Peer Support with Children and Young People with Intellectual Disability

Literature review

Christiane Purcal
Katherine Evans
Ariella Meltzer
Kelley Johnson
Karen R. Fisher
Sally Robinson
Ngila Bevan
Rosemary Kayess

UNSW AUSTRALIA

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SPRC
Social Policy Research Centre

Social Policy Research Centre, UNSW Australia
Karen R. Fisher, Kelley Johnson, Christiane Purcal, Rosemary
Kayess, Ariella Meltzer, Katherine Evans, Zach Parker

People with Disability Australia
Ngila Bevan

Centre for Children and Young People,
Southern Cross University
Sally Robinson

Community research partners
Belonging Matters, Inclusion Melbourne, Youth Disability
Advocacy Service (YDAS)

For further information
Karen Fisher, Social Policy Research Centre
T: +61 2 9385 7800
E: karen.fisher@unsw.edu.au

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Abbreviations

NDIS   National Disability Insurance Scheme

1 Summary

This literature review is part of a research project called Social Action Partners. In the project, children and young people with intellectual disability and their families join groups for peer support and research about their experiences of self-directed disability support. The project aims to build capacity for transition to the National Disability Insurance Scheme (NDIS).

Inclusive research with children with disability

Inclusive (or participatory) research assumes that research should be done *with* people and not *on* or *for* people. It is consistent with principles for ethical research. It is also often combined with action research, which aims to influence social change. This approach to research with children and young people with disability is a way of upholding their rights and place in society.

Ways that children and young people can participate in research include being informed, expressing a view, influencing decisions, and being the decider. Involving children and young people with disability in research is less common than involving other children. It is, however, increasing, especially if the research is about services they use or decisions that affect them. Inclusive research prioritises careful planning, such as considering the time, place, and support the children would prefer. Useful research strategies include adopting skilled communication methods; engaging with supporters who the children trust; and using communication aids.

Most children and young people live in a family context, which means that inclusive research also needs to consider, and sometimes include, their family members. The distinct and sometimes contradictory stories from each family member need to be gathered and woven together, without marginalising the child's voice.

Using peer support in research

Peer support is a practice and action research method based on giving and receiving help. It assumes that people can help each other when they face similar situations. Peer support ranges from informal and ad hoc support, to unpaid and organised support, and through to peer support that is organised by paid facilitators. Relationships in peer support are dynamic as people learn from each other, and good peer support adopts processes that consider this potential learning. Success factors for formalised peer support include clear role definitions, resources to facilitate interaction and training, and support for peer support workers.

Inclusive research and peer support methodology are based on disability rights principles and are regarded as respectful and empowering ways to conduct research with people with disability. They are increasingly used although children and young people with intellectual disability are as yet rarely included in research projects. While some studies are now emerging about inclusive research and peer support with children and young people with disability, including intellectual disability, few of these studies also include families. As Australia moves towards self-directed disability support, more research where children, young people, and their families decide how the research is conducted is needed to inform policy development.

2 Introduction

This literature review is part of the research project Social Action Partners and is funded by a grant from the Disability Donations Trust in Victoria (Purcal et al., 2014b). The project involves inclusive action research about the experiences of children and families with self-directed disability support. In the project, children and young people with intellectual disability and their families join groups designed to facilitate both peer support and research in Victoria. The project aims to build their capacity for the transition to the National Disability Insurance Scheme (NDIS). The project also aims to generate useful information for the disability community, particularly for policy and practice, about the experiences of children and young people with intellectual disability and their families.

This document reviews the literature on inclusive action research that has informed the project design. It uses related terms for this type of research, including inclusive action research, social action research, participatory action research, and peer support research (Section 3). These terms each indicate that the research aims to facilitate the inclusion and participation of the people who the research is about; and that the aim is to support them to improve their situation. The review focuses on action research, which uses peer support methods, and research which includes children and young people with intellectual disability and their families.

2.1 Background to the project

Traditionally, disability support in Australia has been organised through government and service provider agencies. However, new options of individualised, person-centred packages of support – called self-directed support – are now available. Self-directed support aims to increase the opportunities of people with disability for autonomy, decision-making, and social inclusion. These goals align with the obligations in the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006). A range of government policies also aim to achieve these goals through measures summarised in the National Disability Strategy. The National Disability Insurance Scheme (NDIS) reforms and their focus on self-directed disability support are one of these mechanisms.

In this policy context, little is known about the needs of children and young people with intellectual disability and their families in relation to self-directed support services. For example, what are the effective ways to assist them to participate in self-direction, and how would they like to be involved (Franklin, 2013). Further, this group often remains marginalised from opportunities for information sharing and for developing decision-making capacity. This means that little is known about their preferences for participation, or about how they would like their support to be organised. Further research – such as the project undertaken here – about how they are managing the transition towards self-directed disability support would address this problem. Such information is crucial if the new approaches to disability support are to improve equity of access, quality, and availability of support and better social outcomes (Ungerson & Yeandle, 2007).

2.2 Social Action Partners project

The Social Action Partners project, conducted with children and young people with intellectual disabilities and their families, is about their experience of self-directed support. It builds on experience from the research team's previous inclusive studies (Purcal et al., 2014a – national adult peer support groups; Robinson et al., 2014 – photo research with young people with cognitive disability about belonging and connectedness). These projects found that people with disability valued each other as trusted sources of information regarding their opportunities for inclusion, options for support; and about how to organise their support in ways that meet their preferences. The current project extends these methods to children and young people with intellectual disability who have high needs and their families, including parents, siblings, and other relatives (Purcal et al., 2014b).

The project is led by the Social Policy Research Centre (SPRC) in partnership with:

- the national disability organisation, People with Disability Australia (PWDA)

- local Victorian disability community organisations; Belonging Matters, Inclusion Melbourne and Youth Disability Advocacy Service (YDAS)

- the Centre for Children and Young People at Southern Cross University (SCU), which conducts inclusive research with children and young people with disability and regional experiences

- an advisory group of representatives from the Association of Children with Disability, the Queensland Disability Network, the NSW Council for Intellectual Disability and JFA Purple Orange.

The project uses an inclusive methodology where researchers, children, young people with disability and their families work in partnership (Bigby, Frawley, & Ramcharan, 2014). Researchers from the universities and PWDA approached the three local community organisations to participate in the project. Together, they planned the project and developed resources for the research. The local organisations invited children, young people and their families to form groups that meet regularly to talk about self-directed support. The research was conducted in the meetings, which generated information about what they had done to learn about self-directed support, what they wanted to know more about, and what they would do in the future. The project is intended to build capacity, strengthen peer support, and develop research competence within the disability community.

2.3 Literature review method

This literature review was conducted by searching online databases and websites of government and non-government agencies, disability advocacy groups and service providers, and through consulting researchers in the field. Search terms included the concepts used in the project design: inclusive research, action research, peer support, and children and young people with disability and their families. It was not a systematic review. Further research could extend this review by using systematic review processes and by engaging with children and young people with disability and their families about the concepts they would prioritise.

3   Inclusive research

3.1   Importance of inclusive and action research within disability research

The terms inclusion and participation are often used interchangeably in research. Inclusive or participatory research models are premised on the belief that research should be done *with* people and not *on* or *for* people (Brock and Pettit, 2007). There are a diversity of such research models, where participation may include a wide continuum of involvement (Kirby et al, 2003; Sinclair, 2004; in Franklin, 2013; Nind, 2014, p. 11). For example, participation may include taking part, being involved, present, or consulted (Franklin & Sloper, 2006), or it may involve the transfer of power so that the views of participants influence the research decisions, focus, and design (Franklin & Sloper, 2006). In any case, participatory research and inclusive research include participants 'as more than just research subjects or respondents' (Walmsley, 2001, p. 187). A further step is emancipatory research, which occurs where participants control the research process itself and are encouraged to own the outcomes (French & Swain, 1997).

Participatory and inclusive approaches are also often combined with action research models, bridging the gap between research and action to influence social change (Krech, 1946; Walmsley & Johnson, 2003). Participatory action research is one such model. It engages people in reflecting on and improving their own situation within a supportive environment (DHHS with DLA Piper Australia, 2012). It is usually political, involves the participants in all stages of the research process (Walmsley & Johnson, 2003), and creates a culture of continuous improvement (DHHS with DLA Piper Australia, 2012).

The political, active orientation of each of these research models is particularly important for people with disability. It links to a recent shift from a medical discourse about disability to a focus on addressing and improving the disabling barriers such as social exclusion, prejudice and discrimination that influence the lives of people with disability (Franklin & Sloper, 2006). Accordingly, in much current disability research, there is a focus on including people with disability in research and policy processes (NDRDA 2011) and on promoting social participation, rights and social change (Mortier et al, 2011). Inclusive, participatory, and participatory action models of research are all well suited to address these social concerns and, as such, have become key models of disability research.

Further, the right of children and young people with disability to participate in research that affects their interests is also recognised by the United Nations through the UN Convention on the Rights of the Child (CRC 1990) and the UN Convention on the Rights of Persons with Disabilities (CRPD 2006). For example, in the CRPD, Article 7.3 requires governments to "ensure that children with disabilities have the right to express their views freely on all matters affecting them", and general principle (h) affirms "respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities". For this reason, research with children and young people with disability is not only becoming an increasingly important area of research practice, but is also important for upholding their rights and place in society.

3.2 Inclusive research with children and young people with disability

Literature on involving children and young people in general in research, that is, children and young people without disability, is well developed (Foster-Fishman et al 2010; Franklin & Sloper 2006). It examines methods to engage with young people (Foster-Fishman et al 2010), ethics, power implications, and legal contexts of doing so (Fraser et al., 2004), as well as how their participation can effect social change (Franklin & Sloper 2006). It reflects conceptual changes about 'childhood' and capacity and reflects the increasing importance placed on involving children and young people in decision-making and processes of change (Nind et al, 2010; Davis & Watson, 2000). Some of the research argues that, particularly for children and young people, participation in research should correspond to their circumstances, capabilities, and choices (Kirby et al, 2003).

The involvement of children and young people *with disability* in research has historically been less common, as this group has often not been included as research participants or in participatory or inclusive practices (Lewis and Lindsay, 2002; in Mortier et al, 2011). Franklin (2013, based on Alderson and Montgomery, 1996) identified four levels at which children might participate in research:

1. being informed

2. expressing a view

3. influencing the decision making process

4. being the main decider.

In examining the participation of children and young people with disability in research, Franklin (2013) suggests that the first two levels of being informed and expressing a view have often been unavailable to children and young people with disability, and accordingly, that their opportunity to engage in the next two levels of participation have also been limited. As a result, children and young people with disability have historically not been included in the research process.

The involvement of children and young people with disability in research is, however, becoming increasingly common. Several studies have begun to address the experience of disability in childhood (Foley et al., 2012; Watson et el., 1999, Goodley and Runswick-Cole, 2012, Curran and Runswick-Cole, 2013) and young adulthood (Slater, 2012, Abbott and Carpenter, 2014), examining this area from the perspective of children and young people with disability themselves. One study confirmed that children and young people with disability value voicing their opinions about services in a respectful environment and value involvement in decision-making processes (Beresford 2002 in Franklin, 2013). Similarly, other work has suggested that children and young people with disability want to participate in decisions and policies that affect them and in planning services that they use (Council for Disabled Children, 2009).

Even though research that includes children and young people with disability is becoming more common, children and young people with disability are, however, still predominantly included in research specifically about the experience of disability itself. They are, in other words, rarely included in research that is about children

more generally (although there are some exceptions, e.g., Skattebol et al., 2013). Further, most studies include children and young people with disability as research participants (e.g. Watson et al., 1999, Goodley and Runswick-Cole, 2012, Abbott and Carpenter, 2014), with only a few including them in participatory or inclusive practice where they are involved in research decisions (e.g. Gray and Winter, 2011; Curran and Runswick-Cole, 2013). This latter area of inclusive practice would therefore benefit from further development. As indicated below, advancements in ethics and methodologies may assist in moving this area forward.

Ethical research

In increasing the participation of children and young people with disability, principles of ethical research should be considered. Drawn from child rights and informed by children's studies, principles of ethical research with children include the following areas, as detailed by Graham et al. (2013) and Simmons & Robinson (2014):

- view children and young people with disability as persons in their own right and as worthy and capable of recognition, respect, and voice in research

- assume young people's involvement in research takes place with the active support of people around them, who will provide appropriate assistance and guidance as and if needed

- acknowledge the importance of research focused on understanding and improving young people's lives and circumstances

- engage critically with ethical principles of respect, benefit, and justice

- promote the importance of communication and reflection in attending to the complex ethical issues that may arise in research of this nature.

Research methodologies

Research methodologies have recently been developed that begin to foster the inclusion of children and young people with disability. Many of these methodologies are particularly important for including children and young people with intellectual disability as they address the complex power relations and communication complexities that may arise for this group in the research process.

Lewis and Porter (2004) propose guidelines for conducting research with children with intellectual disability. They suggest carefully planning research and communication processes and apportioning appropriate lengths of time to give an effective voice to children and young people with intellectual disability. They also highlight the importance of consent as well as the use of visual or enactive methods such as photographs, video, movement, and drama.

A selective account of some other inclusive research methodologies is summarised in Table 1. This is not intended to be an exhaustive account of the relevant methodologies, but rather a suggestion of a few strategies that are appropriate and useful in conducting research with children and young people with disability.

Table 1: Research methodologies with children and young people with disability

Skilled communication	Kelly (2007) highlights the importance of using sensitive, skillful and structured questioning techniques when doing research with children with learning disabilities.
	Skilled communication is especially needed when using methods that involve complex situations to communicate in. For example, in order to conduct focus groups with adults with complex communication needs (that is, who have unclear speech or no speech, but rather written or symbolic communication), group facilitators must be proficient in a wide range of communication strategies in order to cater to the different communication needs of participants (Hemsley et al., 2008). This type of skilled communication would also be important if conducting focus groups with children.
Supporters	Children and young people with disability may sometimes wish for supporters to help them communicate during the research process. This could mean involving a person who knows the participant well or someone else with intellectual disability to help gather and interpret information (Whitehurst, 2006). Family members may assist in understanding a child's communication and preferences (Kelly, 2007). Supporters such as advocates or family members may be particularly important for facilitating thorough informed consent (Nind, 2008).
Communication aids	Augmentative and alternative communication may also be used to facilitate inclusive research. This could include informal or symbolic systems that children and young people with disability may use in their everyday lives or may include clear and simple written information supported by images to assist with comprehension (Scope, 2007, 2008).
	For example, a project including children who do not use speech to communicate used 'Talking Mats', which is a visual framework using symbols (Murphy and Cameron, 2008). In an interview format, cards with a subject area were presented to the child, and they were able to choose from a range of responses to place alongside that card to answer the questions (Rabiee et al, 2005). A range of other symbolic systems are also available as well as other visual methods and oral and life history approaches that facilitate communication in research (Atkinson, 2004, Owens, 2007, Boxall and Ralph, 2009).

3.3   Including families in inclusive research with children and young people

Irrespective of disability, most children and young people live in a family context. This means that inclusive research with children and young people with disability needs to consider the role of their family members. However, very little research has been conducted about the complexities of navigating the different interests and

perspectives of children and young people with disability and family members in an inclusive project targeted to both groups simultaneously. Some studies have involved separate action research with family members (e.g. young carers, Moore & McArthur, 2007); however, including people with disability and family members *together* in an inclusive project and combining their perspectives is uncommon. Young and Chesson (2008) included people with intellectual disability and family members together in an agenda-setting study about health, and Nierse and Abma (2011) included two people with disability and a parent in an agenda-setting study. Yet, neither reflected on the methodological challenges or benefits of their dual participation. For example, the studies did not reflect on the benefits of family members acting as supporters to people with disability in the research process, nor did it reflect on what can be done to accommodate everyone's needs and perspectives. This methodological reflection remains a gap in the field.

Studies outside of disability research have included methodological reflections on the complexities of including multiple family members together in research. These studies highlight the benefits and challenges of eliciting and including multiple perspectives. Benefits include, for example, that multiple perspectives allow a deeper understanding of family experience (Harden et al, 2010). Challenges, however, include dealing with complexities where a child or young person's views may be influenced by their anticipation of the accounts of older family members (Harden et al, 2010), and being careful not to give preference to the accounts of more vocal family members over others (Forbat & Henderson, 2003). In creating a 'family story', it is important to weave together the distinct and sometimes contradictory stories from each family member to create an overall narrative of the family experience (Warin & Lewis, 2007). In the context of disability, where people with disability's voices have often been marginalised, but where there are also benefits to supporters contextualising their views, there is great importance to further exploring the application of this literature about multiple family perspectives to children and young people with disability and their families. This is therefore an important area that the current Social Action Partners project can address.

4   Using peer support in research

Peer support is a practice and an action research method based on giving and receiving help (Mead, Hilton & Curtis, 2001). It is a process by which participants understand each other's situation empathetically through sharing emotional, psychological, and practical experiences (Mead et al., 2001). The approach assumes that people who have overcome adversity can help others facing similar situations (Davidson et al., 2006).

4.1   Peer support processes and benefits

Types of peer support vary, as does its potential impact (Repper & Carter, 2010; Williams 2011). The Mental Health Foundation (2012) describes three approaches to peer support:

1. informal and ad hoc support among community members or service users, such as families coming together in a playground;

2. organised but unpaid peer support undertaken by volunteers, such as some self-help groups or peer mentoring; and

3. paid peer support, where participants are contracted to provide services to service users, such as consumer representatives, peer advocates, and peer advisers.

A core component of peer support is the relationships it contains. Relationships in peer support are dynamic as people learn from each other, and good peer support adopts processes that consider this potential learning (Mead et al., 2001). One learning process is the reflective nature of action research. Both the peer support members and other people might learn from what the peer support discovers (Mead et al., 2001). However, to facilitate this learning, the peer support must be effective. McLean et al. (2009) identify factors indicating the success of formalised peer support including clear role definitions, access to appropriate training and support for peer support workers, and training and support for staff to ensure that workers are part of larger teams.

A direct benefit of peer support is that it can help participants to meet people in a situation similar to themselves (Mental Health Foundation, 2012). Research about peer support for people with mental illness has demonstrated benefits for the people in the peer support group, the workers supporting the process, and the wider mental health system (Mental Health Foundation, 2012). Benefits include increased perceived empathy between peer supporters, outcomes of empowerment and of strengthening people's sense of "self-efficacy, self-esteem, and the belief that positive personal change can come about through one's own efforts" (Campbell & Leaver, 2003:14 in Mental Health Foundation, 2012:3; see also Hibbard et al., 2002). The Social Action Partners project will explore whether and how these benefits may be carried over to children and young people with intellectual disability and their families through participatory action research based on a peer support model.

4.2 Examples of peer support with children and young people with disability

Some projects in the UK have aimed to foster the development of peer support as a method to promote the action research participation of children and other people with mental illness or intellectual disability (FPLD, 2002-2004, 2008, 2012). These studies found that young people with disability find peer support a valuable way to overcome barriers to inclusion. In particular, peer support reassured them of their ability to transition into colleges and secondary schooling (FPLD, 2008). Action research has also been used to support young people with intellectual disability transitioning into adulthood, as well as supporting the emotional and mental health needs of their families and carers (FPLD, 2002-2004). Involvement in such research not only identified their needs and problems, but also assisted them in being involved in subsequent projects (FPLD, 2002-2004).

Another UK project used peer support to build leadership skills of family carers and to give them a voice in the development and delivery of support to young people with learning disability through direct payments and personal budgets (FPLD, 2012). This project found that peer support groups were an effective way for families to learn from one another about how to improve the quality of support available to people with learning disabilities (FPLD, 2012). The peer support did not include the young people themselves although the resources the groups developed, focused on approaches to encourage young people's direct involvement.

Other research has also demonstrated that informal peer support can arise more naturally in the places and spaces that people with disability inhabit, especially where support comes from incidental social relationships rather than from formalised programs. For example, some people with intellectual disability connect to support from peers and workers in the collective or community spaces that they frequent (Hall, 2010; Power, 2008). Support in these places is important for people with intellectual disability to feel comfortable and able to connect with others. In a recent Australian project, young adults with intellectual disability talked about how they valued both the spaces and relationships where they felt fully accepted by their peers (Robinson et al., 2014).

While the approaches highlighted above bear most resemblance to the Social Action Partners project, other approaches to peer support in research are also emerging. For example, in Australia, there is an increasing focus on capacity building in service-oriented research and in the evaluation of services used by children with disability. Approaches such as Asset Based Community Development (Boyd et al. 2008), wrap-around planning, and building family and community capacity (Mistry, 2012) have been applied in research with children and young people with disability to build both individual and community capacity for inclusion (Notara and Robinson, 2013). While these approaches are not the focus of the current Social Action Partners project, they show the importance of the nexus between peer support and research for children and young people with disability.

5 Conclusion

Inclusive research and peer support methodology are based on disability rights principles and are regarded as respectful and empowering ways to conduct research with people with disability. They are increasingly used although children and young people with intellectual disability are only recently beginning to be included. Although some studies are emerging about inclusive research and peer support with children and young people with disability, including intellectual disability, few of these studies also include families. As Australia moves towards self-directed disability support, more research where children, young people and their families decide how the research is conducted is needed to inform policy development.

The Social Action Partners project aims to address these identified gaps in the literature and to extend the methods of inclusive action research and peer support to children and young people with intellectual disability and their families.

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