Literature and practice review: Support to make decisions that promote personal safety and prevent harm

Prepared for:
NSW Council of Social Service (NCOSS)

April 2017

Ariella Meltzer, Sally Robinson, Yvette Proud, Karen R. Fisher

Research Team

Social Policy Research Centre:

Karen R. Fisher

Rosemary Kayess

Christiane Purcal

Sandra Gendera

Ariella Meltzer

Southern Cross University:

Sally Robinson

NCOSS:

Carolyn Hodge

Yvette Proud

For further information:

Ariella Meltzer +61 2 9385 7800, a.meltzer@unsw.edu.au

Social Policy Research Centre

UNSW Arts & Social Sciences

UNSW Australia

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

Suggested citation:

Contents

Preface

The NSW Council of Social Service (NCOSS) is undertaking an action research project to develop (1) a practice model of delivering supported decision-making with a safeguarding focus for people with disability and (2) organisational capacity to provide best practice individual safeguarding support to a diverse range of people with disability. The Social Policy Research Centre (SPRC) has been commissioned to provide research advice, training and action research practice support to NCOSS.

The project seeks to explore a series of issues, focused around three major research questions:

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?

This document details a literature and practice review undertaken to synthesise information from existing academic and practice evidence to inform the approach of the project. It is published in order to assist with other research and practice development on this topic.

Method

The literature review was a search of academic journals. It was conducted by SPRC using combinations of search terms about safeguarding (i.e. 'safeguarding', 'risk', 'harm'), supported decision-making (i.e. 'decision support', 'supported decision-making', 'capacity building'), the current policy context of the roll out of the National Disability Insurance Scheme (i.e. 'personalisation', 'individual budgets') and social context (e.g. 'social inclusion', 'relationships'). These terms were searched in conjunction with the terms 'disability' and 'intellectual disability'.

The practice review draws on experiences in supported decision-making projects run through Ageing Disability and Home Care (ADHC) and the Department of Family and Community Services (FACS) NSW. NCOSS staff conducted the practice review, gathering and analysing information drawn from participation in the NSW Supported Decision Making Community of Practice, publicly available resources, consultations with project staff, conference presentations and prior experience in leadership of one of the projects in the review. As none of the reviewed projects have yet released formal evaluations, the practice review is supported by the academic literature review on the research topics to bring together both existing evidence and promising practice.

1. Introduction

As Australia moves towards the full implementation of the National Disability Insurance Scheme (NDIS), supporting people with disability to make decisions that promote personal safety and prevent harm is important. This can include people with a range of different types of disability, particularly those who may have missed out on opportunities 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 a series of factors that negatively impact the likelihood of people with disability receiving effective and timely support if they do experience abuse. This includes a reluctance to believe the high rates of abuse experienced by people with disability among professionals, pathologising of disability, disbelief of their accounts and a lack of skill in providing appropriate support (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.

Further, as choice and control is extended through the NDIS, people with disability will be required to make a broader range of everyday decisions about their relationships, support services, community, economic participation and other activities. Ensuring that people have the support to balance risk and choice within these decisions is important for responsibly implementing the NDIS policy changes towards personalisation. Significantly, the *NDIS Quality and Safeguarding Framework* notes the importance of developmental measures to strengthen the capability of people with disability for safeguarding, alongside preventative and corrective measures to respond to issues that have already arisen. In this context of both preventing abuse and supporting people to balance risk and choice, this review examines the available evidence about support to people with disability to make decisions that promote personal safety and prevent harm. It focuses on support to people with intellectual disability in particular, as this is a group who have very often missed out on opportunities to develop their decision-making skills, however many of the findings may be applicable to other persons with disability who need support with making decisions about safeguarding.

Existing academic research has identified consistent safeguarding issues that arise under policies of personalisation (Manthorpe et al., 2009, 2011, 2013, 2015, Carr, 2011, Campbell et al., 2012, Ellis and Preston-Shoot, 2012, Junne and Huber, 2014, Stevens et al., 2016), highlighting tensions between choice and control on the one hand and safeguarding or harm reduction on the other (Manthorpe et al., 2009, 2015, Ellis and Preston-Shoot, 2012, Stevens et al., 2014). However, less research has identified and/or evaluated strategies to support the decision-making that can address these tensions. Further, little academic research has directly asked people with disability about their perceptions of what it takes to support them in decision-making about promoting personal safety and preventing harm (Robinson, 2013). The infrequency of studies reporting on the perspectives of people with disability about safeguarding and risk is a problem also noted more generally in the literature, where the ethical concerns about asking people with disability about sensitive subjects such as abuse are noted, but so are the hazards of not studying risk and safeguarding for this group and thereby not generating the knowledge needed to improve their outcomes in these areas (Fyson and Kitson, 2007, Northway et al., 2013b).

Further to the available academic research, a new emergent evidence base is also developing based on Australian projects aiming to support decision-making for people with disability. In recognition of the increased need for support for decision-making under the NDIS, Australian state and federal governments have moved to provide a number of supported decision-making projects. These projects are focused on building self-determination under individualised decision support, prioritising a rights-based approach and building from practice experience to implement principles of co-design and mentoring, as well as focused learning opportunities and skill and capacity building. The projects thus represent an important evidence base that complements and extends the available academic literature, picking up on some of the most recent developments that are not yet reflected in the published academic studies.

In this context, this review draws together the findings of the available academic literature and practice evidence, in order to begin to answer the research questions in the preface to this paper and understand the subjects about which people with disability seek decision-making support for promoting personal safety and preventing harm; types of support that are useful and promising practices for delivery; the sources of support that people with disability draw on; and the experiences of different groups. The review first reports on the academic and practice evidence on each of these areas and then ends with implications and conclusions for the action research project currently being undertaken by the NSW Council of Social Service (NCOSS), as described in the preface to this paper.

In reporting on the academic literature, the review includes research from multiple perspectives, but, where possible, foregrounds a focus on the small number of studies that have drawn directly on the perspectives of people with disability, particularly intellectual disability, themselves. In reporting on the practice evidence, the review primarily focuses on insights from eight supported decision-making projects funded by Ageing Disability and Home Care (ADHC), the Department of Family and Community Services (FACS) NSW, and run by a range of other agencies. The projects are:

Project name	Implementing agency
1. Advanced Support Decision Making Initiative (incorporating two projects)	Jaanimili Uniting Ability Links St Vincent de Paul Society
2. Financial Decision Making and Financial Literacy Skill Development (includes a sector training project)	NSW Public Guardian and NSW Trustee and Guardian
3. The Rights Project	NSW Ombudsman
4. Supported Decision Making Workshops (for 14-18 year old with disability, family and carers)	Carers NSW/Mirri Mirri
5. Supporting Transition and Independence in Leaving Care Program	Create Foundation
6. Developing and Piloting a Continuum Approach to Decision Making	St Vincent de Paul Society, LaTrobe University and NSW Public Guardian
7. Assisted Boarding House Resident Capacity Building Project	NEAMI National
8. The ADHC Group Homes Capacity Building Project	NSW Council for Intellectual Disability, with My Choice Matters

Social Policy Research Centre 2017
Literature and practice review: Support to make decisions that promote personal safety and prevent harm

3

Key learnings about these projects have been developed through consultations, publicly available resources, conference presentations and information shared in the NSW Supported Decision Making Community of Practice. These programs have not all been evaluated yet, but promising practices are emerging.

1.1   Glossary

For the purposes of this review, key terms are defined as follows:

Safeguarding	"Actions designed to protect the rights of people to be safe from the risk of harm, abuse and neglect, while maximising the choice and control they have over their lives" (NDIS Quality and Safeguarding Framework, p. 102).
Supported decision making	"Supported Decision Making is the process of assisting a person with disability to make their own decisions, so they can develop and pursue their own goals, make choices about their life and exercise some control over the things that are important to them" (www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making).

2. Subject of support

2.1 General areas of support

While little academic research draws directly on their own perspectives, much research has focused on areas of life in which people with disability might be at risk of harm. A body of research has focused on areas including:

- Violence and domestic abuse (Dixon and Robb, 2015, Frohmader et al., 2015)

- Harm in close family relationships (Hughes et al., 2011, Daniel et al., 2013)

- Harm from service providers (Saxton et al., 2001, Robinson and Chenoweth, 2011)

- Exiting abusive relationships (Warrington, 2013, Frawley and Bigby, 2014)

- Sexual abuse and exploitation (Warrington, 2013)

- Exposure to sexually transmitted diseases (Cambridge, 1998)

- Neglect (Jenkins and Davies, 2006, Hernon et al., 2015)

- Bullying (McGrath, Jones and Hastings (2010) as cited in Northway et al., 2013a, Bourke and Burgman, 2010)

- Hate crime (Goodley and Runswick-Cole, 2011, Richardson et al., 2016)

- Financial abuse (Manthorpe and Samsi, 2013, Junne and Huber, 2014)

- Legal troubles (Northway et al., 2013a, French et al., 2010)

- Malevolence in online settings (Bowker and Tuffin, 2003, Caton and Chapman, 2016)

Other research has emphasised that beyond situations where people with disability are at direct risk of harm, personal safety can also be promoted generally in everyday life at home and in the community. This can include thinking about and ensuring safety in areas such as:

- Creating relationships of mutual trust (Daniel and Bowes, 2010)

- Reducing emotional reliance on paid relationships (Robinson, 2013)

- Receiving assistance from others (Marsland et al., 2007)

- Training (for people with disability, family members, support workers, managers, wider community) (Ottmann et al., 2016)

- Advice, planning and disclosing one's plans (Ottmann et al., 2016)

- Health (e.g. mental health, healthy living, wellness, nutrition and chronic illness management) (Hallahan, 2012, Ottmann et al., 2016)

These areas of safety may be relevant throughout a range of different types of social, economic and community participation. Further, they focus on developing relationships, reducing social and physical isolation and building strong and ongoing formal and informal networks for people with disability across multiple areas of their lives (Daniel and Bowes, 2010, Hallahan, 2012, Marsland et al., 2007, Robinson, 2013). These areas of relational safety are important as evidence about

abuse prevention shows that the risk of harm is reduced for people with disability when their dignity and humanity is respected and they are treated as valued and included community members and full citizens.

This range of research detailed above highlights a number of areas where people with disability may benefit from decision-making support to promote personal safety and prevent harm, including making a distinction between support that is related to addressing direct abuse (reactive support) and that which is instead about promoting general safety in everyday life (proactive support). Others have conceptualised related distinctions, for example, protecting physical safety (e.g. physical safety from fires, emergencies and within one's home) compared to safety in relationships (e.g. protection from abuse, violence and maltreatment) (Robinson, 2014).

The practice evidence suggests that current supported decision-making programs focus on two main areas: (1) preventing the unnecessary use of substitute decision-making and (2) safety and decisions in everyday life. Limited attention to explicitly cultivating decision-making for preventing or addressing abuse or harm was found in the review. Participants in the programs do not appear to be directly seeking support for decisions about safety, risk or harm. This may perhaps in part be due to program focus or to the time-limited nature of many of the programs, where there is often not the necessary time available to address very sensitive or complex areas that have implications for wellbeing. Many of the programs do however appear to adopt a trauma-informed approach, suggesting that while they do not explicitly address safeguarding, they conceptually and practically connect personal safety promotion and harm prevention – and the histories of trauma that may sometimes be involved in this – with their supported decision-making program development. In the reviewed projects, many also promoted a starting point of existing strengths, rather than the perceived or real vulnerabilities of people with disability. There were several activities and resources that helped shine a light on these strengths to empower and provide decision-making guidance that promotes personal congruence.

2.2   Areas of support specific to the NDIS context

Little academic research has examined which specific issues related to promoting personal safety and preventing harm people with disability may require decision-making support about within a context of policy changes towards personalisation through the NDIS. The main area reflected in the academic literature is that people with disability have identified particular concerns around breakdown of trust with close family members, friends, housemates and service providers and the harm that can occur in such relationships (Daniel et al., 2013, Robinson, 2014, 2015a, Saxton et al., 2001). Such concerns may be heightened as people with disability are required to navigate closer personal relationships with support workers when using self-managed funding packages, individualised service provision and other new personalised models of disability support (Robinson, 2015a), as will be the case under the NDIS. Navigating closer relationships with support workers when using self-management has been a concern for people with disability in recent action research about the NDIS (Purcal et al., 2014). Decision-making support about promoting relational safety and preventing harm in close relationships may therefore be one particularly important area in which people with disability may currently or increasingly seek support. It is however also a complex area as these close relationships may not only be a potential area of risk or harm, but also

a key source of the decision-making support required to navigate risk and harm, particularly for people with intellectual disability (Arstein-Kerslake, 2016).

Complementing the academic literature, the practice evidence suggests that, in the developing context of the NDIS, the focus of current supported decision-making programs appears to be less about direct safeguarding measures and more about developing the capacity of people with disability to make decisions that will help them make personal plans and manage their NDIS packages. The three main focuses of the current programs are:

1. Developing financial decision-making and literacy;

2. Developing decision-making capacity for planning needs, goals and supports;

3. Developing decision-making as a general life skill.

In some cases, these areas may intersect with safeguarding considerations. Sometimes this intersection is directly about preventing harm. For example, building capacity for financial decision-making and literacy is a policy response to a situation in which people with disability have historically been seen as vulnerable to financial exploitation and abuse and have therefore commonly had their financial decision-making authority removed and substitute decision-making orders applied instead. In this context, support for financial decision-making can be seen as a safeguarding measure aimed at reducing financial abuse and restoring autonomy. This focus of the Australian practice evidence on financial decision-making also reflects growing international concern about financial abuse as self-directed budgets have become more common (Manthorpe and Samsi, 2013, Junne and Huber, 2014).

At other times, the intersection between the current focus of Australian supported decision-making programs and safeguarding is about promoting safety in everyday life. For example, decisions about promoting safety may be embedded across the broader decisions about lifestyle, living arrangements and social, economic, community and civic participation that people with disability are supported to make in current Australian programs. In this context, safeguarding becomes one component of a broader curriculum of supported decision-making, and one embedded across a range of life decisions. The shared emphasis of the programs on an empowerment approach also highlights their advocacy context and their role in supporting self-determination of the people they support.

Drawing the academic and practice literature together, the topics or subjects of safeguarding decisions that people with disability may require support with are about addressing abuse and harm, but also often about promoting safety within what is happening in their day-to-day lives, both at home and in the community. In this sense, they may require both reactive and proactive forms of support.

3. Types of support and promising practices for delivery

3.1 Support to people with disability

The existing academic literature has identified types of support that people with disability say they seek and/or value when making decisions about promoting personal safety and preventing harm and has identified some promising practices for the delivery of these types of support. There appears to be only a small amount of literature that addresses these areas directly, much of it related particularly to people with intellectual disability. Other partial insights can however be gleaned from a broader range of studies.

However, practice development is currently ahead of evidence from the academic literature and suggests further promising practices, both for working with groups and individuals, as well as identifying more general useful practices. The programs from which these practice insights are drawn have not all been formally evaluated yet. However, as noted in the introduction to this paper, key learnings have been taken from personal consultations, available resources, conference presentations and information shared in the NSW Supported Decision Making Community of Practice.

Drawing from the academic and practice evidence, key types of support to people with disability and promising practices for delivery of it then include:

Type of support	Promising practices – academic evidence	Promising practices – practice evidence

Being provided with **information** (Stevens et al., 2014), including information about their **legal rights** and about how other people should be expected to treat them (Northway et al., 2013a).	Information can be effectively provided through multiple accessible formats, including DVDs and comics (Northway et al., 2013a). In some cases, accessible resources have been developed for specific groups, for example, people who use alternative and augmentative communication[1], although other research has also reported that a lack of such resources is a major barrier to discussing safeguarding issues (Oosterhoorn and Kendrick, 2001).	Group work:
		• Co-develop rights and empowerment language
		• Physical activities to illustrate concepts
		
		Individual work:
		• Scaffolding learning
		
		General strategies:
		• Visual resources and tools, e.g.:
		  - About emotions
		  - About a spectrum of control of decisions

Having opportunities for **problem-solving** discussions and activities (Daniel et al., 2013).	Promising practices for delivery of these discussions and activities often draw on tailored and innovative methods (Robinson, 2015a), such as role play, consideration of different scenarios and use of pictures (Daniel et al., 2013).	Group work: • Discussion of a vignette scenario • Discussion of amusing pop culture examples • Modelling qualities admired in mentors • Reflection activities Individual work: • Diaries, photo/video journals, video storytelling General strategies: • Education about decision-making processes • Identifying the steps in making a decision

---

[1] For example: www.speakupandbesafe.com.au

Type of support	Promising practices – academic evidence	Promising practices – practice evidence
Having opportunities to **gain advice and/or support** from a trusted person or trusted supporter (Northway et al., 2013a, Robinson, 2015a, Taylor et al., 2015).	To be effective as a trusted person or supporter, a range of qualities are often necessary, including good interpersonal and communication skills (Dixon and Robb, 2015, Carr, 2011), a non-judgemental demeanour (Daniel et al., 2013) and enacting an effective balance between care and control (Stevens et al., 2016). In some cases, knowledge of complex communication needs may also be necessary (Taylor et al., 2015). In one study, peer educators who also had an intellectual disability played a role (Frawley and Bigby, 2014).	Group work: • Co-facilitation by peers • Personal stories from peers • Peer-to-peer storytelling • Active listening General strategies: • Reassurance
Practice at knowing how to talk with people to address problems (Daniel et al., 2013) and at **knowing how to 'speak up' more generally** (Northway et al., 2013a).	Role play may be a promising strategy for practising these kinds of interactions (Daniel et al., 2013). Practical examples of speaking up could also relate to specific areas, for example, knowing how to make a complaint or a person having a say in which service providers and staff work with them (Robinson, 2014)	Group work: • Role play power relationships • Practising presenting/speaking in front of peers • Leadership opportunities Individual work: • Leadership opportunities • Observation of behaviour General strategies: • Focusing on strengths, not deficits

In the academic literature, programs or approaches for providing these types of support vary. Formal safety training and education programs are common (e.g. Mazzucchelli, 2001, Khemka et al., 2005, Lund and Hammond, 2014, and others as noted in Dixon et al., 2010), with such programs designed to teach people with disability about specific risks where there is a large chance of harm. Many of the programs are specifically for people with intellectual disability. Such programs have identified that people with intellectual disability can learn about safeguarding principles and successfully apply what they have learnt to specific situations in their lives (Mazzucchelli, 2001, Khemka et al., 2005). However, critiques have also recognised that such programs may not empower people with intellectual disability (Mazzucchelli, 2001), as they may only teach them strategies for dealing with a limited range of specific high-risk situations, often centred on abuse, rather than developing their more general skills for recognising a range of risks that may be less readily identifiable and for promoting safety in their everyday life at home and in the community (Ottmann et al., 2016, Schaafsma et al., 2015). For this latter area, capacity building for decision-making has been recognised as needed (Ottmann et al., 2016), but has more rarely been provided, although as evident from the practice evidence detailed in this paper, programs are currently developing in this area and may continue to do so. The practice evidence also suggests a need to focus on a comprehensive understanding of decision-making, including the activities preceding, during and after a decision.

Further, the practice evidence identifies the importance of allowing sufficient time and different types of opportunities for using the strategies highlighted above and for the development of self-determination for people to accomplish change that is proactive and meaningful to them. This requires sustaining supported decision-making projects over time. Some of the projects worked with project participants over extended periods, especially in projects that were able to secure extensions. Others focused on short group experiential learning to 'start the ball rolling' and then may have provided intermittent support over several months. Another project provided a series of regular group sessions to build on concepts, run exercises and establish intentionality, while another harnessed a mix of individual and group work to maintain enthusiasm and momentum and set up many opportunities for decision confidence and capabilities to develop. This took advantage of multiple real-life opportunities for both the participant and supporter to test, develop in and then work through decision steps towards an outcome over the course of a year.

Overall, considering the academic and practice literature together highlights that practical-oriented, accessible and personalised types of support that are sustained over an appropriate and often extended time period appear to be appreciated by people with disability and that there are a range of emerging promising practices for delivering these types of support. In particular, capacity building for decision-making appears to be a key area identified for further work and development.

3.2   Support to supporters and service providers

Notably, beyond direct support strategies to people with disability, the academic literature and practice evidence also highlights what is required to develop the capacity of other people – such as supporters (including, but not limited to, family members) and service providers – to effectively provide support to people with disability for making decisions that promote personal safety and prevent harm.

For supporters, the practice evidence suggests the importance of reflection opportunities to ensure supporters are thinking thoroughly about supporting the person with disability to really make their own decisions. It also suggests that formalised decision-support roles can be useful in particularly complex or sensitive decision-making or safeguarding contexts.

For service providers, key practices highlighted in the academic literature include shared training between staff involved in personalisation/self-direction and safeguarding (Campbell et al., 2012) and managing organisational culture, workforce development and client capacity building to best enable support (Ottmann et al., 2015). The practice evidence also suggests that ensuring that trained decision supporters are personal contacts (rather than paid staff) is key. Service providers providing support to make decisions to promote personal safety and prevent harm also links to a more general need for service agencies to focus on prevention and protection, rather than only reactively responding to individual instances of abuse or maltreatment (Robinson and Chenoweth, 2011).

Further, in the practice review, a mix of individualised work with people with disability and engagement with project workers, service staff and families on decision and decision support development was seen as productive. Boosting this mix with group learning showed added benefits, including addressing new concepts in a supportive peer environment; being exposed to a variety of views and practices; and experiencing activities that can prepare both people with disability and their supporters for applying ideas in their private and community lives. It also increases the understanding and confidence of facilitators rapidly, especially if a collaborative learning approach is taken. There has also been success in bringing people with disability, their families and other supporters together for skilfully facilitated experiences with each other that 'tweak' or 'nudge' existing roles and open the door to growth.

Together, these literature and practice insights highlight the importance of providing support to and expecting capacity building from not only people with disability, but also the people around them. In the current policy context in Australia, this could extend to family members, NDIS planners, supported decision-making staff and a range of other service providers and informal supports.

4. Sources of support

While not focusing directly on who people with disability seek support from for making decisions that promote personal safety and prevent harm, the academic literature does provide some insight into this area. As noted earlier, trusted supporters appear to be a very common source of support – the most common source highlighted in the literature – with many people seeking support from family, friends and trusted support workers (Northway et al., 2013a, Robinson, 2015a, Hollomotz, 2012). The key role of this kind of relational support also creates challenges where breakdowns in the trusted relationships from which people may be seeking decision-making support can also be a significant source of risk and harm, particularly for people with intellectual disability (Daniel et al., 2013, Robinson, 2015a, Arstein-Kerslake, 2016).

Despite the key role of trusted supporters as sources of support, past studies have highlighted that people with disability, including intellectual disability, prefer to be supported by such people to develop their own strategies to deal with potential risks, rather than having these people actually deal with issues for them or on their behalf (Daniel et al., 2013, Northway et al., 2013a). This is important as it again affirms the role of capacity building for people with disability's own decision-making.

Other sources of support used by people with disability, including particularly people with intellectual disability, that are highlighted in the existing academic literature include safety education programs (Khemka et al., 2005), peer advocates and peer support groups (Northway et al., 2013a, Frawley and Bigby, 2014), service provider agencies (Hollomotz, 2012), paid staff (Schaafsma et al., 2014), schools (Lamorey, 2010) and the police (Hollomotz, 2012, Northway et al., 2013a). These sources of support may however have varying impact and be subject to some constraints. For example, one study recounted an instance of police involvement being over-ridden where a service agency said that they preferred to deal with a violent incident internally (Hollomotz, 2012). Other research has highlighted that lack of choice and control, problems with paid staff, inter-relational troubles and fear could all sometimes constrain the extent to which particularly people with intellectual disability could enact their decisions and strategies for keeping safe and preventing harm (Robinson, 2014).

Across the programs reviewed for the development of practice evidence, sources of support similarly included family members, project staff/service providers and, increasingly, peer advocates (e.g. advocates with intellectual disability supporting other people with intellectual disability). The practice evidence also suggests some insights about how these different sources of support may operate and/or interact with each other. It suggests that:

- Co-design of support with peer advocates and/or people from a similar cultural background to those being supported can enable greater relevance of concepts, language, activities and resources, and increased likelihood of sustainability of supported decision-making – having an Indigenous-led program for Indigenous people, for example, was beneficial;

- A mix of individualised, group and peer-learning opportunities is valuable for maximising a range of opportunities to learn and develop decision-making, thus drawing on different combinations of sources of support; and

- People with disability's decisions can best be upheld where attention is given to the relationships they share with a range of supporters and to ensuring that those supporters are assisted to manage clashes of interest in the implementation of decisions, be supported in their own right and be powerful enablers the person with disability's own decisions. This may particularly apply to family members of people with intellectual disability, who care deeply about their family member with intellectual disability, but may have had responsibility for managing situations that have not turned out well in the past. Where attention is not given to these issues for supporters, the decisions made particularly by people with intellectual disability may not be upheld.

In this respect, the practice evidence builds on the academic literature's insights about who are key sources of support, to extend to insights about how these sources of support work together as a spectrum of support to people with disability and the range of support that may be required across this spectrum. The review therefore highlights that trusted supporters are critical and very much valued, but also part of a range of sources of support. This is significant in that it means people with disability may draw support from across their social structures, including close friends and family, but also through their communities, services and wider society.

5.   Experiences of different groups

Limited information is available from the academic literature about the experiences of different groups of people with disability with regard to support to make decisions that promote personal safety and prevent harm. This is perhaps a consequence of the relatively small number of studies that have directly asked people with disability about their experiences and perceptions in this area. A large number of studies identify specific groups of people with disability, particularly intellectual disability, who are at increased risk of harm – including women (Brown, 2004), people in prison (Chan et al., 2012), people who identify as lesbian, gay, bisexual or transgender (McClelland et al., 2012) and people with complex communication needs (Collier et al., 2006) – but this literature does not always extend specifically to *support for making decisions* about safety, risk and harm.

Some life-course specific information is available. For example, recent research has identified that older people with intellectual disability are more concerned about health-related safety than those younger than them (Ottmann et al., 2016) and that young people are concerned about relationships, interactions with strangers and the implications of following or not following rules (Robinson, 2015a). These studies extend to policy implications for how to support decision-making, including acknowledging the role of tailored and innovative methods to enable discussion of safeguarding issues (Robinson, 2015a) and acknowledging the key role of trusted supporters in capacity building for decision-making (Ottmann et al., 2016).

Without examining the issue in detail, a few academic studies have also noted that some groups of people with disability, particularly intellectual disability, may be at a disadvantage in seeking support for decisions about promoting personal safety and preventing harm. This includes people with limited social support, as given the key role of trusted supporters discussed earlier, those people who do not have such connections lack a key source of support (Ottmann et al., 2016). Further, people who are living in congregate residential accommodation may not be able to enact their decisions or strategies to keep safe and prevent harm if the conflict is with another resident, as they may be unable to stay away from them (Northway et al., 2013a), especially if movement, household management and/or staffing restrictions are in place. Notably however, while these issues have been raised in passing in the literature, they have not been thoroughly explored, nor have been the implications for providing support for decision-making. More conceptual work has however noted the need for cultural change in congregate residential accommodation toward taking a preventative approach to safeguarding, rather than a reactive response to individual cases of abuse (Robinson and Chenoweth, 2011).

Notably however, the practice evidence is currently moving forward in this area and is beginning to fill in some of these gaps in the academic literature. In particular, there has been a focus on developing forms of decision-making support to people with disability living in congregate residential accommodation, including people living in group homes, boarding houses, out-of-home care and who are transitioning out of large residential centres (LRCs). Programs supporting these groups acknowledge a range of issues that make support for their decision-making particularly complex, including current transitional service and staffing arrangements in LRCs, limited family support, limited choice about living arrangements, entrenched cultural barriers often focusing on a medical approach to disability rather than empowerment, gaps in staff understandings of the

complex communication preferences of some residents, lack of role models of personal decision-making and dispersal of support in some of the rural locations in which the congregate care is commonly located. In this context, the developing practice evidence suggests strategies for supporting decision-making of those living in congregate residential care, including:

- Observing and documenting information about individuals' complex communication preferences, so that it can be better conveyed to new and future staff;

- Documenting knowledge of individual residents to aid transfer to new or future staff;

- Co-designing support with other people with disability;

- Drawing in other people with disability, particularly intellectual disability, as peer mentors who can model empowerment;

- Building in appropriate time to develop trust between decision-making support program staff and residents;

- Running decision-making support programs in familiar settings, including the group homes and LRCs;

- Facilitating contact with other community members beyond only paid staff;

- Acknowledging and sensitively managing any tensions with the management of the residential accommodation and providing education and training for management and staff, where required.

Further, the practice evidence also highlights the experiences of some other specific groups. For example, it suggests that decision-making support to Indigenous people with disability should be trauma-informed, Indigenous-run, establish trust over time, use agreed language and concepts and prioritise interactions with family and kinship caregivers and group learning. In another example, the practice evidence focuses on decision-making support to people with high support needs, highlighting that it is appropriate to have multiple supporters who together give a holistic understanding of a person and to observe and document the person's communication strategies.

These considerations highlight that while support for decisions that promote safety and prevent harm will be increasingly relevant across a range of people with disability as the NDIS rolls out fully, some specific considerations are relevant for specific groups. While the academic literature has not so far reflected much about these groups' experiences or support requirements, developments in the practice evidence highlight the importance of paying attention and catering to the context in which different groups of people with disability experience safeguarding concerns.

6. Implications for Skilled to Thrive action research project

This document details the findings of the literature and practice review undertaken to inform the approach of the Skilled to Thrive action research project. It has synthesised information from existing academic and practice evidence. Much of the academic and practice evidence is about people with intellectual disability specifically, although the findings may be applicable to a range of people with disability who require support for decisions about safeguarding.

Key implications for the Skilled to Thrive action research project, based on the findings of the review, are:

1. **Empowerment approach to promoting personal safety and preventing harm**	The review has highlighted a range of promising practices that are based in empowerment, strengths-based and values-driven approaches. Together these approaches support people with disability to understand that they are active agents in small and large decisions affecting their own lives and that they have rights and responsibilities and can develop their identities, decision-making skills and support-seeking skills to increase their choice and control.
2. **Strengths-based and values-driven approach to promoting personal safety and preventing harm**	For decision support in situations of heightened instability, risk and vulnerability, the review highlights the tension between maintaining personal congruence in decision-making while finding acceptable safeguarding solutions. The implication is that the Skilled to Thrive action research project will need to consider ways to uncover empowerment, strengths and values that can anchor individual people and be carried forward through situations of pressure and adversity; can be used to support time-limited decision-making; and may be used in future decision-making that promotes safety and prevents harm.
3. **Allowing time for development of self-determination to accomplish real-life, proactive change**	The review found that support for decisions to promote personal safety and prevent harm needs to be sustained over an appropriate and often extended time period. The proposed Skilled to Thrive action research project will take place with advocacy agencies as project partners, over a 3-5 month action learning cycle. Participants may be drawn from a pool of people including those seeking assistance about imminent risk or who have recently experienced harm. In these cases, time pressures to provide an appropriate response and support may be significant or there may be a temptation to

attempt to condense decision support activities into a timeframe that is not adequate.

In this context, the Skilled to Thrive action research project may need to introduce a screening tool (if the partner organisations do not already use one) to ensure that people who are at greatest risk and may require immediate crisis intervention and advocacy support are able to receive appropriate and timely supports. It is noted, however, that invitations can be extended for participation in project activities post-crisis that include follow-up recovery and capacity-building activities that promote future safety and prevent harm.

| 4. | **Co-design and implementation by specific target groups** | The review found that practices of co-design and implementation of programs by representatives of the specific target groups for decision support (e.g. Indigenous-led program for Indigenous people) enabled greater relevance in the development of concepts, language, activities and resources for supported decision-making, and increased the likelihood of sustainability of decision-making.

Based on this insight, the Skilled to Thrive action research project may consider including co-design elements and/or targeted capacity-building group-work that can address positive risk enablement concerns and build organisational capacity to run programs into the future. This can provide intrinsic expertise to shape approaches to the project incorporating cultural strengths and attitudes. Approaches may include consultation, resource development and community linking, among many other possibilities. |
| 5. | **Individualised, group and peer learning opportunities, including mentoring** | The review highlighted that a mix of individualised work with people with disability and engagement with project workers, service staff and family members on decision and decision support development was productive. The review also highlighted productive opportunities for skilled facilitation and mentoring by peers who have been through decision support and risk enablement experiences.

Reflecting these learnings, the Skilled to Thrive action research project may consider using a range of individualised, group and peer learning opportunities. To do this, it may need to consider how individualised NDIS package funding (e.g. support coordination) or wider Information Linkages and Capacity Building (ILC) funded projects may be utilised to assist people with disability and those around them to navigate |

	blocks and barriers to self-determination in interpersonal relationships and service environments.
6. Communication, relationships and facilitation skill-building	This review found that without work to address relationships, many decisions by people with disability, particularly intellectual disability, can remain unfulfilled. The practice review highlighted that the potential for clashes of interests in the implementation of decisions, especially when family members may have had responsibility for managing situations that have not turned out well in the past. However, it was unclear how practice has so far addressed supporter conflict of interest.
	In this context, the review highlighted that it is important to provide support to and expect capacity building from not only people with disability, but also the people around them, including family members, supported decision-making staff and a range of other service providers and informal supports. Sensitive facilitation, skill-building approaches, informal advocacy and sometimes formal advocacy may be required.
	In this context, it will be important for the Skilled to Thrive project to consider how best to work with the people around people with disability. This may include supporting partner organisations on the project to explore questions of core business through their participation in this project, and consider how they build on existing skills to address opportunities that may snowball as a result of a new support paradigm with choice, control and self-determination of people with disability at its centre. Given that practice is still developing in this area, it is a core area to which the project can contribute.

7. Conclusions

The review has drawn together academic and practice evidence to understand the subjects about which decision-making support is required to promote personal safety and prevent harm; types of support that are useful and promising practices for delivery; key sources of support; and the experiences of different groups of people with disability. These focuses reflect the research questions highlighted in the preface of this paper.

Reflecting these focuses, key findings of the review are that:

- People with disability require support with both promoting personal safety and addressing or preventing harm, thus encompassing both proactive and reactive elements. Historically, most support has been reactive (responding to specific instances of abuse), although current supported decision-making programs appear to have a more proactive focus. There are however challenges in making clear connections between supported decision-making and personal safety agendas.

- Practical-oriented, accessible and personalised types of support, provided over an appropriate and often sustained or extended time period, appears to be appreciated by people with disability, and there are a range of promising practices for delivery. Capacity building for decision-making has been identified as an area where more work is required.

- There are support practices used in the reviewed projects that point to continued development of a proactive, capacity-building culture, moving from substitute to supported decision-making as a broad, rights enabling tool. However, there are further opportunities to extend the range of investigation with a more specific safeguarding lens. This lens would recognise current or recent risk of harm and actual harm and explore how to prevent further harm by empowering people to take back control of their lives and move forward. It would represent a shift away from providing a protection-only response, which has been common to date.

- Trusted supporters (often family, friends and close support workers) are key sources of support, but also part of spectrum of support across the social structures of people with disability. People with disability can also sometimes draw support from their communities, services and wider society. Considering the interactions between different sources of support is important, as is managing clashes of interest between supporters and people with disability in the implementation of decisions and ensuring that supporters are also supported in their own right.

- The specific needs of different groups of people with disability (e.g. Indigenous people, people living in congregate residential care or those who have few informal supports) have not generally been well-reflected in the academic literature, but are emerging as key and developing considerations in the practice evidence. The practice evidence suggests the importance of paying attention and catering to the very specific contexts in which different groups of people with disability experience safeguarding concerns.

Overall, this review has established that there is limited, but developing, research and practice evidence that establishes (1) what people with disability want with regard to support for decisions

that promote personal safety and prevent harm; and (2) how to build the understanding of people with disability, particularly intellectual disability, of what knowledge is needed to live full, safe lives.

From the available literature and practice evidence, some key tensions emerge which are critical for NDIS contexts. For some people with disability, support provided may not best match what they perceive that they need. Planning processes may not respond to the safety priorities of people with disability or their families, particularly if they challenge existing structures or have resource implications (Northway et al., 2013a, Ottmann et al., 2015, Robinson, 2014, Robinson, 2015b). Promising practices identified in this review which helpfully work into this area focus on building capacity for decision-making, supporting the development of self-determination and confidence and maximising forms of choice. It is nuanced, understanding that differences in people's gender, living circumstances, location, cultural diversity and other circumstances mean that a range of approaches to supporting decision-making are needed – both within and across programs.

Building organisational capacity – both for people making supported decisions, and for supporters of those decisions – is a critical task as the NDIS moves into full implementation. The relationships between individual people with disability and those who support them with their decisions sit within a wider culture that can either support or constrain effective supported decision-making. Some of the elements identified in this review – such as building facilitation skills, trauma-informed practice and effective use of quality resources – hold potential for building organisational capacity which may support not only stronger supported decision-making relationships at the micro level, but also bolster organisational and wider community support practices in other domains in which people with disability often receive support, such as employment, leisure and accommodation.

References

ARSTEIN-KERSLAKE, A. 2016. An empowering dependency: exploring support for the exercise of legal capacity. *Scandinavian Journal of Disability Research*, 18, 77-92.

BOURKE, S. & BURGMAN, I. 2010. Coping with bullying in Australian schools: how children with disabilities experience support from friends, parents and teachers. *Disability & Society*, 25, 359-371.

BOWKER, N. & TUFFIN, K. 2003. Dicing with deception: People with disabilities' strategies for managing safety and identity online. *Journal of Computer-Mediated Communication*, 8, 0-0.

BROWN, H. 2004. A rights-based approach to abuse of women with learning disabilities. *Tizard Learning Disability Review*, 9, 41-44.

BROWN, I. & SCHORMANS, A. F. 2014. Quality of life, children with intellectual and developmental disabilities, and maltreatment. *International Public Health Journal*, 6, 185+.

CAMBRIDGE, P. 1998. Challenges for safer sex education and HIV prevention in services for people with intellectual disabilities in Britain. *Health Promotion International*, 13, 67-74.

CAMPBELL, M., HOGG, J., PENHALE, B., HUNTER, S., MANTHORPE, J., RIDLEY, J., CORNES, M. & ROSENGARD, A. 2012. When self-directed support meets adult support and protection: findings from the evaluation of the SDS test sites in Scotland. *The Journal of Adult Protection*, 14, 206-215.

CARR, S. 2011. Enabling risk and ensuring safety: self-directed support and personal budgets. *The Journal of Adult Protection*, 13, 122-136.

CATON, S. & CHAPMAN, M. 2016. The use of social media and people with intellectual disability: a systematic review and thematic analysis. *Journal of Intellectual and Developmental Disability*, 41, 125-139.

CHAN, J., FRENCH, P., HUDSON, C. & WEBBER, L. 2012. Applying the CRPD to safeguard the rights of people with a disability in contact with the criminal justice system. *Psychiatry, Psychology and Law*, 19, 558-565.

COLLIER, B., MCGHIE-RICHMOND, D., ODETTE, F. & PYNE, J. 2006. Reducing the risk of sexual abuse for people who use augmentative and alternative communication. *Augmentative and Alternative Communication*, 22, 62-75.

DANIEL, B. & BOWES, A. 2010. Re-thinking harm and abuse: Insights from a lifespan perspective. *British Journal of Social Work*, 820-836.

DANIEL, B., CROSS, B., SHERWOOD-JOHNSON, F. & PATON, D. 2013. Risk and decision making in adult support and protection practice: User views from participant research. *British Journal of Social Work*, 1233-1250.

DIXON, D. R., BERGSTROM, R., SMITH, M. N. & TARBOX, J. 2010. A review of research on procedures for teaching safety skills to persons with developmental disabilities. *Research in developmental disabilities*, 31, 985-994.

DIXON, J. & ROBB, M. 2015. Working with women with a learning disability experiencing domestic abuse: How social workers can negotiate competing definitions of risk. *British Journal of Social Work*, 773-778.

ELLIS, K. & PRESTON-SHOOT, M. 2012. Squaring another circle in policy and practice: Personalization and adult safeguarding. *Journal of Care Services Management*, 6, 161-171.

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.

FRENCH, P., DARDEL, J. & PRICE-KELLY, S. 2010. *Rights Denied: Towards a National Policy Agenda about Abuse, Neglect & Exploitation of Persons with Cognitive Impairment*. Sydney: People with Disability Australia.

FROHMADER, C., DOWSE, L. & DIDI, A. 2015. *Preventing Violence Against Women and Girls with Disabilities: Integrating a Human Rights Approach*. Hobart: Women with Disabilities Australia.

FYSON, R. & KITSON, D. 2007. Independence or protection–does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall. *Critical Social Policy*, 27, 426-436.

GOODLEY, D. & RUNSWICK-COLE, K. 2011. The violence of disablism. *Sociology of Health & Illness*, 33, 602-617.

HALLAHAN, L. 2012. *Towards Quality and Safety in Disability Services: Confronting the 'Corruption of Care'*. Report to SA Health & Community Services Complaints Commissioner. Adelaide: Flinders University.

HERNON, J., BRANDON, M., COSSAR, J. & SHAKESPEARE, T. 2015. Recognising and responding to the maltreatment of disabled children: A children's rights approach. *Social Work and Social Sciences Review*, 17, 61-77.

HOLLOMOTZ, A. 2012. 'A lad tried to get hold of my boobs, so I kicked him': An examination of attempts by adults with learning difficulties to initiate their own safeguarding. *Disability & Society*, 27, 117-129.

HUGHES, R. B., LUND, E. M., GABRIELLI, J., POWERS, L. E. & CURRY, M. A. 2011. Prevalence of interpersonal violence against community-living adults with disabilities: A literature review. *Rehabilitation Psychology*, 56, 302-319.

JENKINS, R. & DAVIES, R. 2006. Neglect of people with intellectual disabilities: A failure to act? *Journal of Intellectual Disabilities*, 10, 35-45.

JUNNE, J. & HUBER, C. 2014. The risk of users' choice: Exploring the case of direct payments in German social care. *Health, Risk & Society*, 16, 631-648.

KHEMKA, I., HICKSON, L., REYNOLDS, G. & MACLEAN JR, W. E. 2005. Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal on Mental Retardation*, 110, 193-204.

LAMOREY, S. 2010. Risk reduction education voices from the field. *Remedial and Special Education*, 31, 87-96.

LUND, E. M. & HAMMOND, M. 2014. Single-session intervention for abuse awareness among people with developmental disabilities. *Sexuality and Disability*, 32, 99-105.

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.

MANTHORPE, J. & SAMSI, K. 2013. 'Inherently Risky?': Personal budgets for people with dementia and the risks of financial abuse: Findings from an interview-based study with adult safeguarding coordinators. *British Journal of Social Work*, 43, 889-903.

MANTHORPE, J., STEVENS, M., RAPAPORT, J., CHALLIS, D., JACOBS, S., NETTEN, A., JONES, K., KNAPP, M., WILBERFORCE, M. & GLENDINNING, C. 2011. Individual budgets and adult safeguarding: Parallel or converging tracks? Further findings from the evaluation of the Individual Budget pilots. *Journal of Social Work*, 11, 422-438.

MANTHORPE, J., STEVENS, M., RAPAPORT, J., HARRIS, J., JACOBS, S., CHALLIS, D., NETTEN, A., KNAPP, M., WILBERFORCE, M. & GLENDINNING, C. 2009. Safeguarding and system change: Early perceptions of the implications for adult protection services of the English individual budgets pilots—A qualitative study. *British Journal of Social Work*, 39, 1465-1480.

MANTHORPE, J., STEVENS, M., SAMSI, K., ASPINAL, F., WOOLHAM, J., HUSSEIN, S., ISMAIL, M. & BAXTER, K. 2015. Did anyone notice the transformation of adult social care? An analysis of Safeguarding Adult Board Annual Reports. *The Journal of Adult Protection*, 17, 19-30.

MARSLAND, D., OAKES, P. & WHITE, C. 2007. Abuse in care? The identification of early indicators of the abuse of people with learning disabilities in residential settings. *The Journal of Adult Protection*, 9, 6-20.

MAZZUCCHELLI, T. G. 2001. Feel safe: A pilot study of a protective behaviours programme for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 26, 115-126.

MCCLELLAND, A., FLICKER, S., NEPVEUX, D., NIXON, S., VO, T., WILSON, C., MARSHALL, Z., TRAVERS, R. & PROUDFOOT, D. 2012. Seeking safer sexual spaces: Queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, 59, 808-819.

MEPHAM, S. 2010. Disabled children: The right to feel safe. *Child Care in Practice*, 16, 19-34.

NORTHWAY, R., BENNETT, D., MELSOME, M., FLOOD, S., HOWARTH, J. & JONES, R. 2013a. Keeping safe and providing support: A participatory survey about abuse and people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 236-244.

NORTHWAY, R., JENKINS, R., JONES, V., HOWARTH, J. & HODGES, Z. 2013b. Researching policy and practice to safeguard people with intellectual disabilities from abuse: Some methodological challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 188-195.

OOSTERHOORN, R. & KENDRICK, A. 2001. No sign of harm: Issues for disabled children communicating about abuse. *Child Abuse Review*, 10, 243-253.

OTTMANN, G., MCVILLY, K., ANDERSON, J., CHAPMAN, J., KARLYAWASAM, I., ROY, A., SATARI, N. & STEFANO, A. 2015. Barriers and enablers to safeguarding children and adults within a disability services context: Insights from an Australian Delphi study. *Social Policy & Administration*.

OTTMANN, G., MCVILLY, K. & MARAGOUDAKI, M. 2016. 'I walk from trouble': Exploring safeguards with adults with intellectual disabilities–an Australian qualitative study. *Disability & Society*, 31, 47-63.

PURCAL, C., BEVAN, N., COOPER, S., FISHER, K. R., MELTZER, A., WONG, M. & MEYER, P. 2014. *Self-Directed Disability Support: Building People's Capacity Through Peer Support and Action Research [Final report]* SPRC Report 7/2014. Sydney: Social Policy Research Centre, UNSW Australia.

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.

RICHARDSON, L., BEADLE-BROWN, J., BRADSHAW, J., GUEST, C., MALOVIC, A. & HIMMERICH, J. 2016. "I felt that I deserved it"– Experiences and implications of disability hate crime. *Tizard Learning Disability Review*, 21, 80-88.

ROBINSON, S. 2013. *Preventing Emotional and Psychological Abuse and Neglect of People with Intellectual Disability: Stopping Insult and Injury,* London Jessica Kingsley Publishers.

ROBINSON, S. 2014. Safe at home? Factors influencing the safety strategies used by people with intellectual disability. *Scandinavian Journal of Disability Research*, 16, 99-113.

ROBINSON, S. 2015a. *Feeling Safe, Being Safe: What is Important to Children and Young People with Disability and High Support Needs about Safety in Institutional Settings?* Sydney: Royal Commission into Institutional Responses to Child Sexual Abuse.

ROBINSON, S. 2015b. 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.

ROBINSON, S. & CHENOWETH, L. 2011. Preventing abuse in accommodation services: From procedural response to protective cultures. *Journal of Intellectual Disabilities*, 15, 63-74.

SAXTON, M., CURRY, M. A., POWERS, L. E., MALEY, S., ECKELS, K. & GROSS, J. 2001. 'Bring my scooter so I can leave you': A study of disabled women handling abuse by personal assistance providers. *Violence Against Women,* 7, 393-417.

SCHAAFSMA, D., KOK, G., STOFFELEN, J. M. & CURFS, L. M. 2015. Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. *Journal of Sex Research*, 52, 412-432.

SCHAAFSMA, D., KOK, G., STOFFELEN, J. M., VAN DOORN, P. & CURFS, L. M. 2014. Identifying the important factors associated with teaching sex education to people with intellectual disability: A cross-sectional survey among paid care staff. *Journal of Intellectual and Developmental Disability*, 39, 157-166.

STEVENS, M., ASPINAL, F. J., WOOLHAM, J., MANTHORPE, J., HUSSEIN, S., SAMSI, K., BAXTER, K. & ISMAIL, M. 2014. *Risk, Safeguarding and Personal Budgets: Exploring Relationships and Identifying Good Practice.* London: NIHR School for Social Care Research.

STEVENS, M., WOOLHAM, J., MANTHORPE, J., ASPINALL, F., HUSSEIN, S., BAXTER, K., SAMSI, K. & ISMAIL, M. 2016. Implementing safeguarding and personalisation in social work: Findings from practice. *Journal of Social Work*, early view, 1-20.

TAYLOR, J., CAMERON, A., JONES, C., FRANKLIN, A., STALKER, K. & FRY, D. 2015. *Deaf and Disabled Children Talking About Child Protection.* Edinburgh: University of Edinburgh/NSPCC Child Protection Research Centre.

WARRINGTON, C. 2013. *Partners in Care? Sexually Exploited Young People's Inclusion and Exclusion from Decision Making about Safeguarding. Critical Perspectives on Child Sexual Exploitation and Related Trafficking.* Springer.