SPRC
Social Policy Research Centre

REPORT
SERIES
2014

CHRISTIANE PURCAL
NGILA BEVAN
SAM COOPER
KAREN R. FISHER
ARIELLA MELTZER
MELISSA WONG
PHOEBE MEYER

UNSW
AUSTRALIA
MANU ET MENTE

Self-directed disability support
Building people's capacity through peer support and action research

Never Stand Still   Faculty of Arts & Social Sciences   Social Policy Research Centre

SPRC
Social Policy Research Centre

July 2014

Self-directed disability support

Building people's capacity through peer support and action research

Christiane Purcal[1]

Ngila Bevan[2]

Sam Cooper[1]

Karen R. Fisher[1]

Ariella Meltzer[1]

Melissa Wong[1]

Phoebe Meyer[1]

1 Social Policy Research Centre, UNSW
2 People With Disability Australia

CONTENTS

LIST OF TABLES

ABBREVIATIONS

CARD   Community action research disability group

NDIS   National Disability Insurance Scheme

PWDA   People With Disability Australia

PWI   Personal Wellbeing Index

SCU   Southern Cross University

SDDS   Self-directed disability support

SPRC   Social Policy Research Centre

ACKNOWLEDGEMENTS

Thank you to the CARD members and facilitators for participating in this project, and the research team and colleagues for advice and comments.

1 SUMMARY

1.1 ABOUT THE PROJECT

In this project, people with disability all over Australia met in small groups to talk about their disability support. The project had two goals: peer support, with people in the groups learning from each other; and action research, with people doing research activities and sharing their findings about disability support with other people, for example, in this report.

Disability support in Australia is changing, and people with disability increasingly have more opportunity to decide the details of their support—about how, when and by whom it is provided. In this report, this is called self-directed disability support (SDDS). The one year project was to find out how people with disability experience and manage the transition towards SDDS.

1.2 HOW IT WAS DONE

This was a nationwide project, as groups of people with disability in each Australian state and territory took part in the research. The project used a participatory action research approach, where the local groups collected and used the research data. This was a new way of doing research about disability, while building peer support. The groups were called CARDs (community action research disability groups) and were supported by a group facilitator from a local disability community organisation, by People with Disability Australia (PWDA) and by researchers at the UNSW Social Policy Research Centre (SPRC) and the Centre for Children and Young People at Southern Cross University (SCU). National advisors were consulted about the design and findings. Research data included the group members' experiences with disability support and the experiences of other people with disability in their community.

CARDs met about six times during the year, explored aspects of disability support and shared and recorded their experiences. The methods included discussions, photos, interviews and artwork.

Each group had 3–12 members. The size of the groups changed as new people joined and others left. Young and old people participated, men and women, and people from cities and rural areas. Most people were born in Australia, and most had a physical disability, although the groups and the people were diverse.

1.3 FINDINGS ABOUT DISABILITY SUPPORT

Here is a summary of some of the things the groups found about aspects of disability support. People had a wide range of personal experiences with their disability funding, which cannot all be included in this report.

Characteristics of disability support: Most CARD members used formal disability services, and some did not. There were many different support arrangements, offering varied levels of self-direction. Many people with support from service providers felt limited in their choices, and people with self-directed options were generally more positive. They said it was important for everyone to know their rights and what they could use their support or funding for. Most people said they wanted support in the future to be more person centred.

Organising support: Many CARD members felt they did not have enough information about options for self-directed support and about managing self-directed support. This made it difficult to make informed decisions about changing to new programs. Governments and service providers did not always share the information people needed, and people did not always know which questions to ask. People considered disability advocacy organisations and peer support groups the most reliable information sources. They had some apprehension about the NDIS, how it would work in practice and what it meant for existing support. People who already had self-directed support talked about how they managed support workers and paperwork, often with the help of friends or family.

Participation: Many CARD members had poor transport and inflexible support services, and this reduced their ability to live as they wished and do what they wanted. Some people with self-directed support had fewer barriers. It was easier for them to go to TAFE, university or their employment, because they could arrange for workers to provide the specific support they needed. Group facilitators pointed out that a whole of government approach was needed to make communities more accessible for people with disability.

Relationships with support workers: Relationships between CARD members and their support workers were the most intensely discussed topics in the groups. Self-directed support helped people to recruit workers who suited them, so they could build strong and productive relationships. People who had little experience in recruiting said they needed a resource book and helpline to assist them. Their discussions about difficulties in relationships with support workers highlighted the interdependence and vulnerability of both people with disability and support workers. Tips for regular, good communication between people with disability and support workers were seen as essential.

1.4 FINDINGS ABOUT DOING ACTION RESEARCH IN GROUPS

Here are some of the findings about using action research and forming peer support groups. Generally, taking part in this project was a good experience for CARD members. The groups were flexible and could accommodate people's preferences and needs.

The groups provided **peer support**, where members saw the group as a safe place for sharing stories, and where they were reassured and empowered to hear that other people had similar experiences that could be resolved together.

The groups offered **networking** opportunities for people with disability. Seven of the eight groups expressed that they wanted to continue after the end of the project.

CARD members also enhanced their **self-advocacy** skills through the project. They were supported to express their wishes, and they were encouraged by other people's stories to change their support arrangements. One group advocated in the local community about issues they were concerned about.

All groups built **research capacity** by collecting information about aspects of disability support. Some groups did additional research activities in their communities, such as a surveys and interviews.

The project achieved **data collection for further research**. Using diverse data sources, including surveys, notes, audio recordings and artefacts such as photos and butcher's paper notes, enabled people with different preferences and needs to take part.

1.5 HOW GROUPS CAN WORK WELL

CARDs were a new way of doing research, while also building peer support. They were flexible in how they were set up and how they operated. Four important aspects helped the groups to come together and run well.

Flexible recruitment allowed facilitators to form groups according to local conditions, preferences and capacities. Some of them built from existing networks, some started from new. As a result, groups were quite different in size and characteristics of their members. Flexibility seemed a successful strategy, as all groups continued and collected data throughout the project.

Fostering group cohesion was an important facilitator task. Facilitators assisted CARD members in getting to know each other, they helped to create a comfortable space for members to take part in group activities, and they supported pre-existing peer networks. Facilitators also arranged support to help ensure that every person was able to participate.

Variety in group activities was important so that everyone could share their experiences in the way they preferred. Each group also agreed on which topics to discuss and in which order.

Support from facilitators was essential to the project. Facilitators (including the leaders of existing networks) provided leadership in forming the groups, by recruiting members; commitment in keeping the groups going, by arranging meetings, providing support for people to participate and making the meetings positive experiences for the group members; and research contributions, by giving feedback to the project team through notes, audio recordings and other research data from the groups. Facilitators found that regular support from PWDA and the university researchers, as well as each other, was essential to retain momentum, address challenges and reflect on the findings.

1.6 WHAT DOES IT ALL MEAN?

CARDs were a new way of doing research and peer support together, and this project shows that they can work well. As intended by the project, the groups produced research data, and they were useful for the CARD members, mainly by providing a safe, trusted place for peer support, networking and advocacy. People's preference for such groups in finding and sharing information is important to consider for governments, service providers and advocacy organisations in the transition to the NDIS and other self-directed support options.

2 INTRODUCTION: WHAT WAS THIS PROJECT ABOUT?

In this project, people with disability met in small groups to talk about their disability support. One goal was peer support: the participants exchanged their experiences and their wishes for the future, and thereby learned from each other and supported each other. Another goal was action research: the participants conducted various activities, recorded their findings about experiences with disability support and distributed these findings to other people, for example through this report.

The project ran from February 2013 till February 2014. It was conducted by the Social Policy Research Centre at UNSW, in collaboration with People with Disability Australia (PWDA) and the Centre for Children and Young People at Southern Cross University (SCU). We consulted with national advisors during the project to seek input into the design, preliminary findings and reporting.

This report explains how the project was run, what we learned about disability support and what we learned about action research in peer support groups. More details about the background, research framework, project methods and management are in Fisher et al. (2013) and Meltzer et al. (2014).

This project is important because disability support in Australia is changing. Historically it has been organised and financially managed through government and service provider agencies (agency funding). Increasingly it is offered through individualised, person-centred packages of support (individual funding), which allow people to decide and manage how their own funds are spent. In practice there are also many in-between ways of organising disability support that give people various degrees of decision making autonomy about their support. We call this self-directed disability support (SDDS). In line with the National Disability Insurance Scheme (NDIS) reforms, opportunities for SDDS are expanding across Australian states and territories.

We wanted to find out how people with disability manage the transition towards self-directed disability support. There has been little research on this topic so far. This project aimed to understand disability support and its current changes from the perspective of people with disability. This includes the experience of the people themselves, of families/carers and of support providers. The findings can be a baseline for a longitudinal study examining service delivery pre and post the introduction of the NDIS. It was a nationwide, comparative study, with groups of people with disability conducting the research in each Australian state and territory.

The aim of the findings is to help to advance disability rights and the sustainable provision of effective, good quality social support. The findings can inform self-directed support policies, help disability support providers to respond to the new policy landscape, and empower the disability community to use the opportunities presented by self-directed support.

3 METHODOLOGY: HOW WAS THE RESEARCH DONE?

3.1 PARTICIPATORY ACTION RESEARCH

This study used a participatory action research approach. In line with the 'nothing about us without us' philosophy, participatory action research is collaborative: researchers and people from the community work together to develop knowledge and effect change (Balcazar et al., 2004). Participatory action research sees people as experts in their own lives. It aims to create knowledge that reflects what is important to the participants and that can be used to create change.

In each of the states and territories, a local group of people with disability (and their families/carers where relevant) collected the research data, with support from PWDA, a local disability community organisation and the university researchers at the SPRC and SCU. Research data included the group participants' experiences with disability support, and also the experiences of other people with disability in their community.

The action research process is specifically focused on being useful for the group participants themselves. It can:

- provide peer support for the people in the group – people exchange their experiences, support each other and learn from each other. It can empower them to make changes and advocate for disability support for themselves and their peers, and

- develop people's research capacity – people learn skills about gathering information and analysing it and can use those skills in the future, for example, when deciding and advocating about new disability support options.

3.2 COMMUNITY ACTION RESEARCH DISABILITY GROUPS

In this project the groups of people conducting the research were called CARDs (community action research disability groups). CARDs were formed in each state and territory and included people using disability support through individual funding or agency funding arrangements, as well as people not using formal disability support.

CARDs were coordinated by PWDA and had a facilitator who worked for a local disability community organisation or was a key local person. The role of the facilitators was to recruit CARD members, organise group meetings and forward research data to the university researchers. Having local groups enabled diversity between the groups, depending on the local priorities, characteristics, strengths and needs, and as a result the roles of facilitators differed slightly. The groups included people who had more or less experience of participating in similar groups before, and people of different ethnic and language backgrounds, ages, genders, types of disabilities and levels of support need. The groups are described in detail below, as are the project activities summarised in Table 1.

Table 1: Timeline of project activities

Activity		Month
Recruit CARD facilitators		February – March 2013
Draft CARD resources		February – March 2013
Ethics approval from UNSW		March 2013
Training workshop for CARD facilitators		March 2013
Facilitators recruit CARD members		March – May 2013
Finalise CARD resources		April 2013
Set up website for group work		April 2013
Research plan published		April 2013
CARD meetings		May – December 2013
Monthly teleconferences with CARD facilitators		May – December 2013
Transfer of research data from CARDs to university researchers		May – December 2013
Finalise analysis and project report with feedback from CARDs		February – April 2014
Share findings through workshops, publications and new projects		2014

GROUP ACTIVITIES: WHAT DID CARDS DO?

Each CARD met about six times, usually monthly. The first meetings were in May 2013 and the last, in December 2013. Meetings lasted for about two hours, and participants usually focused on one or more of the six suggested research topics about SDDS (see below). CARDs used a range of data collection methods according to their preferences, and to encourage the participation of a wide range of people. The inclusive focus also extended the project beyond the CARDs to other people with disability in the community, incorporating their views into the research.

CARD methods included art, discussions, photos, recordings, conversations and fun activities, such as having a meal together. Some groups also carried out research outside the group, such

as a survey of community members about their experiences with disability support. Some possible methods for action research and peer support groups are described in Appendix 2 and published in Meltzer et al. (2014).

CARD members and community participants were encouraged by the facilitators to complete two short surveys: a demographic survey and the Personal Wellbeing Index (PWI) (Cummins and Lau 2005) at the beginning of the research, usually during the first or second group meeting. People were then encouraged to repeat the PWI in the last meeting, in order to measure change.

Audio recordings from CARD meetings were sent to SPRC, along with other data from the meetings (e.g. butcher's paper notes, photos and surveys). CARD facilitators also wrote notes about the CARD process and research findings after talking with the members. Facilitators and CARD members were invited to comment on drafts of this report.

RESEARCH TOPICS: WHAT DID CARDS TALK ABOUT?

During their meetings, CARDs explored aspects of their disability support. In the first meeting, they agreed on preferred topics and the order, although they kept it flexible throughout the project. All topics related to the general research question for CARDs: What are your experiences with your disability support, and what kind of support do you wish for?

Below is a list of the six relevant research topics that were written at the beginning of the project by SPRC together with PWDA, SCU and the facilitators, partly based on findings from other research. These six topics covered the important parts of the research question. They were suggestions only and could be varied in content and order according to each CARD's preference.

The six suggested research topics were:

- Characteristics of your disability support: flexibility, control, choice, self-determination, size of the package

- Organising support services: access to information about what support is available, administration, help to manage funding packages, advocacy

- Social life: Family and social networks, valued relationships, leisure, recreation

- Participation in the community: employment and education, accommodation, health services

- Arrangements and relationships with support workers

- Reflection on the research process and outcomes: How have you found this process? What does it mean for disability support? What do you want to tell other people?

- Most CARDs talked about all topics during the course of the project. Their main findings are summarised below, in Sections 4 and 5.

GROUP SUPPORT: HOW DID THE PROJECT ORGANISERS HELP THE CARDS?

The SPRC, PWDA and SCU partnership supported the CARDs in their activities such as recruitment, publicity, research training and data collection. They developed resources for the group facilitators, including topic guides about SDDS with prompts and discussion ideas, how-to guides for inclusive research methods, Easy Read resources and facilitation guides for including people with different types of disabilities and support needs.

These resources were discussed with the facilitators at a one-day workshop and then improved, according to what the facilitators considered useful for themselves and the groups (Appendix 1). The workshop also covered research skills and methods, as well as research ethics processes to engage participants without coercion, deal with any potential distress among CARD members and keep personal information confidential.

During the time when the CARDs were organising meetings, from May till December, the SPRC, PWDA and SCU provided ongoing support. The PWDA contact person was available to the facilitators by phone and email. At monthly teleconferences, the CARD facilitators, PWDA, SPRC and SCU, shared and discussed their experiences and reflected on what it meant for the research. A secure website for group work was created, where the facilitators, SPRC, PWDA and SCU communicated with each other and posted minutes of the CARD meetings and other useful documents.

Facilitators were paid for preparation time, running CARD meetings and writing meeting reports. Expenses for conducting CARD meetings and other activities, such as room hire, materials, food and transport, were covered by research funds, as well as a small compensation for participants' time. Project funds were inadequate to fully cover the costs for anyone involved in the project. Group members, facilitators, PWDA, SPRC and SCU all contributed additional time and practical support.

GROUP MEMBERS: WHO PARTICIPATED IN CARDS?

CARD groups had between three and twelve members approximately. In most groups membership changed during the course of the project, as some people left and others joined.

A total of 45 CARD members completed the demographic survey. They were from seven of the eight CARD groups. People from Victoria did not participate in the survey, due to the way this group was set up. The Victorian CARD facilitator conducted the SDDS project activities with an already existing peer support group. As membership of that group changed from month to month, the survey was not appropriate. In the seven remaining CARDs, between one and eleven people participated in the survey. Detailed numbers, as well as other demographic tables generated from the survey, are in Appendix 3. The survey shows:

- slightly more women than men participated in the CARDs (55% women; 45% men)

- most people were born in Australia (88%)

- few people spoke a language other than English at home (3 people, or 7%)

- no one said they were from an Aboriginal or Torres Strait Islander background. A longer project could be more suitable for adapting the method for their needs.

- three-quarters of people lived in major cities,18% in regional areas, and 7% in remote locations (Table). This was because of where the facilitators were located.

- ages ranged from 19 to 73 years (Table). The ACT group was youngest, with four out of the six members aged under 30 years, while half of the NT group members were aged 65 years or older.

Most people (80%) had a physical disability, and psychological, sensory or intellectual disabilities were reported by 11% each. Eight people (18%) had multiple disabilities. Compared with all people with disability in Australia, the CARD groups had a fairly similar distribution of disability types (

Table 6). The CARD groups were quite different to each other (Table):

- physical disability was more prevalent in QLD (27% of all CARD members with a physical disability) and WA (22%)

- all people in the ACT group reported psychological or mental health disability

- all people with sight, hearing or speech disability were from QLD or SA

- CARD members with intellectual disability were in the TAS, ACT, QLD, SA and WA groups.

CARD groups made specific arrangements to enable a variety of people to take part, such as transport and inclusive research methods.

The group members lived in various settings, including with partners, their family, friends, alone or in a group home. Some people were employed, others were unemployed or studying. This reflects the lives of people with disability in Australia, of whom 53% were employed in 2012 (Australian Bureau of Statistics [ABS], 2012).

4 FINDINGS: HOW DID CARD MEMBERS EXPERIENCE SELF-DIRECTED OR OTHER DISABILITY SUPPORT?

4.1 CHARACTERISTICS OF DISABILITY SUPPORT

Most CARD members who completed the survey were using formal disability services (79%), and the other 21% were not. People who used formal disability services mostly lived in WA and QLD, and all CARD members who were aged under 30 years used these services.

Among the people who used formal services, both people using an individual funding package or other kind of self-directed funding (46%) and agency funding (38%) were involved in the groups (Table 2). The project was designed this way so that people could learn from each other's different experiences. Five percent of people were unsure about what funding they used, and 33% of people used a type of funding that did not easily fall into the individual or agency funded categories.

Table 2: Types of funding among CARD members using formal disability services

	n	%
Individual package or other self-directed funding package	18	46
Agency funding	15	38
Other	13	33
Not sure	2	5

Source: Survey of CARD members
Note: Some people had multiple funding packages.

In the CARD meetings it became clear that people had a wide variety of support arrangements. These included:

- individual funding, where the person with disability held all the funds and did all their own administration

- other forms of self-directed support, where the person with disability decided how funding was spent but the administration was done by a service provider

- support that was fully funded to and directed by agencies

- agency support where people with disability had some control over how funding was spent

- agency funded support for a limited number of support hours

- no formal support

- grants to fund additional support services, and

- disability support through the group home where people lived.

Disability support arrangements differed among states and territories and within them, as each location had different policies and different geographical and social contexts. In the Northern

Territory, for example, remoteness and the cultural needs of Aboriginal communities were important.

People's experiences with their support also varied. Some group members said they had some choice about their agency funding. For example, one person had received grants to pay for additional health and wellbeing support, such as fitness classes and modified fitness equipment. Another person living in a group home said the activities they could do were flexible; and a few people with agency funding decided together with their support worker what they would do each day. Reflecting on these experiences, CARD members commented:

> It is important to be able to advocate for yourself. (CARD member)

> Our group found that it was necessary to be pushy and 'personally strong' when trying to find answers from the agencies. (CARD facilitator)

Many people with agency funding felt restricted in their choices. During the CARD meetings, some people expressed frustration with agencies and distrust of agency staff. Some people in one group felt that some service providers put their own needs above those of the people using the support. They gave examples that some support workers would not provide support at the times they were needed. This restricted people with disability, for example making it impossible to attend TAFE or university. Other experiences with agencies included:

> When the agency is involved it is more complicated (CARD member)

> The agency did not show a lot of support for one person moving onto self-managing own funding, even though it was part of their individual planning goals (CARD facilitator)

> On one occasion, the service provider raised the price for services when the person went to SDDS but kept the same service provider, who billed the person directly. (CARD facilitator)

Some people felt disempowered because they were compelled to 'put up with' whichever support worker they were provided with, even if they did not like them or did not enjoy the support they were providing. People in remote areas in particular pointed out problems with continuity of services, as they had experienced high transience, both with government health services and the workforce.

Two of the groups found that some support providers made assumptions about the level and type of support that they needed, and underestimated their capacity. Some people seemed unclear about their funding and what it could be used for. This made it difficult for them to make demands of their agencies. One person said:

> If you don't know your rights, what you are entitled to, it is hard to negotiate with the agency about what to use the funding on and how to increase the amount. (CARD member)

People with self-directed support were generally more positive. They talked about increased flexibility, choice and control as standard elements of their support arrangements. Almost all of them used their funding for mainstream or personalised support, such as internet, modifying household appliances, and engaging in fitness activities and recreation. They also valued transparency, with some people saying they had a good understanding of where their funding was going and what it was buying. People with self-directed support said:

> When the agency was in charge of the money, they told me how much I had and how much was leftover etc. Also, when with the agency, if I needed

something, I had to get approval from the agency; whereas, now I can just go ahead and get it myself. (CARD member)

Being on self-directed funding means being a lot more on top of things. (CARD member)

However, information and understanding of their self-directed support package was a problem for some people. They discussed not knowing what they could and could not use their funding towards. One person found that:

It helped to be creative in what you call things in order to get grants and when to keep your mouth shut. (CARD member)

In general, people said they wanted support in the future to be more person centred, and they agreed that self-directed support offered that opportunity. Most people who currently had agency funding were looking forward to self-directed support. They said:

SDDS will be a surge forward in our ability to have control over our funding and services. (CARD member)

SDDS will be a huge step forward in people with disabilities being able to manage better, not only their funding but also their disability. (CARD facilitator)

4.2 ORGANISING SUPPORT SERVICES

CARDs discussed needing information about self-directed support options and about how to manage self-directed support. Several people stressed that 'knowledge is power'. Without adequate information, people felt they had less control over their support and their lives, and they could not make informed decisions about changing to self-directed support programs.

CARD members considered that governments and service providers had primary responsibility for providing information. Most CARD members felt they did not have enough information about:

▪ what support services were available

▪ how to access self-directed funding options

▪ what government policies were about how to change to self-directed support

▪ the practical elements of NDIS implementation, and

▪ how to manage the administration of support workers (payments, insurance etc.).

They were frustrated about having to go through several service providers before finding the information they needed; knowing that self-directing options were available in their state but not being able to find out whether they were eligible; and wondering whether service providers were withholding information about opportunities to self-direct or whether they just did not have this information. One person said it was difficult to find the information they needed as they 'don't know what questions to ask'. This often applied to people who were new to self-directed support, and who might need very detailed information. They said:

There are more people set up to help you find the answers but not so many to help you find the questions. (CARD member)

> There is a fear of being taken advantage of, some could find it overwhelming. (CARD facilitator)

People from all CARDs expressed some anxiety about the transition to the NDIS. They did not feel that people with disability, support workers or disability services had enough information about how it would work in practice (for example, can unused hours be rolled over); and how it would interact with existing systems (for example, what would happen to state based taxi subsidy schemes). Some people were apprehensive about how they would manage directing support workers after living with restrictions about what they could do for so long. Managing paperwork and administrative tasks was seen as a difficulty. They said:

> The main problem is the paperwork. (CARD facilitator)

> Completing extra paperwork, such as worker's compensation, would be difficult for people with profound disabilities. (CARD facilitator)

Receiving help from family or friends in managing self-directed funding eased the process. One person with self-directed support said:

> When there is a pay dispute, I get some help from other people. (CARD member)

Another person found organising his own carers worked well for him, and he was helped by his wife, who organised the payroll. Payroll could also be managed by an agency if a support worker registered with them.

CARD members suggested that they needed practical resources to help with administration of support funds, such as:

- lists of commonly used acronyms

- suggested 'interview questions' for choosing potential service providers

- reporting templates

- a 'one stop shop' hotline for information about award wages, administration trouble shooting, what funding could be spent on, the role of brokers, and how to contract support workers.

People pointed out that all resources needed to be adaptable to specific contexts, for example isolation in the Northern Territory, and different cultures, languages and literacy levels. Also, the particularities of each person's circumstances meant that some questions and the answers could be quite specific.

People exchanged their own experiences about how they filled gaps in their knowledge, what preparations they were making to be ready to self-direct, and what additional skills they thought they needed to use the new opportunities. Some people said they persisted in asking questions of governments and service providers, and did not give up. Across the groups, people relied mainly on other people with disability, independent advocacy services, disability advocacy organisations and peer support—such as the CARDs—to get the information they needed to make informed choices. Many people said they considered these the most trustworthy sources of information.

4.3 SOCIAL AND COMMUNITY PARTICIPATION

Some people had a positive outlook towards their community participation. One person said:

> I do some volunteering. I try to expand my relationships and am making progress. (CARD member)

People in the CARDs talked about barriers to their social and community participation, mainly transport and flexible disability support. People felt these barriers reduced their ability to live as they wished and to do what they wanted where and how they wanted. Some barriers were fewer for people who self-directed their support.

TRANSPORT

Three groups said that poor access to transport, the prohibitive cost of transport, and an inability to travel freely were major hurdles to their community participation. In one group, none of them drove a car, and one person commented that with relying on taxis to get around 'I don't get out enough'. The cost of taxis from home to the city prevented one person from having a regular social life. He used taxis for a night out when friends were not available to drive him. Another person noted that when public transport was available, it was much cheaper than taxis with the use of a disability concession pass. Another group said that cost was a barrier to owning a car, because funding was available only for vehicle modification, not purchase.

Self-directed support had enabled some CARD members to get out more. For example, one person who had funding left over at the end of the year could use it to buy a hoist for her car. Another woman had arranged with her support worker to use her own car to drive her where she needed to go in exchange for a payment per kilometre.

FLEXIBLE SUPPORT WORKERS

Three groups identified the availability and flexibility of support workers as the key factor to participate at TAFE, university and in employment. While people with agency funding were limited in the hours and times they could receive support, people who self-directed were able to arrange for their support workers to help them on campus or at work. Examples were: organising support before work or at lunchtime, paying a friend to provide extra help at the end of the semester when the person gets tired, or employing fellow university students as support workers. Others said:

> I have been able to get the support workers to help me with my self-employed work projects. They are flexible, so I can get around a fair bit. (CARD member)

> One person said she uses her package for work. She negotiates with the carers to come to her early so that she can then get to work on time, and to be flexible. When going on holidays, though, the person would have to pay for the support worker's tickets and wages. (CARD facilitator)

People said the key was to use their funding to live the life they wanted – be it with more or less social contact, and more or less training or employment. In one instance, self-directed funding provided support for a person not wanting employment.

Self-directed disability support Findings: How did CARD members experience self-directed or other disability support?

© Social Policy Research Centre UNSW

14

COMMUNITY ATTITUDES AND ACCESSIBILITY

Negative community attitudes could make social activities more difficult. One person said:

> Some people are hesitant to come and interact with me because of my disability, and my disability prevents me from going out with them. (CARD member)

Facilitators pointed out that a whole of government approach was needed to ensure that communities were accessible for people with disability, as required through the implementation of the National Disability Strategy (NDS) and including improved transport, housing, employment and health services.

People felt they improved their personal relationships as a result of having self-directed support. For example, one person who had the goal of 'being a supportive husband' could use his funding to buy a modified ironing board so that he could do his wife's ironing. Self-directed support had enabled another man to move out of a supported residential setting and into his own home, where he lived independently. He now had friends and neighbours who were happy to help him get to hospital appointments, made sure that he was eating properly, or simply spent time with him as a friend. One of the facilitators pointed out that such positive scenarios might depend on pre-existing personal support structures and not self-directed support per se.

4.4 RELATIONSHIPS WITH SUPPORT WORKERS

The relationship between CARD members and their support workers was the most intensely discussed topic in the groups. In many cases, self-directed support enabled people to recruit workers who suited them, which helped to build strong and productive relationships with support workers. Several people described how choosing their support workers meant that they could employ people with the personal characteristics they liked. For example, one person recruited backpackers who were available only temporarily so that she always had someone new and interesting to talk to. Another person recruited workers who had similar interests, and this had led to more recreation opportunities. Other people chose the gender of the worker to match different tasks, such as showering and personal care.

CLEAR COMMUNICATION

One group debated whether job descriptions restricted flexibility or provided clarity to manage conflict. Some people found prescriptive conditions created inflexible attitudes in support workers, whilst others found them useful in managing the workers' time. One person found them useful to manage conflict. The group concluded that people may need to experiment in finding what works best for them in self-directed support.

One person said it was important to communicate regularly with support workers to build a good relationship:

> It is always good to talk to them, telling them where you are and if you are going to be late. (CARD member)

Another group talked about the importance of being able to make contact with their support workers at any time in case of an emergency. If support workers could not come, some people found their own replacement, and in other cases the person chose a preferred replacement. One man had set up and paid for an employee dispute program with a psychologist, where his support workers could discuss work-related issues. Some people said that the person with

disability and workers needed to exchange telephone numbers to assist with communication but that some agencies did not encourage or allow this to happen.

People spoke about how the relationship with support workers could also be a positive experience:

> You can't help forming a relationship with carers. If you work well with them, then you have to relate to them. (CARD member)

However, people discussed the ideal extent of such relationships; in particular whether socialising with support workers was good or bad. They said that they had to be clear about the obligations of the support relationship as distinct from the friendship to avoid misunderstanding.

CONTROL IN THE RELATIONSHIP

Most groups spent a lot of time sharing accounts of how they had dealt with workers' industrial conditions and protections, because some people had had problems already and other people anticipated it could be a problem. For instance, they talked about how they had met occupational health and safety requirements, negotiated the length of shifts, and responded to increased award wages.

People who had little experience recruiting workers said they needed training in interviewing potential support workers, and others said they were apprehensive about hiring and firing workers. One person used job descriptions which he had written himself, after he had had experience and training. People said they would benefit from a resource book and helpline.

People in most groups also discussed how they had resolved difficulties in their personal relationships with support workers. These included support workers having a lot of information about the person with disability and their family; support workers feeling uncomfortable with the level of intimacy between a person with disability and their partner; or the person with disability acting as a form of counsellor helping the support worker with their problems. Some people spoke about having to address the power imbalance in the relationship, for example when showering.

Sometimes preferences of support workers and people with disability clashed, especially around food. People in one group commented that at times they had to be careful not to offend support workers with different beliefs about food. Another group found that support workers and agencies would say they had to have healthy food. At times food was poorly prepared or not made according to the person's preference. Another group said these problems extended to preferences about drinking alcohol and accessing sex workers. One group member advised others:

> Always keep control of the shopping, because then you can keep control of the kitchen. (CARD member)

One facilitator pointed out that such problems highlight the interdependence between support workers and people with disability, where both sides are vulnerable. Support workers may be underpaid, underemployed and lack training, and people with disability may be susceptible to ill-treatment and abuse. The facilitator said, 'these issues need to be honestly addressed if self-directed support is to work effectively'. A CARD member also advised:

> If you want the support workers to treat you with respect, you have to treat them with respect. (CARD member)

Overall it appeared conflict was reduced in the relationships between people with disability who self-directed and their support workers compared to where people had agency funding. Reasons for improved relations with workers in self-directed support included that people with disability could:

- choose to retain workers with whom they had good relationships

- control their arrangements as employers

- provide an understanding and flexible workplace

- have more direct communication with the support worker

- meet regularly to resolve conflict

- pay a fair amount, and

- demonstrate mutual respect.

5 FINDINGS: HOW CAN ACTION RESEARCH AND PEER SUPPORT GROUPS WORK WELL?

5.1 ACHIEVEMENTS OF ACTION RESEARCH: WHAT ARE THE BENEFITS FOR CARD MEMBERS AND RESEARCH?

Using participatory action research methods, together with establishing CARDs, appeared to be a positive experience for many CARD members. Benefits included increased peer support and self-advocacy, research capacity building and networking. CARDs collected research data about experiences with disability funding, which created knowledge and a basis for further research. Details are reported in this section.

To include a measure of change in the research, CARD members were encouraged to complete the Personal Wellbeing Index (PWI) survey in the first meeting and to repeat it in the last meeting. Forty-five people completed it in the first round, and only ten people chose to complete it again in the second round, indicating that repeat use of the PWI was not compatible with the flexible way groups were organised. Survey findings of the first round are in Table 8. The repeat sample was too small to draw any conclusions as to how CARD members' wellbeing had changed throughout the year. As a group, the 45 people who completed the survey at least once were generally happy about various aspects of their lives. The highest score was about how they got on with people they knew, while the lowest scores related to health and to happiness about things later in life.

PEER SUPPORT

The CARD structure was a flexible way of organising groups of people according to each group's preferences and needs. Facilitators observed that, as groups consolidated, many people 'settled in', became familiar with each other and appeared to see the group as a safe space for sharing stories, ideas and experiences. Many CARD members felt it was 'comforting and empowering' to hear that other people had similar experiences. One facilitator noted:

> By contrast, in day services, agencies and other such places, there isn't much sharing of options for self-directed funding. (CARD facilitator)

CARD members also used the groups to help with decision making and problem solving. One facilitator said that some people did not attend meetings regularly but were able to make use of the group when there was a specific issue they needed more information on. Another facilitator noted that some people viewed their attendance 'as a fact finding mission'.

Having people with different types of disability support funding in one group meant that they could compare what was available and how each arrangement worked. In one instance there was a group meeting of three people with disability who all used different types of support. The meeting was a forum for them to ask each other about the pros and cons of their support. Most groups had similar experiences. No-one said anything negative about the experience of sharing information with peers.

NETWORKING

Of the eight CARDs that were formed, six were new groups of people, and two were formed through existing structures. One of these had been an online group that had not had any previous opportunities for participants to meet or discuss topics in a similar environment to the CARD. The other was a peer support group for people with disability that served a different purpose, although members were happy to participate in CARD activities.

At the end of the project, one group decided that they did not want to meet again. Group members felt the meetings were too regular, taking time from their otherwise busy lives. The other seven groups intended to continue. Some were planning to merge with other self-advocacy or peer support groups, and others aimed to carry on their activities as stand-alone groups. This suggests that people considered the group experience worthwhile. It is reflected in one facilitator's comment that the process was as much about having participants come together for peer support as it was about exploring the nominated research topics.

The continuation of the groups means the project approach and methods may benefit participants into the future. Some of the groups felt that an interactive platform which would allow them to communicate with peer support groups in other locations would be a welcome initiative. One group believed the project could provide evidence to support advocating for a national network of peer support groups focused on self-directed funding, and some group members were very passionate about this.

SELF-ADVOCACY

There were several examples of groups and individual members enhancing their self-advocacy skills through the project. One group reported that discussions about problem solving helped to build their confidence and ability to speak up for themselves, for instance through 'unearthing pragmatic solutions' to questions that they could then use as examples in trying to get what they wanted.

In one group, which discussed the recruitment and management of support workers, one participant shared a story about when she fired a support worker, and others spoke about how they managed dynamics between their partner and their support workers. The information and group support encouraged another group member to change the arrangements with his workers.

Some participants were not used to being asked for their opinions, and through the CARD gained experience in thinking about and expressing what they would like. Two of the group facilitators said that some people would need further capacity building to make informed decisions about planning self-directed support. One facilitator highlighted the difficulty for some participants in identifying what changes would be positive in their life when they had little experience beyond their current situation.

One group saw the project as an opportunity to advocate in the local community on issues of concern that they had identified. The group contacted local disability advocacy organisations to build their own skills and capacity, and to meet other people with disability to share experiences with and learn from.

In another group, participants viewed participation in the project as a form of advocacy. Participation allowed their voices to be heard and was seen as a way of speaking to the government in that state.

Several people said that advocacy was not a priority for them when participating in the group. Instead they focused on the peer support and information sharing opportunities of the project.

CAPACITY BUILDING FOR RESEARCH

All groups built their capacity for research by using research methods to collect information about disability support during their meetings (Section 4). Three of the groups did additional research in the community through designing, creating and conducting questionnaires (online, in person or on paper). One group reached out to people who lived in group homes, and the others conducted interviews in the community. Their common motivation was to find out what other people in the community thought about the topics that they were discussing. One group also wanted to identify problems in order to advocate for solutions. People who were involved in the additional research said it made them feel 'engaged and purposeful'.

Participants in other groups decided they did not have time to do extra activities outside of the CARD group meetings. One of these groups had a lot of discussion about the trade-off between personal time, what would be gained from doing extra research activities, and the benefits for the research project. A motivation for participating in this CARD group was to provide information to the university researchers and the government that could improve other people's access to self-directed support.

DATA COLLECTION FOR FURTHER RESEARCH

Various types of data were sent from each CARD to the university researchers involved in the project. Data included:

- demographic surveys, with attached Personal Wellbeing Index data (hard copy and online versions)

- notes from the facilitators (via template, minutes)

- artefacts from the meetings (photos of whiteboard notes, butcher's paper notes, photos of artwork and diagrams, links to videos shown, photos contributed by CARD participants)

- notes of monthly teleconferences with the facilitators, and

- audio recordings of the CARD meetings.

The diversity of data sources made it possible to collect information about people's experiences of disability funding, and about doing participatory action research through the CARDs. For example, the teleconferences with the facilitators provided insights into how to set up the groups, how the group process worked and what the groups were finding. The recordings, notes and artefacts from the CARD meetings contained people's discussions about support types and their own experiences.

Including diverse artefacts from the meetings also ensured that the process was flexible to the ways, preferences and needs of the CARD participants, rather than restricting the data to set and distinct types, such as surveys or teleconferences.

Most people participated in the survey that was prepared by the university researchers, about people's demographic details and their wellbeing. Some people did not complete the survey; one person felt it was not useful for them; and the Victorian CARD had a fluctuating membership and therefore did not consider the survey appropriate, as mentioned above.

The CARDs were not designed to be representative of all people with disability in Australia. They were small groups intended to enable peer support for people who self-selected to take part. The data collected by the groups reflect people's individual experiences, which are important for understanding their views about current disability support, and for guiding future research. The data are exploratory and qualitative in nature and not intended to make general statements about specific groups of people with disability, for example women, young people, those who live in the country, or those with particular types of disability. Some qualitative findings about people with different characteristics could possibly be generated in a similar project, however the main data collection methods used here – meeting summaries and voice recordings – did not provide information on who said what. CARD facilitators were running the groups and did not have capacity to keep detailed records of the discussions.

5.2 FACTORS FOR SUCCESS: WHAT DO GROUPS NEED TO WORK WELL?

This section describes four aspects that helped the CARDs to come together and run well: flexibility in recruiting group members and arranging meetings; managing the group dynamic so that people are included and comfortable; using a variety of research methods and group activities to keep up interest; and ongoing group support from committed facilitators.

The diversity among people who participated in the CARDs (Section 2.2) meant that set up, composition and functioning of the groups needed to be flexible. Forming the CARDs was a new approach to disability research, and the project design left scope for facilitators, group members and university researchers to adopt a variety of structures and test what worked best. Group structures and activities developed organically and changed throughout the course of the project.

FLEXIBLE RECRUITMENT

The initial goal was for groups to consist of six people with experience of using some form of self-directed disability support and six people without (Fisher et al. 2013). In practice most groups were smaller and not of balanced composition. This did not limit the success of the groups. Meetings with as few as two participants created a good opportunity for discussion and peer support. One facilitator believed the groups had capacity for only five to six people, both because of budget and the time needed for contributions from all participants. Two facilitators preferred a smaller group size, and they felt stability in group membership was more important than size, as stability created deeper connections between participants. Other groups enjoyed the flexibility of people moving in and out, responding to their interest in each topic.

Reasons for the generally small group sizes included difficulties in agreeing to a time and place for meetings, in arranging support workers to enable people to participate, in accessing and paying for transport, and a feeling of over-consultation. The project was able to help by:

▪ providing extra funds to cover travel costs

▪ using Skype to include people who lived remotely, and

▪ being flexible about meeting times and frequency.

One facilitator commented on the difficulties of recruiting similar numbers of people with and without self-directed support:

> [There was the] major issue of obtaining unequivocal information about personal matters such as individual funding arrangements. Asking questions was considered intrusive and potentially unethical (e.g. how was this information to be managed and secured). The decision was made to ignore this 'balanced sample' requirement and focus on the participatory aspect of the project. (CARD facilitator)

Recruitment periods were flexible, according to the needs of individual facilitators, and lasted between two and four months before the first group meetings. One facilitator suggested that in future projects more time be allocated for recruitment.

It was difficult to form groups which internally reflected the diversity of people with disability. This was partly due to the reasons above, such as difficulty in getting support to participate, which had a greater impact on people with higher support needs. It was also influenced by the networks of the local facilitators, the type and number of disability services and advocacy organisations in the region, and level of community engagement regarding the changes in disability support. More than one facilitator said service providers did not want to advertise the groups to clients for fear they would 'whinge' about their service. Another facilitator said some people 'were not happy about being researched'. One facilitator found it particularly difficult to recruit people with intellectual disability who were supported by family and suggested families might not believe they could be included in the CARD groups. As a consequence some groups were made up of members with similar characteristics, for example physical disability, intellectual disability, or closeness in age. However, diversity was achieved across the whole project (Section 3.2**Error! Reference source not found.**).

FOSTERING GROUP COHESION

Some groups consisted of people who knew each other well, others had a mix of people who knew each other and those who did not, and a couple of groups had a fluctuating membership, with newcomers appearing from time to time and others leaving. Facilitators took on the task of managing group dynamics to ensure that everyone felt comfortable to participate, so that the groups continued to meet and the project goals—peer support and research—could be achieved. They used techniques such as ensuring all participants had a chance to share their experiences, which at times required reminding participants of time constraints. It also meant fostering an inclusive environment if some participants knew each other from elsewhere and had an established rapport. The facilitators felt it was important that their own role in the groups was clear.

In most of the group meetings, support people were present, including parents, partners and support workers. Despite initial concerns, this did not pose challenges to the groups after it was discussed openly. Facilitators attributed the success to the trusting relationships that people generally had with their family members, and that the people with self-directed support had with their support workers. Some of the younger people in one group, who might not have had a long-term relationship with their support workers, might have restricted what they said in meetings.

Some people were anxious about speaking up in a group setting, others feared having their confidentiality breached, or they did not want to have their voice or opinions recorded on tape. Facilitators identified these issues and adapted the group activities and research methods so that data was collected in ways that recognised people's preferences. For example:

- taking written notes instead of an audio recording

- sharing experiences while doing an activity rather than talking, or

- talking one-on-one.

Adjustments were made to ensure that every person was able to participate. For example, the groups:

- consulted with local service providers to make a visual activity accessible to a participant with vision impairment

- ensured people with speech impairments were understood and asked to direct how they would like their speech clarified

- reduced the length of meetings because some people became physically uncomfortable after long periods, or

- extended meetings to ensure that there was enough time to support people with communication needs and to check that they felt their contribution was recorded in the best way for them.

VARIETY IN GROUP ACTIVITIES

The CARDs used a range of methods to discuss key topics about disability support (Section 3 – characteristics of support, organising support services, social and community participation, and relationships with support workers). Most groups initially decided to discuss one topic per meeting; some groups workshopped two or three topics over the course of a day, or they condensed into shorter sessions those subjects in which they were less interested. One of the pre-existing peer support groups did not formally tell participants the list of topics but gathered the information through conversation, while another group set each meeting agenda through a democratic process at the start of every gathering. As the project unfolded, it became clear that the topics were interrelated and not easily discussed in isolation yet were useful as a guide.

Here are examples of the types of activities that groups used to share and collect information about self-directed disability support:

- In most groups, especially early in the project, people shared their experiences in a focus group style and 'bouncing off' each other's comments and stories.

- Other groups approached the topics by inviting people to talk about challenges they were facing and then helping each other to problem solve or share solutions.

- A couple of groups used a 'world cafe' approach, where sheets of butcher's paper signifying different topics were spread around the room, and group members wrote down their ideas on each sheet. While this was noted as an interesting method for the people involved, more time was needed at the end of the meeting to feed back on the responses of the group as a whole and have an in-depth discussion.

- Two groups found doing an activity was more engaging for the participants and more effective for exchanging ideas. For example, people cut out images from magazines to express the kind of life that they wanted to lead and talked about it during and after the activity.

- Another group conducted an art project facilitated by one of the members of the group. It generated new ideas but was difficult because the members wanted to use the limited time to achieve different things.

- Two groups experimented with the Photovoice technique ([Appendix 2](#)), where participants were asked to take photos that illustrated their feelings about a topic. Not all participants wanted to contribute pictures, but they still discussed the images that other people had brought in.

- Some groups initiated conversations by inviting guest speakers from the community to provide information or to talk about their own experiences. These speakers included representatives of service providers, advocates from disability organisations, experts in individualised funding and family members of people with disability.

- Three groups showed a short film to explain what self-directed disability support is and to demonstrate how it could help people. One group found this a useful approach to set the scene of the project and recommended the process to other groups.

SUPPORT FROM FACILITATORS

Leadership and commitment from the CARD facilitators were essential to the success of the project in establishing the groups, enabling peer support and generating research data. The facilitators' tasks included identifying and recruiting CARD participants; organising the meetings and making the associated arrangements; supporting the participation and confidentiality of the participants; facilitating the discussions and guiding the research where necessary; providing feedback to the project team through notes, audio recordings and other research data generated; and reflecting on the implications of the process and findings with the other facilitators and project team.

Feedback from the facilitators shows that they needed to have a combination of enthusiasm, coordination and problem solving skills, as well as monetary resources, for running the groups successfully. Ongoing support from PWDA and the university researchers, as well as each other, was essential to retain momentum, share resources, brainstorm ideas and address challenges. As mentioned in Section 2.2, the groups received project funding, and non-financial support was provided by telephone and email access to the project team at PWDA, through monthly teleconferences between the project team and facilitators, and by access to an online discussion forum.

This joint process helped build capacity among the facilitators, which was an unexpected, positive outcome from the project. Interaction between the facilitators and project team also acted as a form of peer support. For example, sharing information about the changes in the provision of disability services and support across jurisdictions, increasing knowledge about how self-directed funding can be used, understanding how people with disability feel about these changes in other parts of the country, and building skills in facilitating peer support groups. The project generated a national network of disability advocates who shared experiences and information on these topics.

Capacity building also extended to the disability advocacy organisations that the facilitators were aligned with. All groups received pro bono assistance from these organisations, including providing meeting spaces, supplying administrative support such as photocopying and use of teleconference facilities, identifying participants, and contributing staff to work on the project. As a result, the organisations gained access to knowledge about self-directed disability support, peer support and links into a national network of organisations advocating on the issue.

Three groups were facilitated by people who brought experience from their current roles as peer support facilitators in disability advocacy organisations. One facilitator identified as a person with disability, and two others recruited a co-facilitator with disability for running their group meetings. One of the facilitators with disability said, 'Sometimes on some issues I think the group

felt that I know what I'm talking about because I live it'. Another commented that their experience with self-directed funding helped them to ask relevant questions and gain information from participants. Having a disability or having support from a disability advocacy organisation contributed to the quality of the facilitation and the opportunities for sharing the outcomes with other people with disability.

Facilitators discussed project management and group facilitation issues that they needed to resolve during the course of the project, for example questions from group members about the purpose of the research, and organising the CARD work around the facilitator's main paid job. One facilitator was able to solve workload issues by recruiting a volunteer to complete administrative tasks for the project, such as uploading meeting records. Most facilitators were concerned about finding a balance between enabling a natural flow of conversation and keeping focus on the research topics. They generally agreed that it was best to allow free discussion, with topics acting as a starting point to stimulate conversation.

Facilitators seemed generally happy with their involvement. One facilitator said:

> The overall organisation of the project was impressively top-notch … It was a pleasure to be involved in a project where the common mistake that some research organisations make in treating its 'working partners' as research assistants was completely avoided. (CARD facilitator)

6 CONCLUSION: WHAT DOES IT ALL MEAN?

CARDs were a new way of combining research with peer support. They aimed to produce research data about self-directed disability support and build research capacity, while at the same time benefit the people who participated, for example through peer support and advocacy. This project shows that CARDs can work well. They produced useful information from around the country about how people experience their disability support and what they want for the future. They were also useful for the group members, providing opportunities for peer support and networking, increasing self-advocacy skills and building research capacity.

Peer support and networking seemed most important to the CARD members. The groups provided a safe, trusted place where people could exchange information and learn from the experiences of other people with disability. People's preference for such groups in finding and sharing information is important to consider for governments, service providers and advocacy organisations in the transition to the NDIS and other self-directed support options.

The peer support process and findings have been discussed at national and international workshops with people with disability, service providers, policy makers and researchers. Other people are using this way of sharing information or expanding the way they run peer support based on the lessons from this research.

Participants raised issues about self-directed support that could be explored more in the future:

- They needed to know their rights, what they could use their support or funding for, and have opportunities to make choices within person centred support.

- They used information about options for self-directed support and about managing self-directed support to make informed decisions about changing to new support. They supplemented information from governments and service providers with help from advocacy organisations and peer support groups.

- They arranged transport and flexible support services so they could live as they wished and do what they wanted, such as attending TAFE, university or their employment

- They developed skills to manage relationships with support workers. They needed help to recruit workers who suited them, so they could build strong and productive relationships. They wanted a resource book and helpline to assist them and tips for regular, good communication between people with disability and support workers.

REFERENCES

Australian Bureau of Statistics (2012). *Disability, Ageing and Carers, Australia: Summary of findings, 2012* (Cat. no. 4430.0). Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/E82EBA276AB693E5CA257C21000E5013?opendocument.

Australian Institute of Health and Welfare (2006). Disability and disability services (Cat. no. DIS 43). Retrieved from http://www.aihw.gov.au/publication-detail/?id=6442467812.

Balcazar, F. E., Taylor, R. R., Kielhofner, G. W., Tamley, K., Benziger, T., Carlin, N. & Johnson, S. (2004). Participatory action research: General principles and a study with a chronic health condition. In: L. A. Jason, C. B. Keys, Y. Suarez-Balcazar, R. R. Taylor, & M. I. Davis (Eds.), *Participatory community research: Theories and methods in action* (pp. 17–35). Washington, DC: American Psychological Association.

Cummins, R., & Lau, A. (2005). *Personal Wellbeing Index – Intellectual Disability*. Melbourne: Australian Centre on Quality of Life, School of Psychology, Deakin University. www.deakin.edu.au/research/acqol/instruments/wellbeing-index/pwi-id-english.pdf

Epstein, I., Stevens, B., Mckeever, P. & Baruchel, S. (2006). Photo elicitation interview (PEI): Using photos to elicit children's perspectives. *International Journal of Qualitative Methods, 5(3)*, 1–11. http://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4366

Fisher, K. R., Cooper, S., Purcal, C., Bevan, N., & Meltzer, A. (2013). *Self-directed disability support (SDDS): building community capacity through action research. Research plan (SPRC Report 3/2013)*. Sydney: Social Policy Research Centre, The University of New South Wales.

Folkestad, H. (2000), Getting the picture: Photo-assisted conversations as interviews. *Scandinavian Journal of Disability Research, 2*, 3–21. http://dx.doi.org/10.1080/15017410009510757

Harper, D. (2002), Talking about pictures: A case for photo elicitation. *Visual Studies, 17*, 13–26. http://dx.doi.org/:10.1080/14725860220137345

Hurworth, R. (2003). *Photo-interviewing for research (Social Research Update Issue 40)*. Surrey, UK: Department of Sociology, University of Surrey. http://sru.soc.surrey.ac.uk/SRU40.html

Kusenbach, M. (2003), Street phenomenology: The go-along as ethnographic research tool. *Ethnography, 4*, 455–485. http://dx.doi.org/10.1177/146613810343007

Meltzer, A., Fisher, K. R., Purcal, C., Bevan, N., & Cooper, S. (2014). *What can we do in our research group? Different ways to do research (SPRC Resource 1/2014)*. Sydney: Social Policy Research Centre, UNSW Australia.

Novek, S., Morris-Oswald, T., & Menec, V. (2012). Using photovoice with older adults: Some methodological strengths and issues. *Ageing & Society, 32*, 451–470. http://dx.doi.org/10.1017/S0144686X11000377

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory meeds assessment. *Health Education & Behavior, 24*, 369–387. http://dx.doi.org/10.1177/109019819702400309

APPENDIX 1: CARD RESOURCES

What is participatory action research?

This project uses an approach called 'participatory action research' (PAR). As the name suggests, participatory action research is participatory and action-focussed. It is also a reflexive process. This is explained below.

Participatory

PAR views people as experts in their own lives and aims for research about an issue to be done with and by people who have a stake in that issue. In this way, PAR hopes to create knowledge that reflects what is important to the people most involved in the issue in question.

In this project...
- Groups of people with disability, called 'CARDs', will collect information about experiences with self-directed and agency funding for disability support. They will choose how to collect the information and what they want to talk about in their meetings. In this way, the information collected will reflect what is important to the people involved.

- #### Action

Participatory action research is action-focussed. It aims to create change through the research process and through the knowledge generated by the research. This means the research findings aren't just presented at academic conferences, but used to drive change, for example, by sharing them with the public or policy makers. The research process itself is designed to create change by, for example, building people's capacity for doing research or being part of self-advocacy.

In this project...
- This project aims to build community capacity for research and to develop peer support for self-directed funding. People in the CARDs will gain experience doing research and will be supported with training and resources. By participating in the CARDs, people will develop peer support networks with people with self-directed and other disability funding, as well as with other people from across Australia who are participating in the research.

Reflexive

Participatory action research is reflexive. This means everyone involved continuously reflects on the content and process of the research. Changes are made where needed to the research process as the project continues, and ideas for future projects also might come out.

In this project...
- In this project, CARD members will reflect on what helps and hinders their participation in the project. This will be mainly through reflection in the CARD meetings. Reflection will be used to make changes so that the CARDs work better.

Research ethics

What is coercion and informed consent?

Research is always voluntary. This means that people need to agree to take part without being coerced and that they consent to take part only after being given thorough information about the research topic and the implications of taking part.

Coercion

Coercion means that people feel that they are being forced or required to take part in research against their wishes. This may happen, for example, where someone is heavily persuaded to participate or where they are in an unequal power relationship with those doing the research (e.g. teacher/student, person with disability/funder of services). Where groups with a history of marginalisation or with cognitive impairment take part in research, it is particularly important to guard against actual or perceived coercion. This can often be facilitated by having a trusted supporter or third party participate in the consent process (see below).

Informed consent

Informed consent means that people agree to take part in research only after receiving and understanding thorough information about the research topic and the implications of taking part. It is not enough that the information is just made available, but there must be confidence that it is understood as well. Participants sign a consent form to say they agree to take part.

Points to consider regarding informed consent:

- Have standard and easier copies of the consent information available for people with different levels of comprehension.

- Offer a trusted supporter or third party to assist with the consent process where there is a question of the participant's understanding.

- Remember that consent is required for all forms of participation in the project, including CARD membership and other participation via interviews etc.

- Assume a person's ability to consent, unless there is reason to think otherwise. Where there is doubt, seek dual consent from both the participant and their guardian; a guardian's consent is not enough alone.

What is confidentiality?

Confidentiality is the principle that researchers report *what* participants said, but not *who* they are. This means ensuring that participants' names are not reported, but also that other identifiable characteristics about them are removed from the data (e.g. where they live or work). Confidentiality has implications for the way research is written about, but also for the collection and storage of research data, where identification codes are substituted for names and/or research site locations, and for the responsibilities of those involved in collecting information.

Research participants need to be aware that researchers will always protect their confidentiality, except where required by law – i.e. where someone's safety is at risk or someone is at risk of harm; participants should be made aware of this at the beginning of the research to ensure they can make informed decisions about what and what not to say during the research process.

Recognising and dealing with distress

In research where people discuss their lives, there is a chance that people may become distressed when talking about difficult experiences or when talking about issues that they may not have considered or spoken about before. In these instances, those involved in doing research need to be skilled in recognising and dealing with this distress.

The list below includes resources to draw on for recognising and dealing with participant distress in the research process:

- *Mental Health First Aid*

  https://mhfa.com.au/cms/guidelines

Information on recognising mental health issues and knowing strategies to assist.

- *Lifeline counselling*

  www.lifeline.org.au, phone: 13 11 14

  24 hour telephone counselling and support; available nationally.

- *Local mental health services*

  www.health.nsw.gov.au/mhdao/contact_service.asp, ph: 1800 011 511

Lists information for contacting local mental health services in all states and territories around Australia.

- *Disability Rights and Information Service*

  dris@pwd.org.au, Free Phone: 1800 422 015

Provides advocacy support for people with disability and assistance with resolving issues, addressing complaints and providing representation.

WHERE CAN I FIND OUT MORE ABOUT RESEARCH ETHICS?

You can find out more about research ethics by reading:

- The Australian Code for the Responsible Conduct of Research

  www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r39.pdf

- The National Statement on Ethical Conduct in Human Research

  www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72.pdf

CARD housekeeping

First meeting
- Ethics
  - Discuss any concerns
  - All who wish to participate must read, understand and complete CARD Roles, Rights and Responsibilities document
  - Distribute to everyone the referral information for people who may be distressed or want to talk to someone
  - Provide everyone with Ngila's email address – ngilab@pwd.org.au for if they have any concerns you can't answer or want to discuss the project with someone else
  - Reminder about importance of confidentiality at beginning and end of meeting

- Planning
  - Discuss what people want to get out of the project
    - What do people want to talk about?
    - Decide what topics to talk about and in which order (this can change)
    - What methods do they want to use?
    - Do they want to engage with community members between meetings?
  - Get everyone's best contact details
  - Try and chat to each person individually (briefly; maybe during the break) to make sure they understand the project and if they have any concerns

- Inclusive meetings
  - How do people need meetings run?
  - Discuss and plan support needs for participants
  - Invite people to discuss the costs associated with their participation with you privately (e.g. taxis, extra support worker hours etc)

- Complete summary template

- Upload all documents to wiggio

Regular meeting checklist

- Confidentiality reminder at beginning and end of meeting

- Distribute referral information for people who may be distressed

- Try to chat to each person individually (briefly; maybe during the break) to make sure they are happy with how the CARD is progressing and if they have any concerns

- Complete summary template

- Upload all documents to wiggio

Facilitation techniques

What is a positive group dynamic?

- Friends
- Respectful of differences, of time, of space, of communication needs
- Make a difference
- Learn something
- People feel like they, their time, and their opinions are valued and valid – democratic decision making processes

What can we do to make this happen?

- Know each other's names
- Establish group norms
- In the first session: discuss and decide how meetings will be run

Decision making process

- Modified consensus
    - o Thumbs up/side/down (approve, let it pass, block)

Role of Support People

- Supporters, not participants – see "role of supporters" document

Giving people as much opportunity to get involved as we can

- Accessible materials and activities

Giving people space for complaints and feedback

- Make sure they know feedback is being heard, pass it on
- Make sure it is clear how everyone involved can provide feedback/air complaints
    - o Provide email for Ngila – ngilab@pwd.org.au

What about when things go wrong?

- Challenging participants
    - o Refer to group norms
    - o Discuss individually
        - ▪ Why, how can you help, what they like doing
    - o Split into smaller groups so everyone gets a break at some point
    - o Give them something to do – take minutes, hand things out

- Motivation
    - o Celebrate successes
    - o Know who is there and why they are there – make sure they have the space to achieve their goals and purpose
    - o Get people excited – share ideas, look at benefits in different timescales (short term and long term and longer term)

- Problem solving
    - o Talk to each other
    - o Wiggio
    - o Ngila
    - o Research team

Being a supporter in the SDDS project

What is a supporter?

A supporter is someone who assists a person with disability to communicate in the best way possible during a research activity. For example, in this project, this could be:

- Assisting a CARD member with disability to communicate with other CARD members.
- Assisting either a CARD member or a person with disability from the community to communicate with each other, for example in an interview.

Supporters can be a trusted family member, friend or advocate.

Staff and workers can also act as supporters.

What is my role as a supporter?

Your role as a supporter is to:

- Facilitate and interpret the person's speech or communication
- Rephrase questions in words or ways that the person will understand
- Give an example that might help the person understand better
- Alert the others to subtle signs of the person being upset or distressed
- Moral support and motivation

What is NOT my role as a supporter?

Supporters are *not* meant to answer questions or converse *for* the person with disability – they are instead meant to help that person communicate themselves.

What are my responsibilities as a supporter?

Your responsibilities as a supporter are:

- To help the person with disability communicate in the best way possible
- To assist in ways that are reflective of the person's opinion
- To be discreet about the information you hear from other CARD members and people with disability in the community and to respect their confidentiality. If you are concerned about something you hear, please seek the advice of the CARD group facilitator.

CARD research topic prompts

In each meeting, discussion should focus on people's **experiences** and **aspirations**, including, for example, hopes for the future, how you've achieved goals, experiences when things have gone wrong and future goals and plans for how to achieve them.

Access to information about what support is available, administration, help to manage support services, advocacy

- **Getting to know you**
  - o Who are you?
    Areas for discussion:
    - Your interests or what you like doing
    - Where you live and who you live with
    - How you spend your time – activities, work, services etc.
  - o What are your support services like?
    Areas for discussion:
    - Self-directed or agency-funded
    - Extent of your support services
    - How you use it
    - What workers you have
    - Support or help to use your support services
- **Available information, support and help to manage support services**
  - o What help do you have to make the best choices about using your support services?
    Areas for discussion:
    - Help with knowing what or who is out there for services
    - Help with managing money
    - Help with weighing up choices, making decisions and putting ideas into action
- **Administration**
  - o How do you manage the administrative tasks of your support services?
    Areas for discussion:
    - What you do and what service providers do for you
    - Administrative tasks that give you more choice and control
    - Administrative tasks that are too burdensome
- **Advocacy**
  - o How do you seek help or advice when things are going wrong with your support services?
    Areas for discussion:
    - Information
    - Confidential advice
    - Legal representation

- Managing conflicts with workers and service providers

Characteristics of your disability support: flexibility, control, choice, self-determination, extent of your support services

- Self-determination
  - Do you have support to make sure your support services let you do and achieve what you want with your life?

    Areas for discussion:
    - Your goals and aspirations – day-to-day and long term
    - How you make or plan for your services to fit your goals
    - Changing your services to fit your changing goals

- Flexibility
  - Do you have support to make sure your support services fit your time and your lifestyle?

    Areas for discussion:
    - Regular services versus planning services when you need or want them
    - What factors your services need to be flexible to
    - How you change your services

- Control
  - Do you have support to make sure you are in charge of what's going on with your support services?

    Areas for discussion:
    - What decisions need to be made and who makes them
    - How a decision is made
    - What or who influences the decision making process and to what degree

- Choice
  - Do you have support to make sure you can make the most of all the options available to you in your support services?

    Areas for discussion:
    - Range of options – inclusions and exclusions
    - Enough information about what you can do
    - Support to understand the options available to you
    - Support to change options

- Extent of your support services
  - What does the extent of your support services mean for what you can do with them?

    Areas for discussion:
    - Frequency of services
    - Length of services/shifts
    - Cost of different types of services
    - Equipment, transport, expenses

Participation in the community: work, education, accommodation and health care

- Employment

    - How do you use your support services to help or assist you in working or having a job?

    Areas for discussion:

        - Finding and training for work

        - Day-to-day work life and accessing support at work

        - Developing your future work or career plans

- Education

    - How do you use your support services to help or assist you in education and learning new skills?

    Areas for discussion:

        - Planning and preparing for education

        - Day to day life at your place of education

        - Accessing services or support at your place of education

- Day to day living, health care services and accommodation

    - Do you have support to make sure your support services fit the everyday things you need to do?

    Areas for discussion:

        - Having a place to live and completing household tasks

        - Moving around your community

        - Odd jobs and appointments

        - Personal care

        - Accessing health care services

Social life: Family and social networks, valued relationships, leisure, recreation

- Family, valued relationships and social networks

    - How do you use your support services to keep up good relationships with the people who are important to you?

    Areas for discussion:

        - Keeping up with family, friends, colleagues and neighbours

        - Going to social and family events

        - Employing family and friends

        - Meeting new people

- Leisure and recreation

    - How do you use your support services to let you do things that you find fun or enjoyable?

    Areas for discussion:

        - Leisure, recreation and hobbies

        - Exercise and being outdoors

- Getting out and about (where to?)
- Frequency and variety of leisure and recreation activities
- Holidays
- Transport

Arrangements and relationships with support workers

- **Arrangements**
  - What arrangements do you have with your workers and what impact does this have on each of you?

    Areas for discussion:
    - Interviewing, hiring and training workers
    - The timing and scheduling of services (when do the workers come?)
    - Content of services (what do the workers do?)
    - Insurance, human resources, time sheets, pay cycles etc
    - Information about what you need from workers
- **Relationships**
  - How does the way you manage your support services affect your relationships with your workers?

    Areas for discussion:
    - Power, choice and control
    - Mutually agreeable arrangements
    - Flexibility for both of you
    - Managing conflict

Reflection on the research process and outcomes: How have you found this process? What does it mean for disability support and NDIS? What do you want to tell other people?

- **Participating in the research**
  - How did you find participating in the CARD?

    Areas for discussion:
    - Successes – what worked well
    - Challenges
    - Next time
- **Learnings and findings**
  - What do you want to tell other people that you learnt from this project?

    Areas for discussion:
    - Self-directed funding
    - The NDIS
    - Research process
    - Personal learnings

- Next steps
  - What comes next?

    Areas for discussion:
    - Using our findings to make changes
    - Our CARD group
    - Personal life

CARD facilitator feedback tool

This project is using a web-based tool called WIGGIO designed for sharing information in groups.

The website can be found here http://wiggio.com/ and you will need to set up your own username and password to access the site. Our page is here …., and our group name is ….. There are also Sub Groups for every facilitator.

Why are we using this online tool?
- To share and exchange information quickly and easily between CARD groups, UNSW and PWDA.
- To centralise information about the project so it is easy to find (and inboxes do not get clogged).
- It is free, easy to use and private - only invited members can see the information.
- Transparency, accountability and problem solving.

How will we use this online tool?
- All materials generated by UNSW or PWDA will be posted to the site and stored in the ….File. For example, all the documents in the Facilitator Pack.

- Facilitators can upload all of their CARD's research into their designated ….. File e.g. documents, video, photos etc… for UNSW and PWDA to see.

- Facilitators can use the calendar function to alert UNSW and PWDA of when they will be holding CARD meetings so we know when to expect feedback and can track the progress of the project.

- The site has a 'chat room' tool which will allow facilitators to communicate with each other, UNSW and PWDA about any problems they are experiencing or good ideas they may want to share. Facilitators are free to participate in this to the extent that they wish to.

- There is a group email address … , and emails sent to or from that address go to everyone in the group. The group consists of all the CARD Facilitators plus the teams at UNSW and PWDA. At the moment, the settings will send an email to all members with a summary of the group's activity (if any) at the end of every day. However, you are free to turn off these notifications if you wish.

- The site can be used to hold conference calls between members, to generate opinion polls (for example to aid decision making about changing something in the project), and to create co-authored documents.

CARD meeting report template

State/Territory: _____

Topic of this meeting: _____

Date: _____

Please write as much as you can about each question. The boxes will expand as you type, or you can add extra pages.

1. What were the things you focused on in the topic of this meeting? What were common experiences among the group about this topic? Where did experiences differ?

2. What did the group think is most interesting or important about this topic? What do other people need to know about this topic?

3. What do people with disability, workers, service providers and others still need to work on further about this topic? What needs to happen about this topic for the NDIS to work well?

4. How did the group discuss the topic? Did you use a new activity or strategy? How did you find it? What could a CARD do differently in discussing this next time?

5. What was good about discussing this topic? How did it make you feel? What did you learn from others?

6. Did the group have any other comments?

CARD member survey

First name and surname initial:

_____

State/territory:

_____

1. Are you?
    ☐ Male   ☐ Female

2. What is your date of birth?
    _____

3. Are you from an Aboriginal or Torres Strait Islander background (tick all that apply)?
    ☐ Yes, Aboriginal background
    ☐ Yes, Torres Strait Islander background
    ☐ No

4. Were you born in Australia?
    ☐ Yes
    ☐ No, I was born in _____

5. Do you speak a language other than English at home?
    ☐ Yes, I speak _____
    ☐ No, English only

6. What is your postcode?
    _____

7. What type of disability do you have (tick all that apply)?
    ☐ Physical disability
    ☐ Intellectual, cognitive or learning disability
    ☐ Psychological disability or mental health
    ☐ Sight, hearing or speech
    ☐ Other _____

8. Are you using any formal disability services?
    ☐ Yes (go to Question 9)
    ☐ No (go to Question 10)

9. What type of funding are you using for your disability services?
    ☐ Self-directed funding (for example individual package)
    ☐ Agency funding
    ☐ I'm not sure
    ☐ Other, please specify _____

Can you tell me how happy you are about these parts of your life at the moment?

10. How happy do you feel about <u>your life as a whole</u>?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

11. How happy do you feel about the things you have? Like the money you have and the things you own?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

12. How happy do you feel about how healthy you are?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

13. How happy do you feel about the things you make or the things you learn?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

14. How happy do you feel about getting on with the people you know?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

15. How happy do you feel about how safe you feel?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

16. How happy do you feel about doing things outside your home?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

17. How happy do you feel about how things will be later on in your life?
<table>
<tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr>
<tr><td>Very sad</td><td>A little bit sad</td><td>Neither happy nor sad</td><td>A little bit happy</td><td>Very happy</td></tr>
</table>

Thank you!

Community Action Research Disability groups: Roles, rights and responsibilities

What is a CARD?

A Community Action Research Disability group (CARD) is a group of people with disability who collect information for a research study. They make their own plan about how they want to collect the information and to decide what they think will work best. The aim of this is to make sure the research study represents the views of people with disability. This is a type of participatory research.

What research study is this CARD about?

This study is about the experience of people with disability with self-directed funding and with traditional forms of disability support and what the difference is between the two. The study is organised by People With Disability Australia (PWDA) and the Social Policy Research Centre (SPRC) at the University of New South Wales, Sydney.

There are eight CARDs in this study, one in each Australian state and territory. If you take part, you will collect information about the experiences and views of people with disability in your community about the way their support is organised.

Why is the study being done?

In Australia, disability support is beginning to be via self-directed funding (individual packages of support) rather than funds and services distributed by an agency. There is very little information about the impact of self-directed funding on people requiring support, their carers and service providers.

This study is about understanding how people with disability view self-directed funding and the experiences they have had with their own disability support, be it via self-directed or agency funding.

This study will help us to understand better how self-directed funding can work well and help people with disability have a good life. We hope that it will provide information for people with disability to get better services and help them learn advocacy and research skills. We hope that the study will build support networks for people with disability who are using new ways of funding and organising support.

<u>Roles</u>

If I take part in a CARD, what will I do?

If you decide to take part in a CARD:

- You will attend up to 6 monthly meetings to talk about issues facing people with disability and your own experiences. For example, you might talk about how you organise your support and how this impacts your relationships, community participation, employment and other aspects of your life.

- Together with the CARD, you will plan and prepare how to collect information from other people with disability about their support and experiences, and carry out these plans.

- You will be helped by other people with disability in your CARD, as well as the CARD facilitator and researchers from People With Disability Australia and the Social Policy Research Centre.

CARD groups will meet for about two hours once a month and may do some research in between these meetings if your CARD chooses to. After the study you will be able to get a summary of the research.

<u>Rights</u>

What if I don't want to take part or change my mind later and want to leave the study?

Taking part in this study is voluntary. You do not have to take part if you don't want to. If you decide to take part and then change your mind, you can leave (withdraw) from the study at any time. After starting work with the CARD, you can choose not to answer some questions or do some activities and you are free to leave the CARD or any activity at any time.
Your decision whether or not you take part will not affect your future relations with People With Disability Australia, other services your receive or the University of New South Wales.

What about keeping my information confidential?

Your name and details that identify you will not be included in any reports we write unless you would like them to be. The information you collect and tell us will be completely confidential and will not be told to anyone other than the researchers involved in the study, except as required by law.

<u>Responsibilities</u>

What will be my responsibilities?

Everyone involved in the study will be expected to keep confidential any information that people tell them during the study. This means that CARD members must keep confidential any information talked about in the group meetings and keep confidential any information given to them by other people for the study. If you decide to withdraw from the study, you must still keep people's information confidential.

This study is voluntary. You do not have to take part if you don't want to. This also means that when you are collecting information from people in your community, they must not feel forced into taking part. You will be trained in asking voluntary permission from people to take part.

What if I have complaints about the study?

If you have any questions or complaints at any time about the study, you can contact the UNSW Ethics Secretariat, Sydney NSW 2052 by writing, fax (02) 9385 6648 or ringing (02) 9385 4234, quoting this reference number: HC13002.

Further information

If you have any questions or would like further information about this study, please feel free to contact **Karen Fisher** at the Social Policy Research Centre on (02) 9385 7813 or **Ngila Bevan** from People With Disability Australia on (02) 9370 3100.

Thank you for taking the time to read this and for thinking about joining the research.

What do I do now?

If you're interested in taking part in a CARD, please sign the two consent forms on the next pages and keep the withdrawal form in case you need it later.

Consent form

> Community Action Research Disability groups
>
> Self-directed funding for disability support: building community capacity through action research

You are making a decision whether or not to take part in a Community Action Research Disability group. If you sign here, it means that you have read and understood the information and have decided to take part.

....
Your signature

....
Please PRINT your name

....
Signature of witness

....
PRINT witness's name

....
Nature of Witness

....
Date

Confidentiality form

Community Action Research Disability groups

Self-directed funding for disability support: building community capacity through action research

If you sign here, it means that you agree to keep information talked about in the Community Action Research Disability group meetings and information you collect from people in the community confidential even if you leave the study.

....
Your signature

....
Please PRINT your name

....
Signature of witness

....
PRINT witness's name

....
Nature of Witness

....
Date

Withdrawal of Consent form

Community Action Research Disability groups

Self-directed funding for disability support: building community capacity through action research

If you sign here, it means that you no longer wish to take part in your Community Action Research Disability group and wish to withdraw from the study. You understand that this will not affect your relationship with People With Disability Australia, UNSW Australia or any organisations from which you receive support. You understand that you are still required to keep all information shared with you during the study confidential.

The section for Withdrawal of Consent should be forwarded to Karen Fisher, Social Policy Research Centre, UNSW Australia, NSW 2052 Australia, by mail or fax – 02 9385 7838.

……………………………………
Your signature

……………………………………
Please PRINT your name

……………………………………
Signature of witness

……………………………………
PRINT witness's name

……………………………………
Nature of Witness

……………………………………
Date

APPENDIX 2: SUGGESTED CARD METHODOLOGIES

CARDs or similar peer support and action research groups can use participatory, inclusive methodologies like the ones described below. A comprehensive and accessible brochure is available here:
https://www.sprc.unsw.edu.au/media/SPRCFile/2014_Different_ways_to_do_research_booklet.pdf

Photo interviews

In photo interviews the interviewer presents the participant with photos and asks questions about these photos. Ideally photos will 'break the frame' – present a new view of normal things – to provoke reflection (Harper, 2002).

Photo interviews can create a less formal interview and provide space for the participant to direct the interview by choosing which photos to speak about, which part of the photo to speak about, or to talk about things outside the photo (Epstein et al., 2008). Photo interviews are useful for making abstract concepts more accessible (Hurworth, 2003). They can reduce the feeling of being tested or needing to choose the 'right' answer, reducing yes/no answers and acquiescence (Folkestad, 2000).

Photovoice

Photovoice gives cameras to people to document their lives, communities and what is important to them. These photos are then discussed in groups and priority issues identified. These priority issues guide data analysis, and summaries of the research are distributed widely in the community and presented to policy makers to create change (Novek et al., 2012). Photovoice aims to give people the ability and opportunity to record and create change in their communities rather than be passive subjects of others' research and intentions (Wang and Burris, 1997).

CARDs may adapt the philosophy of Photovoice to other media, such as painting, or selecting various important objects that represent their experiences and aspirations about self-directed support (e.g. a bill from a restaurant they were able to attend with their new support staff).

Go-along interviews

Go-along interviews are in-depth qualitative interviews in which researchers accompany individual participants on natural everyday trips. This provides scope to investigate people's perceptions and navigation of their physical and social environments. The interviewer can ask questions about salient features of the environment, or leave it to the participant to talk about their usual experiences on routine trips and whatever comes to mind while looking at and moving through places. Interviews take about one hour to 90 minutes (Kusenbach, 2003).

CARDs may also choose to use

- Discussions

  o CARDs may choose to informally discuss a topic. This could be simply discussing their opinions or experiences, or using a more structured format, such as *projective discussion*, where they say what they would like to happen in the future and discuss what is needed to get there.

- Interviews

  o CARD members may choose to interview each other or people outside the CARD in an informal way and either report back on this to the group or make a more formal record through voice or video recording.

- Surveys

  o CARDs will determine what information they want to find out in a survey, and researchers from the SPRC will advise on survey structure and questions. CARD members will complete the survey and may ask community members, service personnel, or other people with disability to participate also.

- Focus groups

  o CARDs will determine which questions they wish to discuss as a group or invite other members of the community to join the focus group with them. In a CARD meeting, a focus group could be run by the facilitator, or CARD members could take turns running a focus group in successive months.

- Technological methods

  o A range of technological methods could be used by CARDs, including voice or video recording and iPad apps, to record and organise information, either during or between CARD meetings.

- Visual methods

  o A range of visual methods could be used by CARDS to present their opinion on the research topics, including artwork (e.g. painting, drawing, collage), timelines, mind maps or community mapping (i.e. drawing a map of what they access in the community with the assistance of their support services).

APPENDIX 3: DEMOGRAPHICS OF CARD MEMBERS

Table 3: State/Territory of residence

	CARD members	
	n	%
ACT	6	13
NSW	4	9
NT	8	18
QLD	11	24
SA	6	13
TAS	1	2
WA	9	20
Total	45	100

Source: Survey of CARD members

Table 4: Location

	CARD members	
	n	%
Major cities of Australia	33	75
Regional areas	8	18
Remote areas	3	7
Total	44	100

Source: Survey of CARD members

Table 5: Age

	CARD members	
	n	%
<20*	1	2
20–29	9	20
30–39	5	11
40–49	9	24
50–59	11	18
60–69	8	18
70–79	3	7
Total	45	100

* The person was aged 19.
Source: Survey of CARD members

Table 6: Types of disability

	CARD members[1]		Australian population[2]	
	n	%	*n*	%
Physical disability	36	80	2,907,400	74
Psychological disability or mental health	5	11	432,000	11
Sight, hearing or speech	5	11	412,300	11
Intellectual, cognitive or learning disability	5	11	165,700	4
Other	3	7	28,700	1

[1] Source: Survey of CARD members; some people reported multiple disabilities.
[2] Main disability (Australian Institute of Health and Welfare, 2006).

Table 7: Types of disability among CARD members, by State/Territory

	Physical disability		Psychological disability or mental health		Sight, hearing or speech		Intellectual, cognitive or learning disability		Other	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
ACT	3	8	5	100	0	0	1	20	1	33
NSW	3	8	0	0	0	0	0	0	0	0
NT	7	19	0	0	0	0	0	0	1	33
QLD	10	27	0	0	2	40	2	40	0	0
SA	5	14	0	0	3	60	1	20	1	33
TAS	0	0	0	0	0	0	0	0	0	0
WA	8	22	0	0	0	0	1	20	0	0
Total	36	100	5	100	5	100	5	100	3	100

APPENDIX 4: CARD MEMBERS – PERSONAL WELLBEING INDEX

Table 8: Personal Wellbeing Index first round

	None of the time		A little of the time		Some of the time		Most of the time		All of the time	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
The funding we receive enables us to provide high quality services	28	5.3	70	13.3	163	31.0	203	38.6	62	11.8
We know enough in advance whether funding will be renewed	104	19.5	131	24.6	114	21.4	135	25.3	49	9.2
Our funding is stable from year to year	68	12.8	85	15.9	124	23.3	180	33.8	76	14.3
Processes for applying for funding are simple	131	24.6	146	27.4	170	32.0	74	13.9	11	2.1
We receive funding on time	12	2.2	40	7.5	65	12.1	220	41.1	198	37.0
Government funding covers the full costs of service delivery	178	33.7	104	19.7	117	22.2	94	17.8	35	6.6
Funding levels enable us to pay wages at appropriate levels	94	17.8	102	19.3	125	23.7	133	25.2	74	14.0
The funding we receive covers our overheads	100	19.0	89	17.0	127	24.2	156	29.7	53	10.1
Funders seek feedback on tendering and procurement processes	157	30.4	128	24.8	93	18.0	81	15.7	57	11.0
We get timely information about tendering and procurement processes	78	14.7	145	27.3	162	30.5	123	23.2	23	4.3

Source: Survey of CARD members

CARD members answered the questions on a scale from 1 to 5, with 1 meaning 'very sad', 2 'a little bit sad', 3 'neither happy nor sad', 4 'a little bit happy', and 5 'very happy'. In other words, a higher score is better.