



Never Stand Still

Faculty of Arts & Social Sciences

Social Policy Research Centre

# Social Action Partners

Peer support for children and young people with intellectual disability and their families in Victoria

Project plan

August 2014

Christiane Purcal, Karen R. Fisher, Ngila Bevan, Ariella Meltzer, Sally Robinson

Funded by a Disability Donations Trust Research Grant

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Social Policy Research Centre

August 2014

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ISSN: 1446-4179

ISBN: 978-1-925218-16-9 (online)

SPRC Report 22/2014

The Social Policy Research Centre is based in the Faculty of Arts & Social Sciences at UNSW Australia. This report is an output of the [Self-directed disability support: impact on children and young people with intellectual disability in Victoria](#) research project, funded by Victorian Department of Human Services.

## **Suggested citation**

Purcal, C., Fisher, K. R., Bevan, N., Meltzer, A., & Robinson, S. (2014). *Social Action Partners: Peer support for children and young people with intellectual disability and their families in Victoria [Project plan] (SPRC Report 22/2014)*. Sydney: Social Policy Research Centre, UNSW Australia.

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# 1 Background and rationale

The project will establish local peer support groups of children and young people with intellectual disability and their families in Victoria. These groups will conduct action research about their experiences with self-directed disability support. The intention is to build capacity among participants in the transition to an NDIS-style policy landscape of self-directed support. The research findings will develop a profile of disability support from the perspective of children, young people and their families in Victoria and a baseline for a longitudinal study examining service information systems pre and post the introduction of the NDIS. The short project title is Social Action Partners. It signifies that the project uses social action research methods, which involve acting on social issues and feeding back experiences into the project. The title also signifies that the project is run in partnership between children, young people, families, group facilitators and university researchers.

## 1.1 Background

Disability support has historically been organised through government and service provider agencies (agency funding). Increasingly it is offered through individualised, person-centred packages of support (self-directed support). Opportunities for autonomy and decision making are expanding, in line with the National Disability Insurance Scheme (NDIS) reforms. However, children and young people with intellectual disability and their families remain marginalised from opportunities for information sharing and for developing decision making capacity and autonomy about their preferences.

Further research is required on how children and young people with intellectual disability and their families are managing the transition towards informed decision making in self-directed disability support in Australia. We know little about the impact of information sharing between children, young people with disability, informal carers and support providers on self-directed support (Prideaux et al., 2009). Likewise, there is little systematic evidence about the transition to effective disability support systems (Baxter et al., 2010). Such information is crucial to assess the impact of the new approaches to disability support on equity of access, quality and availability of support, and social outcomes (Ungerson & Yeandle, 2007).

## 1.2 Rationale

The framework of the study centres on knowledge gained from the research team's previous inclusive studies for the National Disability Research and Development Agenda (Purcal et al., 2014 – national adult peer support groups; Robinson et al., 2013 – photo research with young people with cognitive disability about belonging and connectedness). We found that people with disability valued each other as trusted sources of information regarding their opportunities for inclusion, options for support, and how to organise their support in ways that meet their preferences. This project will

extend these methods to children and young people with intellectual disability who have high needs and their families, including parents, siblings and other relatives.

### 1.3 Management

The project, led by the Social Policy Research Centre (SPRC), will be conducted in partnership with:

- a national disability organisation (People with Disability Australia – PWDA)
- local Victorian disability community organisations (Belonging Matters, Inclusion Melbourne and Youth Disability Advocacy Service – YDAS) and
- Southern Cross University (SCU), which specialises in inclusive research with children and young people with disability and regional experiences.

An advisory group will convene to advise on the research design, policy context, analysis, dissemination and follow up plans. The advisory group will be comprised of representatives from the Association of Children with Disability, Queensland Disability Network and NSW Council for Intellectual Disability.

### 1.4 An approach that builds capacity in the disability community

The project will use an inclusive methodology where researchers, children, young people with disability and their families work in partnership (Bigby, Frawley, & Ramcharan, 2014). Groups of children, young people and their families, supported by community organisations and university-based researchers, will conduct the research, collect and analyse the data and produce the outputs. This will build capacity within the disability community, strengthen peer support and develop research competence.

### 1.5 Aims of the research

The aims of the research are to inform the processes and cultural change in local Victorian communities for effective transition to self-directed support by children, young people and families. There are six aspects to these aims, with the project intending to:

- create social action partners through developing peer support groups of children and young people with intellectual disability who have high support needs and their families
- enable peer support for decision making and enhance the capacity of individuals and groups to act on their preferences about disability support
- use peer support to develop steps towards self-directed learning and reflect on any steps taken to implement these steps
- share information about opportunities for social inclusion, support options and how to manage support

- learn about practical experiences with person-centred approaches to disability funding and increase understanding of the mechanics, choices and implications of self-directed support, and
- extend peer support guidelines, tools and dissemination methods between this group of people with disability and their families during their younger years and in preparation for future choices.

The project has the potential to develop the capacity of children, young people and their families, who are the people most likely to be marginalised in the shift to self-directed support. It adopts a prevention and early intervention approach to capacity development.

The findings will advance disability rights and the sustainable provision of effective, good quality social support. They will inform the development of government self-directed support policies, the responsiveness of disability support providers to the new policy landscape, and the capacity of the disability community to use the opportunities presented by self-directed support.

The inclusive action research process will inform future research projects generated by local community organisations and academics. Successful aspects of the methodology will be used for proposed longitudinal action research partnerships.

## 1.6 Research question

The research question is: How are children and young people with intellectual disability who have high support needs and their families managing the transition towards informed decision making about self-directed disability support? The focus includes:

- the rights of people affected (children and young people using or wanting to use support through self-directed and agency funding, families, informal carers and formal support providers) and
- the effectiveness of the disability support system in providing information for autonomy and decision making, equity of access, quality and availability of support, social inclusion and community outcomes.

## 2 Methodology

The project is a comparative study of the impact of self-directed support policies for children and young people with intellectual disability and their families in Victoria, using a mixed-method approach. We propose an inclusive action research process.

Research partnerships with disability community organisations will support the data collection and build research capacity among the organisations, children, young people with disability and their families and supporters.

### 2.1 Local research groups

Local research groups will be formed. The groups will be coordinated by PWDA and facilitated by the local disability community organisations Belonging Matters, Inclusion Melbourne and Youth Disability Advocacy Service (YDAS). Each group will be comprised of about six family units (child or young person and their family members as relevant to the family dynamics and capacity) who are currently using disability support organised through self-directed support, and about six family units whose support is organised through an agency or who do not receive specialist disability support.

We anticipate that three groups will be formed – one by each of the community organisations. The groups have four functions:

- to stimulate reflection and discussion about self-directed approaches to disability support
- to increase local information sharing and research capacity
- to increase social inclusion through social action partnerships between people with shared interests, and
- to collect data about their preferred methods of information sharing and capacity development (see below).

We anticipate that most of the family members participating in the groups will be one or both parents of the child or young person. In many families, parents are the primary carers, teachers (and in some cases gatekeepers) for children, and it is therefore important to include parents in the research and peer support process. Any family members can be included in this project as chosen by the participants.

Each group will meet approximately six times for the data collection activities described below. The group meetings will comprise a mix of collective, child-centred, youth-centred and family member-centred activities so that all members have the opportunity to participate respective to their capacity and support needs. Group facilitators will be experienced in conducting research activities with children and young people as well as adults.

Each group will be encouraged to organise a public event during the project, to facilitate social engagement and broader information sharing at the local level. Such events may include a play day, information workshop, art exchange or photo activity.

The action research process is iterative, where participants try out new ideas between meetings and review their experiences in the group. This will empower children and young people with disability and their families as they gain information about how to use the opportunities presented by the current policy changes; it will improve the person-centred focus of support for people who already use self-directed options; and it will enable quality improvement for those who choose to remain with agency funding and other formal support.

SPRC, PWDA and SCU partnership will support the groups in their activities such as recruitment, publicity, research training and data collection. Resources for the facilitators will be adapted from the partners' previous disability inclusive research. The partners' existing connections with disability community organisations will enable establishment of the groups and working effectively within the given timeframe.

## 2.2 Data collection from children, young people and family members

A sample of 30 to 80 children, young people and families who use or want to use disability support organised through self-directed support and agency funding will be recruited across the groups. The core sample will be from the group membership and extend beyond that base according to the activities of the local group, which may invite participation from other interested families.

Data will be collected about people's experiences of disability support under both individual and agency funding arrangements; person-centred planning, aspirations, supported decision making and support content; transition processes between agency and self-directed support; and outcomes. Comparative standards for measurement will include the outcomes envisioned in the UN Convention on the Rights of Persons with Disabilities (CRPD), National Disability Strategy (NDS), National Disability Agreement (NDA), Disability Service Standards (DSS) and NDIS.

Data collection methods will include surveys, interviews and innovative narrative techniques reflecting the activities of the local group, including written and pictorial material, voice recordings, group work and social media (Facebook, blogs and twitter). SPRC will facilitate collection of the core dataset from the group activities, as well as encourage and support the groups to collect additional data from other community members, if they choose to.

The purpose of including a range of data collection methods is to support innovative ways of peer-supported learning, and to enable the inclusion of a range of children and young people with disability and their families.

SCU will provide advice on inclusive research methods, particularly regarding non-traditional narrative methodologies; the ethical engagement of children and young people; and the regional and rural participation of children and young people with disability and their families.

## 2.3 Inclusive workshops

Inclusive workshops will be held locally: advisory group meetings; public activities for group members and the wider disability community; a workshop for group facilitators from the disability community organisations; and two national workshops associated with the Australian Institute of Family Studies (AIFS) Conference in Melbourne and the Australian Social Policy Conference (ASPC) in Sydney. The local workshops will contribute to community capacity building at the local level, while the AIFS and ASPC workshops will focus on reflective practice, feedback and dissemination, as well as academic, policy and practice implications nationally and internationally.

## 2.4 Target population

The target population is children and young people with intellectual disability who have high needs and who are using or want to use disability support through individual and agency funding arrangements. This includes people who are unable to access, in the current service system, the support they need or the social and economic participation opportunities they want. The research group facilitators will encourage diversity in membership and research participation (gender, Indigenous, culture, language, location, age, support needs, socio-economic status and interests). Local groups will encourage diversity between the groups, depending on local priorities, characteristics, strengths and needs.

## 2.5 Research setting

Inclusive action research has a local social engagement focus. Coordination through the research partners ensures academic rigour and community engagement. The project is feasible considering the partners' established research collaboration in this program area (Purcal et al., 2014; Fisher et al., 2010). The research methodology relies on our extensive community engagement and disability inclusive research reputation and experience, particularly in relation to self-directed support, including in Victoria (Purcal et al., 2014; Robinson et al., 2013).

## 2.6 Framework for data analysis

The qualitative and quantitative data will be analysed against the research questions, comparing by group, type of support arrangement, and characteristics of the person and family. The conceptual framework, common to all data collection and analysis, is derived from the comparative standards for change in outcomes from the CRPD, NDS, NDA, DSS and NDIS (material standard of living; participation, growing and learning; health and wellbeing; social relationships; autonomy; whole of life). We have applied this framework in similar research about rights outcomes and service effectiveness (Purcal et al., 2014, Fisher et al., 2013). The framework can accommodate the rich qualitative and quantitative data without compromising the integrity of individual and family stories or service system information. The workshops described above will contribute to data analysis as part of the inclusive research process.

## 2.7 Expected outcomes for dissemination

- Knowledge gained concerning local disability support and research capacity development for children, young people with disability and their families and disability community organisations
- Baseline data about the experiences of a local sample of children and young people using disability support organised through self-directed support or agency funding
- National report and journal articles
- Resources for local community action research disability groups of children, young people and families
- National and local web-based resources and narratives
- Australian Institute of Family Studies and Australian Social Policy Conference special workshops: disability inclusive research capacity; self-directed support practices
- ARC Linkage Grant application for a cohort study.

## 2.8 Implications for policy development and service delivery

The findings have policy and practice significance for children, young people, families, disability community members, government and nongovernment agencies concerned with disability rights and the sustainable provision of effective, good quality social support and information. The practical implications will be local capacity building in peer-supported decision making and information sharing and state-based lessons to improve the way children, young people with disability and their families and supporters engage with funding choices.

In addition, the project can establish the baseline data and cohort for a longitudinal study, which will generate evidence for effective policy making and service provision.

Local research capacity building will inform further local activities and collaboration on topics such as peer-supported decision making; cooperation between children and young people with disability and their family members, informal and formal supporters; sustainable local financial management strategies; sharing self-directed support experiences with people who are less familiar with service systems; and engaging hard to reach populations.

## 2.9 Limitations of findings

Limitations relate to the short timeframe and limited budget. Action research most directly affects the people involved in the research. The time and budget restrict the number, and therefore diversity, of people participating and the depth at which they can become involved. For these reasons the groups have been designed as baseline groups with a formative focus, in the hope that they will continue to function and inform self-directed support practice after the end of the project. The experience of the previous projects with adult cohorts without family involvement (Purcal et al., 2014;

Robinson et al., 2013) was that most groups planned to continue after project completion.

Since the focus of time and budget is on formative research activities, the amount of quantitative data collection has been minimised, which restricts comparison beyond the sample. This limitation has been addressed by incorporating mixed methods and a conceptual framework from national and international standards, so that the results can be generalised and repeated.

### 3 Timeline

Below is the detailed timeline including dates for critical milestones:

Milestone		Month
Pre project	Community engagement with likely group coordinators and members	May 2014
1. Design	Convene advisory group	Jun 2014
	Finalise group resources for training, support and data collection tools	Jun 2014
	Ethics application	Jul 2014
	Workshop for group coordinators	Jul 2014
2. Data collection and analysis	Convene local groups	Jul 2014–May 2015
	Group training and support to coordinators	Jul 2014–May 2015
	Baseline data collection	Aug 2014
	Baseline data analysis	Sep 2014
	Local Group public events	Feb 2015
	Repeat data collection	Feb 2015
	Repeat data analysis	Mar 2015
3. Dissemination	Advisory group	Apr 2015
	Outputs – public reports, group resources, academic	May 2015
	Dissemination and project follow up in multiple formats	2015
Post project	Continued group activities through community engagement	2015
	Australian Institute of Family Studies and Australian Social Policy Conference special workshops	
	Australian Research Council application for longitudinal follow up	

## 4 Research priorities

In line with the aims of the Disability Donations Trust Research Grant scheme, the research priorities are:

- Explore how to improve outcomes (e.g. life chances, autonomous decision making, well-being, sense of inclusion and participation) for children and young people with a disability
- Investigate the barriers and enablers to reducing social disadvantage and exclusion from the community for children and young people with an intellectual disability. Specific focus should be given to those who are living in situations which reflect diverse family, community and living arrangements and environments, within and/or across different age groups
- Explore new forms of engaging children and young people with a disability in the community and/or their role in social and economic participation
- Prepare children and young people with an intellectual disability for their maximum level of autonomy as clients of the National Disability Insurance Scheme
- Explore the impact of current policy on improving life outcomes for children and young people with an intellectual disability
- Support applied research which will improve the lives of children and young people with an intellectual disability who have high needs
- Make a 'significant impact' on current disability policy and practice to improve the quality of life of children and young people with an intellectual disability in Victoria
- Innovative and rigorous methodology that is the best approach for answering the research questions and meeting the stated research outcomes

### 4.1 Improve outcomes for children and young people

The research focuses on tangible outcomes for children and young people with intellectual disability and their families. Through the inclusive action research process, participants will gain social engagement opportunities with each other, research experience, capacity to articulate their aspirations, increased understanding of self-directed support opportunities, and peer support for decision-making about their life choices and support options. Disability community organisations will gain further insight into the aspirations of the people they support and have opportunities to enhance their relevance in a changing policy landscape.

## 4.2 Investigate the barriers and enablers to reducing social disadvantage and exclusion from the community

The model for the study is designed around local community groups and will include participants from diverse socio-demographic, cultural and geographic communities. Environments influence access to, and experiences with, life choices and disability support. A goal is to explore these different experiences through action research and to build capacity in communities to enhance the ability of children, young people and families to use new opportunities during childhood and transition to adulthood. Action research maximises opportunities for diverse inclusion.

## 4.3 Explore new forms of engaging children and young people in the community and their role in social and economic participation

Engagement and participation are important goals of self-directed support. The project will provide evidence for community groups and policy makers about peer supported engagement and will assist children, young people and their families to use peer information about support to enhance engagement. The project explores how disability rights are affected by the current policy shift to self-directed support, including participation in community life.

## 4.4 Prepare children and young people for maximum autonomy in the NDIS

Peer experience will be shared at the local level to enhance capacity for autonomy. The research responds to a need identified by people and organisations in the disability community for trusted information about transition to self-directed support, and for increasing people's capacity to use these opportunities. The established partnership of UNSW Australia, PWDA and SCU with local Victorian disability organisations makes this project especially practicable in the context of the introduction of the NDIS. As a national disability rights and advocacy organisation, PWDA has local members, both individual members and member organisations (disability advocacy and community groups), that share personal, local and national information about maximising choice and control with regard to the new opportunities.

## 4.5 Explore the impact of current policy on improving life outcomes for children and young people

The research will provide evidence on how disability support policy affects people and organisations, with the goal to improve services to enhance life outcomes. Disability community organisations will participate in the research, so that the study can identify factors to enhance providers' ability to adapt to policy changes.

## 4.6 Support applied research

The research design includes children and young people with an intellectual disability who have high needs and their families in local peer support groups to improve their capacity for using new opportunities of self-directed support. This will improve the lives of the people directly involved in the groups and provide evidence for how to extend the method to other children and young people with high needs in Victoria. The research pertains particularly closely to the National Disability Strategy (NDS) priority areas for action around personal and community support, and health and wellbeing.

The intention of current and future disability support reforms is to promote and facilitate the rights, outcomes and inclusion of children, young people with disability and their families in a range of ways – through specialist support, access to community activities, and fostering of mutual relationships. This research contributes directly to this central aim through formative action research to change practice, and by exploring impact, effectiveness and improvement of the new self-directed support used to fulfil this aim, from the perspective of children, young people and families.

Consistent with the inclusive and formative action research design, the translation into practice will begin within the project itself through the activities of the local groups, workshops for all participants (children, young people with disability and their families, supporters, disability organisations, service providers, government and other researchers), formal reports and articles in multiple accessible formats.

The inclusive action research design means that findings related to self-directed support, peer support, decision making and community-generated research projects can be translated into practice during the project. This project with local activities will ensure that the lives of the people involved will be changed; findings specific to the location can be generated and implemented; and a framework for continuing the activities after the project finishes has been incorporated into the design.

## 4.7 Make a 'significant impact' on current disability policy and practice

The comparative standards in the conceptual framework in the project are derived from the policy context of the UN Convention on the Rights of Persons with Disabilities, the NDIS, the NDS and Victorian policy. The rationale for the framework is that the research can form a baseline experiential profile of the changes in the lives of children and young people as they gain trusted peer information about self-directed support consistent with the NDIS. This will be important for informing equitable, quality service improvement as the NDIS progresses.

The study will provide new evidence of the impact of shifts in policy and practice on the lives of children and young people with disability and their families. This will inform the development and refining of policies and programs. Research findings will be translated into policy and practice and contribute to the national and international

evidence base through the multiple dissemination activities included in the project design.

The research will address gaps in disability research about the way children and young people with intellectual disability and their families prefer to learn about the use of opportunities for self-directed support in Victoria, and thus it will help to maximise their life outcomes during childhood and transition to adulthood. We do not have evidence about how the current policy change towards self-directed support impacts on the rights of people affected – children and people with high support needs, informal carers and support providers – or on the effectiveness of the disability support system at providing trusted information, decision making support or responsive support options.

We propose to fill this gap by using inclusive action research methodologies, resulting in a growing capacity in communities of children and young people with disability and their families across Victoria to undertake peer-support research on topics of importance in their lives. The action research approach ensures that local groups will focus on the gaps relevant to their local communities, such as the service system context and capacity. In this way, the research will address the gap identified in earlier activities of this research team regarding limited local capacity for community-generated information and research.

## 4.8 Innovative and rigorous methodology

The project builds on previous work of the research team and partners on national self-directed support policies; supported living models in Australia; and peer support action research with adults with disability. We will extend these projects to examine the impact of self-directed support on the rights of children, young people and families receiving or wanting intellectual disability support, and on the Victorian service system, and to develop local capacity to maximise the effectiveness of the opportunities in the new support systems.

The project will use innovative, inclusive action research methodology. This methodology builds on our 15 years of practice promoting the inclusion of children, young people with disability and their families in research and training. In addition to using inclusive methods in our projects, researchers on this proposal formed the Disability Inclusive Research Collaboration (DIRC) with colleagues from other universities and organisations. DIRC convened four inclusive disability research events. The success of these events is testimony to our strong links with the disability community, which is vital for the feasibility of the proposal.

In disability research, inclusive studies now focus on including people with disability in research and policy processes (NDRDA 2011). Some studies have separate action research with other family members (e.g. young carers, Moore and McArthur, 2007). Alternatively, family members may act as supporters to people with disability within inclusive practice.

Including people with disability and family members *together* in an inclusive project, combining their perspectives, is uncommon. Young and Chesson (2008) included people with intellectual disability and family members together in an agenda-setting study to determine future health research questions. Nierse and Abma (2011) also included two people with disability and one parent in an agenda-setting study. Neither included extended methodological reflections on the process of including different groups together in inclusive practice.

Other studies beyond these two are just emerging. So far there has been little work on the complexities of navigating the different interests and perspectives of children, young people and family members in an inclusive project targeted to both groups simultaneously, as well as little exploration of how they may work together or what they may offer each other when included together in inclusive practice. Our project offers the opportunity to explore these new areas.

## 5 Participation

The project methodology is inclusive of children, young people with intellectual disability and their families, in research design, collection, analysis and dissemination. Children, young people and their families will be active participants and community researchers. Disability rights are central to this research, as they are part of the conceptual framework and research question. Forming local inclusive groups makes the project efficient and builds local capacity.

SPRC, SCU and PWDA will collaborate with local disability organisations in Victoria. The research partnership between SPRC, SCU and PWDA has been active for over 10 years, collaborating successfully on numerous research studies and capacity building events. In this project, PWDA will coordinate local disability organisations to establish research groups, which in turn will involve other local disability groups and individuals. SCU will advise on inclusive research with children, young people with disability and their families, including in regional and rural areas, using non-traditional research methods.

Research participation of children and young people with disability and their families is central to the methodology of this study. The research groups will generate the primary data for the study, through interviews, surveys and other more inclusive data collection methods that the groups decide on. These will include social media, photos or voice recordings. A variety of innovative data collection methods will ensure that people with a wide range of disabilities can participate in the research. The groups' activities in data collection will also build research capacity among the disability community, to encourage the generation of local research projects. The project partnership will form the basis for follow-up applications to ARC, government and other funding streams.

The design takes a cross-disciplinary approach, with mixed methods adopted from social policy, disability studies and economics. SPRC, PWDA and SCU have extensive experience in conducting research with children and families, developing accessible research methodologies and communicating research findings to a variety of audiences. The members of the research team and partnership actively pursue the community engagement activities required for accessible dissemination and application, such as NGO events, membership, speaking engagements and training.

All SPRC research adheres to strict ethical principles outlined in the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 2007). The planned research methodology and all research instruments and forms will be submitted for clearance by the UNSW Human Research Ethics Committee (HREC) to ensure that the research complies with these standards.

## 6 Dissemination and use

Dissemination of research findings will be through a variety of channels and formats. SPRC, PWDA and SCU have extensive expertise producing accessible research documents. For example, recent SPRC projects that produced easy read documents were: ARTD Transition to Retirement, FaHCSIA Easy Read advocacy documents, and ADHC Supported Living.

In this project, findings will be disseminated through:

- Publications and resources, including this project plan, report of findings, summary report, conference papers and seminars, and journal articles
- Workshops
- Participant evidence presentation and discussion
- Web links to free resources – project plan, guidelines and tools for peer support and research groups, outcomes from research groups that they want to make public, reports and other publications.

## 7 Management

### 7.1 Research team

All research team members have the extensive specialist experience necessary for this complex formative research project, with its diverse objectives regarding disability rights outcomes, community engagement, research capacity building and the social service system.

Chief investigator	Karen Fisher	SPRC
Project leader	Kelley Johnson	SPRC
Project manager	Christiane Purcal	SPRC
Group coordinator	Ngila Bevan	PWDA
Design, collection and analysis	Christiane Purcal, Ariella Meltzer	SPRC
Inclusive methods advice	Sally Robinson	SCU
Group facilitators and members	Facilitated by Belonging Matters, Inclusion Melbourne, and Youth Disability Advocacy Service (YDAS)	

The established research team will work together to deliver the outcomes as demonstrated in their earlier collaborations. UNSW, PWDA and SCU have an established national reputation for inclusive action research with disability community organisations. The researchers are full-time research academics, within applied research centres with dedicated infrastructure to support research outcomes. CI Karen Fisher, project leader Kelley Johnson and project manager Christiane Purcal at SPRC have well-established systems to deliver disability policy research outcomes on time and within budget across simultaneous research projects. Sally Robinson (SCU) and Ariella Meltzer (SPRC) are also dedicated disability researchers, who have established reputations in inclusive disability research with children, young people and family members.

The effective collaboration with Ngila Bevan of PWDA is demonstrated in the 2013 adult peer support project (Purcal et al., 2014). She successfully established and supported eight national peer support groups, including with people with intellectual disability.

PWDA has reached agreement with the disability community organisations Belonging Matters, Inclusion Melbourne and Youth Disability Advocacy Service (YDAS) to support the establishment of action research groups for this new cohort of children, young people and family members in Victoria, building on the earlier projects. PWDA has also reached agreement with representatives from the Association of Children with Disability, Queenslanders with Disability Network and NSW Council for Intellectual Disability to form an advisory group for the project. All of these organisations'

involvement is based on their agreement with, and support of, this project plan. Piers Gooding and John McKenna, who are on the Board of Belonging Matters, were involved in the earlier peer support project, as was Mark Edmonds from the Queenslanders with Disability Network, who will be on the project's advisory group.

## 7.2 Preliminary risk management strategy

Risk	Likelihood	Severity	Solution
Psychological distress or other harm to children, young people with disability and their families	Low	High	Stringently designed recruitment and data collection procedures. Trained facilitators. Follow up and referral protocols.
Failure to form local groups	Low	High	Work actively with SPRC, PWDA, SCU and local disability community organisations.  Group support funds allocated in budget for reasonable accommodation and costs.  Train local participants in action research.
Research compromised due to lack of capacity	Low	High	Research training of group members. Draw on SPRC research skills.
Poor communication between research partners (SPRC, PWDA, SCU, community organisations) and the groups	Low	High	SPRC, PWDA and SCU team members have a long history of working with each other and with local disability community organisations.
Research does not adhere to budget	Low	High	Budget is based on previous experience of several projects, all of which have reported on time and within budget. Risk is borne by SPRC.
Research design does not meet the policy needs of children, young people with disability and their families, government and service providers	Low	High	Design, detailed objectives and dissemination strategy will be developed in collaboration with children, young people with disability and their families, government and service providers through the action research and advisory group.
Poor quality data	Med	Med	Close consultation with local group facilitators to identify and manage data quality.  Use of standardised instruments used in similar studies. Training for researchers and QA systems.
Data gaps	Med	Low	Recruitment assistance and research training for groups and facilitators.
Research team fails to work effectively	Low	Low	Build on history of collaboration and protocols for accountability and communication.
Research team member unavailable	Low	Low	Succession plan within the team for continuity.

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