

Skilled to Thrive: Support to make decisions that promote personal safety and prevent harm

Project research plan

Prepared for:
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Sandra Gendera, Christiane Purcal, Karen R. Fisher, Sally Robinson, Rosemary Kayess

Research Team

Social Policy Research Centre:

Karen R. Fisher
Rosemary Kayess
Christiane Purcal
Ariella Meltzer
Sandra Gendera

Southern Cross University:

Sally Robinson

For further information:

Karen Fisher +61 2 9385 7800, karen.fisher@unsw.edu.au

Social Policy Research Centre

UNSW Sydney NSW 2052 Australia

T +61 2 9385 7800

F +61 2 9385 7838

E sprc@unsw.edu.au

W www.sprc.unsw.edu.au

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Glossary

ADHC	NSW Government Family and Community Services, Ageing, Disability and Home Care
CALD	Culturally and linguistically diverse
CRPD	United Nations Convention on the Rights of Persons with Disabilities
ILC	Information, Linkages and Capacity Building
IDAS	Indigenous Disability Advocacy Service
MDAA	Multicultural Disability Advocacy Association of NSW
NDIS	National Disability Insurance Scheme
NCOSS	NSW Council of Social Service
SCU	Southern Cross University
SRAC	Sydney Regional Aboriginal Corporation
SPRC	Social Policy Research Centre
UNSW	The University of New South Wales

1. Introduction and background

This action research project was initiated and is supported and facilitated by the NSW Council of Social Service (NCOSS). It is implemented and conducted by people with disability and workers from two Sydney-based organisations, the Sydney Regional Aboriginal Corporation (SRAC) and the Multicultural Disability Advocacy Association of NSW (MDAA). The Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW), and Dr Sally Robinson from Southern Cross University (SCU) have been engaged by NCOSS to provide research advice and to support the research and review components of this action research project.

The project objective is for NCOSS to develop a practice guide to inform organisational capacity to support workers who support people with disability to make decisions about personal safety and wellbeing and preventing harm.

This project research plan outlines the project in more detail, the research framework, research methodology and the analysis approach. The study is an action research project, and therefore some of the details in this project research plan (methods, research approach) will change as people with disability and workers have stronger involvement in the project and research process.

1.1 Rationale and policy context

Australia is moving towards the full implementation of the National Disability Insurance Scheme (NDIS). The implementation of more person-centred planning and individual budgets for some people with disability in Australia means they are in a better position to take major life decisions for themselves. Supporting people with disability to make decisions that promote personal safety and prevent harm is gaining greater importance. This can include people with a range of different types of disability, and particularly those who wish to develop their decision-making skills.

In Australia, people with disability experience violence, abuse and neglect at higher rates than the general population (Robinson, 2015b; Reeve et al., 2016), which significantly detracts from their quality of life (Brown and Schormans, 2014). There are also factors that negatively impact the likelihood of people with disability receiving effective and timely support if they do experience abuse. These include a reluctance among professionals to believe the high rates of abuse experienced by people with disability (Manders and Stoneman, 2009; Mepham, 2010). Ensuring that these barriers to support can be overcome will be integral to the successful implementation of choice and control through the NDIS.

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) enshrines the recognition of legal capacity for people with disability, with obligations on governments to ensure that people are supported to exercise their rights to make decisions about choices that affect their life. Evidence for Australia however shows significant barriers to appropriate and effective support for decision making for people with disabilities as well as workers guiding people or involved in that process (Bigby & Tait, 2004; Dowse, 2009; Fisher et al., 2010).

1.2 Project summary

This action research project with people with disability and workers in Sydney will develop a better understanding of what support people and workers need when it comes to supported decision

making around safety and prevention of harm. The project will ask people and workers about their experiences of support and making decisions in various domains such as friendships, relationships, finances, media, community participation, housing, independent living, health and wellbeing, focusing on how they manage their personal safety and prevention of harm. The project will find out how organisations can support workers, who support people in their decision-making process. The project will develop a practice guide to build organisational capacity to enhance the knowledge, confidence and support of workers/staff who work with people to make choices around their personal safety and prevention of harm.

The short project title is Skilled to Thrive. The project uses a participatory action research approach, which involves acting on social issues and feeding back experiences from people and workers (participants) into the project. This participatory action research approach is in line with the 'nothing about us without us' philosophy. It takes a collaborative approach in which researchers and people from the community work together to develop knowledge and effect change (Balcazar et al. 2004). Participatory research views 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. This project is run in partnership between people with disability, workers and staff (from two disability organisations), the NCOSS facilitator, and university researchers supporting the research process.

The project will work with existing groups of people with disability and workers at the two action research partner organisations SRAC and MDAA. People with disability and workers are referred to as project participants in this plan. The action research groups will be supported by the NCOSS facilitator and university researchers to conduct the action research (e.g. refine the questions, collect the data, reflect on what they found, and analyse the gathered information for a wider audience) about experiences making decisions about personal safety and preventing harm, and how organisations can better support workers in this process. The findings will provide the basis for NCOSS to develop the practice guide to enhance organisational capacity.

After NCOSS develops the practice guide, it will be refined in workshops and with input from the participants. During the workshops participants will be invited to discuss the best ways to share the project resources (outputs) and findings (research report) with a wider audience, and how to best implement them within their own organisations.

2. Research framework

2.1 Aims and questions

2.1.1 Aims of the project

The NCOSS Skilled to Thrive project aims to:

1. build capacity (skills, confidence, knowledge) among people with disability (with and without informal support) to seek support for decision making about their personal safety and prevention of harm
2. develop a practice guide to enhance support to workers who deliver support for decision making to people with disability about personal safety and prevention of harm that is responsive to their needs and diversity (cultural, ethnicity, gender, Indigeneity)
3. increase the action research organisations' capacity to deliver support for decision making about personal safety and preventing harm to people from diverse backgrounds
4. develop organisational capacity to deliver support for decision making about personal safety and preventing harm that is outcomes-focussed and financially sustainable
5. contribute to and build the evidence for delivering decision-making supports to diverse groups of people in Australia.

2.1.2 Research questions

The three research questions are:

1. What support do people with disability commonly seek to make decisions that promote personal safety and prevent harm?
2. What practices are effective to deliver support to make decisions that promote personal safety and prevent harm that is responsive to people's needs (including gender, living circumstances, location, Indigeneity, cultural diversity and others)?
3. What practices are effective to develop organisational capacity to provide support to make decisions that promote personal safety and prevent harm to a range of people from different backgrounds and with diverse needs?

The project is designed to enhance the capacity of organisations to respond to the needs of workers who support people in their decision-making process. The purpose of that organisational capacity building is to strengthen the capacity of people with disability who seek assistance to make informed decisions about their personal safety and prevention of harm, across different life domains. The project logic and the detailed questions guiding the research are summarised in the research logic table (Appendix B).

2.2 Participatory action research

Participatory action research is central to this project. It will be achieved through connecting with existing support groups for people with disability and workers in the two partner organisations. The participants in the existing groups (Indigenous Women's group at SRAC; and Community Voices group at MDAA) will be invited to take part and form action research groups (groups). Once the research groups have been formed, comprising people with disability as well as workers, they will collect the research data and analyse the information through inclusive workshops. The research has a local focus (Sydney, NSW), the findings however have wider, national policy implications.

2.2.1 Action research groups

Groups will be established in each of the participating disability organisations. The group participants will be recruited from already existing support groups for people with disability. The groups will include people with disability receiving support, people with or without disability volunteering in these organisations and their communities, and paid workers employed by the organisations. All participants will have provided informed decision making and consent to take part and contribute to the research process.

The participatory action research approach underpins the design and work of the groups. The aim is to share knowledge and build research capacity in the disability community by supporting groups of people with disability and workers to generate information, participate in analysis, reflect throughout the project on this process and take action. Further, this process aims to build peer support for decision making about safety and prevention of harm. Participatory action research mirrors decision making practices by people with and without disability – becoming informed and generating evidence about decisions and actions to inform further decisions and actions assists everyone. Being engaged in participatory action research groups is an immersive, experiential process, developing concepts and language that may be directly transferable to decision making and support for decision-making relationships. The project will generate findings about decision-making support on personal safety and prevention of harm to inform policy and service provision on a wider NSW state and national level.

2.2.2 Action research facilitator and advisors

The groups will be supported and guided throughout the research process. The key person providing support is a researcher from NCOS, who is herself supported by a team of university-based researchers. The support to groups will be mostly face-to-face, in form of consultations and meetings, trainings, workshops, also via phone and email. The details of the support mechanisms and processes, and frequency of contact, will be discussed and agreed with the groups once they have been set up.

2.2.3 Inclusive workshops

Inclusive research attempts to maximise participation of people with a direct interest in the research topic. At least two inclusive workshops will be held with each of the two community partner organisations (SRAC and MDAA). The aims of the workshops are to:

1. build research capacity amongst people with disability and workers collaborating in the groups (pre-data collection)

2. provide group participants with the opportunity to reflect on the process of self-documentation in a group, share their experiences and findings (post-data collection)
3. harness input from group participants on the practice guide to deliver support for decision making by people with disability about personal safety and preventing harm (during practice guide development)
4. invite group participants to reflect on the best ways to disseminate research findings and resources (practice guide etc) (final stage of the project).

The workshops will contribute to community capacity building, reflective practice, feedback and dissemination, as well as academic, policy and practice implications at the local, organisational and on a wider NSW state level.

2.3 Action research partner organisations

The lead agency, NCOSS, has partnered with two disability advocacy and support organisations in Sydney. The services work with people with disability from diverse cultural backgrounds seeking support and information for a range of needs. The organisations address aspects of safety within social support groups, but also on a one-on-one basis, where this is required.

The Multicultural Disability Advocacy Association (MDAA) is a medium-sized organisation specialising in the provision of advocacy support to people with disability from a wide range of cultural and language backgrounds.

The Sydney Region Aboriginal Corporation (SRAC), including the affiliated Indigenous Disability Advocacy Service (IDAS) is a smaller organisation offering support to Aboriginal people, including Indigenous people with higher support needs (disability, mental ill-health, older people, people involved with the justice system).

The project has intentionally partnered with services working with Aboriginal and culturally and linguistically diverse (CALD) groups, for several reasons. The evidence and literature review for this project (Meltzer, A., Robinson, S., Proud, Y. & Fisher, K.R., 2017) identified, on the one hand, that these groups require different forms and approaches to decision-making support; on the other hand, that there is a gap in culturally sensitive and adapted decision-making support for Aboriginal people and CALD groups in Australia. Furthermore, the evidence suggests that Aboriginal and CALD people with disability face higher barriers to accessing services (language and cultural barriers, greater stigma, past experiences of trauma and abuse, etc). To date, academic discourse and national policy directives have not sufficiently paid attention and catered to the context of delivering decision-making supports to different groups. This action research project aims to contribute knowledge to fill this gap in evidence.

2.4 Management

The project involves several actors and partners:

1. people with disability (and some of their informal supporters) currently receiving support (also providing support e.g. volunteers) at the partner organisations

2. workers and staff from two action research partner organisations: SRAC (Sydney Regional Aboriginal Corporation) and MDAA (Multicultural Disability Advocacy Association of NSW)
3. SRAC and MDAA leaders in the partner organisations, including management and governance
4. NSW Council of Social Service (NCOSS)
5. researchers from the Social Policy Research Centre (SPRC) and Southern Cross University (SCU).

The partners and their roles and responsibilities in the project are briefly described below and in more detail throughout this Research Plan:

2.4.1 Project participants

Project participants include people with disability who receive support in existing empowerment groups (and some of their informal supporters, where appropriate), and workers and staff from the two action research partner organisations SRAC and MDAA.

The project participants (people and workers) will be supported to undertake the project together to collect the information, reflect on their findings, discuss them in small groups or one-on-one, undertake the analysis, and contribute to the implementation and dissemination of the practice-based guide (project output).

The action research project will be shaped by the input from these groups of participants. It will evolve and change to a certain degree, with the ultimate aim of developing an evidence-based practice guide to deliver support for decision making by people with disability about personal safety and preventing harm.

2.4.2 Action research partner organisations

The action research partner organisations SRAC (Sydney Regional Aboriginal Corporation) and MDAA (Multicultural Disability Advocacy Association of NSW) have agreed to be involved in and support the research project, and their staff taking part in it, as well as implement and support the dissemination of the project outputs.

The organisations will recruit participants, workers and people with disability to the project, who wish to reflect, discuss, document, and shape directions for support for workers who support decision making by people with disability about personal safety and preventing harm.

Some of the staff employed to work with the support groups (people with disability), may be in charge of collecting project data. Staff and workers deciding to take part in the project will be supported by their organisations to do so (e.g. in the form of time allocation, guidance, other input into the project).

The organisations' advisory committees will be kept informed about the project, its progress and findings throughout the life of the action research project. Where possible, the input from these committees will be considered.

2.4.3 NCOSS

The NSW Council of Social Service (NCOSS) is funding this research project via project funding from NSW Family and Community Services (ADHC) and conducting it. Yvette Proud at NCOSS is the key facilitator on the project. She is in charge of supporting the action research partner organisations to undertake and deliver the project (e.g. run consultations, share information, conduct interviews and focus groups, document decisions made in various groups, provide training and advice to stakeholders/staff, etc) with keeping the ultimate project outcome (policy and practice guide) in mind.

NCOSS also oversees the project management of the action research project, feeds back to other key stakeholders interested in the project outcomes (e.g. ADHC; Disability Advocacy and Information organisations). NCOSS will take a leading role in the dissemination of the research findings and the final output, the practice guide.

2.4.4 University-based researchers

University researchers from the SPRC (Social Policy Research Centre) as well as SCU (Southern Cross University) are providing research advice and guidance to the involved project partners, in particular NCOSS. The researchers will support the project implementation and some of the data collection to undertake the research/documentation component of the action research project.

The SPRC/SCU role has three key components:

Stage 1. Design: Support NCOSS in the design of the action research project. Key outputs of this stage include a Research Plan and ethics submissions.

Stage 2. Implementation: Support NCOSS and the partner organisations in the implementation of the research project. Key outputs of this stage include participation in some of the project workshops, meetings and discussion groups.

Stage 3. Research/ documentation: Research the implementation of the action research project. The learnings from this activity will further contribute to shaping and improving the evidence-based practice guide. Key outputs of this stage include a short research report on the implementation findings and lessons from the project, and advice on the draft policy and practice supported decision making guide.

3. Research methods

3.1 Action research groups

In the partner organisations, MDAA and SRAC, the action research groups (groups) will likely be known or called a different name (aunties group; community conversations), as the groups will form part of an existing support group for people. The action research groups will be coordinated by a local disability staff/worker and supported by the NCOSS facilitator. The groups will be comprised of about six to 12 people, depending on participants' interest in taking part and contributing to the action research project.

The groups have several functions to:

- stimulate reflection and discussion about decision-making support around safety and prevention of harm
- increase local and organisational research capacity to record their practices of decision support. Recording can enhance availability to people with disability in the future, as well as contribute to knowledge development about decision support and safety
- generate research data, reflect on the findings, contribute to the data analysis
- shape the findings on good practice into a culturally sensitive practice guide on decision-making support around safety and prevention of harm
- participate in the dissemination of the projects' findings and outputs.

The NCOSS facilitator, supported by researchers from the SPRC and SCU partnership, will support the groups in all stages of the research project, such as recruitment of participants as group members, research training, data collection and analysis support (in the form of inclusive workshops).

Groups will use a range of data collection methods to support innovative ways of peer-supported learning and to enable the inclusion of a wide range of people with disability. The inclusive focus will also enable the extension of the project beyond the groups to other people with disability in the community, incorporating their views into the research.

3.1.1 Group participants and outcomes

Group participants

Group participants are people with disability receiving support from SRAC or MDAA who have agreed to take part and contribute to the action research project. Group participants may also be people with disability who are volunteering in their organisations, and communities. Finally, group participants are paid staff and workers from SRAC or MDAA who have agreed to participate and contribute to the action research project.

Outcomes for participants and organisations include:

- Knowledge sharing about seeking and providing culturally sensitive decision-making support with a focus on personal safety and wellbeing and prevention of harm:
 - Share good practice about decision-making support in general

- Share good practice about decision-making support focusing on personal safety and prevention of harm, including in peer-to-peer as well as other support for decision making relationships
- Discuss and reflect on poor practice and possible innovations.

➤ Capacity building

Primary:

- Build individual and group confidence for self-advocacy, community participation, challenging exclusion
- Understand the diversity of support needs for decision making by people with disability about personal safety and prevention of harm
- Build organisational capacity to better support workers who support people in their decision-making process

Secondary:

- Respond to consultation opportunities and have policy input
- Increased political participation and potential to contribute to local and state policy processes, including those related to the delivery of culturally sensitive decision-making support.

Outcomes for NCOSS include:

Promotion of inclusive, culturally sensitive practices to support decision making about safety, strengthening networks and membership, particularly Advocacy and Information organisations; capacity building of people with disability, workers and staff; influencing policy directions and processes on state and federal levels.

Outcomes for SPRC and SCU include:

Gathering and analysis of research data about culturally sensitive decision-making supports on personal safety and prevention of harm, developing and strengthening disability-inclusive research practice.

3.1.2 Action research group methods

Action research and project documentation approach

Groups will be encouraged to meet once a month, at least every six weeks, during the project, approximately five times between June and November 2017.

Each gathering is likely to be a one-to-two-hour facilitated meeting in which groups are encouraged to discuss their experiences of the month's topic, and plan any activities between meetings. At the end of each meeting the group will fill in a template reflecting on the meeting, the action research process and what they think is the important and interesting information from that meeting.

Meeting notes and/or audio recordings from the group meetings will be recorded and sent to the SPRC, along with the completed templates and any visual data from the meetings (e.g. butcher's paper notes).

The staff coordinating the group meeting and NCOS facilitator will debrief from each meeting and complete a template reflecting on the group process. This information can, if desired, be shared with the university-based researchers for evaluation/ review purposes of the action research project overall.

Communication between the groups, NCOS and the SPRC/SCU

NCOS will communicate directly with the groups through an identified staff member in charge of coordinating the groups. NCOS and SPRC/SCU have regular fortnightly project meetings to facilitate input and communication between the project partners not involved in the conduct of the action research project.

Group data collection and presentation

Data will be collected about peoples' and workers' experiences of culturally sensitive supported decision making around personal safety and prevention of harm (how and when do people seek this type of support; what are the different forms it is being provided; when does it achieve the outcomes people are satisfied with/ workers are confident in their support provision; what does 'culturally sensitive' mean in the context of personal decisions around safety and harm minimisation).

1. Self-documenting the journey

The data collection methods will be decided in the groups and by individual research participants, depending on their preferences, interests, abilities and previous experiences with research. Potential group research methods are outlined in detail in Appendix A. They can include, for example, taking photos of situations, places, things or people and reflecting about them later, what they meant to the person (Method: photovoice and photo interviews); drawing or painting a situation where and when the person discussed safety, or received supported decision making around preventing harm (Method: art and visual methods); group discussions, 'yarns' or one-on-one interviews about people's and workers' experiences on the topic.

2. Discussing and reflecting the self-documentation data

Once participants have selected their preferred method and collected the data about their experiences, they will be invited to reflect and share them with other research participants during an inclusive workshop or alternatively, if they prefer, in a one-on-one safe setting, with selected project partners/ facilitator (a trusted staff member, or the NCOS facilitator).

3. Shaping the information/ findings for a wider audience

After the completion of the first two stages (self-documentation and reflection of decision-making support around personal safety and wellbeing), the group members will be invited to get together again, to review and provide input and improvements into a draft practice guide on culturally sensitive decision-making support around safety.

During these inclusive workshops (one at each of the groups), participants will be invited to discuss how the finalised practice guide and other outputs from the research (findings report), will be shaped and shared with a wider audience.

4. Presenting the project findings (optional)

Some groups, or individual action research participants, may choose to present some of their own work/data, and/or the practice guide in the organisations they work at, or where they receive support, or their wider community.

For people and workers who would like to get involved in direct dissemination of the project findings and practice guide to advocacy and information organisations and to a wider audience, the NCOSS facilitator and the researchers will establish opportunities for community and academic presentations (e.g. during the bi-monthly SPRC Disability Research Group Meeting, presentation at the monthly SPRC seminar series).

Action research key principles: person-centredness and choice

During the action research process, participants will be given options to choose which means of collecting and sharing their self-documentation journey suit them best. Some people and workers may decide to take part in different forums, for example, discussing their experiences on an individual basis (on-on-one), and reflecting in a group discussion/ workshop.

SCU and SPRC have extensive experience in applying and providing advice on a range of action research and inclusive research methods. The university-based researchers will provide guidance to ensure that people and workers (group members) have access to, and understand, the range of options and forms they can choose to contribute to the action research project.

The NCOSS facilitator has extensive experience in facilitation and supported decision making with people with disability in personal life and in civic contributions; with their informal supporters; and with staff.

Group research topics

During the five or six meetings, groups will discuss various aspects of their experiences with decision-making support.

Below is a list of five relevant research topics that, as a whole, cover key aspects of the research questions. These topics are suggestions only and can be varied in content and sequence according to each group's preferences.

The suggested research topics are:

1. **My Safety:** What does feeling safe and being well mean to you?
2. **My Decisions:**
 - How do people speak about, or make decisions about, being safe;
 - When and where do you think about being safe (e.g. internet, housemates, cooking, making friends, relationships, money/finances etc); and
 - What decisions do people [you] make about staying safe?
3. **My Support:**
 - What experiences do you/people have with supported decision-making about safety and wellbeing? [getting and providing support]

- Who do people go to when they need support about making decisions about staying safe (family, worker, friend)?
- Who do people go to when they need support about making decisions about staying safe when they live away from or don't have family or community to support them?
- When and where do people seek support to plan to stay safe [proactive]; when do people seek support when they feel unsafe [recovery-oriented]?

4. What Workers need to provide support:

- What support do workers need to provide people with support to make decisions about their own safety and that of other supporters?
- How can organisations use NDIS packages or ILC grants to support people and their supporters with making decisions about their safety and staying safe?

5. What Organisations can do to provide support to workers

- How does your organisation [MDAA/SRAC] support workers to assist people to make their decisions about their own safety and staying safe?
- How else could your organisation [MDAA/SRAC] support workers to assist people to make their decisions about their own safety and staying safe?

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

Building research capacity

Throughout the life of the research project, the project partners (NCOSS facilitator and researchers) will develop and provide resources for group meetings, including: documents to assist in the recruitment of group members; topic guides for discussion; guides on different research methodologies; advice on ethics considerations; participant statement and consent forms; reflection templates for groups and facilitator to complete after each meeting/session (documentation of the process); training to group coordinators and staff; and other resources and support as required. Resources will be expanded and refined with feedback from facilitators and group members to make them useful for this and other related projects.

4. Data analysis

4.1 Framework for data analysis

The qualitative and visual group data, and participants' reflections on their self-documentation journey, will be analysed during inclusive workshops. The audio recordings from these meetings will be transcribed and analysed against the research questions, using thematic coding. This analysed information, together with the literature and program review and other resources, will be used in the development of the draft practice guide.

The draft practice supported decision-making guide will be reviewed and amended with input and feedback from group participants and facilitators during inclusive workshops. Both the research questions and process, will contribute to data analysis as part of the participatory action research approach.

4.2 Expected outputs

In addition to the outcomes listed in section 3.1.1, the project will develop and produce several outputs, including

- Practice guide to inform organisational capacity to deliver good support for workers who support decision making by people with disability about personal safety and preventing harm. The guide will be the basis for research-informed guidance to Advocacy and Information organisations about how to operationalise support for decision making about safety in an NDIS and Information, Linkage and Capacity Building (ILC) landscape (responsibility: NCOSS)
- Report on implementation findings and lessons from the action research (responsibility: SPRC)
- Presentations at various policy and state stakeholder forums, and in particular targeting NSW Advocacy and Information organisations (responsibility: NCOSS and SPRC).

The findings have policy and practice significance for disability community members, government and nongovernment agencies concerned with disability rights, advocacy, person-centred and culturally sensitive service delivery.

Lessons learned from this project will be transferable and adaptable to other advocacy agencies, by describing practices that can be operationalised in an NDIS environment. One priority focus of the research project is to provide the disability sector with some guidance and input in applying for Information, Linkages and Capacity Building (ILC) grants. These NDIS grants aim to build personal capacity, 'making sure people with disability and their families have the skills, resources and confidence they need to participate in the community or access' services, and to build community capacity, ensuring services 'become more inclusive of people with disability'.¹

¹ <https://www.ndis.gov.au/communities/ilc-home> (retrieved 15/05/2017)

5. Timeline and responsibilities

5.1 Project timeframe and outputs

The main project stages are the design of the project; project implementation; data collection; analysis and refinement; development of the policy and practice guide; implementation of the guide and dissemination of project findings to a range of stakeholder forums, project partners, and the wider community, policy and disability sector.

The major outputs from this partnership action research project are listed below.

Table 1: Project timeframe

		Month 2017
Design of the project		Jan-May
Literature and evidence review (completed)	UNSW/ NCOSS	March/ April
Meetings with partner organisations (ongoing)	NCOSS	March-
Research plan	UNSW	July
Implementation		May-August
Ethics applications (in progress)	UNSW	
Development of group resources, e.g. templates, questions, and data collection methodologies (in progress)	UNSW/ NCOSS	
Recruitment of group participants, people with disability and staff/workers (outstanding)	NCOSS/ SRAC/MDAA	
Data collection		July- Nov
Collect diverse participant data about perceptions of seeking support and decision-making support around safety and prevention of harm	NCOSS/ SRAC/MDAA	
Reflective data from the discussions of the self-documentation process	NCOSS/ SRAC/MDAA	
Data on the project implementation and research process (for evaluation/ documentation purposes)	NCOSS/ SRAC/MDAA	
Development of the policy and practice guide		Nov- Dec
Develop policy and practice guide for delivering support for decision making about safety (NCOSS and researchers with input from group participants)	NCOSS/ SRAC/MDAA/ SPRC	
Refine practice guide during inclusive workshops with group participants	NCOSS/ SPRC	
Analyse reflective data from the workshops on dissemination of project outputs	SPRC/ NCOSS	
Dissemination of project outputs		Dec 2017- April 2018
Report on the research process and key lessons from the project (SPRC and NCOSS websites and newsletters, policy forums etc)	SPRC/ NCOSS	
Workshops, meetings with key stakeholder groups project partners and external to disseminate the policy and practice guide	NCOSS/ SPRC	

5.2 Project team

Project lead	NCOSS – Yvette Proud
Research lead	SPRC – Karen Fisher and Christiane Purcal
Group coordinator/facilitator	NCOSS – Yvette Proud
Design, literature review, project plan	Ariella Meltzer, Yvette Proud, Sandra Gendera, Karen Fisher, Christiane Purcal
Safety and inclusion advice	Sally Robinson and Rosemary Kayess
Action research partner organisations	SRAC – Sydney Regional Aboriginal Corporation MDAA – Multicultural Disability Advocacy Association NSW

References

- Balcazar, FE, Taylor, RR, Kielhofner, GW, Tamley, K, Benziger, T, Carlin, N and Johnson, S (2004), Participatory action research: General principles and a study with a chronic health condition, in: Jason, LA, Keys, CB, Suarez. Balcazar, Y, Taylor, RR, Davis, MI (Eds.), *Participatory community research: Theories and methods in action. APA decade of behaviour volumes*, Washington, DC: American Psychological Association, 17-35.
- Bigby, Frawley, & Ramcharan, 2014, Conceptualizing inclusive research with people with intellectual disability. *Journal of applied research in intellectual disabilities*. Vol 27, 1, p.3-12. <http://dx.doi.org/10.1111/jar.12083>
- Bigby, C. & Tait, S. (2004) Evaluation of the independent review of a major life decision affecting people who have an intellectual disability. *Psychiatry, Psychology and Law*. 11, 2, 202- 213.
- Brown, I. & Schormans, A. F. 2014. Quality of life, children with intellectual and developmental disabilities, and maltreatment. *International Public Health Journal*, 6, 185.
- Dowse, L.M, 2009, 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21st century', *Disability and Society*, vol. 24, pp. 571 – 584.
- Epstein, I, Stevens, B, Mckeever, P & Baruchel, S (2008), Photo elicitation interview (PEI): Using photos to elicit children's perspectives. *International Journal of Qualitative Methods*, 5, 1-11.
- Fisher, K. R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'aegher, L. & Thompson, D. (2010). *Effectiveness of Individual Funding Approaches for Disability Support*, Occasional Paper 29, Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs.
- Frawley, P. & Bigby, C. 2014. "I'm in their shoes": Experiences of peer educators in sexuality and relationship education. *Journal of intellectual and developmental disability*, 39, 167-176.
- Folkestad, H (2000), Getting the picture: Photo-assisted conversations as interviews. *Scandinavian Journal of Disability Research*, 2, 3-21.
- Harper, D (2002), Talking about pictures: A case for photo elicitation. *Visual Studies*, 17, 13-26.
- Hurworth, R (2003), Photo-interviewing for research. *Social Research Update*, 40.
- Kusenbach, M (2003), Street Phenomenology: The Go-Along as Ethnographic Research Tool. *Ethnography*, 4, 455-485.
- Manders, J. E. & Stoneman, Z. 2009. Children with disabilities in the child protective services system: An analog study of investigation and case management. *Child abuse & neglect*, 33, 229-237.
- Meltzer, A., Robinson, S., Proud, Y. and Fisher, K.R. (2017) Literature and practice review. Support to make decisions that promote personal safety and prevent harm. Sydney: Social Policy Research Centre, UNSW Sydney.
- Mepham, S. 2010. Disabled children: The right to feel safe. *Child care in practice*, 16, 19-34.
- Novek, S, Morris-Oswald, T & Menec, V (2012), Using photovoice with older adults: some methodological strengths and issues. *Ageing & Society*, 32, 451-470.

- Robinson, S. 2015. Preventing abuse of children and young people with disability under the National Disability Insurance Scheme: a Brave new world? *Australian Social Work*, 68, 469-482.
- Reeve, R., Marjolin, A., Muir, K., Powell, A., Hannigan, N., Ramia, I. & Etuk, L. E. 2016. *Australia's Social Pulse*. Centre for Social Impact: UNSW Australia, Sydney and UWA, Perth.
- UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: <http://www.refworld.org/docid/45f973632.html> [accessed 15 May 2017]
- Wang, C & Burris, M A (1997), Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment. *Health Education & Behavior*, 24, 369-387.

Appendix A Group methods

Groups will investigate the experiences that people with disability and workers have with supported decision-making around safety and prevention of harm, using the following or similar participatory methodologies.

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).

Groups may adapt the philosophy of Photovoice to other media, such as painting, or selecting various important objects that represent their experiences with supported decision making around safety and prevention of harm.

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).

Groups may also choose to use

- Discussions

- Groups 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**
 - Group members may choose to interview each other or people outside the group 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**
 - Groups will determine what information they want to find out in a survey, and researchers from the SPRC will advise on survey structure and questions. Group members will complete the survey and may ask community members, service personnel, or other people with disability to participate also.
- **Focus groups**
 - Groups 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 group meeting, a focus group could be run by the facilitator, or group members could take turns running a focus group in successive months.
- **Technological methods**
 - A range of technological methods could be used by groups, including voice or video recording and iPad apps, to record and organise information, either during or between group meetings.
- **Visual methods**
 - A range of visual methods could be used by groups 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 B Research logic

Topic guides for groups of people with disability and workers	Aims for practice guide	Research questions
My Safety What does feeling safe and being well mean to you?	Personal safety and wellbeing 	1. What support do people with disability commonly seek to make decisions that promote personal safety and prevent harm? a. What are the topics/subjects of decisions people with disability are being supported to make that promote personal safety and prevent harm? b. In which areas of their lives are people seeking support to make decisions about these personal safety and harm prevention issues (e.g. activities in the home, in the community...)? c. From which parts of people's social structures do they seek support to make decisions that promote personal safety and prevent harm (at different levels: family and carers, organisation, community, society)? d. What type of support to make decisions to promote personal safety and prevent harm do they seek – proactive (prevention, capacity building) to reactive (response to risk or harm) to recovery-oriented? e. How does the experience vary for people with low levels of informal support , including people living in the community, in supported accommodation and congregate care?
My Decisions How do people speak about, or make decisions about being safe? (1, 1a) When and where do you think about being safe (e.g. internet, housemates, cooking, making friends, relationships, money/finances etc). (see b.) What decisions do people [you] make about staying safe? (see b. and a.)	Person makes decisions about their safety and wellbeing 	2. What practices are effective to deliver support to make decisions that promote personal safety and prevent harm that is responsive to people's needs (including gender, living circumstances, location, Indigeneity, cultural diversity and others)? a. How can the practices be operationalised in an NDIS environment (individual packages, ILC projects)? b. How can support to make decisions that promote personal safety and prevent harm be made accessible to people who have few informal supports or who live at a distance from support networks such as family and friends, including people living in their community, in supported accommodation and congregate care ?
My Support What experiences do you/people have with supported decision making about safety and wellbeing? [getting <u>and</u> providing support] (see D.) Who do people go to, when they need support about making decisions about staying safe (family, worker, friend)? (see C.) Who do people go to, when they need support about making decisions about staying safe when <u>they live away from or don't have</u> family or community to support them? (see 1e. or 2.b) When and where do people seek support to plan to stay safe [proactive]; when do people seek support when they feel unsafe [recovery-oriented]? (1 d.)	Support to make decisions about safety 	3. What practices are effective to develop organisational capacity to provide support to make decisions that promote personal safety and prevent harm to a range of people from different backgrounds and with diverse needs?
What Workers need to provide support What support do workers need to provide people with support to make decisions about <i>their own</i> safety and other supporters? How can organisations use NDIS packages or ILC to support people and their supporters with making decisions about their safety and staying safe? (see 2.a)	Worker knows how to support the person and their other supporters in their decisions (workers' capacity) 	
What Organisations can do to provide support to workers How <u>does</u> your organisation [MDAA/SRAC] support workers to assist people to make their decisions about their own safety and staying safe? (see 3.) How else could your organisation [MDAA/SRAC] support workers to assist people to make their decisions about their own safety and staying safe? (see 3.)	Organisation supports the worker to provide decision making support (organisational capacity) 	
Practice Guide To inform organisational capacity to support workers, who support people to make decisions about personal safety and wellbeing and prevent harm		