

# Peer Support Practice Review: Final Report of Stage 1A Findings

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# Peer Support Practice Review: Final Report of Stage 1A Findings

Prepared for:

Australia New Zealand School of Government (ANZSOG) and National  
Disability Insurance Agency (NDIA)

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# Abbreviations

ACD	Association for Children with a Disability
ANZSOG	The Australia New Zealand School of Government
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
CICD	Community Inclusion and Capacity Development
CDAH	Community Disability Alliance Hunter
DDA	Disability Diversity Alliance
DPO	Disabled People's Organisation
DSO	Disability Support Organisation
FPDN	First Peoples Disability Network
ILC	Information, Linkages and Capacity Building
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW CID	NSW Council for Intellectual Disability
PWDA	People with Disability Australia
QDN	Queensland Disability Network
SARU	Self Advocacy Resource Unit
SCU	Southern Cross University
SPRC	Social Policy Research Centre
UNSW	The University of New South Wales Sydney

# Executive Summary

The Social Policy Research Centre (SPRC), in partnership with the Australian New Zealand School of Government (ANZSOG), was engaged by the National Disability Insurance Agency (NDIA) to undertake a practice review of current approaches to peer support delivery. The purpose of the practice review was to identify current good practice in peer support delivery and future capacity building needs. This report presents the findings from the practice review, which will inform the development of good practice guidelines and further resources for the sector. The implications of these findings are presented first and include implications for broader policy development as well as implications for the next stages of the project.

The practice review involved a program and document review of current peer support provision, including the Disability Support Organisation Project (the DSO Project), and in-depth, semi-structured qualitative interviews with 17 peer support project managers and 5 peer support leaders from peer support networks around Australia.

## Implications for policy and future resources

*1. Guidelines for peer support delivery that aim to capture the key values and principles behind good practice peer support delivery rather than operational standards would provide guidance without limiting sector responsiveness.*

The practice review found that approaches to peer support delivery were diverse, ranging from the more common face-to-face peer support meetings of 5-15 participants, to one-on-one peer mentoring, larger structured workshops, and online and phone-based approaches. Providers adapted their peer support approaches in response to participant needs, often revising their initial strategies to peer support provision in response to consultation and feedback. All approaches were reported to have positive impacts on the lives of participants. Some approaches yielded stronger benefits in different areas, i.e. some in individual capacity building, some in information and knowledge sharing, and others in forging links with community organisations and mainstream services.

Despite variation in peer support delivery, common values and principles of good practice peer support emerged from the review. Review participants described good practice peer support as:

- flexible – responsive to participant needs and preferences
- user-led – led by people with disability and their families, and based around their lived experience
- capacity building focused – embedded with a strong individual capacity component, with training provided to peer leaders that increases their knowledge and confidence
- mediated or facilitated through a community organisation – linked to a community organisation that can support peer leaders and participants, support the relationships that are key to the success of peer support, provide up-to-date information, and connect participants to the broader disability community

- semi-structured and purposeful – organised with a blend of issue and information-based content (at least at the beginning) and more informal or unstructured forms of support to best engage participants
- community based – including a focus on forging links between peer support participants and mainstream community organisations, services, businesses and local government.

These findings indicate that it would be beneficial for good practice guidelines to be flexible enough to encompass different approaches to peer support delivery, whilst still capturing the most important elements of good practice peer support.

*2. Good practice guidelines and resources that recognise the importance of sustained individual and community capacity building and investment to peer support delivery would reflect current good practice approaches in the sector.*

The practice review found that all provider organisations broadly adopted a facilitated / mediated approach to peer support provision. Review participants reported that facilitated peer support delivered the most extensive benefits for participants, but was resource intensive, demanding a high level of staff engagement and presence within the peer support groups, information development and provision, and staff training and peer leader training. They emphasised that good practice peer support delivery required sustained individual and community capacity building, which was dependent on continued investment in terms of both staff time and government funding. These findings indicate that good practice guidelines and resources should seek to reflect and build upon the lessons learned by peer support providers about the benefits of sustained individual and community capacity building.

*3. Building on resources from the peer support provider community of practice and engaging in knowledge-sharing with organisations that are developing innovative practice would expand practices that are relevant to the sector.*

The practice review found that the peer support provider community of practice had developed extensive resources that they found useful and then shared. As the national support agency in the DSO Project, JFA Purple Orange facilitated a community of practice amongst peer support providers to share knowledge, strategies and resources about peer support. This included:

- state-based community of practice workshops for peer support providers
- co-design of a suite of online peer support resources and the “Peer Connect” website with other peer support providers
- dissemination of an e-bulletin which shared stories of good practice.

The review found that peer support providers often used these resources as a starting point for their practice. They also developed their own information and resources tailored to the needs and priorities of their peer support leaders and participants.

Several organisations have developed new good peer support practice beyond the approaches already supported by the community of practice resources, such as online contact and adapting practice for harder to reach priority groups. Continuing to work with the organisations who have

developed practice in these areas would therefore be valuable in the resource development stages of this project.

Building on these existing resources and engaging in knowledge sharing processes with organisations that are developing innovative practice could ensure that further resources to support good practice peer support delivery would consolidate current practice and explore new practice in ways relevant and useful to the sector.

*4. Working with organisations that are currently developing strategies for engaging marginalised persons and groups in peer support to design and develop guidelines and resources could build on emerging practice and inform other organisations to increase their reach.*

The practice review found that there were gaps in peer support delivery for some individuals and groups, including:

- Aboriginal and Torres Strait Islander people
- people from a culturally and linguistically diverse background
- people living in boarding houses and group homes
- people with contact with the criminal justice system
- people living in regional, rural or remote locations
- people with complex communication support needs
- young people with disability
- older people with disability
- male carers and family members.

The practice review also found that several organisations have been pioneering new strategies for engaging these groups in peer support. Working with these organisations to design and develop resources that consolidate current practice and explore new practice could assist other organisations to extend their reach to these groups.

*5. Working with organisations that are currently developing new strategies for delivering online and phone-based peer support to design and develop guidelines and resources could build on emerging practice and inform other organisations to increase their reach.*

The practice review found that organisations are exploring through online and phone-based peer support options to extend the reach of their peer support activities and respond to the preferences and circumstances of participants through online and phone-based peer support options. Working with these organisations to design and develop resources about online and phone peer support could assist other organisations to extend their practice in these areas.



*6. Working with organisations that have developed formal feedback and evaluation strategies to design and develop guidelines and resources could build on their current good practice and assist other organisations.*

The practice review found that feedback and evaluation mechanisms were applied unevenly across the peer support providers. Some relied on informal or sporadic feedback from participants while others had developed formal strategies for eliciting feedback from participants and peer leaders. They preferred narratives and qualitative measures to capture the complexity of the outcomes. Working with the organisations that have developed formal feedback and evaluation mechanisms to design and develop guidelines and resources could build on current good practice and assist other organisations in this area.

*7. Maintaining a community of practice (online and/or physical) amongst peer support providers and maintaining an online clearinghouse or other forum for sharing resources, tips, and strategies, could be an important way for providers to continue to share and build on current good peer support practice.*

The review found that many peer support providers developed or adapted their own resources and strategies for peer support delivery. They also reported benefits from sharing the resources and participating in the community of practice facilitated by Purple Orange in the DSO Project, as well as other forums and opportunities for collaboration with other organisations. Maintaining and building on the current community of practice between peer support providers is an important policy consideration. Drawing on existing information and knowledge exchange practices could be beneficial for the design, development and dissemination of further resources, including those developed in future stages of the practice review.

## **Practice review**

The practice review involved interviews with organisations based in different locations across Australia (NSW – 5, Vic. – 4, SA – 2, Qld – 1, ACT – 1) with different target memberships and funded through various sources. All the providers interviewed were either user-led or community advocacy organisations rather than direct service providers. They included organisations of and for people with disability and organisations of and for carers and family members, and the groups they established were diverse in terms of participant location and characteristics, and organisations adopted varied approaches to peer support delivery.

The majority of peer support program managers interviewed were from amongst the 18 organisations funded to provide peer support through the DSO Project, initiated through the Sector Development Fund in December 2014. Most of these organisations have established between 20-25 functioning peer groups. Participant numbers within these peer groups vary from small groups of 5-10 people, medium-sized groups of 15-20 people and larger groups of 40-50 members (usually only a proportion of members attend meetings regularly). Some of these organisations also support other peer support groups, in addition to the funded DSO groups.

Interviews were also undertaken with the three organisations that form the NDIA Advisory Group for the peer support project – JFA Purple Orange, the Self Advocacy Resource Unit (SARU), and Carers Australia – and two other organisations with a reputation for good practice peer support

provision amongst other providers, NSW Council for Intellectual Disability (NSW CID) and the Community Disability Alliance Hunter (CDAH).

JFA Purple Orange, a South Australian-based research and advocacy organisation, was appointed as the national support agency for the DSO Project, a role that will continue until at least 30 June 2018. Purple Orange supported DSOs by creating a “community of practice” to share experiences and expertise and foster collaboration across the DSO Project. This support included the development of the co-designed Peer Connect brand and dedicated website (<http://www.peerconnect.org.au>) and other peer support training resources and opportunities to share knowledge with other peer support providers.

## **Other findings**

### **Benefits of peer support**

Review participants (both peer support project managers and peer support leaders) reported the key benefits of peer support for participants to be:

- opportunities for information and knowledge sharing
- confidence and capacity building
- social connection and emotional support
- access to a safe space to share experiences and problem-solve
- access to positive role modelling and leadership from peers
- increased participation in community life.

Broader benefits included the development of an engaged and informed disability community, and awareness and capacity building within mainstream services and community about engaging inclusively with people with disability and families.

### **Good practice strategies for peer support delivery**

Review participants described good practice peer support delivery to involve the following practical elements:

- a focus on lived experience and participant empowerment
- consultation and feedback strategies to determine and respond to peer support participant and leader needs
- supporting peer support leaders through training, capacity building and contact with other leaders and organisational staff
- quality information development and provision, particularly about NDIS processes
- recruitment strategies that blend drawing on existing networks with word of mouth and outreach to new potential networks of participants
- structuring of group discussion through prepared topics, themes and content, and guest speakers.

For some, good practice peer support also focused on strategies to create connections with their local community and build the capacity of peer groups to be active in their community.

## **Challenges of peer support delivery**

Review participants identified some challenges to peer support delivery that providers and leaders must negotiate:

- The new, complex and evolving nature of NDIS information
- Funding uncertainty and resourcing issues, and ensuring the sustainability of peer groups
- Recruiting peer support leaders given the demands of the role and the other commitments of people with disability and family members
- Reaching groups with additional barriers
- Maintaining a community of practice.

## **Future directions of peer support**

Many of the review participants discussed the importance of trying to engage with marginalised groups and outlined their outreach plans and strategies. Some argued that they need more funding to do this effectively, especially for groups in regional, rural and remote areas, people with complex communication needs, and people living in more isolated settings such as boarding houses and group homes.

Some review participants outlined their strategies for delivering online peer support and or their plans to explore online options in the future. The benefits of online approaches included flexibility, increased reach, and cost-effectiveness, while challenges included vetting participants, recruiting moderators and facilitators, and the suitability of online approaches to only some demographics within the community.

Many of the review participants also discussed the importance of sustainability to peer support. They outlined the challenges of achieving sustainable peer support for the groups and individuals they currently supported, and the risks of reaching out to new participants in the context of funding uncertainty. For some, it was difficult to make plans for future peer support programs and networks without knowing what the future funding environment would look like.

# 1. Practice review

The Australia and New Zealand School of Government (ANZSOG) and the Social Policy Research Centre (SPRC) were engaged by the National Disability Insurance Agency (NDIA) to research, develop and pilot good practice guidelines and capacity building resources for the delivery of sustainable models of peer support. To inform the development of these guidelines and resources, the project teams were asked to undertake a practice review of current approaches to peer support delivery in the Australian disability sector (SPRC) and an international research and literature review on good practice delivery of peer support programs (ANZSOG).

This report presents the findings of Stage 1A of this project, which involved a review of current good practice in peer support delivery. The aim of this stage was to identify current good practice in peer support implementation and identify possible gaps and future organisational capacity building needs to inform the development, piloting and evaluation of capacity building materials and good practice guidelines in future stages of the project.

The research questions that directed this stage of the project were:

1. What benefits do peer support providers and peer facilitators aim to achieve for participants, and how do they work towards achieving these benefits in their practice?
2. What materials, strategies and processes have providers developed or used so far to facilitate peer support program delivery?
3. What strategies have been developed by peer support providers to engage marginalised or further disadvantaged people and communities in peer support, such as Aboriginal and Torres Strait Islanders and people from a culturally and linguistically diverse background, people in contact with the criminal justice system and people living in boarding houses?
4. What further capacity building resources do providers suggest are needed to improve peer support provision and to strengthen the ability of organisations to provide peer support?

## Methodology

The findings presented in this report are based on:

1. a program and document review of current peer support provision, including the Disability Support Organisation Project (the DSO Project)
2. 13 in-depth, semi-structured qualitative interviews with 17 peer support project managers from peer support providers around Australia
3. 5 in-depth, semi-structured qualitative interviews with peer support leaders.

The program and document review involved collating and analysing data transferred by the NDIA on the characteristics of peer support providers, the characteristics of the peer support participants, the activities and objectives of the peer support networks and the resources developed and used by providers. It prioritised the identification of capacity building materials related to outreach, specifically to groups that might experience barriers to peer support, e.g. people and communities such as Aboriginal and Torres Strait Islanders and people from a culturally and linguistically diverse background, people living in boarding houses, people with contact with the criminal justice

system and people living in regional, rural or remote locations. A summary of the program and document review findings is included in Appendix A.

Interviews were conducted face-to-face, by phone, and by Skype, and generally lasted an hour. The interviews focused on participants' perspectives on what made good practice peer support provision, as well as the activities and characteristics of peer networks, the strategies participants developed to engage with potential participants, the training provided to or received by peer support leaders and project managers, and possible resourcing and support gaps. The interview questions are included in Appendix B.

The practice review involved interviews with organisations based in different locations across Australia (NSW – 5, Vic. – 4, SA – 2, Qld – 1, ACT – 1). All the providers interviewed were either user-led or community advocacy organisations rather than direct service providers. They included organisations of and for people with disability (6), organisations of and for carers and family members (4), and those with a focus on both groups (3). The peer support groups they established were diverse in terms of participant location and characteristics, and organisations adopted varied approaches to peer support delivery. Organisations agreed to be named in the report. Further details on the characteristics of these organisations are included in Appendix A.

## **Project design and management**

This project is funded by the NDIA and managed by the NDIA's Information, Linkages and Capacity Building (ILC) Branch. The project is led by ANZSOG, with SPRC playing a key role in Stage 1A, and a supporting role in the later stages.

The SPRC team secured ethics approval for this stage of the project through the UNSW Human Research Ethics Committee (ethics approval number HC 17773). The approach, methodology and outputs were designed collaboratively with ANZSOG, NDIA, and other project advisors. A design workshop hosted by NDIA in September 2017 facilitated opportunities for engagement with key stakeholders in peer support provision early on, and these stakeholders and other project advisors continued to be consulted at key points in the research.

The overall project is expected to be completed by December 2018. The other stages of this project are led by ANZSOG, with SPRC providing specialist advice, peer review, and evaluation of the pilot delivery of capacity-building materials.

- Stage 1B: Review of international evidence in peer support programs – to identify current evidence-based practice in peer support internationally
- Stage 2: Development of materials for capacity building – design and development of materials for capacity building, both teaching and learning materials and guidelines on good practice in peer support. This stage will begin with a co-design process with sector representatives
- Stage 3: Pilot delivery of capacity building materials, through seven teaching and learning workshops with organisations currently providing peer support, to be held in July and August 2018
- Stage 4: Evaluation of the pilot capacity building materials – SPRC will evaluate the effectiveness and impact of the capacity building materials and workshops, and recommend any changes to the materials and approach

- Stage 5: Development of good practice guidelines and materials for ongoing capacity building – revising and finalising the materials based on the evaluation findings

## **Report structure**

In this report, implications of the research are presented in Section 2, and findings are discussed in Section 3. The implications section synthesises the key findings of the research to draw out their implications. These include implications for the future stages of this project and implications for NDIA in terms of ongoing funding and support for providers – both support for organisational capacity building and support for peer support delivery.

## 2. Implications for policy and future resources

This section includes an overview of the key findings from the practice review and a discussion of their implications for future stages of this project (development of good practice guidelines and capacity building resources) and wider policy implications.

### 2.1 Good practice guidelines: flexibility and responsiveness

The practice review found that approaches to peer support delivery were diverse, ranging from the more common face-to-face peer support meetings of 5 – 15 participants, to one-on-one peer mentoring, larger structured workshops, and online and phone-based approaches. All approaches were reported to have positive impacts, benefiting participants through information provision, capacity building, and opportunities to share experiences and learn from others. Providers emphasised that there is no one perfect model of peer support, but rather different choices to be made and strategies to be adopted to meet the needs of specific participant groups. These findings indicate that it would be beneficial for good practice guidelines to be flexible enough to encompass different approaches to peer support delivery, whilst still capturing the most important elements of good practice peer support.

The most common approach to peer support, adopted by at least 7 of the 13 providers included in this review, involved the establishment and support of small groups of participants (approximately 5 – 20 people) who met in person in a variety of community-based locations every one or two months. Providers who adopted this approach had 20 – 26 functioning peer groups that they supported at the time of being interviewed.

There were also a variety of other approaches to peer support provision described in the interviews:

- Amaze and Carers Victoria supported small peer support groups like those described above, but also held structured workshops and presentations about the NDIS for larger groups of participants.
- People with Disability Australia (PWDA) established closed Facebook groups for a variety of groups within the disability community, with discussion and information provision facilitated by a peer connector.
- Carers Australia's approach involved linking peer partners with other carers across Australia by phone and Skype, to share their experiences and advice on navigating NDIS processes.
- First People's Disability Network (FPDN) employed peer connectors who connect with people through phone calls, outreach into rural and remote communities, and a portable "café on wheels" where people can talk about the NDIS over a cup of coffee.

Providers generally adopted these varied approaches to peer support in response to the needs and preferences of participants and adapted their practice in response to feedback:

- Amaze and Carers Victoria responded to a "thirst for knowledge" amongst their members about the NDIS.



- PWDA set up Facebook groups for people with low vision, people with HIV/AIDS, and people from the LGBTI community after finding it was difficult for people to travel to a central location for face-to-face peer meetings.
- Carers Australia responded to the needs of their volunteer peer partners to fit peer mentoring around their other commitments and their desire for privacy.
- FPDN found that some people were not comfortable with the group setting, found it difficult to come to group meetings (particularly people living in remote communities) and/or wanted individual time with a peer connector to tell their story, so one-on-one peer mentoring was necessary.

Providers highlighted that different approaches to peer support delivery were designed to meet the needs of specific participant groups and the benefits relevant to them. Some approaches yielded stronger benefits in different areas, i.e. some in individual capacity building, some in information and knowledge sharing, and others in forging links with community organisations and mainstream services. For example, the approach adopted by Queensland Disability Network (QDN) and Community Disability Alliance Hunter (CDAH) involved significant staff time visiting local groups, co-facilitating peer support meetings and creating linkages with local organisations and agencies such as councils and service providers. The approach of these organisations was resource-intensive but resulted in strong benefits in terms of the participants' community engagement and participation. Amaze and Carers Victoria, which both held large workshops focused on NDIS information, extended their reach with this approach to benefit more carers and family members who expressed anxiety about pre-planning. They observed less participation in ongoing peer support group meetings, but received feedback indicating that participants had more positive experiences in their NDIS planning meeting and managing NDIS support after attending these workshops.

These findings from the practice review indicate that good practice guidelines should not be too prescriptive on the operational level, but rather embody the values and principles behind good peer support, allowing providers to respond locally and at a grassroots level to what works for participants. This implication was reflected in a number of comments made by peer support project managers during interviews:

Peer support should be a flexible formula, that doesn't preclude facilitated support.

Peer support comes from the grassroots... [we] can't prescribe from the top down.

There is so much need. All options are good and should be funded, and that way, people can choose.

Despite variation in peer support delivery, common values and principles of good practice peer support emerged from the review. Review participants described good practice peer support as:

1. flexible: responsive to participant needs and preferences
2. user-led: led by people with disability and their families and based around their lived experience



3. mediated / facilitated: linked to a community organisation that can support peer leaders and participants, support the relationships that are key to the success of peer support, provide up-to-date information, and connect participants to the broader disability community
4. capacity building focused: embedded with a strong individual capacity component, with training provided to peer leaders that increases their knowledge and confidence
5. semi-structured: organised with a blend of issue and information-based content (at least at the beginning) and more informal or unstructured forms of support, to best engage participants.

Some providers also indicated that good practice peer support delivery should embed a community capacity building component with a focus on forging links between peer support participants and mainstream community organisations, services, businesses and local government.

## **2.2 Good practice guidelines: sustained individual and community capacity building**

Broadly speaking, all organisations adopted a facilitated or mediated approach to peer support provision. This means that rather than the primary relationship being dyadic, i.e. peer to peer, there were several relationships that providers viewed as key to achieving good outcomes from peer support. Facilitated peer support was still primarily user-led and focused on the importance of sharing lived experience with peers, but also involved organisational support and a strong component of individual capacity building, which relied on continued investment. These findings indicate that good practice guidelines and resources should seek to reflect and build upon the lessons learned by peer support providers about the benefits of sustained individual and community capacity building.

Review participants stressed that the role that the support organisation played in supporting and building the relationships was key to good practice in peer support provision:

We've done a lot of on the job training and a lot of co-facilitating, co-development all the way through.

We've gone to all of the group meetings, at least the first couple, just to help them get started and to help them with anything like, you know, sort of logistical things or, you know, help them with the group process.

To do this work effectively, to sustain peer support groups, you need to do that upfront community capacity building and community development work...

I'm not convinced that the peer support model where people will sit around a table, instantly forge a connection and help each other could work. It doesn't acknowledge the need for reasonable accommodations and support to engage participants.

Providers reported that facilitated peer support delivered the most extensive benefits for participants, but that it was resource intensive, demanding a high level of staff engagement and presence within the peer support groups, information development and provision, staff training and peer leader training, time and travel. Peer support leaders also stressed the importance of assistance with logistics and training about managing group dynamics, presentation skills, and NDIS information as being crucial to their confidence and the wellbeing of participants. One peer

leader from an unfunded peer support group without connections to a disability or community organisation was also interviewed in the practice review. She identified challenges her group faced, including lack of funding for meetings and events, and the demands on her time and the time of other leaders in the group in providing information and facilitating events and discussion without organisational support:

We don't have funding. We have to do it all on our own backs... So, it is peer support but not in any kind of formalised way, but it's the best that we've got at the moment. We're just feeling a bit lost... about what to do with it because the needs are becoming more, especially with the NDIS stuff coming in.

A key finding of the practice review was that while most peer support took time to set up and required funding to support, particularly when it came to identifying and empowering peer support leaders, engaging people from marginalised communities took more time and was more resource intensive. For example:

- culturally and linguistically diverse groups require NDIS-specific and general information and resources in languages other than English, funding for translators and interpreters, and additional support from a provider organisation to source and train peer leaders from those cultural groups
- people living in closed systems such as boarding houses and group homes often have little connection to others who are not staff or service providers, and require outreach and support to become involved in peer networks
- it takes time to build relationships and connections within Indigenous communities, particularly those in rural and remote locations, and some members of these communities may prefer one-on-one connections rather than group settings.

The need for some of the current peer support activities will diminish over time if they are only focused on transition to NDIS. Most peer support served a wider focus more aligned to ILC and NDIS legislation, which is likely to be a sustained need as new people seek peer support to understand disability and disability support. Review participants observed the ongoing needs for peer support for:

- continued capacity building of people currently using peer support, including people eligible for an NDIS plan and those who are not
- new groups and peer relationships in different locations as the NDIS and ILC roll-out continues
- individuals and groups who have not had contact with disability services in the past, such as people living in open boarding houses and many people from Aboriginal and Torres Strait Islander backgrounds and people from culturally and linguistically diverse backgrounds
- new generations of people with disability, carers and families moving through life stages and disability support steps, e.g. identifying with disability, first plan, plan review, early intervention, post-school support, relationships, employment, housing and ageing.

Given the challenges of staff turnover and program uncertainty experienced by many of the organisations (discussed further in later sections), sustainability also requires a commitment to security of funding. It would mitigate stress to participants and loss of organisational knowledge as well as change the way peer support was designed for longer time expectations.

### 2.3 Further resourcing of peer support

As the national support agency in the DSO Project, JFA Purple Orange (Purple Orange) facilitated a community of practice amongst peer support providers to share knowledge, strategies and resources about peer support. This involved:

- hosting state-based community of practice workshops for DSOs in SA, Vic./Tas. and NSW/Qld
- co-design of a suite of online peer support resources and the Peer Connect website with other peer support providers
- dissemination of an e-bulletin – ‘Peer Support Network Stories: a round-up of good things happening in peer networks’, which shared stories of good practice.

The resources Purple Orange co-designed with other peer support providers include information and guidance on topics such as establishing peer support networks, facilitation skills, meeting logistics, and the NDIS, and are publicly available on the Peer Connect website to view and download. There are a variety of links to the websites and contact details of peer support providers across Australia included on this website, as well as details of workshops and meetings and an array of links to other sources of peer support resources. There is also a series of webinars available to view on the website, including two that focus on peer support with Aboriginal and Torres Strait Islander communities and welcoming participants from culturally and linguistically diverse communities. Purple Orange indicates that over 13,000 people have accessed the website since its inception, with over 62,000 total page views.

The guides and resources available on the Peer Connect website represent organisational knowledge about facilitating peer support that in many cases has not been captured and shared in the Australian context before. At the time of interview, the Peer Support Network Stories e-bulletin was up to its 64th issue. It has been an important resource for peer support providers to share news about their activities and learn from each other.

The review found that peer support providers often used these resources as a starting point for their practice:

There’s a huge amount of resources around to support our facilitators...even just looking at the Peer Connect website, there’s a lot of resources out there on how to talk about subjects, and where to go for information.

They also developed their own information and resources tailored to the needs and priorities of their peer support leaders and participants, including

- training workshops and training videos/webinars for peer support leaders
- information about the NDIS (pre-planning guides, guides to planning meeting and plan review processes, guides to self-managing and dealing with service providers)
- webinars, easy read resources and materials in other languages for peer support participants.

Most of these resources were internal documents. Some were shared on the Peer Connect website, and some may also have been shared in state-based community of practice workshops between the peer support providers.

Several organisations have developed new good peer support practice beyond the approaches already supported by the community of practice resources, such as online contact and adapting practice for harder to reach priority groups. These will be described in the following sections. Continuing to work with the organisations who have developed practice in these areas would therefore be valuable for designing and developing future resources to support peer support delivery.

## **2.4 Resources for engaging marginalised persons and groups**

The practice review prioritised the identification of capacity building materials and good practice strategies related to several groups that might experience barriers to peer support from the outset. These groups included:

- Aboriginal and Torres Strait Islander people
- people from a culturally and linguistically diverse background
- people living in boarding houses and group homes
- people with contact with the criminal justice system
- people living in regional, rural or remote locations.

Both the review of the program and documents and the provider interviews confirmed that there are gaps in peer support delivery and resources to guide practice to these groups. In addition, the practice review identified some additional people and groups that are not currently well-engaged in peer support:

- young people with disability
- older people with disability
- male carers and family members
- people with high/complex communication support needs.

Many providers spoke of a desire for more support to engage these groups, especially for engaging culturally diverse groups in more isolated and regional areas. Further guidelines and resources for engaging marginalised groups could therefore be beneficial for organisational capacity building.

The practice review also found that several organisations have been pioneering new strategies for engaging these groups in peer support effectively. For example, PWDA facilitated an arts-based program for a group of people with disability living in boarding houses. The PWDA peer support project manager stated that the arts program was the hook to get this group participating in the community, and peer conversations were secondary to this focus. She added that people living in boarding houses have generally lived quite limited lives and are very new to the NDIS, so their capacity to benefit from peer to peer support without other sources of support also offered is likewise limited:

People living in general boarding houses are outside of the traditional disability services sector. The key challenge is building connections to mainstream services and ILC services. They live very isolated lives so getting together is a big challenge.

The focus of the PWDA program was to build self-advocacy and decision-making skills, using drawing as the medium. For instance, the facilitator initiated a conversation about 'home' while participants were drawing and asked them to draw and reflect on what was most important to them as individuals when considering their future housing plans.

First People's Disability Network (FPDN) developed several approaches to engaging Aboriginal and Torres Strait Islander people, including in rural and remote locations. FPDN peer connectors started a mobile café to get people talking about the NDIS in an informal and neutral setting, established a Facebook page to answer questions and facilitate discussion, offered one-on-one telephone and face-to-face peer mentoring services, and organised community yarning circles and NDIS workshops in regional areas.

An FPDN Peer Connector stated that it took time to connect with the community and build relationships. Peer facilitators cannot always expect people to come to them or gather in a group setting; people often want individual time to tell their story. For this reason, she often went to people's homes and spoke to people one-on-one or in a family or kinship group. The peer connector was sometimes the first person who had gone into some communities to ask people with disability what they wanted and needed, as many people from rural and remote communities had no prior contact with disability services or community organisations. This meant peer mentoring focused on educating people about their rights and entitlements and how it is okay to speak up about their needs and wants in planning meetings:

You're giving people choice and control who have never had choice and control before. It's about building capacity about their rights, getting around a proper plan – some have one that barely scrapes the surface of their needs.

Other organisations had developed strategies for engaging groups that face barriers to participating in peer support and groups that other organisations want to engage in peer support further:

- Disability Diversity Alliance (DDA) developed culturally-specific training materials and resources for peer leaders with NSW CID and CDAH through the 'Team Up!' project, and other organisations including Carers Victoria, Amaze, and ACD have facilitated peer support within some CALD communities in partnership with translators and peer leaders from those communities.
- CDAH, QDN, and Amaze established peer groups in regional locations.
- Purple Orange has a long-standing youth peer support network.
- There were some isolated examples amongst different organisations of men's peer support groups.

Working with these organisations to design and develop resources that consolidate current practice and explore new practice could assist other organisations to extend their reach to these groups.

## **2.5 Resources for alternative approaches to peer support, including online options**

The practice review found that several organisations explored online and phone-based peer support delivery to extend the reach of their peer support activities and respond to the preferences

and circumstances of participants. Examples include Carers Australia, PWDA, Carers Victoria, ACD, QDN, and Amaze. This is another area that would benefit from additional resources to build on emerging practice and inform other organisations moving into these approaches.

Review participants commented that online peer support was an important option to offer to people living in isolated areas and people who want to connect with others who have the same identity or disability support needs as they do:

The idea of the online groups is to help meet that need for people who aren't in an area where we have a group, so that they can connect in as well.

People living with a particular disability, and perhaps it's a rarer disability, can find those connections through the online support, which may not be local, obviously they can be nationally, or internationally based as well...

Others also noted that online peer support was an important option for specific demographics, including young people and people whose life circumstances and other commitments make it difficult for them to attend face-to-face meetings:

One of the things that we've been doing in the last couple of months to try and [connect with younger people] is delivering a version of our program online, via Facebook. We've found that's a really good way to engage with young people and particularly young parents who just can't get to face-to-face [meetings].

Some review participants also noted that online forums were also a useful way for participants to connect between their regular face-to-face peer meetings and for peer leaders and facilitators to share information and resources. This is a new approach for many organisations, and some preliminary challenges to online support have already emerged around managing registrations, mediating discussion and finding the most appropriate platforms.

The review found that many organisations also used phone-based support to support peer leaders and facilitators remotely, particularly when problems emerged in the peer groups that needed troubleshooting, or when peer leaders required additional NDIS information and expertise. This enabled staff to stay in touch with peer leaders even when they did not attend peer group meetings in person.

Carers Australia linked peer partners (peer mentors) with other carers across Australia via teleconferencing or Skype to share their experiences and advice on navigating NDIS processes. Peer Support was provided either in a group session, or more commonly one-on-one. Staff members provided a teleconference number to both parties, dialled in to provide initial introductions, and then left the peer partner and carer to their conversation, which typically lasted between 20 and 60 minutes. The Carers Australia peer support project manager explained the peer conversation process further:

Peer Partners are provided induction on how to hold a conversation that is supportive and solutions focused. They learn how to structure the conversation to be supportive and recognise triggers through understanding their personal values. They also learn the process of active listening and how to close a conversation to be respectful of their own time.



The phone-based approach was adopted because during initial consultations about the peer conversations project, peer partners expressed a preference for peer support and peer mentoring to take place via teleconferencing rather than in local face-to-face meetings. This was firstly due to a lack of time (many carers of children and people with high support needs do not have time available to commit to face-to-face peer support due to caring and working commitments), and secondly, due to concerns about anonymity (both carers' own privacy and the privacy of the person they care for). Carers Australia have also begun developing an online platform to support peer-to-peer engagement with the NDIS.

## **2.6 Resources to support evaluation and feedback strategies**

Purple Orange worked with other providers in the DSO Project to co-design an evaluation framework, which was implemented for the first two years of the project prior to funding extensions. This evaluation had 5 data sources:

1. Peer group journals and meeting records (reported by peer group facilitators)
2. Peer group self inquiry and feedback
3. Direct feedback from peer group participants (surveys and interviews)
4. Feedback from peer group facilitators (stories, surveys and interviews)
5. Feedback from NDIA and DSS

The NDIA also commissioned SVA to conduct an evaluation of the DSO project in 2017. Since then, Purple Orange has not been involved in evaluation and reporting, which is internal to each peer support provider and involves quarterly reports to the NDIA.

The practice review found that feedback and evaluation mechanisms were uneven across the peer support providers. Feedback mechanisms were developed internally by each peer support provider, and sometimes by each peer support group. Organisations part of the DSO Project noted that evaluation and reporting requirements changed mid-program and that they received no extra funding for evaluation and reporting once the funding extensions were in place and Purple Orange was no longer implementing this framework.

Some organisations developed formal mechanisms for capturing participant feedback and program data and outcomes, such as Families4Families. At the time of interview, Amaze was in the process of redesigning a monitoring and evaluation framework for their peer support programs and creating program logics aligned with the ILC outcomes framework:

It will be questions that are the same as the NDIS participant framework, and also aligned with the ILC framework. So, "Are you accessing more mainstream services? Are you feeling more socially connected? Are you going out more?" "Do you feel confident choosing services for you or your child?" All those kind of things that are measurements of self-agency, confidence, social connectedness, choice, and control.

Carers Australia also used formal feedback mechanisms with participants in the Peer Conversations program, such as post-peer support survey questionnaires and follow up emails:

An online survey is sent out to carers, group convenors and workshop facilitators who have participated in the peer conversations. It asks whether participants received the information they needed, and has an open comments section. If participants didn't get what they wanted or needed from the peer conversation, staff follow up with them to send them additional and information and point them towards resources that might be of assistance.

Peer leaders found feedback and evaluation to be a useful way to track participant experience as well. A peer leader from a peer support network facilitated by Purple Orange discussed the formal feedback mechanisms that were implemented in her peer group:

We had really fantastic feedback because Purple Orange conducted their own sort of objective survey to find out what participants actually thought about it. They did an email survey and also a verbal survey.

The peer leader also described a "review and discuss and share" session for peer leaders, in which the leaders sat around a table to discuss the program, were asked permission for their feedback to be recorded or written down, and also left the room to give their feedback individually to Purple Orange.

Other organisations relied mainly on informal and/or occasional feedback methods:

We do connect with a lot of the group members who tell us their experiences and the great things that they're doing... and we've got a lot of feedback in testimonials.

If we get a flag that there is going to be a need to ensure that there's equity in the group and that everyone can have a say then we will tightly structure it, we'll have a running sheet and be prepared....

All the feedback I get, it's usually via email.

The providers interviewed for this practice review stated a preference for qualitative, outcomes-based approaches to evaluation, given the flexibility of their peer support programs and the additional time it takes to establish peer networks within harder to reach groups in the community. Some mentioned the evaluation framework implemented by Purple Orange as an example of a positive blend of qualitative and quantitative evaluation measures. The Purple Orange e-bulletin 'Peer Support Network Stories: a round-up of good things happening in peer networks' is an example of a positive and engaging way to qualitatively capture peer support outcomes in a case study format rather than a standardised quantitative evaluation measure.

Some organisations also suggested that additional funding and evaluation guidelines and resources were required to engage in rigorous and adequate reporting:

A full social impact assessment of personal outcomes for participants and the value-add of local groups to communities and to the NDIS rollout would be a really good evaluation process. But that would take a bit of resource to do that well.

These findings indicate that evaluation and feedback is an additional area that could benefit from further resources to build on and extend current good practice.



## 2.7 Maintaining a community of practice in peer support delivery

The previous sections described how many organisations created their own resources to guide peer support practice in response to the needs of their participants, particularly around engaging marginalised groups, and exploring alternative mediums for peer support including online and phone-based options. There appears to be a high level of internal expertise within particular providers about what strategies and processes work best for engaging particular groups in the community. Maintaining and building on the current community of practice between peer support providers is therefore an important policy consideration. Drawing on existing organisational information and knowledge exchange practices within the peer support community of practice is also an important consideration for the design, development and dissemination of further resources in future stages of this project.

Many organisations mentioned the value of a peer support community of practice as a space for sharing strategies and resources:

Developing a sort of collective approach to the work has been one of the really good outcomes of the project. Sharing experiences, sharing challenges, and making sure that this is a genuine user led practice, because there aren't many of those around.

We have a meeting now and then, and we keep in touch, and we share what we're learning, and then feed that progress back through to JFA

The positive that's come out of that is that we've all learnt that it's so important for us to work together, to share information, to share resources...There is still an openness around collaboration

One state-based community of practice facilitator for Purple Orange stated that the community of practice offers practical support to peer support managers, and this is particularly important during turnover of key staff, as there are other peer support project managers available to provide orientation for newcomers. She also noted how organisations that are not part of the DSO Project joined the community of practice to discuss peer support and share strategies and resources, widening the pool of knowledge participants could draw on. Peer support managers from CDAH and NSW CID also described the benefits of collaboration between their organisations and DDA in the Team Up! Project, which allowed them to draw on each organisations' expertise to design and implement a project that each organisation individually would not have had capacity to manage.

These findings indicate that there may be continued value in a national support organisation to facilitate knowledge-sharing and a community of practice amongst peer support providers, and to provide resources and national, state, and sector-based information. The need for continued knowledge-sharing about strategies for meeting the gaps in current peer support provision also indicates that a national clearinghouse for peer support resources, such as the Peer Connect website, and a national organisation/agency to maintain and build the clearinghouse as practice changes over time would be beneficial to the sector as a whole. Given the number of organisations involved in peer support delivery and their varied approaches, there may also be a need to consider a state-based support role to facilitate a peer support community of practice and work in partnership with the national agency.

### 3. Findings

#### 3.1 Benefits of peer support

Review participants, including organisational staff and peer support leaders, reported a range of positive benefits for peer support participants.

In the NDIS context, information and knowledge sharing and confidence and capacity building were considered by most to be very important benefits of peer support. The provision of accessible information about the NDIS was a key focus of organisations funded through the DSO Project, which reflected the initiative's original rationale and aim to build the capacity of people with disability and their families to engage with the emerging NDIS and the shift to individualised support:

In this context it was all mainly about the NDIS, the scheme, the process, planning, how to navigate the scheme...

The information needs of the groups is evolving. But there is ongoing need for accessible information about the NDIS, and new people will still need NDIS information.

Peer support appeared to reduce participants' anxiety about NDIS planning by providing them with accessible information, tailored to their needs:

People have said that they came into groups being very scared of this big bureaucratic beast and being able to bring it down to something that was manageable, and fitted within their family, with something that they credit being part of the groups with.

A lot of people reported feeling a lot more confident about the NDIS and more confident about their rights and they were armed with more knowledge about what their rights were in general and who to go to if they had a complaint and to set up a complaint.

Peer support reportedly enabled people to share their lived experiences of negotiating NDIS processes, pathways and challenges and of how they achieved their goals and solved problems. Some review participants reported that people who had been part of a peer network had better experiences in NDIS planning meetings, because they were able to clearly articulate what their needs were. If they had a negative experience with NDIS processes, they had a network to draw on including their peer group and the support organisation to seek advice from.

Peer support managers also reported that NDIS information was often just the beginning of what participants sought from peer groups. For many review participants, there were broader reported benefits to peer support as well: the development of an engaged and informed disability community, and awareness and capacity building within mainstream services and community about engaging inclusively with people with disability and families. Longer term and wider benefits included increased confidence in their ability to influence their lives and environments, increased participation in community life and increased access to mainstream services. This is an important consideration for the NDIS and ILC implementation. For example, one peer leader discussed how she observed broader benefits to participants' confidence in decision making and self-advocacy in dealing with both mainstream services and NDIS processes:

Confidence building gives you capability. That was all about developing skills around communication and confidence and how to ask for things, how to talk to your support workers, how to build your confidence, how to, you know, how to create a complaint effectively. Your rights and the law, I carried that one...

Organisations not funded through the DSO Project spoke to the benefits of peer support for individual capacity building, confidence building, self-advocacy, and decision-making, including for negotiating NDIS processes, but NDIS readiness was less of a focus in their peer support networks.

Sometimes benefits were weighed differently according to the approach to peer support adopted by an organisation, or according to the benefits most relevant to a particular participant group. Organisations that engaged in peer support for some more marginalised groups such as people from Aboriginal and Torres Strait Islander backgrounds, people living in boarding houses and group homes, and people with intellectual disability, also spoke more to the benefits of confidence building and decision-making support, stressing that these groups often needed sustained individual capacity building as a first step before peer support could focus on NDIS information. This was reflected in the more intensive staff time and staff facilitation of peer support required in the approach of these organisations to peer support delivery. Other approaches also yielded weighed benefits:

- One-on-one peer mentoring yielded stronger benefits in confidence and capacity building.
- Face-to-face small group peer meetings yielded stronger benefits in sharing experiences and social connectedness.
- Organisations that also facilitated larger, structured workshops on NDIS topics observed stronger benefits for information and knowledge sharing for workshop participants, and benefits in social connectedness for people who chose to participate in peer group meetings after attending a workshop.

In general, peer support leaders focused most on the benefit of social connectedness and emotional and practical support for participants, the benefits most directly related to their own roles of peer mentoring and facilitating discussion:

... there's so much social isolation and it's scary because our little community has quite a high rate of deaths ... if we can decrease that isolation we can increase people's exposure to help... we need to find some way to keep people in the loop somehow.

While the benefits of support were weighed differently by providers according to the approach to peer support they had adopted and many benefits were interlinked, there were common themes. These are summarised here and illustrated with quotes from the interviews.

### *1. Information and knowledge sharing*

Peer support provided a forum for participants to access formal information developed by the provider organisation, as well as opportunities to informally share knowledge with peers about what they have learnt from their own experiences of navigating the NDIS and other formal and informal support:

Because they are with their peers they are able to feel that they can ask and seek, share information within that space.

The groups get guest speakers to come in and talk about different topics, so it's also building their own knowledge.

## *2. Confidence and capacity building*

Training and support from provider organisations as well as informal leadership opportunities were reported to help peer support participants to build confidence and skills in communication, decision-making and self-advocacy:

It has helped build their confidence to be able to speak up for themselves.

The information has a knock-on effect in terms of the capacity building of the peer members themselves. As they built knowledge they felt more confident to go out and navigate the system, or talk to the school or apply for the job or whatever it is that they were doing.

## *3. Social connection and emotional and practical support*

Peer support was reported to be a source of belonging, understanding, and friendship for many participants:

There is a degree of I call it 'the get-it factor'... So, having that shared experience and that shared emotion then can help parents go "Oh God, I'm not the only one".

People come to a group, vent their problems, find common experiences, and meet people they trust – "we are all Indigenous, we all have a disability, we all struggle in society".

Through the groups, friendships are formed... They end up carpooling together or helping each other out...

## *4. Access to a safe space to share experiences and problem-solve*

Informal conversations between peers in which they shared experiences were reported to help peer support participants think through solutions and other options for overcoming common challenges:

It's good for all of us to kind of learn about other people's experiences and when things change for us asking what other people are going through and what sort of things they've done.

Sharing experiences and lessons learnt is the main benefit... There's even informal referrals – people tell each other about the best support workers, the best services...

### *5. Access to positive role modelling from peers*

Peer support was reported to offer opportunities for participants to access positive role models through encouraging each other to develop aspirations and goals within a positive and facilitated environment and through their engagement with peers in leadership positions:

Participants gained strength from hearing stories from older people with disability who have forged a life, a job, a career, a home... it's very much a space where people can say, well you could do it.

People feed off each other in forming positive roles and goals. They hear from another survivor and it clicks that a good life is possible.

### *6. Increased participation in community life*

Peer support was reported to be particularly beneficial for participants who experience social isolation, because it led to increased social interaction in a group setting in the community:

Seeing people who were never included in [the] community getting there and being part of it...

They encourage each other. They're encouraged to go ahead and try it and give new things a shot.

## **3.2 Good practice strategies for peer support delivery**

This section reports on the strategies and processes that review participants (peer support project managers and peer support leaders) adopted for facilitating good practice peer support. These strategies were developed through both formal and informal mechanisms. Many were the product of discussion and collaboration within a peer support community of practice that review participants took part in. Many project managers also consulted potential peer support leaders and participants to develop their approaches. Most had guidance and input from other staff members from their organisations, and some from their organisation's board members. Peer support managers and leaders also responded to the needs and circumstances of their participants and potential participants as they emerged, adapting their approaches to peer support provision if initial strategies were not working. The strategies they developed focused on the following common themes: valuing lived experience, consultation and feedback, capacity building for peer leaders, quality information provision, recruitment and outreach, structuring peer support, and community linkages.

### *1. A focus on lived experience and participant empowerment*

Review participants described good practice peer support as focused on lived experience. They commonly linked participant empowerment, a key aim of their programs, to the opportunity to connect with peers to share knowledge and understanding, and experience a sense of solidarity. The term 'peer' had slightly different applications across the programs included in the practice

review, which was consistent with the diversity of the participant groups the programs targeted and the emphasis on facilitated or mediated peer support common to all approaches.

The composition of peer groups was varied. Some peer support groups were specific to disability type or support needs, some were for carers, parents and family members, and some were open to all people with disability and family members who wanted to participate. All, however, focused on the value to participants of sharing lived experience:

We come together about shared experiences and supporting each other.

There's a need there, people want to connect in some way. [It starts] quite small, one or two people, and from there the word gets out that this is different from other groups, it is something that is beneficial, and it's run by somebody who has lived experience.

We had a very strong ethic around ensuring that stories... [and] language used made the space safe for people with disability.

Often group composition was primarily due to the membership of the organisation. Sometimes conscious decisions were made by peer support project managers to create separate groups to meet targeted needs for equity reasons, to ensure everyone in the groups had the chance to speak up as peers no matter their support needs, and to address information and equity gaps which emerged as the groups progressed. For example, Community Disability Alliance Hunter (CDAH) established peer support groups that included members with a range of disability support needs as well as family members. CDAH also established some additional peer support groups to cater to the communication support needs of people with intellectual disability, for equity reasons:

We understand the additional barriers that people with intellectual disability experience to access information in ways that is supportive and accessible. So, we do run separate peer support meetings for people with ID. Some other members often come along to those because they're so useful. They use language that is easy to understand and they're very empowering spaces where everybody gets a chance to have a say.

Through the Team Up! project CDAH supported people with psychosocial disability and people from the deaf and DeafBlind communities to establish their own peer support networks, based on the desire of these groups to come together around their own lived experience.

Providers emphasised the value of recruiting peer leaders with lived experience of disability to facilitate peer support:

We strategically hired a team of people that have a caring role... just so there is a degree of 'the get-it factor'.

All of the peer coordinators that we have around the state come from our state-wide membership network that we already have.

Finding peer leaders and facilitators with the lived experience, people-skills, knowledge and flexibility to run peer support was sometimes a challenge:

You don't just want to put a body in the front of a group. You want to put the right person. And you may find a great person, but whether it's right for that group. You've got to mix. That's the challenge, is finding the right person for the right group.

Peer leaders were sometimes volunteers from the community or from the organisation's pre-existing membership, sometimes paid workers who were employed specifically to take up a peer facilitation or mentoring role, and sometimes internal staff members of the organisation. New staff were employed by several organisations as peer mentors, peer connectors, or facilitators. For example, ACD employed a team of paid peer facilitators for their DSO peer groups; FPDN employed peer connectors to undertake peer mentoring and outreach activities, and PWDA employed a part-time peer facilitator to oversee online peer support groups.

The demands on volunteer peer leaders is discussed as a key challenge later in this report. Some organisations found they had to rely on staff as well as peer leaders to facilitate discussion and undertake mentoring activities, so as to enable positive peer support experiences for all:

Our support groups are run by peer leaders, except for when you're hosting a workshop, and then you, or other staff members go in, and deliver more expert knowledge about NDIS and processes.

An additional strength of the peer support was that many paid staff members from the organisations that participated in this practice review had lived experience of disability and/or caring roles that was shared with peer support participants in their programs. This reflected a point raised by one peer support project manager, who commented that organisations of and for people with disability can be viewed as a source of peers and often act in a peer support role for their members, so staff facilitation was not uncommon.

## *2. Consultation and feedback strategies to determine and respond to peer support participant and leader needs*

Peer support providers often adapted their initial strategies to peer support provision in response to consultation and feedback from potential participants and peer leaders. Determining participants' needs involved agreeing on the purpose/s of the peer support group and what participants were seeking to achieve or gain by attending the groups. Organisations with an established membership tended to already have a clear sense of what their membership wanted from peer support, but for organisations entering this space for the first time, it often took longer to establish peer networks because providers were trying to find out what people wanted.

For example, Carers Australia held forums around Australia to find out what the needs of carers for peer support are, and what potential peer partners (peer mentors) would like this support to look like. At these consultations, carers said they wanted to talk to someone they could trust, a peer, who could share their experiences of navigating the NDIS. The peer partners expressed a preference for these conversations to be by phone rather than face-to-face, which informed the approach to peer support the organisation adopted.

PWDA established Facebook groups because the organisation found that it was difficult to get people to attend face-to-face peer group meetings, particularly given the participant groups they



targeted, such as LGBTI people with disability and people with disability from different cultural groups, are geographically dispersed:

We tried face-to-face peer support groups but haven't been able to get bums on seats. With the Facebook groups, members can be anyone from the target group, and not just from NSW, so we can widen the net.

Council for Intellectual Disability NSW (NSW CID) expanded their “train the trainer” program for new peer support leaders after finding that the initial training program was insufficient to peer leaders’ needs. They were committed to ensuring that people with disability would become the facilitators of future training for future peer support leaders and adjusted the program in response to feedback that the peer leaders wanted more training about presentation skills as well as opportunities to deliver practice presentations.

Other organisations found that they needed to rely more heavily on staff facilitation than they had initially planned, due to the demands of the facilitation role on peer leaders, whose capacity to meet these demands as volunteers was limited by other life commitments. For example, Carers Victoria found that their membership had a “thirst for NDIS knowledge”, which was key to engaging potential peer support participants. They held a combination of larger, strongly structured and facilitated sessions where they presented NDIS information, and smaller groups of about 10 to 15 people where they provided tasks for participants to complete. At the first workshop, facilitators asked participants to “Give us all your questions”, which was productive in responding to information needs directly before participants engaged with formal workshop content.

Peer support providers also found that participant needs evolved with time. Some groups that originally expressed a strong desire for NDIS-related information, later became more focused on social and community connections once their initial need had been met:

People come for a reason. And it's hard sometimes to know exactly what that reason is. So, for the DSO groups it's information on the NDIS ... If it sustains past that, it's a connection with each other.

For others, NDIS-related information needs changed as participants moved from pre-planning processes to negotiating their first plan or plan review. For many providers, this meant a constant process of developing and updating content:

In the early days, we did lots of planning with people... now people want assistance around their reviews and are looking to each other for assistance around their [NDIS] reviews.

Over the life of the Peer Conversation Project, it has emerged that there is a particular demand for talking with peer partners with experience in early childhood intervention services.

### *3. Supporting peer support leaders through training, capacity building and contact with other leaders and organisational staff*

Review participants identified that sufficient training and support for peer leaders, mentors and facilitators was one of the most important features of good practice peer support delivery. They agreed that it was very important that peer leaders felt supported by the provider organisation, its



resources and connections. Not only did training and supporting peer leaders lead to greater benefits for peer support participants, it also represented an important investment in individual capacity building. Building the capacity of individual peer leaders was seen to have several flow-on effects, including positive role modelling and demonstration of leadership to peers and contributing to a confident, engaged and informed wider disability community.

The practice review found that peer support leader training generally focused on all or most of the following competencies:

- Group facilitation and dynamics strategies
- Confidence building and leadership skills
- Presentation skills
- NDIS information

Peer support project managers at each organisation in the practice review had a key role in supporting peer leaders. They provided them with up-to-date and accessible information about the NDIS, assisted them to develop other content and topics for discussion, debriefed them after peer group meetings, and discussed problem solving strategies within the peer network or group:

If you are a peer facilitator and a particular question that requires NDIA expertise comes around, there's one of us that will be available as a phone a friend backup.

Regular teleconferences involving all the peer partners are held to update them on new information and discuss how things are going.

Peer leaders valued the training experiences they received from provider organisations:

They called it a capacity building workshop... I found that I learnt a fair bit about - because I mean, while I've always lived with my disability you don't always understand there's a wider concept. So, I found that was really good and they have NDIS nuts and bolts sessions they're called.

One peer leader also noted that some peer leaders needed more training, depending on their starting point:

We were trained up for about a day, no two days of training which was great for me but for some of the others that had never had any teaching experience or training...they need more.

All organisations stressed that peer leader training was key to good peer support. They adopted different approaches to the delivery of this training and support, but common forms were face-to-face training workshops, peer leader manuals and guidebooks, online slideshows and training webinars, and co-facilitation and mentoring.

For example, QDN provided initial face-to-face training and a manual to peer leaders, which was focused on how to facilitate a peer group. Staff members attended the first few meetings of the peer group to provide facilitation support in person. Staff continued to support peer leaders in an ongoing manner through phone calls, monthly teleconferences with all peer leaders, and by linking peer leaders to other peer leaders for mentoring.

Carers Australia provided face-to-face induction training to all peer partners and an induction workbook about how to hold supportive, positive and solutions-focused conversations, whilst being respectful to their own time and confidentiality of the person they care for. Project staff supported Peer Partners with debriefing post peer support conversations, where needed, which is most commonly for new Peer Partners.

Amaze developed online training workshops and slides that peer leaders could complete in their own time, a fortnightly newsletter which was distributed to peer leaders, an annual conference for leaders, and online resources for peer leaders to refer peer support participants and their families to.

CDAH adopted a co-facilitation strategy in their peer support groups until peer leaders felt confident to take on a lead role themselves. The organisation matched peer leaders with disability with other facilitators according to how they could complement each other's skills and expertise:

There will always be someone who was employed for the expertise of experience, and then somebody employed for their expertise in community development, community facilitating, community organising, peer network building. It's quite resource intensive, but it's a way that we way found really useful for people developing the skills to become confident peer leaders.

The organisations involved in the Team Up! project, CDAH, DDA, and NSW CID, adopted "train the trainer" models where a small group of people with disability received intensive training until they were confident enough to train other people with disability to be peer leaders and facilitators.

Many peer support providers also discussed how they were creating a community of practice for peer support leaders, peer facilitators and peer mentors associated with their organisation:

We've learnt the value of linking coordinators together more formally to be able to actually build their own community of practice across each other. We also hold monthly teleconferences to make sure that we're keeping the convenors up to date with big picture policy stuff we're hearing about.

The main benefits of building connections between peer leaders in this way were that they could circulate information and support each other to brainstorm discussion topics and how to deal with common challenges.

#### *4. Quality information development and provision, particularly about NDIS processes*

Review participants identified the development of good quality, accessible information about the NDIS as an important strategy to support and engage participants in peer support. For the organisations funded through the DSO Project, quality information provision was a major rationale for their peer support delivery, and a reason why many participants were attracted to peer support in the first place:

For some people it just wasn't enough to go along and be in a room with other peers... so there had to be some kind of hook or reason for people to show up in the first place. So essentially it was about the NDIS.

Peer support providers found it challenging at times to develop and deliver this information in an accessible and engaging format, primarily because NDIS systems and processes are new to the disability sector, and the information was updated and changed over time:

NDIS information is all a moving target and it's evolving and there's not a lot of documentation around as of yet.

Providers adopted one or more of three key strategies to meet this challenge:

- a co-facilitation approach to group-based peer support, where staff members of the provider organisation worked with a peer leader to facilitate group discussion about the NDIS

We've done a lot of on the job training and a lot of co-facilitating, co-development all the way through.

If you are a peer facilitator and a particular question that requires NDIA expertise comes around, there's one of us that will be available as a phone a friend.

- drawing on staff or guest speakers who presented NDIS information to peer groups

Support groups are run by peer leaders, except for when you're hosting a workshop, and then you, or other staff members go in, and deliver more expert knowledge about NDIS and processes.

- converting NDIS information and resources into small, 'bite-sized chunks', tailored to their participants' needs, which were delivered over time and updated as the information changed.

Parents just have an overwhelming sense of gratitude about the information, because it's being broken down into bite-sized chunks, and it's spread out over time...

Peer support project managers noted that each of these strategies required an investment in staff time and organisational resources.

#### *5. Recruitment strategies that blend drawing on existing networks with word of mouth and outreach to new potential networks of participants*

Organisations with a pre-existing membership and networks were able to draw on these networks and get the word out about peer support through email lists, e-bulletins and websites, member's meetings and communications, and service providers they had a pre-existing relationship with:

We used our e-bulletins, our Facebook, etc., to let people know that we were starting like a support group, but I can also tell you that there was already a backlog of people who had wanted to start local support groups and we were holding them back because we did not have any resources up here for that to happen.

Other peer support providers relied on word-of-mouth to recruit participants to peer support and found that news spread once a few people had started coming to groups and found them rewarding. The key message from the provider interviews was that this takes time, but eventually leads to people becoming enthusiastic about participating in peer support. Word of mouth was particularly important within Aboriginal and Torres Strait Islander groups and culturally and

linguistically diverse groups. For example, a Peer Connector from FPDN stated that potential peer support participants do not necessarily respond to flyers, email invitations or other common recruitment methods; instead she had the most success reaching people by approaching local elders and drawing on local networks to spread the word about peer support opportunities. Another peer support project manager stated that people from culturally and linguistically diverse backgrounds seldom approached services directly to ask for support, so informal referral was important:

I've been working with a school coordinator out ... where there is a predominantly high number of Arabic-speaking people. She said, "Oh, we can only get four or five people to come along." I said, "That's okay; that's fine." I said, "Four or five people is good." Because in those communities, it's about word-of-mouth...

#### *6. Structuring group discussion through prepared topics, themes and content, and guest speakers*

Many review participants described providing structured, purposeful peer support as key to sustainability or keeping participants engaged over time. They noted that structure was particularly important at the establishment stage, but that the need for structure reduced over time as relationships within the peer support group strengthened and members became more confident in identifying their own topics for discussion.

All providers agreed that unstructured time for sharing experiences, asking questions and social engagement was also necessary, but at the establishment stage, having identified topics each session, guest speakers, and issue or activity-based meetings kept participants interested in returning to the peer groups and reduced unproductive or overly pessimistic discussion. For example, Carers Victoria reported that a structured program they implemented for peer support groups had been successful in treading the line between purposeful and relaxed peer support provision. This program involved a structured activity one month, a guest speaker at the next monthly meeting, and then an open session where participants gather to share "a cuppa and a chat", repeated quarterly. Families4Families also described the importance of identifying a clear purpose and discussion topics for each peer group meeting to limit unproductive discussion, and the importance of distinguishing the social component from the information component of the meeting so participants could take opportunities to develop their knowledge and capability.

Peer leaders also highlighted the need to "be fair and share time, give space to other people" by managing peer group dynamics. One peer leader observed that picking a structure for group meetings that worked for everyone, developing a plan for the peer group with everyone's input, and discussing group rules and group agreements were all strategies that worked for her.

Part of the meeting is about information giving or provision, part of it is hearing back from people... All the meetings always finish with a checkout...

Review participants described their strategies for engaging participants in determining the structure and purpose of their peer support meetings through regular participant feedback and discussion and group plans. NSW CID provided guidance and training to peer leaders about setting up peer support groups and how to establish the values and purposes the groups will be guided by. QDN peer groups made their own annual plans after group discussions about what they would like to

know more about and what guest speakers they would like to invite to their meetings. Purple Orange's youth peer support group was described as autonomous as well as supported:

They decide on what guest speakers, what topics they want to explore, how they want to run the session, what kind of pizza to get, and so they've really run it themselves, as they should, but it has had some overriding admin support from a hosting agency

Formal documents, such as group charters or participant agreements, were also identified as good ways to establish expectations and roles and responsibilities in peer support by some review participants. Families4Families peer groups developed a persons with disability charter and a carers charter to guide the dynamics and discussions of their meetings. Carers Australia developed formal agreements between the parties involved in the peer-to-peer project that set out the aims of the peer conversations and expectations of the parties involved. These include an agreement between the peer partners and Carers Australia staff, an agreement for carers who are dialling in, and an agreement for workshop facilitators (people who have organised a group to participate in a dial-in session with a peer partner, often a service provider). The agreement between the peer partners and staff, for instance, states that the peer partners are not expected to be experts on NDIS policy and rules. They are, however, expected to share their journey and tips and advice with other carers, while staff are expected to support peer partners and point them and participants towards sources of further information.

*7. Strategies to create connections with local community and build the capacity of peer groups to be active in their community*

Some provider organisations also indicated that good practice peer support delivery should embed a community capacity building component, with a focus on forging links between peer support participants and mainstream community organisations, services, businesses and local government. Support from local community organisations was useful for securing meeting rooms, printing resources and engaging guest speakers.

Engaging community was viewed by these organisations as crucial for ensuring the sustainability of the peer groups. For example, QDN described how peer support project staff organised community meetings in each local area where a group was going to be established with key local organisations:

In each of those 24 locations we have had those meetings... so that I can come back and assure the board at the end of them that there would be some level of support within the communities to assist the groups in some way, knowing that we were outreaching and all of the limitations that we have.

Amaze peer support managers also found that engaging with community organisations was important for outreach into regional areas and described how actors such as local school coordinators were pivotal in linking the organisation to potential participants.

Some organisations found that peer support leaders and participants had become active in their communities as advocates and self-advocates, for instance by lobbying local government about inclusion issues and the accessibility of mainstream services and delivering disability awareness

training. They saw this outcome of peer support as contributing to a broader benefit of building community capacity in the context of the NDIS.

### **3.3 Challenges of peer support delivery**

Providers of peer support experienced common challenges related to the complexity of NDIS information; delivering sustainable peer support in a context of funding uncertainty; and the demands on peer support leaders, particularly volunteers; reaching groups with additional barriers; and maintaining a community of practice. Peer support leaders experienced common challenges around new and complex NDIS information and balancing their peer leadership role with their other commitments.

#### *1. Complexity of NDIS information*

Many providers identified the new, complex and evolving nature of NDIS-related information as a key challenge in peer support delivery. Some observed that it was difficult for them as peer support project managers to digest and present this information, and it was even more challenging for peer support leaders:

I think initially when this project was formed, and we were looking at “train-the-trainer” type models, I don’t think a lot of thought was put into the complexity of the information that was going to be delivered... me, as a professional in the disability sector, for over 20 years, could not get my head around this... so how was a peer support leader from a regional town going to?”

if you’re a volunteer, why would you want to be taking on NDIS information? Why would you want to be the go-to person?

As discussed earlier, providers negotiated this challenge by converting NDIS information into more usable and accessible segments, drawing on staff members or guest speakers to deliver NDIS information rather than peer leaders, and/or co-facilitating peer group meetings about the NDIS, but each of these strategies required extra investment in staff time and organisational resources.

Peer support leaders also experienced challenges with finding appropriate and accessible resources and information for participants in the peer support they facilitated. One peer leader commented:

I’m very worried for a lot of people out there because I mean, I’m right across the NDIS stuff and I still find it confusing and scary.

#### *2. Funding and organisational capacity*

Peer support providers identified funding as another key challenge, primarily because they were concerned about the sustainability of the peer groups once they were established:

We technically have no funding after June, so I don’t want to be promising support that I can’t be offering...



Starting a network and then not being able to continue it... and where you're trying to embed the sort of culture of peer support, but you're not sure if the funding's going to be there

We haven't been adequately resourced, so we've been a real blood, sweat and tears operation and mostly voluntary. People don't mind doing voluntary work but they're not going to do it forever.

Community development takes more than a grant cycle. It takes prolonged engagement and targeted support.

Project managers also found that the costs of facilitating peer support varied according to the location and characteristics of peer support participants. This has been discussed in previous sections and is related to the additional resources and staff time required to engage with people from marginalised groups and people with complex needs.

Project managers also commented that funding uncertainty affected the level of trust participants had in their support organisation, and on community stakeholder engagement:

It requires an ongoing commitment I think... It doesn't just happen.

They further identified staff turnover as a key challenge, that while sometimes inevitable, was also worsened by funding uncertainty. Organisations could not guarantee continuing employment to key personnel such as peer support project managers and paid peer leaders. Review participants described retaining staff as key to maximising the benefits of peer support, because of the quality and depth of relationships long-term staff developed with peer support participants and leaders:

The more successful peer networks have probably had the same people there doing the facilitation and really building those very strong relationships with the peer group members... Staff turnover is just a thing, isn't it, that's difficult, or membership turnover, and people engaged and wanting to be part of the group

What do we need, to keep going? Obviously if we had this position funded, ongoing, would be brilliant; and then developing enough resources to sustain the groups independently... to actually really give them that edge that they need, to be better advocates, and more supported, and better information, you need somebody in the role

### *3. Demands on peer leaders*

Review participants reported that the limited numbers of peer support leaders and mentors willing and available to take a leadership role was a key challenge in meeting the high demand for peer support. They commented that it was difficult at times to recruit leaders with capacity, capability and confidence to take up this role alongside their other life commitments:

Every group is very different, because of the people that are in it... That flexibility and skill set in a peer group facilitator is essential. Finding the right facilitators is a really tricky thing

The challenge of recruiting peer leaders was heightened for organisations delivering peer support to carers (who often have intensive caring obligations) and organisations delivering peer support to people with intellectual disability and people with complex communication needs (because training

and capacity building processes were more intensive). This challenge was also heightened for the organisations that drew on volunteer peer support leaders:

It's weird that they thought the peer support group leaders could take this on. I can't believe that they even thought that this would be something that the average person, who is a volunteer, would want to take this on.

It's common theme across the leaders, when you speak to them. They are very passionate, they want to help; but they are also mindful of the fact that they don't get a lot of help from others, as well.

Two peer support leaders interviewed in the practice review noted that they are volunteering their time to leading peer groups and they want to limit their participation in the future due to their work and other life commitments.

Peer support project managers reported needing to be very careful of the danger of burnout amongst peer leaders and the need to ensure that they were not overtaxed by what can be a demanding and time-consuming role. Some organisations responded by providing additional training and support to peer leaders when they recognised that the demands on them were greater than first anticipated. Others responded through co-facilitation strategies or by employing peer leaders.

#### *4. Reaching groups with additional barriers*

As described in the implications section of this report, many review participants encountered challenges in engaging people from marginalised groups and people with complex needs in peer support. Some of the challenges related to the additional barriers potential participants from these groups experience from their life circumstances, but many related to other factors such as funding and the availability of appropriate information.

For example, peer support project managers found that it took additional time and therefore funding and resources to establish connections and build relationships and trust with Aboriginal and Torres Strait Islander people with disability and people from culturally and linguistically diverse backgrounds:

The truth is, you've got to build that trust with those groups, and I think NDIA have to understand that it's going to take time to get those numbers up, with the CALD groups... A lot of these families are not even known to local council, because they're not accessing respite.

They also found that engaging both groups required additional funding and resources because hiring translators for people whose first language is not English is crucial, and more in-depth NDIS information is not always available in other languages:

most of the information's in English, so if you don't speak English, and you don't happen to have someone coming along like we did with our Vietnamese groups, then you're sort of... You're up against it to begin with.



## 5. Maintaining a community of practice

Providers reported positive experiences participating in a community of practice around peer support and benefited from the sharing of knowledge and resources this community of practice facilitated. Some peer support providers noted that the competitive funding environment was a factor that made cooperation between organisations more difficult. They described this as primarily a future worry rather than something they had already experienced. The transition to ILC funding for peer support programs was seen as a move that could lead to competition as organisations might apply for similar grants, which could also lead to a reluctance to share intellectual property in the form of resources about peer support provision. Funding uncertainty was also identified as a possible challenge to maintaining a community of practice:

Losing that expertise that the program's built up, and that trust and stakeholder engagement. It's very hard to build up and very easy to lose...

### 3.4 Future directions of peer support

Many of the review participants outlined their future outreach plans and strategies and discussed the importance of trying to engage with marginalised groups and new participant groups:

There are still unmet needs. The issue for us is the demographic spread.

Reaching out to Indigenous groups and carers living in rural areas... Currently there are no peer partners from rural areas.

We need a new emphasis on people in closed systems. People in group homes and day programs have little connection to anyone who are not staff of service providers.

Men tend not to participate; younger people are also much harder to get in the door. Even just younger parents.

Some argued that they need more support and funding to do this effectively, especially for groups in regional, rural and remote areas, people with complex communication needs, and people living in more isolated settings such as boarding houses and group homes.

Some review participants outlined their strategies for delivering online peer support and/or their plans to explore online options in the future:

I think that space [social media] ... it's a space where maybe we need to move into.

The benefits of online approaches included flexibility, increased reach, and cost-effectiveness, while challenges included vetting participants, recruiting moderators and facilitators, and the suitability of online approaches to only some demographics within the community.

Many of the review participants also discussed the importance of sustainability to peer support. They outlined the challenges of achieving sustainable peer support for the groups and individuals they currently supported, and the risks of reaching out to new participants in the context of funding uncertainty. For some, it was difficult to make plans for future peer support programs and networks without knowing what the future funding environment would look like:

What do we need, to keep going? Obviously if we had this position funded, ongoing, would be brilliant; and then developing enough resources to sustain the groups independently... to actually really give them that edge that they need, to be better advocates, and more supported, and better information, you need somebody in the role

I have no idea where that funding's going to come from after 2020.... The NDIS is changing the landscape for a lot of organisations.

## Appendix A Characteristics of peer support providers

The majority of peer support program managers interviewed (9) were from amongst the 18 organisations funded to provide peer support through the DSO Project, initiated through the Sector Development Fund in December 2014. The DSO Project aimed to build the capacity of people with disability and family members to:

- effectively engage with the NDIS
- effectively engage with mainstream programs, services and activities
- exercise choice and control
- engage with opportunities for independence, self-management and community inclusion.

Most of the organisations from the DSO Project established between 20-25 functioning peer groups. Participant numbers within these peer groups vary from small groups of 5-10 people, medium-sized groups of 15-20 people and larger groups of 40-50 members (usually only a proportion of which attend meetings regularly). Some of these organisations also support other peer support groups, apart from the funded DSO groups. For example, Carers Victoria has contact with about 525 carer support groups around Victoria, only 20 which are DSOs, and one of Amaze's peer support groups has over 200 people on their mailing list.

Interviews were also undertaken with the three organisations that form the NDIA Advisory Group for the peer support project – Purple Orange, the Self Advocacy Resource Unit (SARU) and Carers Australia – and two other organisations with a reputation for good practice peer support provision amongst other providers, NSW Council for Intellectual Disability (NSW CID) and the Community Disability Alliance Hunter (CDAH).

A total of 17 staff members from peer support provider organisations were interviewed in 13 interviews (some interviews involved more than one participant). Interviews were mainly conducted with the peer support project manager of an organisation, but some included the organisation's executive officer, other support staff, or a peer facilitator or leader.

Interviewees were drawn from the following peer support provider organisations:

Peer support provider organisation	Location	Description
Julia Farr Association (JFA) Purple Orange	Adelaide, SA	JFA Purple Orange, a SA-based research and advocacy organisation, and is the National Support Agency of the DSO Project. Purple Orange also supports cross-disability peer support networks, including a youth peer support network. NB: The NSW community of practice facilitator, associated with Purple Orange, was also interviewed.
Carers Australia	Deakin, ACT	National peak body representing Australia's carers
Self-Advocacy Resource Unit (SARU)	Melbourne, Vic.	Support organisation providing resources to Victorian self-advocacy groups for people with an intellectual disability, people with an acquired brain injury, and people with complex communication support needs

People with Disability Australia (PWDA)	Sydney, NSW	Cross disability national disability rights and advocacy organisation
New South Wales Council on Intellectual Disability (NSW CID)	Sydney, NSW	Advocacy organisation of and for people with an intellectual disability
First Peoples Disability Network (FPDN) (including Aboriginal Disability Network)	Sydney, NSW	National organisation of and for Australia's first peoples with disability, their families and communities
Carers Victoria	Melbourne, Vic.	Advocacy organisation representing carers in Victoria
Queenslanders with Disability Network (QDN)	Bowen Hills, Qld	Organisation of and for people with people with disability in Queensland
Association for Children with Disability (ACD)	Melbourne, Vic.	Information and advocacy organisation of and for families with a child or children with disability
Families4Families	Edwardstown, SA	Support organisation of and for people with acquired brain injury and their families
Amaze	Melbourne, Vic.	Organisation for people on the autism spectrum and their supporters in Victoria
The Community Disability Alliance Hunter (CDAH)	Newcastle, NSW	User led peer support organisation run for and by people with a disability and their family members.

The SPRC team decided during fieldwork to increase the number of peer support project managers interviewed to establish a more representative view of the approaches to peer support that providers have adopted. Five peer support leaders were also interviewed about their experiences leading or facilitating a peer group. Findings from these interviews, which provide some insight into the peer support leader experience but should not be considered representative of peer support leader views and perspectives given their limited number, are also included in this report. All information about peer support leaders has been de-identified to protect their privacy.

### NDIA Advisory Group members

JFA Purple Orange, a South Australian-based research and advocacy organisation, was appointed as the national support agency for the DSO Project, a role that will continue until at least 30 June 2018. Purple Orange supported DSOs by creating a “community of practice” to share experiences and expertise and foster collaboration across the DSO Project. This support included the development of the co-designed Peer Connect brand and dedicated website (<http://www.peerconnect.org.au>) and other peer support training resources and opportunities to share knowledge with other peer support providers. Current staff at Purple Orange have extensive knowledge about the other peer support providers that participated in the DSO Project and networks with staff involved in peer support provision from these organisations. This organisational knowledge and role in facilitating a community of practice to share resources and strategies to support peer support delivery means that is important to continue to work with Purple Orange in future stages of this project.

SARU, based in Melbourne, provides resources and assistance to Victorian self advocacy groups for people with intellectual disability, people with an acquired brain injury, and people with complex communication support needs. SARU supports self advocacy groups by acting as a resource for the groups if needed. Its work is different to the work undertaken by organisations in the DSO Project, which aimed to set up peer support groups. SARU provides information about the disability sector, other sources of support, and helps groups network, start up, and attract members. SARU produces tool kits of training materials for self advocacy groups to use, as well as DVDs, posters, flyers, newsletters and other promotional material for self advocacy groups to get their messages

out. It also hosts and supports groups to host forums, training workshops, and conferences, and shares equipment, i.e. cameras, video cameras, printers and computers with group members so they can produce their own material.

SARU was engaged by the NDIA to undertake the National Self Advocacy Project, which will propose a model for a best practice National Self Advocacy Model and a plan for its implementation. The stakeholders consulted by SARU in the first stages of the project (self advocacy groups and other DPOs with an interest in self advocacy) agreed upon their preferred model: a national self advocacy organisation with independently run self advocacy resource centres in each state or territory. The second stage of the project involves developing a national website and resources for self advocacy groups around the country. SARU will work with self advocacy groups and provide them with funding to co-design the resources that they identify as most needed, which will then be made publicly available on their website. Although at the time of interview the SARU project was still in the implementation stages, its outputs are relevant to the planned further peer support resources that will be developed in future stages of this project, and there may be opportunities in the future for sharing resources and co-design strategies.

Carers Australia was not one of the organisations that participated in the DSO Project but was funded by the NDIA as a peer-to-peer support provider. The Peer Conversations project, which links peer partners to other carers across Australia to share their experiences and advice about the NDIS, is discussed throughout this report.

## Appendix B Research Instruments

### Interview questions – Peer support project managers

(Please note, the following questions are a guide only)

4. Please tell me a little about your current role in peer support provision.

Prompts:

What is your role in your organisation? How long have you held this position?

Have you been involved in peer support provision before?

What kind of peer support services does your organisation provide?

5. Can you tell me a bit more about the peer support groups you have established?

Prompts:

Who is/are your target group/s for peer support provision?

How many peer support groups are associated with your organisation?

How many people participate in these peer support groups?

How long have these been running for?

What is the purpose of these groups (and do each have the same purpose, or are there different purposes for different groups)?

Do these peer groups run for a fixed period of time, or are they ongoing?

How do these groups fit within your organisation (resourcing, management structures, etc)?

How are these groups funded, and how has funding changed over time?

6. In your view, what benefits do participants get from being in the peer support group?

Prompts:

What benefits do you hope participants get out of the peer support?

What benefits have you observed for participants, or what have the participants told you they get out of peer support?

What feedback mechanisms (if any), do participants in peer support have access to?

Do you anticipate there will be any longer-term benefits for participants?

7. What strategies have you developed to engage with potential participants in peer support?

Prompts:

How did you get the word out?

How did you approach and recruit potential peer support leaders?

Were there any groups that were more difficult to engage with than others?

... What barriers do these groups face in participating in peer support?

... How did you overcome these barriers?

If sustainability is a goal of your peer support provision, how do you encourage the groups to keep in contact over time? How do you work towards the financial sustainability of the groups?

8. What support do you provide to the peer support groups and their leaders?

Prompts:

How often are you in contact with the members/leaders of your peer support groups?

What support do you provide with logistical arrangements (places to meet, contacting members, transport, catering, etc.)?

How do you help the groups manage group dynamics? (retaining members, creating a safe/welcoming environment, dealing with conflict, etc.)

What support do you provide the groups with organising meeting format, discussion topics and activities?

What support do you provide the leaders and groups to help the participants get the most benefit from the group?

9. Do you provide any training to the peer support leaders in your program?

Prompts (if yes):

What were they?

How did you develop them?

How did the peer support leaders participate (online, in person, etc.)?

What sort of feedback (if any) did you receive back from the peer support leaders?

Did the training and resources evolve over time?

Prompts (if no):

What training and resources would you have liked to provide to peer support leaders in your program?

What skills/ knowledge/experience did the peer group leaders bring to the group?

10. How did you get into the role of managing these peer support programs? Did you receive any training or guidance to support you in implementing these peer support programs?

Prompts (if yes):

What sort of guidance/resources did you draw on?

How useful were these resources?

Did you have to adapt them, and if so, in what ways?

Are there any other ways you learned about how to run peer programs?

11. What have you learnt about resourcing and managing peer support programs since you began this role?

Prompts:

What do you wish you had known from the start?

What has changed in your practice / what will you change in the future?

What would you tell other organisations or other project managers who are thinking about providing peer support programs?

... What tips would you give them?

... What would you warn them about?

12. What do you wish you knew more about? Are there aspects of resourcing, managing, evaluating, or reporting on the peer support activities of your organisation that you would like more information or guidance on?

13. What are the most rewarding aspects of your role in peer support provision?

14. What are the most challenging aspects of your role in peer support provision?



15. Setting aside limitations such as funding, organisational size and capacity, etc., how do you think peer support could achieve even better outcomes for participants? What support and resources would you need to achieve this vision?
16. Is there anything else that you would like to add / Is there anything else you think the researchers should know about peer support and implementing peer support programs?

### **Interview questions – Peer support leaders**

(Please note, the following questions are a guide only)

1. Can you tell me a little about your involvement in peer support?

Prompts:

When did you start being involved in peer support with [name of organisation]

Had you ever been in a peer support group before / been a peer support leader before?

How long has the peer support group been meeting?

How many people are in the peer support group?

Who did you want to be in the group / Were there any people you specifically wanted to take part?

How did they come to be in the group?

How often do you meet?

2. What happens in your peer support group?

Prompts:

What kind of activities does your support group do?

What kind of topics do you talk about in your peer support group?

Is there a particular purpose or goal for your peer support group?

How often does the group meet?

Do participants communicate outside of the meetings (online groups, etc)?

3. In your view, what benefits do participants get from being in the peer support group?

Prompts:

What benefits do you hope participants get out of the peer support?

What benefits have you observed for participants, or what have the participants told you they get out of peer support?

What feedback mechanisms (if any), do participants in peer support have access to?

Do you anticipate there will be any longer-term benefits for participants?

4. How would you describe your role in the peer support group?

Prompts:

What do you do in the meetings?

What do you do before the meetings / how do you prepare for meetings?

5. What are some of the most rewarding things about being a peer support leader?

6. What are some of the challenging things about being a peer support leader?

7. What support do you get from [name of organisation]?

Prompts:

How often do you talk to someone from [name of organisation]?

Do they help you with contacting members?

... finding places to meet?

... financing the meetings?

... deciding what to talk about?

... planning activities?

... getting people in the group enthusiastic about peer support?

... dealing with problems during meetings?

8. How did [name of organisation] help you learn about being a peer support leader?

Prompts:

Did [name of organisation] provide you with any training or other guidance?

What kind of tips/suggestions did the peer support leader training give you? ... What was the most useful thing you learnt in the training?

What didn't the peer support leader training cover? ... What did you wish you had known about before the first peer support meeting?

Were there any other resources or guidance that [name of organisation] gave you?

9. What have you learnt about being a good peer support leader?

Prompts:

What would you tell other people who are thinking about being peer support leaders?

... What tips would you give them?

... What would you warn them about?

10. How do you think your peer support group could be better? / What would you change about your peer support group if you could?

11. Is there anything else that you would like to add / Is there anything else you think the researchers should know about good peer support and being a peer support leader?