with peers, reflecting a human rights and citizenship perspective.(48) This model provides a space for people to share their experiences and knowledge, which supports them in making their own decisions for the future.(48) The empowerment model tends to have less structure, is non-hierarchical and focuses on the process of sharing lived experiences between peers.(48) This model is evident in peer developed peer support with its non-hierarchical approach and influenced by people creating their own communities by reaching out to others as a form of self-help, alternative to the dictation of the medical model.(28)

In contrast, the behavioural change model is based on the assumption that there are specific changes that are likely to improve people's lives and these changes can be best supported by others who are 'like them' but who have already made these changes and have been trained to support others in making these changes.(48) This approach is much more structured and intentional with focus on achieving specific outcomes. It is more hierarchical than the empowerment model. This model has typically been supported with government funding with defined vision, principles, and practices of peer support to meet government oversight requirements.(28)

Three broad models of practice of peer support that reflect the empowerment model and the behavioural change model based off the well-established practice of peer support in the mental health space. These are:(29,36,38,50)

1. Informal and ad-hoc support among communities or peers often as friends in places where a community already live and interact, or in places where people share in social groups
2. Organised but unpaid peer support for example, mentors or peer buddies
3. Paid peer worker where peers are paid to provide support to other peers or within the sector, such as consumer advisers, peer advocates or peer advisers.

In the mental health space and now in the disability space, there has been growth in the establishment of paid peer workers hired into peer positions (such as peer mentors, peer support specialists, peer advocates).(51) Fulfilling a peer support worker role requires both experiential knowledge and background of similar characteristics, because together these facilitate the building of a relationship between peer support worker and peer.(52)

A view in practice

CDAH and DDAlliance uses a mix between each model. Whilst their approach in principle reflects towards an empowerment model as peer-developed peer support, under the funding structure, there is a focus on the behavioural change.

Government programs such as the information, linkages and capacity building (ILC) funding have geared heavily towards the capacity building of individuals to 'move from being dependent clients to active citizens' in the context of the NDIS. At CDAH and DDAlliance this has been integrated in more targeted peer support activities such as training about peer support and becoming a peer worker, and peer mentoring on specific goals.

In practice, peers operate in many different roles, from providing informal advice and support through to trained paid peers to purposefully engage in peer support relationships that promote mutual growth and achievements.

At its inception peer support was largely informal, such as self-help groups, focused on being mutually supportive. Today focus is on supportive service provision based on experiential knowledge delivered to people with disability by those sharing disability. Thus, rather than being mutually reciprocal, where the intent is beneficial to both parties, currently peer support services emphasises assisting those participating, with benefit to the deliverer being a secondary gain, as noted by peers workers themselves.(53)

Consequently, peer support is more structured, rather than primarily providing informal support, and may involve the delivery of practical information and skill building while still providing support to resources and enhancing companionship by sharing experiences and knowledge.(34)

2.5 Benefits of peer support

Peer support has been shown to benefit a wide range of populations, such as young women with disability, people with learning disability, people with acquired disability, young people with disability and parents and caregivers of children with disability or chronic illness, in a variety of different ways.

2.5.1 Benefits to individuals

Research has found that peer support improves people's mental health and wellbeing,(31,48) social connectedness and social skills, providing hope and encouragement,(36) and a real sense of acceptance and empathy of peers through the sharing relationship.(36) This can lead to increased confidence.(54–56) Other benefits include empowerment,(31,48,56) social inclusion, the challenging of stigma and discrimination particularly for marginalised groups,(31,54) and increasing employability skills.(55) However, not all who engage in peer support will receive all of these benefits. The number of improved outcomes for people may be dependent on regular participation, rather than occasional participation.(57)

In addition to the benefits of peer support for recipients, some research has focused on the benefits to people who give peer support. People who give peer support experienced many positive changes in their lives, such as helping them to avoid being withdrawn, regaining confidence and gaining a sense of identity, and the approval of others.(58) Other benefits include self-efficacy resulting from the experience of helping others, increased self-knowledge due to the communication among people sharing common experiences, fulfilling commitments and learning from mistakes, the development of specific skills and talents and improved communication abilities.(58)

Peer workers also reported positive benefits such as increased self-esteem, larger social networks, and increased community participation.(51) People who received support from peer workers experienced better rapport with them than non-peer staff and reported increased hope and motivation, as well as increased social networks, as a result of working with peer workers.(51) Further, being a peer worker helps to challenge self-stigma, engage in one's own self-discovery, enhance their social support network, find positive means to spend their time, and gainful employment therefore, achieving a better quality of life.(34) Moreover, they are offered opportunities for professional growth in terms of learning positive work habits and job skills, as well as having the potential for developing and achieving career goals.(34) Many peer workers simply mentioned the very concrete benefit of earning money and engagement in meaningful activities.(58)

2.5.2 Benefits to families and communities

Peer support for people with disability not only supplements informal supports but it also helps people with disability and their families' access and navigate formal support and service systems.(29) Studies have found that disability peer support run by and for people from CALD backgrounds is a good complement to formal disability support.(56,59) Another

study(35) found that peer support provides a platform for sharing experiences and gaining practical advice to gain a sense of empowerment and to better navigate the health care system. Peer support provided emotional support and opportunities for social connection.

Similarly other studies(60) found that parent-to-parent peer support for parents of children with disability can provide emotional and practical support, increase self-esteem and confidence, and reduce feelings of isolation and loneliness. Participants reported that the peer support group provided a safe and supportive environment where they could share experiences and offer advice and support to one another. The findings suggest that such support can have positive impacts on the wellbeing of both the parents and the children.

Peer support services can be more accessible than mainstream services because they exist within communities and participate with existing peer networks, and therefore have a greater reach into the communities they work alongside,(61) especially among those hard to reach.(62)

2.5.3 Benefits to society
Research identifies that peer support for people living with mental health issues has led to reduced admission and hospitalisation rates.(54,55) It also provides a means of additional support to staff and improving outreach support for people living with mental health issues, especially in areas where services and professionals are limited and resources are scarce.(34,54,55) For staff that are not peers but work alongside peer workers, empathy for and understanding of people with mental health issues increased.(51)

Peers as employees also serve as positive role models which helps to alleviate societal stigma and discrimination against people with disability, seeing them in a more positive light.(34) Further, they contribute to society by being productive citizens and paying taxes and therefore seen to reduce government expenditures and resources.(34)

2.6 Challenges of peer support
There are several barriers and challenges that can limit the effectiveness of peer support. These challenges can arise due to various factors, including societal attitudes, accessibility barriers, and individual differences.

2.6.1 Stigma and discrimination
The internalisation of societal attitudes towards disability has been identified as a barrier to peer support affecting the health and wellbeing of young people with disability, and the effectiveness and engagement of peer support.(63) Internalised ableism can lead to feelings of low self-esteem, reduced confidence, and decreased social participation, which can, in turn, limit the peer support engagement.(63)

People with mental health issues often face stigma and discrimination from others, which can lead to feelings of shame, guilt, and isolation. This, in turn, can prevent people from seeking peer support and participating in peer support programs for fear of judgement or

further stigmatisation.(64) This can also arise as cultural barriers of stigma and discrimination.(65)

2.6.2 Providing peer support

Resistance to peer support can be attributed to the expressed fear that peers will provide inadequate information or inappropriate help, misleading people who seek support.(66) Boundary issues were commonly observed, such as whether to relate to peers as friends or someone you work with.

Limited opportunities for meaningful engagement in peer support activities also presents a challenge as it is seen as a reflection of the value in one's role as a peer supporter.(67) Peers tended to limit their emotional involvement when they did not feel they were making a difference or what they had to offer was not really what was needed.(48)

2.6.3 Being a peer worker

The paid peer worker relationship challenges the notion of equitable, mutual relationships based on shared common experience, a hallmark of peer-developed peer support. Relationships between peer workers and peers can be considered hierarchical, similar to staff and service user relationships in the disability and mental health system, in contrast to the horizontal peer to peer relationship.(28) Some argue the professionalism of peer support could impact on the diversity of peer support offered.(54,55) Additionally, there may be tensions between the peer role and the staff role, such as peer workers being unwilling to give up their unique perspective as a peer to adopt professional beliefs and roles.(58)

Peer workers can also experience unintended negative consequences of being a peer support worker such as uneven power relationships between peers, feeling rejected when peers 'drop out' of the group or one-on-one relationship, peers becoming over-dependent, feelings of emotional entanglement, tension or conflict.(48) This can be considered as the emotional burden of peer work(68) and put peer workers at risk of burnout due to the high demands of their work and the emotional toll of supporting others.(69) Burnout can lead to decreased job satisfaction, reduced effectiveness, and increased absenteeism

Studies have examined the peer support workers' experience of providing support and found that peer workers sometimes felt confronted by their own anxieties and vulnerabilities, and difficulties with peers becoming aware of their own hidden feelings and sensitivities associated with the intimacy of mutual sharing.(70) Issues related to burden of care and time effort were also reported.(48)

Peer workers have also faced numerous challenges, including low pay, insufficient hours equating to less opportunity for peer workers to interact with non-peer staff, negative or rejecting attitudes from non-peer staff, and being treated as "patients" instead of colleagues.(51)

2.6.4 Lack of cultural appropriate structures

Several barriers to peer support is recognised in the healthcare context, including a lack of training and support for peer workers, difficulties in reaching and engaging peers, and challenges in obtaining and sustaining funding for peer support programs.(71)

A practice review of delivering peer support found while most peer support took time to set up, particularly in identifying and empowering peer support leaders, and required funding to support a group; engaging people from marginalised communities took more time and was more resource intensive.(56) Specifically, CALD groups required information and resources in languages other than English, funding for interpreters and translators additional support to train peer leaders from those cultural groups.(56) Group size was negatively associated with perceptions of social support as groups that are too large may make peers feel a sense of alienation and experience difficulty making connections.(48)

2.6.5 Access to peer support

Some studies noted that some individuals with disability may face barriers to accessing peer support, including lack of transportation, difficulty finding support groups, and stigma.(72) This can hinder the effective participation of peers and peer support programs. Other studies also noted in their study that some families may face barriers to accessing peer support, such as a lack of available resources or limited awareness of peer support programs.(35)

3. What we still need to know?

Despite more than nearly half of the Australian population born overseas, (73) there are limited studies on peer support for people with disability from CALD backgrounds and Aboriginal and Torres Strait Islander people with disability.(48) Recent research evidence found that peer support groups run by and for people with disability from CALD backgrounds is a promising approach to culturally responsive supports that meets the needs of the CALD community.(59)

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 in the evaluation process. Much disability research has historically excluded people with disability as decision-makers and thereby stigmatised in research for 'knowledge production'. Whilst disability research has given voice to people with disability who are often marginalised by society, research still tends to give importance to disability over other characteristics of a person with disability. As a result, people with disability are frequently assumed to be homogenous share the same views, experiences, and priorities, regardless of gender, age, cultural background, sexual orientation, socio-economic status, religion, and other categories of difference. This means that the interactions among the diverse characteristics of one's identity are often neglected and certain people with disability will be excluded and given limited, if any, decision-making power. This is also the

case in research where there are limited studies employing the 'Nothing About Us Without Us' principle. This means most research studies view and treat people with disability as 'subjects' rather than people with lived experience of disability and peer support leading the research.

However, there is a growing movement of people with lived experience undertaking research, that improves outcomes for people with disability and researchers.(74) Bigby(75) argues that a collaborative approach "combines the skills of academics with the insider perspectives of people with intellectual disability, to generate new knowledge of the type that neither group could do alone" and requires "reciprocal relationships based on trust and a genuine belief there is much to learn from involvement in processes together".

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 uneven power relationships between peers, the issue of the 'professionalisation' of peer support and its impact on identity; the costs of peer support; and ensuring access to ongoing funding for user-led organisations to build the capacity of peers and peer support engagement.(31,48,52,54,55,59)

In response to these pressing issues, it's also essential to engage in intersectional research that explores layers of difference/diversity in peer support, including for people with disability from CALD backgrounds, and people with disability from the LGBTIQA+ community.

4. Our research questions

To add to the understanding of peer support, our research questions are:

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?

5. Research design

5.1 Approach to the research project

We used participatory action research (PAR) and co-production research with a team of nine researchers with lived experience, two of which were also peer support research coordinators, plus two researcher advisers (including an academic research adviser). PAR is a research approach 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.(76,77) Co-production research is a continuous partnership between researchers with lived experience and researchers without lived experience who work together through all stages of the research process.(78)

5.2 Co-producing our research

The researchers with lived experience are people who bring their own skills and experiences in research, disability and peer support. Four researchers with lived experience have never been involved in a research project before, and four have been part of research teams in the past, and/or are currently studying at university or in vocational education (i.e. TAFE).

As a team the researchers with lived experience led the research, recruited all participants, analysed data and wrote together, alongside guidance provided by the project manager and research advisers. This embodies the disability rights movement concept of 'Nothing About Us Without Us' and ensures the research is inclusive and accessible to all people with disability and people from diverse backgrounds.

Peer support was embedded in how this research was conducted by providing training and individualised peer support. Working groups were created to undertake different parts of the research which was co-chaired by a peer support research coordinators and a researcher with lived experience. For example, working groups were formed including a literature review working group, a recruitment working group, a data analysis working group and a final report working group. This was supported by the two peer support research coordinators, the research adviser and the academic adviser.

The research team worked entirely online throughout the research project. To build rapport while working online, different platforms were explored to find ones that were most accessible. Online platforms of Zoom, Slack, Mural and Natural Reader were used to communicate, share ideas and for data analysis. The research team held key values of humility, accountability and paying it forward, holding each other accountable to attend and do what we say we would do and meet key deadlines in the research project through weekly team meetings. The structures and platforms that we used during our research project are listed below in Figure 1.
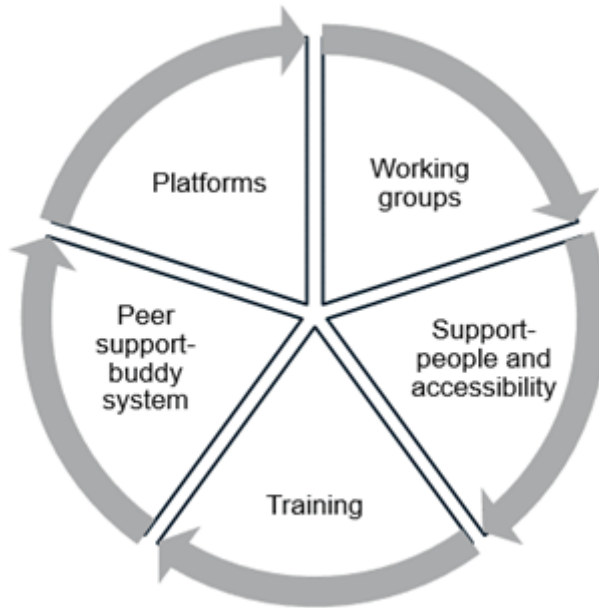
Figure 1 – Structures to support researchers with lived experience

5.3 Research instruments

Data collection instruments were designed to explore peer experiences at CDAH and DDAlliance with peer support, peer support training, leadership and life with disability. Semi structured interview questions and an interview guide was also developed for interviews with the researchers with lived experience (see Table 1 – Data collection instruments).

Table 1– Data Collection Instruments

	Peers learning about peer support	**Peer leaders**	**Peers with disability**	**Researchers with lived experience**
Data Collection Instruments	• Round 1- Pre and post training survey • Round 2- Post training survey	• Round 1- Semi structured interview • Round 2- Semi structured interview	• Round 1- Semi structured interview • Round 2- Semi structured interview	• Round 1- Semi structured interview • Round 2- Semi structured interview

All researchers with lived experience contributed to the interview guide and interviewing of peers with disability and peer leaders. Peer support research coordinators and the research advisers designed the interview guide for researchers with lived experience and interviewed the researchers with lived experience.

The pre and post training survey was modified for Round 2 to be one post training survey because of the challenges of completing two surveys especially during COVID-19. The training survey in Round 2 could also be administered by a phone interview if participants requested it.

Changes to the interview guide for peers with disability and peer leaders were made in Round 2 to explore questions about culture and disability identity with participants.

6. Participants

6.1 How did we recruit people?

Participants were recruited through online and face to face peer events at CDAH and DDAlliance. There were two rounds of data collection:

- Round 1 from May 2021 to January 2022; and
- Round 2 from March 2022 to January 2023.

Language interpreters were used to recruit a diverse range of peers to our study. Information sheets were translated into community languages of Arabic, Korean, Khmer, Vietnamese and Simplified Chinese.

6.2 Who did we talk to?

We talked to peer leaders, peers and researchers with lived experience. A total of 43 participants were interviewed through Round 1 and Round 2, including 16 peer leaders, 20 peers with disability, and seven researchers with lived experience. An additional 13 participants completed the training survey across the two rounds. Twenty-three participants were from CALD backgrounds.

All participants consented to be part of the research.

Survey

Training participants

13
4 CDAH
9 DDAlliance

Interviews

Peers with disability

20
9 CDAH
11 DDAlliance

Peer leaders

16
10 CDAH
6 DDAlliance

Lived experience researcher

7
4 CDAH
3 DDAlliance
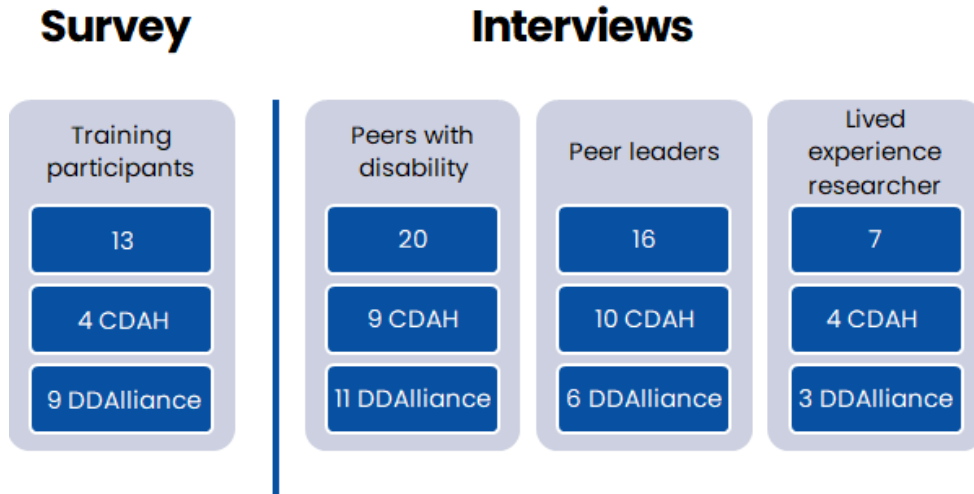
Figure 2– Round 1 and Round 2 number of participants

Out of the 43 participants interviewed, 13 participants were interviewed in both Round 1 and Round 2 to explore changes for peers over time. There were 4 peers with disability, 3 peer leaders and 6 lived experience researchers interviewed in Round 1 and Round 2 (see Figure 3).

Round 1 and Round 2 Interviews

Peers with disability

4
1 CDAH
3 DDAlliance

Peer leaders

3
2 CDAH
1 DDAlliance

Lived experience researcher

6
3 CDAH
3 DDAlliance
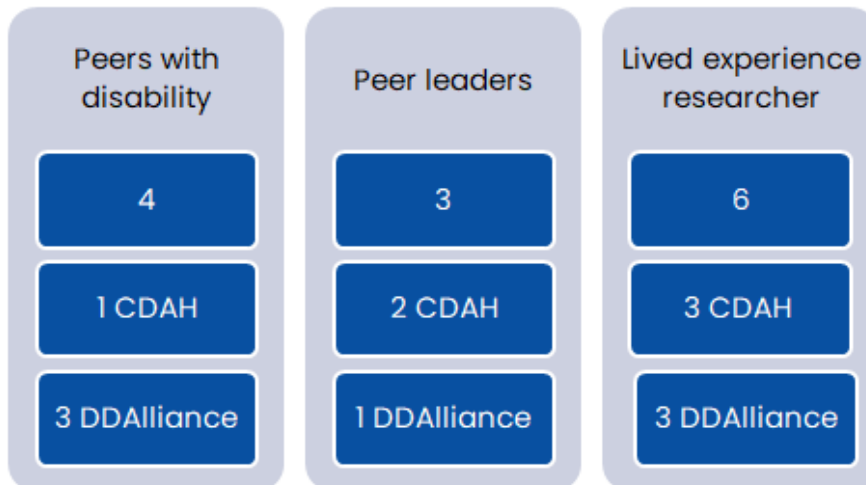
Figure 3– Round 1 and Round 2 number of re-interviewed participants

7. Data Analysis

All interviews were recorded, transcribed and de-identified. Transcription was initially completed by the interviewer, however, an external transcription provider was brought in due to time constraints.

The peer leaders and peers with disability transcripts were analysed by the data working group. The data working group included 6 researchers with lived experience (3 from DDAlliance and 3 from CDAH), a Peer Support Co-ordinator and a researcher adviser. The group developed a protocol for how team members reviewed transcripts. All transcripts were further de-identified by the peer support research coordinators before being shared with the data working group. Researchers with lived experience were encouraged to speak up if they felt uncomfortable reading a transcript because of the content. Peer support research coordinators provided support to team members to analyse transcripts with some people choosing not to continue analysing specific transcripts.

The Data Working Group met online (via Zoom) twice a week for 2.5 hours with either a Peer Support Co-ordinator or research adviser as support to identify key themes from the peer leader and peers with disability interview transcripts. The researchers with lived experience were encouraged to bring their unique lived experience to the data analysis. The academic adviser provided support or guidance to the data working group as required. All team members were allocated time to review the transcripts from peer leaders and peers with disability before each meeting and used Mural (https://www.mural.co/), an online collaboration tool, to analyse the data by different themes and quotes. Data working group team members were encouraged to add any data to the visual data map between working group meetings.

The Data Working Group regularly reviewed our data analysis process. In the Round 1 data analysis Leximancer (www.leximancer.com), a qualitative data analysis software tool was trialled, but the data working group found it easier to do data analysis online together via visual mapping on Mural, which also allowed them to remain close to the data. The Data Working Group decided to continue with analysing the data via themes on Mural.

Regarding the researchers with lived experience, all interviews were recorded, transcribed and de-identified. The peer support research coordinators and researcher adviser analysed the Round 1 data thematically via Mural. The Round 2 data was analysed thematically via Mural by the Peer Support Co-ordinators.

The training survey data was analysed descriptively by a small group of the Data Working Group and presented back to the Data Working Group for feedback.

8. Key Findings

Interview findings from Rounds 1and 2 are laid out to answer each of the four research questions:

- What are the benefits and challenges of peer support for people with disability in peer-led support organisations?
- How can peer support for people with disability be improved?
- In what way can support structures facilitate the development and engagement of people with disability in peer support?
- What are the experiences of involving researchers with lived experience in the research of peer support in peer support organisations?

Due to the small sample for the training survey data, they are presented as a separate section below.

8.1 Peer support training

Training surveys formed part of our research to understand people's attitudes towards disability, peer support and the experiences of participating in peer support training. Training surveys ran in two rounds from May to December 2021, and May to December 2022. A total of 13 participants completed the surveys.

Round 1 surveys were structured as a pre and post training survey where four participants completed the pre training survey and two completed the post training survey. Three people from DDAlliance and one from CDAH participated.

The second round of survey collection used an amended shorter version to combat the challenge of low survey participation. This change also involved using one post survey following completion of peer support training and cutting down on non-pertinent questions.

In Round 2, nine participants completed the training survey. Six people from DDAlliance and three people from CDAH participated.

Overall, we received responses from people of culturally diverse backgrounds, including Australia, Hong Kong, India, Korea, Solomon Islands and Fiji. They reported a range of languages spoken at home including English, Cantonese, Korean, Pidgin English, Fijian and a variety of languages from India and South Asia. Participants also varied in age ranging between 22 to 67 years old. The majority of participants were female (nine respondents), three were males, and one non-binary. Two participants identified as being from the LGBTQIA+ community.

Survey participants had a variety of experience with peer support. More than half of the participants (n= 9, 69%) indicated they have been involved in peer support before. Those who had experience ranged from attending other peer support groups run by different organisations to participating in online groups and supporting peers.

Results also indicated that people interpret the meaning of providing peer support to be quite literal in the sense of helping people with disability, helping others complete forms and by sharing food and clothes. This indicates peer support can mean different things to people and can be provided in formal settings and informal daily situations. In addition, 50% of the participants indicated they had not participated in peer support training before and the majoritywere people from CALD backgrounds.

Participants indicated they wanted to do peer support training so they could:

- Learn and develop new skills
- Find something that would suit their interest
- Be more involved in supporting others in the community
- Become a mentor by sharing information and knowledge

Everyone indicated they found the training accessible and easy to follow. Almost all but one participant received the support they needed during training. Similarly, almost all but one participant felt they were listened to a lot by the facilitators and their peers.

As a result, participants all indicated a positive change towards peer support and themselves, an improved understanding of peer support and development of specific skill sets. This included:

- Growth in self-confidence
- Increased interpersonal relationship skills such as listening and having difficult conversations
- Self-improvement and mentoring techniques such as using goal setting
- Seeing perspectives from others
- Eagerness to continue peer support practise

"[Training] made me see that peer support is a giving opportunity to support to make a person better and help yourself... now I feel positive about offering peer support to other people, which I didn't have before. I didn't feel confident giving peer support."

"[I learned] what skills to have, how to be a better listener, how to have difficult conversation, how to see the rainbow in some else cloud, help some to see their goal and support them."

"I loved the training because it has given me lots of idea to put to practice, to get involved more in community support and put some of the views and points learned into practice."

Participants also enjoyed the interactive nature of the training and the opportunity to meet people.

"[I liked] meeting people. Peer support is helping people that really need help to learn something new."

"Very interactive, a lot of group work, got to know the other peers and mentors, new network of support people for me."

After training, 85% of peers (n= 11) agreed that they know what is best for them more than anyone else such as medical professionals; 69% (n= 9) believe information they get from other people with disability is useful (two of which were undecided and two of which strongly disagreed); and 69% (9) believe their own life experiences can be valuable to other people and society (one of which was undecided and three preferred not to answer). It is worth noting that those who were undecided specifically identified from an Asian background.

After the training 77% of peers (n= 10) said they wanted to give support to others in the future; 53% (n= 7) said they wanted to help someone else run peer support, 38% (n= 5) indicated they wanted to get support from others and 23% (n= 3) wanted to become a peer leader in the future. Two participants were not sure what to do with peer support in the future.

One of the peers said they were not sure what to do with peer support whilst they started to see themselves as someone that would benefit from it. This peer is a non-permanent resident in Australia and did not know if they were eligible to be involved in peer support.

"I would have like to learn more about how I could do more peer support and more information about what I am eligible to get involved in peer support or not e.g. if I am allowed to be involved if I'm not a permanent resident."

This reflects the unique barriers people with disability from migrant backgrounds experience. It suggests organisations need to provide additional support and clearer information to people with disability from migrant backgrounds to increase their engagement with the broader community, especially people who may be on precarious visa situations who may not know what free services and supports are available to them.

Feedback from the participant who felt they did not receive enough support and listened to a little by the facilitators primarily focused on training being more accessible. They suggested making sure facilitators who don't have a vision impairment read each slide out loud and having multiple language interpreters support each other so they can take breaks.

"The facilitator who was vision impaired read out what was on the slides, however the other two facilitator[s] who don't have a vision impairment didn't. As I am vision impaired this needs to happen for me to follow along."

Other suggestions to improve training included providing training resources at the start of the session such as the training booklets and keynotes, shortening the training and content, and having more opportunity for interactions and catch-up sessions.

> *"Eight session is very long and very structured, not many catch up session. And zoom link wasn't sent early enough, needs to be a day before."*

Many participants from CALD background were just glad to have the opportunity to attend peer support training.

> *"Thank you for your help in giving us this training."*

> *"I am happy that you came to us, to help us to learn more about supporting people and the community. And to help people with disability."*

Whilst the training survey data is limited, it does support the notion that peer support is a unique opportunity to enable people to gain new skills and make worthwhile contributions to the community. It also presents an opportunity to formalise what people have long been doing in a skills-based way that can be transferred to other people in the community.

8.2 The benefits of peer support

Interviews with peer leaders and peers with disability described a range of benefits of peer support, such as understanding culture, disability and identity, challenging internalised ableism, building inclusion and community connection, empowering people and building skills and capacity of peers. Each of these are discussed in the section below.

8.2.1 Connection to disability and identity

Peer leaders and peers with disability described how peer support can be a transformational experience. A peer's journey through peer support will often change their understanding of their disability, where they have come from, who they are and understanding of their own self through their experiences of disability.

> *"Now living with a disability … in the last few years, I've felt really able to embrace it as part of my identity … through meeting other disabled people … from a sense of pride in my identity and connection, and I'm just having language for my experience and realising that I'm not alone." (Peer with disability, #45)*

> *"I also feel a lot more educated and have different coping mechanisms, which really helps me sort of educate my family about the lived experience that I've gone through as well. Which is really beneficial in that sort of situation." (Peer with disability, #10)*

A peer described how they learnt to come to terms and adapt to being a person with disability and shifting their attitude to their disability from a medical model of illness (and deficit) to the social model.

"Before then, I wasn't describing myself as someone with a disability, I was describing myself as someone with an illness. And that's really different. Because there are a lot of really great people coming up with really specific ideas that I hadn't encountered before and that changed, not only my idea of understanding disability, but my understanding of myself." (Peer with disability, #15)

Involvement in peer support has helped them gain a distinct perspective on their experiences of disability and how that relates to their worth as a person in society.

"… I'm here, I exist, that's enough, that's all… I don't have to do anything with that. I don't have to go "well, I knocked five things off my to-do list today, therefore I am a worthwhile human being." No, I got nothing done, straight nothing. I got out of my bed and I ate some food, and then I went back to my bed. Still a worthwhile human being, that's really important." (Peer with disability, #15)

These experiences indicate connection to peers and that the peer community can support the development of a disability identity.

8.2.2 Intersectionality of peer identities

Peers from DDAlliance described specific challenges in relation to the impact of culture on their disability identity and how they navigate identity in their community. The language used by peers from diverse backgrounds often reflected a medical (deficit) model of disability, and the impact of internalised ableism.

"I don't see that there is anything good about living with a disability. I wish that I would have been normal, without any disability at all, I wish that I lived a normal life like every other person." (Peer with disability, #4)

"… if you come from say another culture, a lot of people don't know about how to help disability." (Peer with disability, #5)

Language may stem from peers' experiences of stigmatising cultural attitudes towards disability, such as a family's limited expectations of a person. This may affect self-worth and self-esteem.

"It's just, you're expected, but because you are a person with a disability you have to live at home with your parents for the rest of your life, and then because I've always heard about my sisters, like my family and my relatives talking about my sisters moving out of home, my sisters getting married, my sisters having kids, and none of this about me… Because like I said they have zero expectations of you just 'cause you're a person with a disability'. You know, they don't expect you, like for me, I left school in year 10 because I didn't have anyone to force me to stay to year 12 and go to uni." (Peer with disability, #29)

Other peers described complexity in their family dynamics as they attempted to discuss or disclose their disability. One peer described the experience of how their family responded to their disability, which contradicted their own view of their identity.

> "But I did lose relationships with my family because they were not prepared for the fact that it was Cerebral Palsy, and they obviously felt shame around that. They weren't very supportive about me being open about it or the need to be open, that's the way I process things. So yeah, I did lose family members around that. I am a peer and I know what it's like to lose family members over part of my identity." (Peer leader, #23)

While family attitudes can influence unique experiences of peers with disability from CALD backgrounds, peers said that families played an influential role in shaping and influencing their understanding of disability. They were also an important part of a peer's support network and instrumental in getting them access to supports. Peers described how peer support can support them to navigate complex family dynamics in relation to their disability.

> "My mum was one of my biggest supporters ... I am so appreciative of her, love her to death." (Peer with disability, #27)

> "I also feel a lot more educated and have different coping mechanisms, which really helps me sort of educate my family about the lived experience that I've gone through as well. Which is really beneficial in that sort of situation." (Peer with disability, #10)

Peer support provided through DDAlliance empowered and connected peers to navigate these challenges, attitudes and barriers.

Peer support also seems to offer a space for peers from diverse backgrounds to explore the relationship between their multifaceted identities. Some peers reflected on their queer identity and the parallels between being challenged and embracing the parts of who they are from within the LGBTQIA+ community and the disability community. This highlights the long standing intersectional issues of LGBTQIA+ and disability rights that can impact on peers' experiences of forming their identity.

> "My disability is normally how I identify [myself] and the identity people associate with more than my bisexuality. But people have been dismissing disabled people's sexuality for centuries now." (Peer with disability, #23)

Other peers said that having access to intersectional peer groups, such as queer peer groups, supported them to bridge the gap between their disability and queer identity.

> "Queer Peers is sort of like, finding like the missing piece … because the intersection of being queer and disabled is like, obviously significant." (Peer with disability, #45)

"I wished so much that I didn't have CP, that I wasn't disabled. So to have a moment where I was like, "Oh you know … this is actually like, part of who I am" and to realise like I could have it. And it's really interesting how like the discovery of my queer identities helped me embrace my disability." (Peer with disability, #45)

Peers from CALD backgrounds described how through DDAlliance they were able to establish a connection between their cultural community and their disability community. Peer support supports the sharing of experiences and knowledge between communities, enabling a viable pathway into the 'hard to reach' communities.

"DDA supported me and provide me all the skill and the knowledge that I need to share my knowledge with my [culturally specific] community group... because with DDA, we have a voice to help understand our rights" (Peer leader, #7)

"When I deal with the people outside, it's completely different from when I am dealing with my groups. When I deal with my groups, I feel comfortable, I feel that I am part of this group." (Peer with disability, #4)

These experiences captured suggest peer support can help people with disability navigate and explore their intersectional identity, for example being a peer with disability from a CALD background or being a peer and from the LGBTQIA+ community.

8.2.3 Creating awareness and challenging ableism

Peers from CALD backgrounds shared how they could gain an understanding of human rights and create awareness of rights, which can be an unknown concept to migrants. For example, one peer described how getting access to an interpreter or information in their first language was not necessarily seen as 'human right'.

"And it's been, I guess it still is, a challenge, to make peers at ease to access and work with interpreters. A lot of our peers who speak, who require an interpreter at times feel like they are putting us off, it's an extra thing, so they feel like they owe us, or we are doing them a favour, by providing an interpreter. When really it's everyone's basic right to be able to communicate right? So I guess instilling a rights based approach across all our community members, all our peers." (Peer leader with disability, #30)

Peers described how their sense of self changed, particularly by challenging ableism and internalised ableism, through their involvement in peer support. This supported peers to develop an awareness of how attitudes in the wider community culturally exist and have impacted them and others with disability.

"I already had this sort of conception of who I am and how the world works. It's not like, I despised disabled people or had any particular negative opinions about them or anything. But there was a bunch of unpacked internalised ableism in there, you know? Because I had never had to sort of deal with it." (Peer with disability, #15)

At the same time CDAH and DDAlliance has also been a space where peers feel comfortable to come together and talk about medical needs and support each other to navigate being a person with disability and the challenges that come with it. CDAH and DDAlliance through peer support have created a support system of knowledge to navigate the NDIS. This has enabled peers to come up with strategies and methods to challenge larger systems like the NDIS and the medical model that limits the inclusion and participation of people with disability.

> *"Look, things that have been challenging is that the NDIS support services are not very choice and control orientated and very flexible, in terms of what we can do and what we can't do, under the NDIS. And also, they are trying to adapt to that, but there has to be more awareness of the whole person if the person has multiple disabilities. It's not ticking a box of one disability and assuming his or her side effects. You need to have a non-judgmental approach to a person. That's my approach to a disability." (Peer with disability, #9)*

8.2.4 Forming connections

Peers talked about gaining a sense of community from been involved with CDAH and DDAlliance. Peer leaders and peers with disability said that by using their own lived experiences, they were able to contribute towards a community and help people meet their own needs.

> *"Well, I think the biggest thing is now being part of a community, a real community, where people are actually looking out for each other. We are creating like [a] legacy, that is going to be there long after we go on and being involved in creating some of these systems, we can actually help to improve people's lives." (Peer leader, #12)*

> *"Through connection with the peer community, it enhances the support that is received and improves people's lives to develop their own structures of support." (Peer leader, #12)*

Peer support has helped peer leaders gain unique relationships and connections due to shared experiences.

> *"Peer support means there has been someone there who have walked in your shoes and understand what you have gone through. And [have] more insight to what you might need or what you might be more able to get, they get you more than carers or your family because they have walked in your shoes, not beside you, basically." (Peer leader, #2)*

The power of shared experiences becomes particularly important when layered with the diversity of peers in CDAH and DDAlliance. Engaging with peers and creating peer groups that connected people with similar interests and lived experience with identity specific peer groups was important to maximise being able to provide meaningful peer support.

"So many positive experiences from being involved with CDAH. Being involved with the smaller peer groups that are more specific to my own living experience" (Peer with disability, #25)

Peers described how having these opportunities were 'life changing' in that it created a sense of belonging and community for peers from different backgrounds.

"When I deal with the people outside, it's completely different from when I am dealing with my groups. When I deal with my groups, I feel comfortable, I feel that I am part of this group." (Peer with disability, #4)

"Some of the things that are good about peer support, especially now is that you have other people out there who have been through similar situations." (Peer leader, #12)

Peers from DDAlliance described how their involvement in peer support was like being part of a 'family' where they feel connected and comfortable being themselves, something that they don't get in other parts of their life. This may relate to broader attitudinal barriers within CALD communities.

"When we speak about our peers we say DDA family, because … it feels like that for a lot of us. For me, outside of DDA and other people with disability that I know, nobody else understands what you go through on a daily basis." (Peer with disability, #29)

8.2.5 Enhancing inclusion and advocacy

Peers with disability and peer leaders said that CDAH and DDAlliance have created a platform for people with disability to be actively involved within their local community, including in paid employment. This has been a crucial point for peers to contribute to society and help not only other peers' develop skills but more broadly.

"I would like to say I have helped someone to achieve their goals. As a peer facilitator for my employment in that work, I would like to say that I helped people with disability get a better job and help employers get more confident in employing people with disability." (Peer leader, #13)

Whilst some peer leaders had already been involved in work opportunities using their lived experiences before joining CDAH and DDAlliance, their involvement with CDAH and DDAlliance had enhanced these opportunities.

"In the past I've worked in a couple of government agencies, but I wasn't actually a leader at the time, I was actually working in a team. This is really new to me... it gives me opportunity, there's also opportunities out there to lead in the community or get involved in the community and also the disability sector as well." (Peer leader, #1)

Peers described how their involvement in peer support and being involved in the broader peer movement empowered them to advocate for themselves and their community, such as advocating for human rights for people disability. Educating the broader community was central to this.

> "It has given me opportunities to do things that I never thought for instance, that I would be lobbying and speaking to Premiers and Prime Ministers to what it is actually like to have a disability. And I suppose, it has just now become a part of what I do." (Peer leader, #12)

> "It was so comforting, to know that we are global citizens... you know that cliché we're all in this together, seeing disability advocacy at that level, and seeing people, or peers, involved in making their local groups, local communities" (Peer leader, #30)

8.2.6 Building skills, capability and capacity

Peer leaders identified that their skills, and their role as a peer leader was to support other peers to identify transferable skills and build confidence so peers could continue to develop their awareness of themselves and their capability.

> "I think being a peer worker in a leadership sense is, instead of voicing yourself or your voice onto their situation, you're kind of more taking a step back and just observing. As a leader, for me my job is to identify people's strengths, weaknesses, and confidence levels. Because I feel like a lot of times we misread lack of skills when it's a lack of confidence." (Peer leader, #23)

Peers with disability experienced a growth in skills which influenced confidence not only socially but also to try new things.

> "… ever since I joined the space, you build interpersonal skills, communication skills, I guess, relationship skills, self validation skills, endurance skills. Yeah, they're the main ones. Also, confidence. You can build your confidence once in that space, to connect with your peers around you. And once that's all done, I guess, that could extend to networking skills … just building community " (Peer leader, #38)

> "Well, it's a bit like peer support, you know? Like, one person will say to me that me writing my stories…. had made it possible for them to start telling their story and that was the moment, you know? It was like, even if there are only a few people out there that this can enable, it's worth doing." (Person with disability #25)

The continuous idea of sharing their stories to encourage other peers, paying it forward, strongly aligns with the instilled core values of peer support.

As people got involved with peer support at CDAH and DDAlliance they spoke about a change that they found in themselves where they became passionate about equity for people with disability, increasing their capacity to live within a human rights-based society.

> *"… fighting for other people feels good, even though, [we] don't necessarily win all of the time or even some of the time... I want everyone to be happy, I want everyone to be free, and I want everyone to have what they need." (Peer with disability, #15)*

Peers From CALD backgrounds also experienced skills development through participating in peer support. These skills developed can be particularly important given the context of the NDIS and the provision of goods and services.

> *"We learn how to complain. We learn how to go to fair trading for help. A presentation about that to different communities in New South Wales … New skills yeah, that you ask me." (Peer leader, #7)*

Peers described how their involvement in peer support has been a liberation from the medical model of disability; as peer support is centred around the social model of disability. It has been an empowering experience understanding disability issues through a social model lens. They found that by understanding the lived experiences of others, it supported them to create their own story and become resilient and confident.

> *"... [what] I found super interesting about doing the peer support course was they don't care about the medical stuff and that was liberating. I've been in the medical model for so long, where it is very much managing your symptoms and talking to the doctors, and trying out different supplements ... And to get to the CDAH and it's just like "Oh you're disabled, cool, don't need details." And I was like "what is this?" This is different and fun. That feels very different..." (Peer with disability, #15)*

8.3 The challenges of peer support

Peers with disability and peer leaders described many challenges of peer support, particularly during the COVID-19 pandemic. Challenges include keeping peers engaged and involved in peer support, understanding what peer support is in the broader community, pathways to peer support and using these skills in the broader community, experiences of people with a non-visible disability, navigating peer support and relationships, and the impact of family on disability identity.

8.3.1 Keeping peers engaged and involved in peer support

Peer leaders and peers with disability described several barriers contributing to being unable to fully engage with peer support, potentially affecting the efficacy of peer support. Peer leaders mentioned difficulty with the promotion of and keeping peers engaged in their peer group. This included making sure key values were principally upheld, for example holding people accountable to turn up and participate in the group, but also in building initial relationships for a strong foundation.

> *"It's hard work. It's a lot of one on one conversations. It's a lot about creating that space [for] some of that informal stuff to happen." (Peer leader, #30)*

This was especially challenging during the COVID-19 lockdowns in 2021. Peer leaders and peers with disability talked about how the communication could have been clearer from both CDAH and DDAlliance to keep peers informed.

> *"Sometimes I find the organisation and communication of things can be confusing. A lot of the email correspondence can be difficult. But as well as that just COVID-19 and lockdowns." (Peer with disability, #11)*

Peers from CALD backgrounds also described the importance of getting access to information, such as about peer groups and events, in a range of accessible formats. However, one peer described the challenge of getting accessible information.

> *"I work in the CALD space for people with disabilities as an advocate on behalf of them. So I always lived the access to information spree and I also suffer, I also encountered those same access to information needs as a person who is legally blind or has low vision as well because only five percent of accessible information is available in braille and audio. So it's only available if you ask … And to be aware of those things or aware of asking, not many people do. Because they don't have the strength or the communication ability to ask. Because they think they're dependent on organisational support, and they feel that they're being too matter of fact about it, and they can just soldier on without it." (Peer with disability, #9)*

One peer described how they used augmentative and alternative communication and said that the meetings were not fully accessible for them. This could potentially hinder a peer's full participation and ability to gain the benefits of per support.

8.3.2 Peer environment

A number of peers and peer leaders identified as having a non-visible disability and they shared specific challenges that they have had in engaging in the peer support space.

> "… you'll get peers who are neurodiverse, or peers with intellectual disability, [they] often get left behind. And, not part of the conversation as much as other peers. It's been really challenging." (Peer leader, #30)

> "But a lot of people who have a hidden disability, people don't wanna speak up about it and say, "Oh I've got a hidden disability." Where if you have like a physical, like a wheelchair or vision, then people recognise that you have a disability."(Peer with disability, #5)

These perspectives highlight the diversity of the disability community and variations in disability identity. Careful consideration in how peer support is organised and structured is important to avoid excluding peers.

Two peers mentioned how different perspectives of disability can push people away and be a barrier to peer support and developing a strong sense of disability identity.

> "I think there is a level of disconnect between myself and some others at DDA … I tried to say, it's important to have these realistic expectations of a person's disability, to recognise that there are some boundaries that just can't be crossed. And the general response to that was, the typical affirmations of "You shouldn't let that get you down, you really can, anything is possible" which I disagree with." (Peer with disability, #8)

This indicated that peer support should meet a person where they are; match their level of understanding, identity or views. This could also ensure meaningful engagement in peer support activities as limited opportunities can become a barrier towards providing the emotional connection necessary to facilitate peer support.

8.3.2 Understanding of what peer support is in the broader community

Peers described how peer support is not well understood in the broader community with the focus on the individualised responsibility of people taking care of themselves rather than people supporting each other amongst a community. This creates challenges for peers to create change as a collective society and instil the values of peer support in others i.e humility, accountability and paying it forward, especially within the CALD community.

"We've moved away from people watching out for each other, and supporting each other, and building people up, and holding each other to account. We stopped doing that and we now live insular lives which means that people don't sort of do this stuff naturally, and it's sad that we have to retrain people to do it. Whereas, if we actually listened to other cultures where it's actually not that clever, it's just what you do, it's what we dismantled." (Peer leader, #39)

"It's not enough to attend peer events ... there needs to be an ongoing and active commitment. And I think externally, it's a much more, it's a different barrier. And much more difficult to overcome than internally." (Peer leader, #13)

Empowering peers from CALD backgrounds takes time and peer leaders talked about some of the challenges in supporting other peers in their community to step up and take charge. Despite the benefits and potential of peer support, in essence to empower individuals, and the conceptual understanding of peer support, it does not necessarily get reflected in practice.

"Often in the CALD community, when they get into the peer support space. It's sort of like, "Oh, can you do a form for me? Can you fill out a form for me?", they expect you to do the work. So, it's not really, "Oh, what can I do or how can you help me you know, filling out that form?" (Peer leader, #38)

However, peers from CALD backgrounds also described the challenges of translating and interpreting the meaning and concept of peer support in diverse communities and languages. It takes time and engagement with peers from different communities to educate and explain what peer support means. This could explain the incongruence between understanding and practice, given that peer support can take a longer time to establish in CALD communities.

"In a lot of cultures, it's not something that exists really and even the words and the concepts that we often talk about in peer support are not part of the language which is why we did a project. This would have been two or three years ago. We took 18 common term and common concepts in peer support, and we worked with peers and translators to translate those words into community languages, and it was quite a process." (Peer leader, #30)

8.3.3 Pathways to peer support and using these skills in the broader community

Some peers described that they had learnt skills from attending training and mentoring programs and that they wanted more opportunities to use these skills.

> "And there's also kind of not a pathway, you've joined CDAH now what? So, the idea that there might be some, it's a blob of great things, but it's not kind of like "hey, here are some pathways for you to follow." (Peer with disability, #15)

People also mentioned the importance of the skills of peer support being formally recognised as part of a peer's expertise and the need for pathways to peer support. This could potentially remove barriers and provide opportunities to support and grow peer support in the broader community and create meaningful societal change that is peer driven.

> "I just think if we can formalise what it is to do peer work and then really go into industry and go into broader society and say "This is the work that people with disability are capable of doing, this is why you should pay them a real wage to do it, and this is why you should value the skills that they bring." And so it's not just holding a piece of paper, it's what that piece of paper means. That says "This is validating what we do and that this work is bloody critical", it's pivotal work." (Peer leader, #39)

8.3.4 Being a peer worker

Peer relationships are essential to the foundation of being able to provide meaningful support. This can be tricky when the nature of peer support work requires a personal and emotional connection. Peers described challenges in navigating relationships, setting boundaries, navigating conflict in peer groups and in some peer relationships, especially for some women with disability. Peers described the importance of respect and knowing how to navigate boundaries to ensure personal safety and what is a healthy limit in peer relationships.

> "I mean lots of different people have ways of navigating that, but that's always a bit of a challenge for me. I can get really committed to doing something and maybe go beyond what's a healthy limit for myself, yeah. Just not wanting to let other people down and be accountable. It's that one again. So it's finding the balance of looking after yourself and contributing to new things. (Peer with disability, #25)

> "So I think that moving forward in the peer space that we have the right peers supporting both women and men in education around boundaries for men, and what harassment looks like and respect and then for women, keeping ourselves safe and definitely around consent". (Peer leader, #40)

Other peers discussed the difficulty with navigating conflict and value differences when facilitating a peer support group and how that impacted them because of their own lived experience.

> *"I was kind of expected to hold space for everyone with different experiences, and you know, that's really tricky. Especially when they're issues that also affect you." (Peer with disability, #45)*

Peers also described challenges in understanding other peers' lived experience that conflicted with their own lived experience regarding peer mentoring and how to provide support.

> *"I am worried that if I become a peer mentor, and I'm assigned a peer who is in distress about their disability, I am worried that I will try to push them too hard to see my point of view when that would not be very conducive to their wellbeing or state of mind" (Peer with disability, #8)*

> *"So I wasn't able to help them as much as I could because I had a different experience. And so it was like, I've got a different experience, what can I give to that experience that would make it easier for you, and that wasn't helping...and that was sort of the end of the peer relationship. (Peer leader, #13)*

This highlights the importance of timing, the matching peers to appropriate mentors and switching the roles of peers and mentors can create challenges for the peer relationship.

8.4 How can peer support be improved?

Peers described many ways in which peer support could be improved. Peers expressed how important listening and hearing from peers to design peer support training and peer events was. Engaging with peers, getting their feedback on what worked, what did not work and using this feedback to change how training and peer events are developed and run was important.

There were common themes in which peers and peer leaders, and researchers with lived experience highlighted that organisations need to pay particular attention to meet the diverse needs and expectations of community members to improve the experiences of peer support.

8.4.1 Issues for both CDAH and DDAlliance

a) Clearer pathways

Peers from both CDAH and DDAlliance described how there was a lack of clear pathways for using their peer support skills within the organisations and in the broader community. Some peers described a delay between attending peer support or peer mentoring training and then not being connected to a mentee in a timely way to implement the skills they have learned. Others described how they had some existing skills in peer support, but they were not recognised and acknowledged by CDAH and DDAlliance.

"I know it's hard for them but follow up with individuals after they've done training and support to help them work out where they can use those trainings throughout the organisation." (Peer with disability, #25)

b) Accessibility

Peers had to transition using online platforms, such as Zoom, during the period of this research because of the COVID-19 pandemic. Some peers discussed the positive aspects of using technology in that it had provided opportunities for peers to get more consistently involved in online peer support, and different peer support groups being created.

"The plus side to us going online is that DDA has grown massively like the number of peer cafés and the different groups that we have, compared to before COVID, it's grown massively." (Peer with disability, #29)

However, there were also immense challenges for peers and for CDAH and DDAlliance. This included learning how to use new technology and ensuring that it was accessible for all peers. Some peers reported that the technology was not accessible.

"I use an assistive technology for screen read, so I use Zoom Text, which is a program for reading any documents or anything that's readable. Most screen readers however do not work with images in a document, so that's why my documents need to be in a text or Word document. I also suffer a lot from visual fatigue because I have depth perception problems, [and] the screen, because I have side perception loss as well. So, I get a lot of visual fatigue through Zoom calls." (Peer with disability, #9)

Peers described the benefits of getting information from CDAH and DDAlliance via email and social media. Providing information to peers in a range of accessible formats, such as in their language preference, easy read format and using interpreter services, was also important. Some peers described how information was not provided in an accessible which created a barrier for them.

"Maybe have some easy read format, as some people might not know what is peer support and explain to them in details before going to the depths about them. Peer support in other languages may be completely different." (Peer with disability, #38)

"We need to work on how we engage our deaf blind peers in all the peer groups that they might want to be engaged in. Because a lot of those peers don't use Facebook for example, and we were only discussing the other day, that that's how we do a lot of our communications. So we really need to be aware of that and that sort of thing." (Peer leader, #41)

c) Delivery format

Some peers described that they wanted face to face sessions rather than online zoom sessions, however, CDAH and DDAlliance were constrained because of the limitations from the COVID-19 pandemic. Additionally, peers said they wanted smaller groups online for shorter periods of time because it was easier to concentrate.

> *"The mentoring needs to be flexible for the person's disability and the circumstances. I'm a bit zoomed out of these zoom sessions at the moment, I would like face to face sessions, I am telling you that honestly. It is a different perspective when you do it as a shared group activity." (Peer with disability, #9)*

8.4.2 Specific issues for CDAH

a) Support for skill development

There were two areas of skill development for peers of CDAH. The first area identified the need for continuous development of peer mentoring and peer training skills, and to maintain the existing space to discuss issues and develop as mentors.

> *"CDAH currently has a peer mentoring network where we … freshen up on skills and we discuss the various issues in relation to peer support and how we can build ourselves as better peer mentors. And I think it's just the continuous training, as opposed to a one-off training, is crucial." (Peer leader, #13)*

The second area CDAH peers talked about was the need to develop leadership skills to create change, and needing to build better structures to learn how to do that within CDAH's peer community.

> *"When I talk about being supported to do stuff, that's where I see the leadership comes in. And for me it's around, when you see peers that are new to the model, [you need] to encourage them to stick around … Sometimes they're just not aware how to take the next steps." (Peer leader, #12)*

b) Member engagement

CDAH peers highlighted the importance of promoting peer support in the broader community. A specific example was conferences to engage other communities to increase member engagement.

> *"What could be better? I think getting more people involved. And I really love the idea that DDA and CDAH [are] having a conference towards the end of next year to promote some of the work we're doing. The forethought that people actually had in, to actually put in for that money when the ILC was handing it out. Here is it some 2.5 years later, and to see how the peer supports grown." (Peer leader, #12)*

"For me I think to better peer support, collaboration not only needs to come from within the disability community, but from the non-disability community to actually promote awareness of these peer organisations." (Peer leader, #13)

However, there were additional support needs needed by CDAH peer leaders to be effective in engaging members within CDAH.

"[They should have] supported me to get new members ... like help me make the phone calls every week. Or give me a phone with a CDAH number on the phone. Half the time I phone, people don't pick up if they don't know the number and people didn't like zoom.... If they have done that and done that to [help] me do the work that they hired me for, I think it will have been a lot better." (Peer leader, #2)

Peers also suggested that peer groups could be smaller to allow for better engagement between peers, managing interruptions and help with facilitation, especially in an online format.

"It's a bit much on zoom to take it in because it's hard to control the whole session, even though the people who are there to support you and everything. Sixteen people, is too much... you only need to be eight to ten people, really. And then with the support staff it becomes too much on zoom. It has to be in smaller groups." (Peer with disability, #9)

8.4.3 Specific issues for DDAlliance
a) Length and flexibility of training

DDAlliance peers highlighted it was important to have flexible peer training courses that catered to the life circumstances of peers. This included being able to have better options for how long training will take to be completed, additional catch-up sessions to build connections with peers and additional having resources available after the training.

"It's not that the content in the training is bad, I just wish the content could be compressed into say 5 or 4 weeks of sessions instead of 8 weeks." (Peer with disability, #8)

Some peers described the impact of the different formats of training which needed consideration and flexibility depending on the format used and information provided in different formats.

"Maybe the session is a bit too long and often there's a lot of slides, a lot of information, and right now is delivered via Zoom and eyes can get tired, when I done mine course before Covid it was face to face and I believe is ok, as often there's a lot to cover in one day and a lot of preparation and hard to focus when there's a lot of information. You try to digest all the information and tend at times you forget." (Peer with disability, #38)

The training survey data showed that people learnt new skills and knowledge from the peer support training and peer mentoring training. However, some people wanted more training in communication, learning how to adapt and use diverse ways of communication.

b) Support for peer leaders

One participant from DDAlliance raised the importance of open communication and DDAlliance facilitators being flexible with unforeseen life circumstances, or challenges around a peers' disability. It was also important to have a backup alternative plan to peer training in case somebody cannot facilitate a training session.

Peers also said that DDAlliance could break training into smaller groups for each session to make facilitation easier and be less overwhelming, especially in the presence of multiple languages, and to give more time and attention to different training content. It also makes it more manageable when using multiple interpreters by reducing interruptions.

> *"There will be three or four groups and the interpreters are taking turns … So sometimes it will be hard to concentrate, [what] was the discussion? You concentrate and then you break, again they come in … it can be helpful for all the participants to like keep concentrating throughout the session." (Peer with disability, #6)*

Providing more opportunities for peer leaders to connect with other peer leaders was also important.

9. Support structures that can facilitate the development and engagement of people with disability in peer support

This section describes the findings from all data sets from Round 1 and Round 2, about the structures that can facilitate the development and engagement of people with disability in peer support.

9.1 Space and opportunity to connect

CDAH and DDAlliance have given peers the opportunity to create a knowledge support system where peers feel comfortable to come together and talk about issues, such as health issues, navigating the NDIS, employment, housing, using technology and communication. They support each other to navigate different issues and systems. Peers said that it was important to create opportunities for peers to connect from their community to overcome language barriers. Some of the DDAlliance peers described being part of the "DDA family".

Peers and peers facilitating peer events described the importance of having opportunities to debrief after events, or after peer to peer cafes (for DDAlliance) to reflect on their learnings and prepare for the next event.

> *"So I guess that's pretty much what we do at DDAlliance … having those informal discussions … after every session, after every peer-to-peer café that we do, it's so important to have a debrief with the peer facilitators and the peer mentors. There's always the learning that you can take away from any session, from any café." (Peer leader, #30)*

> *"It's the building rapport that's quite important and this is the best place to do that in. Because you know having that common ground already to begin with already opens up the dialogue to kind of more honest conversation, more trusting relationship." (Peer leader, #30)*

The debrief after peer events embedded peer support in the planning and hosting of events which worked to build trust and relationships between peers.

9.2 Working with interpreters

Both CDAH and DDAlliance work with interpreters including language interpreters, AUSLAN interpreters and deafblind interpreters. This relationship and access to interpreters is extremely important to engage as many people from the disability community regardless of background and disability type. There are unique skills and terminology that interpreters need to know to effectively interpret in the disability peer space.

As outlined in the challenges of peer support (section 2.6.4), some languages and cultural communities are not familiar with key concepts of peer support. DDAlliance has created resources in different languages that explain common peer support words and concepts. This resource is important because there isn't always an exact translation of words in

different languages and requires a nuanced understanding that comes with time and exposure to peer support. If the interpreter doesn't have the base understanding and vocabulary, then they won't be able to effectively interpret for that peer. This further supports engagement and enhances the mutual benefits between peers.

> "That's also a way for peers to get into and understand peer support, and it's helped with interpreters… Whenever we bring a new interpreter in to work with us, we actually share the resource to them…" (Peer leader, #30)

Peers however do require training and support in working with interpreters in both an online and face to face format and ongoing support to ensure that it is inclusive of all peers including arranging for interpreters.

9.3 Funding of peer support and peer led organisations

Peer leaders shared their perspectives on the importance of funding of peer support by government and other sources. It was expressed without funding of peer led organisations, such as CDAH and DDAlliance, the structures of peer support that connects peers together would not exist. The funding of peer support in peer led organisations like CDAH and DDAlliance creates opportunities for peers and peer leaders to connect and to be connected into the broader community.

> "When it comes to finance, or looking for governance structures, and trying to chase funding and liaising with other external providers etc. You've got to take a leadership role, but so much of what you do, what you take into those discussions is the collective voice of your members, of your peers." (Peer leader, #39)

However, this requires government to understand the value of peer support and the diverse voices of people with disability.

> "How do you tell government that it's important? How do we tell government we need funding for people with disabilities, and how do you measure outcomes with that? So we need a good outcome structure or a good measurement system, I guess. Around measuring outcomes there also needs to be fluid as well." (Peer leader, #23)

10. Experiences of researchers with lived experience

The team of researchers with lived experience are diverse in terms of their lived experience and experience in doing research. This resulted in varied experiences during this research project that demonstrates the unique opportunities for people with disability, the value they have received and the value they have provided.

10.1 Amplified voices and perspectives

Researchers with lived experience shared how their involvement in the research project has amplified their voices and provided opportunities to share their lived experience. One researcher describe how people can utilise their own life experiences and then share this with the team in the context of the research.

> *"Because its being able to get a bunch of different voices together and come up with something really good, come up with different perspectives, different viewpoints and different life experiences." (Researcher with lived experience, #21)*

Researchers also reflected on the importance of lived experience, and the value of involving peer support principles, such as empathy, in the research as there is a shared cohesiveness, and level of understanding of one another as individuals within the team.

> *"Yeah so I guess one of the main things is that nearly all of the team members in the project are disabled. Instead of being this kind of thing in the background."*
> *(Researcher with lived experience, #21)*

> *"I have felt exactly supported in this team … whenever I let someone know that I'm unable to make it to a meeting specifically because I wasn't able to do this task at hand in time. I've had people saying, "Oh that's fine", "Oh you know you can take as much time as you need, and we can always meet up at this time later on if that's OK?" And I quite like that, I like not being judged or being criticised harshly because of that. I like that it's casual, it's being supportive and knowing that I could have another chance. (Researcher with lived experience, #21)*

Other researchers reflected on the experience of presenting at conferences. This opportunity was transformational for this researcher, both in terms of confidence but also in realising the power of lived experience to influence research.

"It has given me confidence in general about people's appetite for lived experience researchers. That [has] come out of the conference that we did ... it was so amazing to get that feedback from people ... and this can be done and potentially influence the way that things can be done in the future... I think it goes back to strengthening that lived experience stuff, that's changed it and I have always kind of wondered how to do this ... I think we have a very unique view and input into research this way and I think that for me knowing, I guess a lot of it is personal, knowing the boundaries of this stuff and with my new job... it's like how do we actually navigate that in the research space?" (Researcher with lived experience, #16)

These opportunities provide people with disability a meaningful role in contributing to research and acknowledges the value of lived experience rather than traditional academic and clinical research approaches towards people with disability.

10.2 Speaking up

Researchers with lived experience described how they have become more comfortable speaking up and about their disability. Members of the team have a range of lived experience of disability, diversity, and peer support and have learnt from each other through working collaboratively and sharing their stories.

"I think I've definitely noticed being more excited about this project and being a bit more direct about people with disabilities and disability rights." (Researcher with lived experience, #21)

Due to the COVID-19 pandemic this research has completely been an online research project which had created some challenges. One researcher described how it has been challenging to speak up online but needing to adapt.

"I think it can be really difficult, particularly on Zoom, speaking up and saying you know what you think or asking questions or making a comment ... So it does take a bit more confidence to just start talking." (Researcher with lived experience, #21)

"I'm not a fan of virtual meetings. I mean sure, you can still see someone's face when you talk and you can still get an idea of how they're going or how they're feeling because you can see facial expressions in their voices but yeah, it's not the same as face to face. Because you can't see body language." (Researcher with lived experience, #22)

Considering the diversity of experience members of the research team had, the skill and ability to confidently speak up about disability should not be overlooked. It also provides opportunities for organisations to respond to what researchers with lived experience are saying.

10.3 Creating an inclusive research team

Researchers with lived experience described how they were supported during the research project and that this support provided an inclusive, safe and supportive team.

> *"This community. It's the understanding of each other and it's all mixed work, which makes it a little bit easier. And when you do that one it's relaxed. You do the work, but it's relaxed. But we work hard." (Researcher with lived experience, #19)*

> *"I feel I have been supported. If someone in the team is not well, we support them and check in with them. But if I have any questions or anything, or if the members of the team need support in or expertise in other stuff that I can support them in." (Researcher with lived experience, #17)*

One research team member spoke about how proud they were of the team and all that the team has achieved, particularly having to work online because of the COVID-19 pandemic.

Researchers with lived experience also shared how it has been interesting learning about a different peer organisation, for example CDAH researchers learning about DDAlliance and vice versa. Furthermore, they shared how they had learnt a lot more about diversity because of working in the research team.

10.4 Skills development and training

Researchers with lived experience described the skills and knowledge they had learnt through training during the research project. This includes learning how to do research, learning how to use online platforms and software (such as, Microsoft skills including using one drive documents, Mural, Zoom and Slack, Natural reader), learning data analysis skills, recruitment skills, presenting skills (such as conference presentations), chairing skills, writing skills and interview skills.

> *"It's been fun, it's been interesting, it's been challenging, and it's been a real eyeopener in terms of what research work is all about. I was a bit naive, in terms of how much work goes into doing research projects. In short, it's been very educational." (Researcher with lived experience, #22)*

> *"Another skill that I have further developed is interviewing. Although I've only done one interview, I still think it improved my interview skills a fair bit." (Researcher with lived experience, #22)*

Researchers spoke about the ongoing tools and the support structures created over the two years to develop their skills. For example, being matched with another peer researcher in the team and using a 'buddy system' and using a text to speech software called 'Natural reader' to analyse the transcripts.

> *"It was actually one of the other peers that asked that question … just speaking about it afterwards after one of those meetings [I thought] "Oh yeah that's a really good idea." [I'm] talking about using natural reader." (Researcher with lived experience, #17)*

> *"I think that's one thing I like about the buddy system, if you're reading a really long transcript and sometimes I found that if I've read it on my own for some reasons, they weren't available. When I've gone back to the transcripts, it's like "Oh well, where did I get up [to]?" That sort of thing. I think the buddying system has its benefits." (Researcher with lived experience, #20)*

Two researchers with lived experience described how they would like more skill development in using a laptop and Microsoft Office.

Researchers with lived experience described the benefits of the training and personalised support provided by CDAH and DDAlliance and the peer support research coordinators. For example, researchers described how the Accidental Counselling course provided useful and practical experiences that they could use in both their research and peer work.

> *"The Peer Support Co-ordinators for DDA and CDAH have been fantastic. Having peers in the research team who have university experience means that we can provide support to our peers. It goes back to the value of peer support and we are actually building their capacity that makes me feel good" (Researcher with lived experience, #16)*

> *"The support given to me by [the peer support research coordinator] has been really helpful so far. Like it's been really good to have both as kind of like a safety net, if that makes sense." (Researcher with lived experience, #21)*

In comparison, the peer support research coordinators reflected on their skills in leadership once they were given the higher role, and discussed the importance of having peers with lived experience in a coordinator position. This highlights the importance of lived experience fostering reciprocal relationships that is beneficial in providing the right support; the essence of peer support.

"[The] capability of my skills has changed since then because I'm now a lot more embedded in the coordinator role than what I was when I first did that first interview … I never thought that I could do a coordination role. But I think I've really stepped up in terms of accountability to learn the skills, to coordinate and support people." (Researcher with lived experience, #18)

10.5 Unintended consequences

Weekly team meetings and the working group structures had created a system whereby all researchers with lived experience with different skills at various levels could choose which parts of the research project they want to be involved with. Whilst a great idea in principle, this had several consequences.

Some researchers raised that the time needed for skill development and training, to ensure that they could participate, was not accurately accounted for during the research application, resourcing needs and project timelines. This meant that project activities needed to be postponed for skill development and training. Therefore, much of the training and support provided had a more reactive than a proactive nature to it. Often a team member with more research experience would notice a skills gap and have to develop training and resources to address it.

"I'll often feel frustrated that someone's not getting it but then I realise that's possibly because of the consequences of the lack of training we may have had in the very beginning of the project. People aren't going to pick up skills, at like, a university level when there's been no long-term training." (Researcher with lived experience, #18)

"I think if there was possibly like recruitment of the employees first that then actually developed how we do this research project from scratch, we could have been thinking about doing training long before jumping into the research project." (Researcher with lived experience, #18)

This then led to some team members with more skills in doing research feeling under pressure with limited time to mentor and support other team members who required more support but saw it as necessary in the peer environment context.

"I think it is finding the time to support one another … everyone is at different levels, so you are kind of having to take a different approach with each person and there are some who as not responsive as others." (Researcher with lived experience, #16)

When revisited a year later it was found that this level of support to other researchers in the team was not without risks for researchers who take on an additional role of responsibility to ensure commitment and accountability from other researchers. Without levels of negotiation and clarity of expectation, this created uncertainty around boundaries and

overextending their peer and researcher role to support their fellow peer colleagues to do the work.

> *"We are in a team, we are doing this together and you have committed. I have struggled with those difficult conversations and I don't know if that's my place either? To have that? So some of those things are a big thing. Like, you know how much support can you give someone until you know they just can't do it? (Researcher with lived experience, #16)*

Emphasis on flexibility and focusing on strengths in skills based approach across the whole team also led to blurred understanding of responsibility and de-prioritising the workload at different times during the research.

> *"I don't know how much people are contributing or other people are leading. I'm always conscious of that, though … I guess, expectations? From me knowing what to expect and then them also knowing what is expected of them? Maybe that wasn't done very well from the start in terms of the recruiting and the "Look we want to engage you but here's the expectation." Maybe I think we did do that to some extent? But you know, again, a lot of times, even for myself it feels like this is a project I can push aside." (Researcher with lived experience, #16)*

Researchers also spoke about the potential impact that the project design has had on the function of the group and the research direction itself. The funding application for the research project was initially done by staff from CDAH and DDAlliance who then contracted it to a project manager to fulfil. The researchers with lived experience were then employed at a later stage via open recruitment by each organisation's staff. It was felt that perhaps the researchers with lived experience should have been included in the original set up process to set expectations and scope of the research with their input:

> *"I feel like it started out really well with really good intent to be inclusive and peer led at the forefront and there were all these amazing conversations about doing that, and I was excited! Like, I could feel myself having a lot of hope and excitement and felt like there was a real sense of cohesion and belonging. Because we were like finally! Like, this is what we wanted all along, to do this type of research project like this. The management side [is] where inclusion often can get overlooked. I do kind of feel like the power dynamic of it changed a bit where we were always told in the beginning that we were the leaders of this." (Researcher with lived experience, #18)*

> *"I think I commented last time that I don't think we, the peer researchers, were involved right at the start just to shape this. Which is why we're also having a bit of trouble now." (Researcher with lived experience, #16)*

Researchers also spoke about needing to navigate the peer and researcher relationships, not only within the team but also within the peer community as peer researchers researching fellow peers. As CDAH and DDAlliance are both small peer organisations, participants of the study may have at various times during the research be known to the researchers. This raises ethical considerations over confidentiality, and safety for both researchers and participants, and the need for formalised processes to identify conflicts of interests only when necessary which may deter the nuances within certain communities especially from CALD communities. The team developed processes and protocols for supporting researchers to identify and actively manage conflicts of interest, which were reviewed throughout the research project. While this was a challenging aspect in being a researcher with lived experience, it highlighted the strength of connection to the peer community and how the protocols supported researchers with lived experience.

> *"When reading the transcripts through some of the peers. I've found that sometimes challenging, because it's really hard, what I'm finding hard is when I'm too close to the person and they're people that I know … I was able to separate myself, even though I know these peers outside. I was able to separate that." (Researcher with lived experience, #17)*

10.6 Pathways for researchers with lived experience

All the researchers with lived experience spoke about the sense of pride that they have had in being a part of a team and the enthusiasm they have for inclusive research in the future as opportunities.

> *"And this project is for other people with disability to do this research. That's a little bit different to maybe before where an agency would incorporate some disabled people, things like that. But this one is totally the disability people who do the research." (Researcher with lived experience, #19)*

They have also used this experience to actively look for future opportunities where they can continue to utilise their skills and create more beneficial employment opportunities.

> *"So I've actually been able to negotiate a higher salary and evidence that hey, you know I have experience in research, and I used the links that were public from the conference presentations that we did. So yeah, that's been a real good way to indicate expertise and experience and yeah, get more then, you know, get me to places where I want to be."* (Researcher with lived experience, #16)

> *"I'm interested in continuing on as a researcher. Because out of this whole project I've really enjoyed what I'm doing, those sorts of aspects. But I'd love to continue that sort of stuff in the future."* (Researcher with lived experience, #17)

By involving peers with lived experience of disability intimately in their research role through participatory action methods over a two year period, the research team have been able to set the foundations for the structures of work and supports needed for lived

experience researchers to thrive in this project. However, this design and support structure may not be universal across other research opportunities. Researchers noted this as a potential barrier for the future of researchers with lived experience when pursing pathways in research.

> *"You know, we want to make sure that people have jobs … and that's less likely with other organisations or other university research projects. Are we setting people up to thrive in those experiences? Or go in and be like, um wait what? I thought I was doing it before but this is completely different."* (Researcher with lived experience, #16)

> *"I think there's more support that is needed to do that in terms of pathways. Employment pathways for peers who are interested in doing other research projects, lived experience research projects and stuff like that."* (Researcher with lived experience, #16)

11. Discussion

Legislation and disability policy has been found as a significant facilitator in social inclusion of people with disability.(13) This research contributes to one type of understanding of social participation and inclusion that can shed light on neglected research areas that limit understanding or affect policy decisions of people with disability. Collaboration between people with disability and decision makers not only increases social participation, but also creates better solutions that are responsive to the needs of people with disability.(13) For marginalised populations, such as those most at disadvantage in our systems and for people of diverse background, who have had poor experiences with mainstream services, peer support is vital. The inclusion of people with disability and their organisations is crucial for people with disability to be heard, to be seen as a resource and as partners to get their real needs expressed and met.

This research sheds light on how people with disability can be empowered in a culturally responsive way and how empowerment and participation is understood and developed in various ways through peer support. It also considers how experiences with peer support impact people with disability and their actions, both at an individual level and more broadly across and within the community and eliminates the notion of 'otherness'. It also serves as a reminder how disability issues need to continue to be in the spotlight especially to inform systems, policies, programmes and strategies that continue to be directed at people with disability, often without their input. As an evolving culture, peer support has the opportunity to forge social change.

Specifically, this research has provided a wealth of information on the way peer support and related training has enabled peers to be part of an inclusive community. This has led to opportunities in both personal skills development and opportunities within society. For others the connection to the disability community through peer support has influenced and changed the way people identify, connect, and perceive disability. Many people with disability have found value in their lived experience and have used that within the context of peer support and to empower others and themselves. They continue to seek opportunities to develop their skills and participate in peer support especially through more support from CDAH and DDAlliance.

Without a peers' intimate and innate understanding of the communities in which they exist in, the ability to respond to the diverse needs of the community would be severely limited. Peers, by nature of their shared lived experience, offer unique understandings of their communities and supports that complement government services. Today, when discrimination, stigma and systemic barriers still exist, the need for strong and well-supported peer networks remains as important as ever. This especially makes peer support an important strategy to engage individuals who are alienated from or not easily reached by formal services. Through participation in peer support, people with disability can achieve and exercise their human and civil rights.

For these types of organisations supporting people with disability within the peer community, communication and flexibility focused on accessibility is key to enabling and supporting peer participation. This is in recognition that the disability community is extremely diverse and come from different backgrounds which can influence how people engage and how people respond to new communities. However, it is noteworthy that without such organisations such as CDAH and DDAlliance the opportunities to build peer communities and personal skills wouldn't exist including the opportunity for researchers with lived experience to lead this current research study.

The experiences for our researchers with lived experiences have seen profound changes in their skill development in research and overall confidence in themselves. Namely it has been an opportunity to amplify the voices and perspectives of researchers with lived experience to influence research now and for the future. This wouldn't be without the support of the team structures in place to support each researcher using principles of peer support and inclusive research design.

Whilst there are always challenges when it comes to supporting and enabling such a broad and diverse community to participate in society using their lived experience, research such as this one provides the opportunity to understand the gaps so that organisations and individuals can improve. Even more so, research using PAR gives researchers the ability to be flexible to respond to important information as it emerges so that the research stays relevant, engaging and is guided by what's important to people with disability to research and explore.

Going forward, peer programs with lived experience at the heart and centre must be ensured and delivered in partnership between peer organisations and members of the community. It is crucial peers are included throughout processes and listened to, recognising that they have fundamental understanding and specialised knowledge of their communities. They play essential role in program effectiveness and instilling change at an individual and community level.

12. Recommendations

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

12.1 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.

12.2 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.

12.3 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.

12.4 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.

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