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# Preface

The NSW Council of Social Service (NCOSS) is undertaking an action research project to develop  
(1) a practice model of delivering supported decision

# 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 6 (c)-(o)-3.4 (lo)7.5 (6 (t))TJ 6one -0

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 fo (e Mnh )4-2 (hj]TJ 0D 2 (hj]TJ 0D 2 (h ( bei)2.6 (n-2 (-2 (.)-6.6 ( )] 0D.3 (r)











## **3. Types of support and promising practices for delivery**

### **3.1 Support to people with disability**

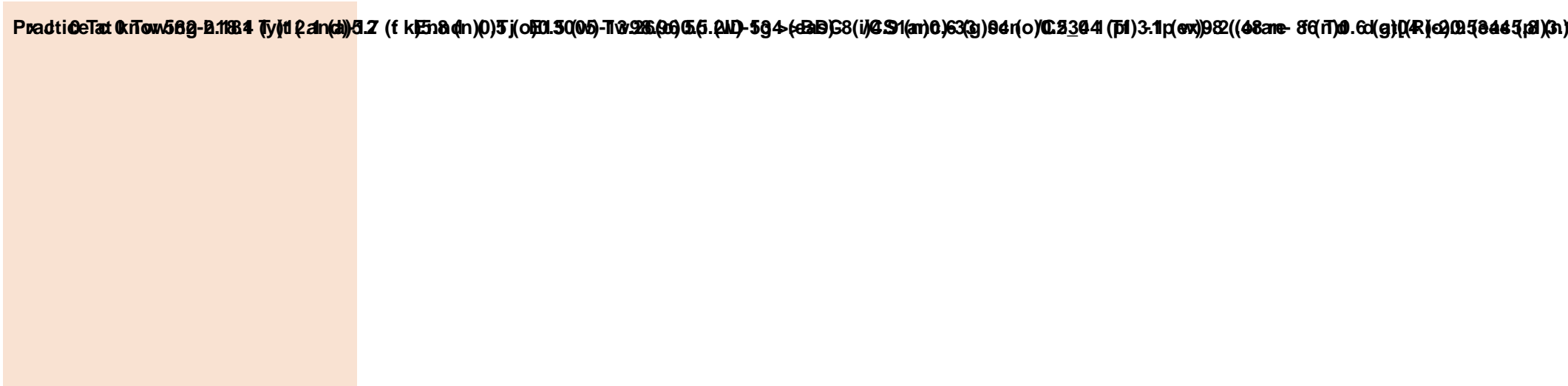
The existing academic literature has identified types of support that people with disability say they seek and/or value when making decisions about promoting personal safety and preventing harm and has identified some promising practices for the delivery of these types of support. There

**Type of support**

**Promising practices – academic evidence**

**Promising practices –**

Type of support	Promising practices – academic evidence	Promising practices – practice evidence
<p>Having opportunities to <b>gain advice and/or support</b> from a trusted person or trusted supporter (Northway et al., 2013a, Robinson, 2015a, Taylor et al., 2015).</p>	<p>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).</p>	<p>Group work:</p> <ul style="list-style-type: none"> <li>x Co-facilitation by peers</li> <li>x Personal stories from peers</li> <li>x Peer-to-peer storytelling</li> <li>x Active listening</li> </ul> <p>General strategies:</p> <ul style="list-style-type: none"> <li>x Reassurance</li> </ul>



In the academic literature, programs or approaches for providing these types of support vary.

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.

## 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



- x 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

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:

- x Observing and documenting information about individuals' complex communication preferences, so that it can be better conveyed to new and future staff;
- x Documenting knowledge of individual residents to aid transfer to new or future staff;
- x Co-designing support with other people with disability;
- x Drawing in other people with disability, particularly intellectual disability, as peer mentors who can model empowerment;
- x Building in appropriate time to develop trust between decision-making support program staff and residents;
- x Running decision-making support programs in familiar settings, including the group homes and LRCs;
- x Facilitating contact with other community members beyond only paid staff;
- x 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. **to promoting personal safety and preventing**



















