



# Living with Disability

RESEARCH CENTRE



*Supporting inclusion of people with cognitive disabilities*

## Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas.

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## **Executive Summary**

The right to make one's own decisions is a central premise of the United Nations Convention on the Rights of Persons with Disability, and intrinsically linked to quality of life, health and wellbeing. Sources of support include legal guardians as substitute decision makers or informal support through family and service providers. Those in the informal sphere are both unregulated and given little guidance to provide support to ensure that the will and preferences of people with cognitive disability direct decisions that affect their lives. The situation is compounded by a lack of empirical research into the practice of support for decision making.

This report presents the findings of a study undertaken by the La Trobe Living with Disability Research Centre that explored the processes and dilemmas associated with supporting people with cognitive disabilities in decision making. The study is part of a larger project, *Supported Decision Making and Guardianship: Building Capacity within Victoria*, being undertaken by Scope and its partners and funded by the Legal Services Board. The study reported here had two components: 1) a systematic search of the peer reviewed literature from 2000 to identify published research on processes of support for decision making of people with cognitive disability, and enablers and barriers to the provision of support, and 2) an exploratory study into processes and key dilemmas that arise in providing effective support for decision making to people with cognitive disability, with particular focus on people with intellectual disability and acquired brain injury. In-depth interviews and focus groups were held with 46 participants; including people with cognitive disability, family members, workers in disability support services and legal professionals. Data were analysed using an inductive thematic approach.

The literature review identified little robust research and a weak evidence base about processes of effective support for decision making. The empirical findings provide insight into the process of supporting people with cognitive disability to make both day to day and major life decisions. They are presented in three main themes: understanding support for decision making to people with cognitive disability; processes and approaches for support; and dilemmas and tensions in providing support.

The exploratory study found that participants, including those with cognitive disability, mostly supported the broad concept of supported decision making. However supporters saw this as a complex, dynamic and frequently chaotic process.

Fundamental to the process were relationships and tailoring support to the individual. The skills and knowledge required included communication skills, self-awareness, the capacity for reflective discussion, conflict resolution skills, and knowledge of strategies for tailoring the decision making process to the individual. The study revealed multiple dilemmas and tensions associated with supporting someone with cognitive disability to make a decision but most commonly mentioned were remaining neutral, managing conflicting perspectives amongst differing supporters, balancing rights with risk and best interests, and resource constraints. The study provides some key insights into the practice of supporting people with cognitive disability to make decisions and knowledge that can be incorporated into training programs for people in this role. The findings also highlight the need for further research in this area, particularly in relation to ‘what works’ in support for decision making for people with cognitive disability.

Based on both the literature and fieldwork into the processes used by supporters, as well as the dilemmas they face in providing decision making support to people with cognitive disability, we make the following tentative recommendations about elements that should be taken into account in policy, practice and the development of relevant training resources.

- Informed by a human rights perspective, and articulated in section 12 of the UNCRPD, supported decision making is in many ways a break from philosophies of the past. Family members and some people in paid supporting roles are not necessarily fully informed nor convinced by the philosophical underpinnings informing supported decision making. Lack of full engagement and commitment to the fundamental philosophy inevitably undermines effective support with decision making. Supporting people with cognitive disability to make decisions needs to be underpinned by the philosophical principles of supported decision making. There are various interpretations of supported decision making and debate about its formal adoption into legal structures in Australia, however the Law Reform Commission (2014b) has clearly articulated for key national decision making principles that capture a rights perspective to support for decision making. These are principles are:

***Principle 1: The equal right to make decisions***

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

***Principle 2: Support***

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

***Principle 3: Will, preferences and rights***

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

***Principle 4: Safeguards***

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

- Supporting people with cognitive disability to make decisions requires knowledge about and skills in communication with people with varying levels of cognitive disability, self-awareness and reflection, conflict resolution, and the range of potential strategies identified in this study for tailoring support for decision making to individuals.
- Supporting people with cognitive disability to make decisions frequently involves tensions and dilemmas such as managing power differentials, the risk of undue influence, and negotiating the inherent tensions between enabling rights and managing risk. People who provide support require opportunities to explore, in a safe environment, these dilemmas, and the ways in which they can be addressed.
- Collaboration between the different supporters involved in the life of a person with cognitive disability, and strategies to identify others who might potentially become involved in supporting decision making, is essential. Practitioners require understanding of the differing roles, contexts and challenges confronting different types of supporters.
- Supporting people with cognitive disability with decision making is a complex and at times challenging process. All supporters, whether they are family members, support workers or lawyers need ongoing opportunities for training and supportive environments to reflect on the tensions they confront, further enhance understanding and hone their strategies of decision making support.

## **Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas**

### **Introduction**

The exercise of individual choice and control is central to contemporary disability policy and the National Disability Insurance Scheme (NDIS). The right to make one's own decisions is embedded in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) to which Australia is a signatory. This right realises a deep philosophical value associated with the health and well-being of individuals. Over one million Australians or 5% of the population have a cognitive impairment as a result of intellectual disability or acquired brain injury (ABI) (Australian Institute of Health and Welfare, 2013). This group are high users of disability services and will constitute over 60% of participants in the NDIS. The move to individualised funding and market driven models of human service delivery, exemplified in the NDIS, means they are likely to be confronted with more choice making situations, and an increase in the range and complexity of decisions they are expected to make (Carney, 2013).

People with cognitive disability require significantly more support for decision making than other adults in the community (Australian Institute of Health and Welfare, 2013). Good support for decision making that enables the preferences and values of people with cognitive disability to be central to their decisions will enable greater control over their own lives, and positively affect their self-identity, psychological wellbeing and quality of life (Brown & Brown, 2009; Nota, Ferrari, Soresi, & Wehmeyer, 2007). It is also clear that in systems of individualised funding, people who have strong family support for decision making do much better than others in terms of access to resources and satisfaction with services (Neely-Barnes, Graff, Marcenko, & Weber, 2008).

Until the UNCRPD little attention had been given to avenues of support for decision making. For people with cognitive disability, there has been the choice between appointing a guardian as a substitute decision maker or unregulated informal support for decision making (Carney, 2015). In Victoria a least restrictive approach to guardianship has meant most support for decision making remains in the informal sphere with family and service providers who support the person on a day to day basis

and who know them well. Unregulated informal support however, places few expectations on supporters and offers little guidance about support for decision making. At times, this has led to confusion about the legal standing of informal supporters; and a tendency to resort to informal substitute decision making or undue paternalism (Bigby, Bowers & Webber, 2011; Bowey & McGlaughlin, 2005; Kohn & Blumenthal, 2014)

Informal support for decision making has generally not been done well, and research suggests that people with cognitive disability have very limited or no involvement in either the major or minor decisions that affect their lives (Antaki, Finlay, & Walton, 2009; Bowey & McGlaughlin, 2005). Decisions may reflect the values of others, be made in haste, driven by resource issues, or be contrary to values and rights embedded in policy (Bigby, Bowers, & Webber, 2011; Dunn, Clare & Holland, 2010).

The UNCRPD has generated significant debate about the concept of supported decision making. The foci of Law Reform Commissions in Australia and internationally (Australian Law Reform Commission (ALRC), 2014a, 2014b; Law Commission of Ontario, 2013, 2014; Victorian Law Reform Commission, 2012) have been on new structures to enable people with cognitive disabilities to access support for decision making without removal of their rights (Power, Lord, & deFranco, 2013). In Australia, the NDIS legislation (National Disability Insurance Scheme Act, 2013) provides for the appointment of a plan nominee who can make any of the decisions that would otherwise be made by a scheme participant. Carney (2015) suggests that this provision is a mix of substitute, supported and informal decision making but that section 80 (1) of the legislation does place expectations on how nominees approach their decision making role, stating that it is the “duty of a nominee of a participant to ascertain the wishes of the participant and to act in a manner that promotes the personal and social wellbeing of the participant”. The ALRC (2014b, para 1. 4) has proposed reform of all Commonwealth nominee provisions in line with four national decision making principles:

***Principle 1: The equal right to make decisions***

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

***Principle 2: Support***

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

***Principle 3: Will, preferences and rights***

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

***Principle 4: Safeguards***

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

These principles resemble those articulated by the Convention, and represent a paradigm shift from paternalism and support based on ‘best interests’. The ALRC also proposed two possible kinds of formal appointment where a person needs substantial support with decision making or informal assistance is inadequate: a “supporter” or “representative” (Australian Law Reform Commission, 2014, p. 99-119). Whether these recommendations will be adopted across all Australian jurisdictions is unknown at the time of writing.

The challenge lies in translating principles such as these into practice. Attention to the creation of appropriate legal structures, has neglected the crucial issue of the actual practice of delivering support for decision making in whatever context. There is little evidence on what works in terms of ensuring the will, preference and rights of people with cognitive disability are actually at the centre of decision making.

Early adopters of supported decision making, such as Sweden and Canada, provide little evidence on the operation of mechanisms, such as micro boards, Sweden’s *Godman* or the practice of decision making supporters (Boundy & Fleischner, 2013; Browning, 2010; Then, 2013). Several small projects in Australia have piloted approaches to support for decision making (Carney, 2014). Although not subject to rigorous research, they point to the need for decision making supporters to have positive expectations about involvement of the support receiver, and difficulties in determining the extent to which support should extend beyond the exercise of choice to the actual implementation of decisions. One consequence of limited empirical investigation into the practice of support for decision making, is that tools developed to guide support are untested and based primarily on ideology, knowledge and principles drawn from social, health and legal professional practices, or practice wisdom rather than empirical evidence (Department of Human Services, 2014;

Watson & Joseph, 2011).

Researchers at La Trobe's Living with Disability Research Centre have developed empirically based propositions about four domains and factors within each that contribute to effective support for decision making (Douglas, Bigby, Knox, & Browning, 2015). These propositions were developed from recent qualitative studies (Bigby et al., 2011; Bigby, Frawley, & Phillips, 2014; Douglas, Drummond, Knox, & Mealings, in press; Knox, Douglas, & Bigby, 2015a, 2015b, 2015c; Browning, Bigby, & Douglas, 2014), the Australian pilot studies (Carney, 2014) and the literature on maximising choice at a micro level for people with cognitive disability (Willner, Bailey, Parry, & Dymond, 2010). The four domains are orchestration, commitment, support principles and strategy development.

*Orchestration* captures the importance of two aspects of the role of a primary supporter in support for decision making. First, a primary supporter needs to have a relationship with the person with cognitive disability. The relationship does not have to be 'excellent' or 'perfect' but rather it needs to be 'good enough,' that is, characterised by trust, genuine positive regard and honest interpersonal interactions. Second, a primary supporter needs to recruit and/or orchestrate the involvement of other supporters, both paid and unpaid, around the person with cognitive disability.

*Commitment* is key to effective delivery of support for decision making. Effective supporters recognise that having knowledge of the person's history, the dynamic nature of their preferences, and the effect of their specific cognitive impairments on their decision making needs is crucial to the process. They are committed to developing this knowledge, continually learning about the person with cognitive disability and changing their own expectations based on new knowledge.

*Support Principles* lay the foundation for effective support. These principles relate equally to collective and individual approaches to support and they represent essentials of practice for those providing support. Several principles can be drawn from examples of 'effective' support and 'good' experiences: recognise that the decision making agenda is based on the desires of the support receiver and that these can be realised in many different ways; be cognisant of one's own values and their potential impact on the support process; understand risk and its potential benefits; preserve the self-identity of the person being supported; and be able to articulate the reasoning processes involved in supporting and reaching a decision with a person.

*Strategy Development.* Effective supporters need to develop a repertoire of

flexible strategies that they can call upon readily as personal and contextual demands vary. Strategy use depends on time, situation, the significance, scope and nature of the decision and who else might be involved in or affected by the decision. Strategies include: use of supporters as a sounding board for issues; provision of information; testing options and potential experiences that might result from a decision; introducing and nurturing the seeds of ideas about options; bringing in others to trial a situation; creating distance to enable greater autonomy; breaking a decision into smaller components that are shared across the person and supporter; imagining or re-imagining the future; teaching skills; and considering choice options within defined boundaries or parameters.

These propositions provide a foundation for developmental work to further tease out the factors that contribute to effective support for decision making that can inform resources to guide supporters. The literature review and study in this report contribute to that work.

### **Study Aims**

The La Trobe Living with Disability Research Centre was commissioned by Scope to undertake a literature review and a study to identify processes and key dilemmas that arise in providing good support for decision making to people with cognitive disability. This report summarises the findings from the study undertaken during 2014. This report is part of a larger project, *Supported Decision Making and Guardianship: Building Capacity within Victoria*, being undertaken by Scope and its partners and funded by the Legal Services Board. The aim of this project is to build knowledge on how people with cognitive impairment can be supported to make major life decisions, decisions that may be the subject of a Guardianship hearing. It further aims to develop and test resources to build the capacity of families, carers, service providers and legal professionals for improving the support they provide for decision making.

There is no clear Australian definition of supported decision making and the term is often subject to differing interpretations, as Browning, Bigby and Douglas (2014, p 5) explained,

The term “supported decision making” is used in many different contexts, and it is often unclear exactly what people mean when they refer to it. Supported

decision making is referred to as a process, a mechanism, a system, and a framework. The literature suggests it is a process of supporting people with their decision making, a system that affords legal status, and a means of bringing a person's will and preference to the centre of any substituted decision-making process (ACT Disability, Aged and Carer Advocacy Service, 2013).

To ensure clarity, in writing the report we distinguished between *support for decision making* and *supported decision making*. In the current Australian legal context support for decision making occurs largely in the informal sphere but also in the work of formal substitute decision makers. In contrast debates about supported decision making more closely engage with issues of legal capacity in the context of reforming legal frameworks to more formally recognise or appoint, for example, decision making supporters, co decision makers or representatives with specific mandates about their scope and the way they must act to support decision making. At the time the study was conducted, there was no formal legal framework for supported decision making in Victoria.

## **Literature Review**

### **Aim and Method**

The aim of the review was to identify published research on processes of support for decision making of people with cognitive disability, and enablers and barriers to the provision of support. There is some degree of overlap in the literature in the use of terms, particularly *choice* and *decision making*. Choice has often been used as a proxy for decision making but is more correctly seen as a subsidiary part of decision making. This distinction is illustrated in the definition of decision making as “making a choice among options, implementing the choice, and evaluating the effects of the choice...” used by the World Health Organisation (2001) in the International Classification of Functioning. Making a decision implies making a choice, but making a choice does not necessarily mean decisions are made. For example, a person may choose what to eat but not whether they want to eat, or when they will do so.

Much of the research on choice making has been experimental, conducted in laboratory rather than everyday settings and offering contrived options rather than those likely to be commonly encountered. Nevertheless, some studies have explored how people with a cognitive disability exercise choice in their daily lives (Agran, Storey, & Krupp, 2010; Antaki, Finlay, Walton, & Pate, 2008; Beadle-Brown,

Hutchinson, & Whelton, 2012). The primary aim of these studies has been to examine the conditions and staff practices that optimise the opportunities of choice for people with cognitive disabilities in their daily lives. Choices such as this however are seldom conceptualised in terms of contributing to decision making in people's lives.

A systematic search of the peer reviewed literature from 2000 using electronic data bases was undertaken and completed in September 2014. Appendix 1 sets out the detailed search strategy and inclusion criteria. In summary, papers were excluded if: they were commentaries rather than reporting research; did not specifically address the processes of support for decision making of people with either intellectual disability or ABI; involved children rather than adults; focused only on measurements for assessing capacity; reported experimental assessments of choice making in artificial as opposed to real life settings, and; only described the absence of choice or decision making rather than processes of support. A total of 54 papers including three in press articles were identified and are summarised in Table 1.

Two large and significant bodies of literature, indirectly related to the practice of support for decision making that might be considered to provide an underpinning knowledge base were excluded from the review. The first is experimental work examining optimal conditions for the act of choice making, such as how many objects to present, at what speed or in what form. This work is largely conducted in settings that do not reflect the every-day situations or decisions encountered by people with cognitive disability. It is concerned primarily with stimulus or response conditions and/or reinforcers that enable individuals to demonstrate choice or preference. For example, Bailey, Willner, and Dymond (2011) explored whether the use of a visual aid to support decision making would improve participants' quality of decision making and ability to justify decisions they made about their own lives. Knowledge such as this while important requires translation into more practical applications to be useful to decision making supporters. The literature search identified several papers reporting the successful translation of this knowledge into cognitive assistive devices and visual aids to support everyday decision making (Davies, Stock, & Wehmeyer, 2003; Fisher, Bailey, & Willner, 2012; Wennberg & Kjellberg, 2010). The increasing pace of technological developments and small devices such as smart phones and iPads will undoubtedly see an increase in research on the effectiveness of this type of aid. Notably however, Wennberg and Kjellberg's (2010) study suggested the effective use of technology by people with cognitive disability was reliant on the attitudes and

support of staff and family.

The second body of work excluded from the review focused primarily on methods used to assess an individual's cognitive and decision making capacity. While assessment of cognitive capacity is important in existing legal frameworks, it is likely to become less so in new regimes of support for decision making which include co-decision makers or representation agreements (see Browning et al., 2014). More broadly, the assessment literature can provide knowledge to inform strategies of support for decision making. For example, Cea and Fisher (2003) examined the abilities of adults with mild, moderate, or no intellectual disability to understand hypothetical treatments using the Assessment of Consent Capacity-Treatment based on Appelbaum and Roth's psycho-legal consent standards, and Kennedy and Niederbuhl (2001) examined the consensus of psychologists on recommended criteria for confirming capacity to consent to sexual activity.

### **Overview of literature**

Table 1 in appendix 2, provides a brief summary of the 54 papers identified in the review. Information about the aims, methods, context and participants of each study is summarised, together with findings about overall processes of support, processes specific to the individual, the role of supporters, social structures and outcomes of support for decision making. Overall as already flagged this is a relatively small body of literature reflecting a weak evidence base, with few robust designs or large scale studies. Very few of the studies reported specifically focused on processes of support for decision making. Rather choice or decision making were included as one of many factors investigated. For example, Ellem, O'Connor, Wilson, and Williams (2013) included support for decision making as part of their study of social work practice with marginalised groups, and Beadle-Brown et al. (2012) included data on choice as one of a number of domains that have better outcomes as a result of staff practice being based on Active Support.

Across the literature, choice and decision making were not clearly defined or distinguished from each other and the large majority of the studies was concerned with people with intellectual disability, reflecting the much longer history of research about this group. The recent published work by Knox, Douglas and Bigby (Knox et al., 2015a, 2015b, 2015c) represents the beginning of a literature concerned particularly with people with acquired brain injury (ABI). Notably, one of these

studies included spouses as supporters of decision making for people with ABI (Knox et al., 2015a). The spousal perspective contrasts with studies of people with intellectual disability where spousal supporters are largely absent and family supporters are typically parents or in the case of older people, siblings.

The types of choice or decisions considered varied widely, although there were indications that issues of sexuality and health have received more attention than other areas. Issues of risk and best interests as well as the constraints of specific time frames for decisions were evident. For example, the study by Burgen (2010) highlights how the timeliness of support may actually reduce the options that might be considered in making decisions about pregnancy. The situational context of the studies also varied across the body of research. Studies have looked at support for decision making in the context of service provision by staff in supported accommodation or vocational settings (Conder, Mirfin-Veitch, Sanders, & Munford, 2011; Ferguson, Jarrett, & Terras, 2011; Rossow-Kimball & Goodwin, 2009; Timmons, Hall, Bose, Wolfe, & Winsor, 2011), in group situations such as self-advocacy, planning, transition or interdisciplinary meetings (Abreu, Zhang, Seale, Primeau, & Jones, 2002; Caldwell, 2010; Espiner & Hartnett, 2012; Garcia-Iriarte, Kramer, Kramer, & Hammel, 2009; Pilnick, Clegg, Murphy, & Almack, 2010), in health settings by nurses and other medical professionals (Ferguson et al., 2011; Goldsmith, Woodward, Jackson, & Skirton, 2013; Sowney & Barr, 2007) and in family contexts (Healy, McGuire, Evans, & Carley, 2009; Knox et al., 2015a, 2015b; Mill, Mayes, & McConnell, 2010). These studies conceptualise decisions in different ways, with no apparent commonly used typology. Decision types are most commonly broken up by magnitude and life space such as “big” life space - sex, who you live with, what kind of job you have or “everyday” life space – whether you have strawberry or chocolate ice-cream.

#### *Enabling support for decision making*

Positive attitudes of others towards the importance of choice and control and attention to creation of opportunities are identified as important factors that enable people with cognitive disability to be involved in decision making (Agran et al., 2010; Caldwell, 2010; Garcia-Iriarte et al., 2009; Kjellberg, 2002; Knox et al., 2015a; Mill et al., 2010; Renblad, 2003; Timmons et al., 2011). This is illustrated, for example, by the very different approaches to supporting choice and control taken by different staff

teams in the accommodation services studied by Rossow-Kimball and Goodwin (2009). The study by Knox et al. (2015a) provided examples of decision making supporters actively identifying opportunities for decision making in which to involve the person with cognitive disability, and Caldwell (2010) talked about the reflections by self-advocacy leaders about being encouraged to take risks in their lives which had built their confidence. In contrast some studies alluded to the negative impact that staff or family expectations can have on opportunities for decision making, for example by restricting the available options (Antaki et al., 2009; Healy et al., 2009). As well as reflecting on enabling factors, the self-advocates in Caldwell's (2010) study also talked about the oppressive nature of some family support.

Several studies identified the positive impact of Active Support on the degree of choice exercised by people with intellectual disability in supported accommodation services (Beadle-Brown et al., 2012; Robertson et al., 2001). However, there is also some evidence of the difficulty of embedding the practice of Active Support in organisations so it is continually and consistently used by staff to enable engagement and choice. For instance, the study by Koritsas, Iacono, Hamilton, and Leighton (2008) suggested that gains to choice reduce over time. This finding is supported by a current study of the long term impact on staff practice and resident outcomes in organisations that have adopted Active Support (Mansell, Beadle-Brown, & Bigby, 2013).

The study by Cooper and Browder (2001) tested the impact of a staff training program on choice and demonstrated its success in terms of increased choice making by service users. Unfortunately, the longevity of change was not addressed as there was no longer term follow up and data about maintenance of change over time could not be collected.

The study by Ellem et al. (2013) of social work practice was the only one that looked at support for decision making from the perspective of case managers rather than direct support workers or families. It pointed to the importance of being able to suspend one's own judgments and adopt a neutral and non-judgmental stance in providing support for decision making. Self-awareness and continual reflection and questioning were suggested as important skills for decision making supporters.

The nature of the relationships with supporters, who might be spouses,

parents, other family members, clinicians and service providers, was identified as important in enabling good support for decision making in several studies. For example, the centrality of familial or social relationships and having a positive relationship based on trust and understanding was highlighted in Knox et al.'s work (Knox, Douglas, & Bigby, 2013; Knox et al., 2015a, 2015b). Burgen's (2010) study showed the importance of the relationship with a supporter for young women with mild intellectual disability deciding to seek advice about pregnancy. The Swedish study by Kjellbert (2002) identified a relationship with a 'contact' or independent person appointed under the Swedish LSS legislation enacted in 1994, as facilitating decision making support. Notably however, the implementation and operation of the Swedish provisions for appointing an independent "Godman" to support decision making for people without other support independent of the service system have not been directly studied.

Closely linked to evidence about the centrality of relationships in support for decision making are findings, from a number of studies about the importance of tailoring support and communication to the strengths and weakness of the individual. This notion of tailoring support has implicit expectations about knowing the individual sufficiently well to do this. For example, Conder et al. (2011) identified some services as more able than others to adjust their responses to the needs of mothers with intellectual disability; Antaki et al. (2008) used conversational analysis to identify positive examples of tailoring communication to the individual and checking back for understanding; Rossow-Kimball and Goodwin (2009) identified the use of simple adapted communication strategies such as color coded buttons on a TV controller to enhance decision making for service users in an accommodation service; and, Garcia-Iriarte et al. (2009) illustrated the use of accessible materials in supporting members of a group to exercise greater choice and control. Knox et al. (2015a, 2015b) highlighted that knowing a person who has an ABI challenges a supporter to have an understanding of the changes that have occurred since the injury and how different a person may be now as compared to before the injury.

Knox et al. (2015a) and Schelly (2008) draw attention to the importance of knowing about a person's cognitive impairment and adjusting communication to take account of its impact on comprehension and executive functions. Knox et al. (2015a) provided examples of practical support as well as what they called 'cognitive

scaffolding' as strategies to involve people with ABI in decision making which for example involved breaking a big decision into smaller part steps. Similarly Ellem and her colleagues (2013) identified the need to acknowledge that people with cognitive disability often have difficulty expressing their wants, making it hard to represent or know their interests. This study highlighted the importance of being 'truthful to person's real expressions' and the concept of 'deep listening' to look for the core message behind a person's actions. Espiner and Hartnett (2012) also used the concept of deep listening but in the context of person centred planning meetings.

The studies by Espiner and Hartnett (2012), Pilnick et al. (2010), and Abreu et al. (2002) illustrated support for decision making in the context of formal meetings as well as more individualised interactions. Espiner and Hartnett showed that strategies such as adjusting communication, knowing the individual and deep listening are part of the repertoire of skills required for person centred planning. Their study raises questions about the relationship between person centred planning and support for decision making, suggesting many similarities. Both Pilnick et al. (2010) and Abreu et al. (2002) provided examples of the way meetings involving professionals and people with cognitive disability can be disempowering and obstruct rather than facilitate their involvement in decision making.

There is some evidence in these studies of the contextual factors that facilitate choice and decision making. At the micro level Cobigo, Morin, and Lachapelle (2009) showed that things happening in a person's immediate work environment, such as noise, detracted from the exercise of choice. At the macro level, studies suggested that smaller sized accommodation settings and living in one's own home were associated with increased opportunities for choice (Robertson et al., 2001) and that size of organisations managing services, organisational procedures, and the restrictiveness of accommodation or vocational setting affected opportunities for choice (Neely-Barnes et al., 2008; Tichá et al., 2012; Wehmeyer & Bolding, 2001).

Various studies demonstrated the effectiveness of education or training programs in improving decision making skills of people with cognitive disability about particular topics. Examples have been published in the area of sexuality (Agran et al., 2010; Dukes & McGuire, 2009); later life options (Heller, Miller, Hsieh, & Sterns, 2000), avoiding abuse (Khemka, 2000; Khemka, Hickson, & Reynolds, 2005) and use of health care systems (Webb & Stanton, 2009).

Management of risk and protecting people's best interests were identified as important aspects of providing support for decision making. For example, Knox's studies illustrated how supporters mediated decision making of people with ABI by shaping options and their involvement, and oversight and monitoring of decisions. There were examples too in other studies of supporters actively shaping decisions to reduce risk or ensure an outcome they perceived to be in the best interests of the person with cognitive disability (Ferguson et al., 2011; Pilnick et al., 2010).

#### *Obstacles to support for decision making*

Many of the factors identified as creating obstacles to involvement of people with cognitive disability in decision making or provision of effective support were implicitly the reverse of enabling factors. As Table 1 shows a number of papers illustrated poor support for decision making where control of agendas and power exerted by supporters meant the preferences of people with cognitive disability were overridden and their rights compromised (see papers under the heading 'illustrations of exclusion from decision making and poor practice').

Several papers highlighted the impact of limited resources on options available and thus decision making (Hodges & Luken, 2006; Kjellberg, 2002). The negative impact of staff without adequate communication skills, knowledge of the impact of cognitive disability, or awareness of their own values were evident in a number of studies (Antaki et al., 2009; Ferguson et al., 2011; Sowney & Barr, 2007). Such factors were compounded by risk averse organisational management (Hawkins, Redley, & Holland, 2011) or the pressured nature of some environments in which decisions have to be made (Bigby et al., 2011; Sowney & Barr, 2007). In particular one UK study illustrated the poor outcomes of relying on checklists as a resource for support workers to support decision making when they are inadequately trained in reflective practice and unaware of the influence of their own preferences and values (Dunn, Clare, & Holland, 2010).

## Research Study

### Method

This study aimed to explore the perceived processes and dilemmas experienced by people who provide support for decision making to people with cognitive disabilities, or are in receipt of support for decision making. The study adopted a social constructionist theoretical perspective and an exploratory qualitative design using interviews and focus groups, thematic analysis and grounded theory methods.

#### *Sample and Recruitment*

The sample comprised people with cognitive disability with experience of being supported to make decisions, and people with experience of supporting someone with cognitive disability to make decisions. Criteria for inclusion of participants with experience of being supported were having mild to moderate cognitive disability and good enough verbal communication skills to participate in an interview. A formal assessment was not undertaken and reliance was placed on the fact that participants had been deemed as eligible for the disability support services they received. Criteria for inclusion of other participants were experience of supporting someone with cognitive disability to make decisions and to be a legal professional, family member of a person with cognitive disability or a worker in the disability service system.

Information about the project was circulated through organisations on the reference group as well as other key service providers in the disability sector, via newsletters, mailing lists including those of National Disability Services, VALID, AMIDA, the Legal Services Board and the Federation of Community Legal Centres. Scope researchers advertised the study through direct personal contact with potentially interested participants, either individually or through sector forums. Advertisements invited interested people who met the participant inclusion criteria to contact the research team to participate in the interviews and focus groups. People with cognitive disabilities were offered \$25 to participate and other prospective unwaged participants were advised that any travel costs would be covered by the research team.

#### *Participants*

A total of 46 people participated in the study. They comprised twenty-one family members, eight people with cognitive disability, five legal professionals and twelve

workers in disability support services. Participants with cognitive disability were people with intellectual disability while the other participant groups included those with experience of supporting either people with intellectual disability or acquired brain injury or both. Detailed demographic data was not collected about participants.

The 21 family members included parents and wives of people with multiple disabilities whose primary impairment was either intellectual disability or acquired brain injury and who lived at home, in shared supported accommodation or independently with drop in support. Most of the parents and wives were over fifty years and had a family member who was middle aged but three were younger and had young adult family members.

The eight people with intellectual disability were aged between twenty-three and thirty years. Six were female and most attended a day support and skills training program for young people with disabilities. The five legal professionals occupied varying positions in the legal system, and included a magistrate, a children's court lawyer, and lawyers with experience of working in community legal centres. All had worked with people with cognitive disabilities and several had specialised in mental health or intellectual disability law.

The 12 workers from disability support services worked either in a day support and training service for young people with disabilities or in a large disability support organisation that managed day support and shared supported accommodation services. They included front line direct support workers as well as coordinators and managers.

### *Data Collection*

The young people with intellectual disability participated in individual interviews; one young woman was accompanied by her mother. Four were interviewed twice in order to seek follow up information. The interviews were conducted by the second author and most lasted for less than 30 minutes. Lawyers participated in interviews conducted by the second author which lasted between 30 – 60 minutes. Eighteen family members participated in one of three focus groups that were conducted either by the second author alone or with the third author, and three participated in an individual face to face interview with the second author. Disability workers participated in one of two focus groups, conducted by the first and second

authors or the second author. Focus groups with family members and workers lasted between 30 minutes and 120 minutes, and interviews between 20 to 90 minutes.

A semi structured interview schedule with parallel questions tailored to each participant group was used to guide all the interviews and focus group discussions. The schedule sought information about participant's understanding of supported decision making and experiences of being supported or supporting others with cognitive disability in decision making.

Ethical approval was given by the Human Research Ethics Committees at both La Trobe University and Scope. All participants gave informed consent to be interviewed. All data in this report has been de-identified including the organisations and the individuals who participated in the study.

### *Data Analysis*

All interviews and focus groups were digitally recorded and transcribed word for word. NVivo was used to manage and code the data. Data from each participant group, individuals, family members, lawyers and workers were analysed separately. Data were analysed using an inductive thematic approach (Braun & Clarke, 2006) and line by line grounded theory coding techniques. Initially data was sorted into broad topics using open coding and then focused codes were used to identify themes which were then clustered together into broader thematic categories. Themes were then compared and contrasted across participant groups. At various stages during the analytical process the emergent themes were discussed and refined by the authors.

### *Limitations*

This was a small study that more successfully captured the experiences of family members, lawyers and support workers than people with cognitive disability. While the young people with intellectual disability who participated talked about the types of decisions they had made or would like to make they found it very difficult to identify and discuss the processes of being supported to make decisions. This means data about the experience of being supported to make decisions is not as rich as that of the experiences of providing support for decision making. A much longer period of engagement with people involved in receipt of support for decision making preferably during a period when decisions are being made would be a better design to capture their experiences of support. People with acquired brain injury were not included as

participants in this study, although people who provided support to this group were. An in depth study with similar aims focused solely on people with acquired brain injury was being conducted at the same time as this study by a PhD student supervised by the first and third authors. Given the relatively small pool of potential participants with acquired brain injury and the similarity of the study aims the research team decided to draw on the published findings from the more in depth study rather than duplicate data collection and potentially overburden participants (Knox et al., 2015a, 2015b, 2015c).

Participants self-selected on the basis of their experiences of supporting people with cognitive disability to make decisions or receiving support to make decisions. Given the exploratory nature of this research, the broad concept of supported decision making was explained in the information circulated about the study and used in the interviews but participants were left to place their own interpretation on the concept of supported decision making. Similarly, no criteria were specified about the quality or nature of the support they either received or gave. The findings therefore reflect the range of processes and dilemmas about support for decision making experienced by the participants rather than being confined to what might be regarded as ‘good support’.

## **Findings**

The findings are organized to reflect the main research questions; 1) understandings about the meaning and scope of support for decision making to people with cognitive disability; 2) processes and approaches to support for decision making; 3) dilemmas and tensions in support for decision making. The themes and sub themes are not presented separately for each of the participant groups but where appropriate we compare and contrast the perspectives of different participant groups or issues identified as specific to a particular subgroup of participants.

### **Understandings about Support for Decision making with People with Cognitive Disability**

*Making sense of support for decision making - ‘You have to start with the philosophy’*

Family members, workers and lawyers talked about decision making as a difficult, dynamic and chaotic process. They drew parallels with their own experiences suggesting that the need for support was not confined to people with

cognitive disability as everyone makes decisions with the support of others. One lawyer said for instance, “decisions are really hard to make. I can’t even decide what job I want”. As discussed in later sections, it was apparent however that relationships people with cognitive disability had with those who supported their decision making were not necessarily similar to those people without cognitive disability had with decision making supporters– they were less equal and possibly more fraught with implicit assumptions about practical boundaries, risk management and best interests.

Participants had not engaged with the current debates about supported decision making and were largely unaware of the imperatives in section 12 of the UNCRPD. However, the people with cognitive disabilities had a strong sense that making their own decisions was important. One man with intellectual disability said for example, “I make my own decisions and I’m quite happy about it”. Most other participants either implicitly or explicitly understood supported decision making from a human rights perspective, recognising the right of people with cognitive disability to make their own decisions and be accorded the same respect and dignity as other citizens. When participants were asked what supported decision making meant to them, they said for example,

The focus is taken off me as an individual or a paid employee and put back on the person that ultimately that decision is going to benefit... At the end of the day, it’s not going to be me that’s participating in whatever the decision will be so why should I be the one making the ultimate decision as to how it’s going to all play out (worker).

...always having in mind it’s what that person wants, not what I want, or my boss wants, or their mother wants or what a service provider wants (lawyer).

These people are human beings and deserve as much respect and dignity as anybody (family member)

Participants saw supported decision making as a break from philosophies of the past where people with cognitive disability had not been perceived to have rights or the capacity to make or be involved with decision making. One family member commented for example that attitudes used to be “oh they’re intellectually disabled; we’ll just make decisions for them”. The break however had not been clean. Participants were concerned about lingering attitudes from the past and consequent

poor staff practices that compromised involvement of people with cognitive disability in decision making. They said for example,

...basically whether it is explicit or not, he [service user] doesn't make decisions for himself. If [at the supermarket he says] 'I would like baked beans on toast for tea' and the support worker doesn't feel like cooking them, he goes 'don't worry mate, we'll have spaghetti instead' (worker).

There are still people out there, working in the field who... have the same mentality as 20 or 50 years ago working in the institutions which is 'you come over here and sit down here and don't get that food on you, wipe that off your mouth, everyone get into your pyjamas now, it's time for bed' (lawyer).

### *Differing types of decisions and perspectives*

People with cognitive disabilities talked about the scale and content of the decisions they needed to make in their lives. These ranged from: day to day things such as what to eat, what social activities to attend or whether to use taxis; things about their short term future such as whether or where to work, which day program to attend or which classes to enroll in, and; major life decisions such as whether to get married, have a baby, or move out of home.

From a different perspective one of the most common types of decision that participants with cognitive disability talked about was taking up offers presented to them which were straightforward take it or leave it options about things such as attending a particular activity. Such decisions involved yes/no alternatives rather than deciding between a limited a range of options that might be on offer. For example, one young woman with intellectual disability spoke of how her teacher had suggested she attend a choir. Through this choir she developed a love of singing and met other young people.

Workers, family members and lawyers were often involved in differing types of decisions. Although workers and family members spoke about similar decisions to the ones mentioned by the participants with cognitive disability, they also spoke about others types. These were ones related to health such as whether or not to have a particular treatment, level of physical activity, weight loss, or type of clothing, and more nuanced decisions such as whether to get engaged rather than married.

Lawyers were more likely to mention 'one off' life changing decisions with legal

dimensions than decisions with only day-to-day implications. For example, they talked about decisions such as whether to plead guilty in a criminal case, to apply for increased access to a child in the care of paternal grandparents or to move to a nursing home.

Workers and family members tended to see decisions as cumulative having flow on effects for the future. For example, deciding to participate in a group program would constrain future decisions by having to take account of group as well as individual needs. Conversely smaller decisions had an impact on bigger overall directions. As one worker said,

...if we have a student come to us and their goal, their first plan was to learn this particular skill, but now they're ...saying 'art all day, art all day, art all day'. And they're meant to be doing work ready skills or independent living skills. I can't then say 'no you can't do art', but I have to say 'hang on what other things do you want to learn'.

### **Processes and Strategies of Support for Decision making**

#### *Relationships as the context of support for decision making*

Support for decision making took place in the context of relationships – between the person with cognitive disability and each of their supporters – and between the supporters. Participants with cognitive disability identified that they had established relationships with the people who had supported them to make decisions. They said for example, “Well, we talk to our parents”, “And we talk to our teachers as well”, “...Um, my mum helps me”, “...it was my dad's idea”...“the work experience teacher”.

One young woman had a ‘circle of support’; a group of people with whom she could “discuss any issues that have cropped up”. She had chosen members of the group herself, which included her parents, the church community care worker and other relatives and family friends. Participants talked about their supporters as being ‘funny’ ‘a nice person’ someone they could ‘rely on’ or have ‘good conversations with’.

Support for decision making was perceived as integral to the work of support workers, family members and lawyers. A family member said about support for decision making for example, “it's the stuff we do every day” and a worker said, “you

just do it as a matter of course”. The type of relationship supporters had with the people they supported with decision making set the context of their support and both shaped and limited its nature. Some support workers for example, drew attention to the limits of their role, particularly with respect to health related or risky decisions. Summing this up one worker said, “there are lines...and those lines are there for a reason”. This was illustrated by one worker who talked about a situation where she had realised that supporting one of the service users in the house to decide about a major medical procedure was beyond both her expertise and role. She said,

I coordinated a house with a female who was going through some...women’s issues...hysterectomy. How does that work? Where does the information for that sort of decision making and choice come from? I was quite new to the role as coordinator. Where do I go? I engaged my manager at the time. We engaged OPA, [the Public Advocate] we got an independent advocate. We ended up going off to VCAT [tribunal] and there was a big process involved. And I wouldn’t even contemplate having that decision making put back on to me or anyone in that paid employment. So, no, sorry, not my gig.

Lawyers tended to have limited and short-term relationships with the people they supported with decision making. Busy court lists meant when they were allocated to people with cognitive disability through the duty systems, lawyers often didn’t have time to get to know their client and/or get adequate instructions. One lawyer said for example,

It’s often very challenging because you normally meet the clients in these cases for the first time on a day when you are on the roster...kids have usually been taken from their parents the night before, often the parent doesn’t know where they have been placed so it is very emotionally charged, they haven’t met you at all, it is busy at court, you’re trying to find a private quiet space and you’re often sitting literally in the hallways of court trying to get instruction so it’s not ideal.

### *Relationships among supporters*

Workers, family members and lawyers all described support for decision making as collaboration between supporters of the person with cognitive disability. Ideally they thought this enabled him or her to discuss options with different people and hear

a range of perspectives. Supporters said for example,

So she [daughter] will tell Sophie [friend] stuff that she won't tell us so it is helpful to have some insight from others, they won't breach her confidentiality (family member).

Families are involved in how people ultimately make their decision, other services and stakeholders can be involved... So it is sort of ensuring that the person has the benefit of all the people that they believe help them to make a decision (worker).

In the case of the young women who had a circle of support, the collaboration among supporters was long standing with an agreed way of working together. Mostly however collaborations among supporters were fluid involving the people supporting the person at the time that particular decisions being made. Participants said for example,

So it is sort of ensuring that the person has the benefit of all the people that they believe can help them to make a decision (worker).

We were in contact with the young woman's family, a lot through the initial process of that relationship as it began to grow and where they were going to live and they lived together and the family were supportive for them to live together before they got married (worker).

I always ask support workers for feedback and they are getting better at communicating back to me how it went (family member).

One of the lawyers talked about the importance of working with the others involved in a person's life. He said,

Sometimes it is quite manageable and you can sit down and talk to the other professionals and it is a matter of saying hey.... we're all on the same railroad, we just see how we get there slightly different, we're all wanting the best thing, we just have different ways of approaching it so that usually works.

Participants gave many examples of different perspectives of supporters about rights, risks and best interest which had led to conflict among them, particularly between family members and workers. Approaches to naming and managing conflict among supporters presented difficult dilemmas for both workers and families. These are

discussed in later sections.

### *Being neutral*

A very strong theme of being neutral rather than providing support for decision making from a stance of what was in the person's best interests ran through the comments of workers and lawyers. For example they said,

We receive instruction from the person with the disability and then we pass them onto to someone else, it might be to a tribunal for example. So...even if the tribunal is going to say well the person doesn't have capacity to give you instructions we will then say, 'we're telling you what this person wants, what their wishes are'... we've really got to establish we are there to act on their behalf, their instructions and not a best interests model and I always try to establish that really early on because lots of people have been trapped with a best interests model where everybody is trying to help and look after them and their needs can be lost in the process (lawyer).

Being conscious to not direct them towards what you might think is right for them but rather presenting the information and getting to them to get to their own conclusions (worker).

Being neutral was not straightforward, and workers in particular talked about how easy it was to influence the direction of a person's decisions by inserting their own values into the processes of support. This influence happened through for example, the nature of the options they presented, the way pros and cons were discussed, their reactions to proposed decisions or even the strength of their relationships with the person whereby their own appearance or interests were perceived as a role model. They reflected for example,

it makes you wonder, that stuff about how you influence people because you're always a role model (worker).

I see how much potential I have to influence people's decision ... one of the guys that I work with has changed the coffee that he drinks because he drinks the same that I drink now (worker).

making sure that I remain really neutral and I don't express any preferences what so ever (worker).

...trying not to put your own values when people are making a decision (worker).

Part of being neutral was seen as respecting decisions made by the person with cognitive disability, whether or not they were perceived as good or sensible. Workers and lawyers said for example,

We don't always make decisions that benefit us...but it means that people are making an informed decision (worker).

...everybody has the right to make a bad decision, people should be supported to make their own decisions and that they can make the wrong decision, it's their decision, doesn't matter if you disagree with it" (lawyer).

We'd fight, we'd argue about stuff, but at the end of the day if she said 'no', 'no' was the answer (worker).

But I think also that once somebody makes a decision, that it's really important to remain that way [neutral] because if somebody then makes a decision, you'll go 'Oh, fantastic. What a great decision.' They'll know they've made the right one for you, whereas they need to be making the right one for them (worker).

Self-awareness, being aware of one's own values, was identified as a key strategy by workers and lawyers in providing neutral support for decision making. This meant for instance being sufficiently self-aware to identify situations about which they were uncomfortable providing support and having the necessary back up from their organisation for their withdrawal to be feasible. Illustrating this point and awareness of the potential impact her own values could have on the support for decision making she might provide to a person one worker said,

understanding that and knowing that that's ok to say 'Look, I'm really uncomfortable supporting this person to go to church every Sunday morning' ...knowing that it's ok from the organisation as well. That you're not refusing to support someone, but just there are sometimes you're just not the right person (worker).

### *Actively shaping decisions*

Family members gave less emphasis to being neutral than workers or lawyers.

For them an important part of support for decision making was to have an overarching vision for the person's life, and goal setting to enable smaller decisions to be aligned to the overall direction of a person's life. For example, family members said,

You have to have a philosophy, there is no point in having supported decision making without having a very clear commitment to the model, this is the model I believe is appropriate... I believe very strongly that everybody has the right to a meaningful life.

You've got to let him do it, which has been our philosophy over the years because we've just brought him up as normal. He's got every chance that everybody else has got.

...people who have been part of this journey will have got sick of me talking about it because my view, with or without [name of daughter] input, is very much that within ten years or even less, I would like to see [name of daughter] working five days a week and if not in some sort of accommodation, independently supported accommodation... she should be working within the community, living within the community, supported as appropriate.

For some family members, goal setting was dictated by funding cycles and requirements. For example, one family said, "We sit down and work out his goals for the year.... This is for financially doing his commitments".

Although family members were silent about whether creation of an overarching life vision by them as a key process of decision making support precluded discussion about wider possibilities, they did talk about how they actively shaped the directions of decisions in the way they presented information or by sowing the seeds of particular ideas. One family member said for example, "we did provide [the information] in such a way that we knew what decision she would make". Another spoke of how she and her husband decided to go on a holiday to Bali. Their daughter was keen to go too but they knew she wouldn't enjoy it, as she didn't like heat, the beach, animals or spicy food. They had talked about the holiday with her saying:

These are the sorts of things we're going to be doing. We're going to go to the monkey forest, go and look at an elephant, the zoo, we're going to be eating out a lot, the sorts of food available over there is Indonesian style food

and is quite spicy and Bali is an island, we're going to be going to the beach  
As predicted her daughter decided not to go. Another mother talked about sowing the seeds of ideas to help her daughter arrive at a decision about leaving home. She said,

[My daughter should eventually live] in her own flat, her own apartment. But I've got to provide seeds for that....I'm trying to sow those seeds and it sort of sounds very callous but I as a parent have to commit myself to do that so systematically over a period of time she can take on that knowledge or vision gradually. There is a real estate agent who delivers these booklets...full of glossy pages of pictures of apartments and houses and inside them. [Name of daughter] will now look at that book saying 'this one looks nice, maybe that's the one I should have'... she won't be living anywhere anytime soon, we're talking a five to eight year horizon before that happens but that's the process of making it a tangible visual experience as much as anything else so she can look and see and touch...and actually grasp.

In another example however, this process of 'sowing the seed' involved narrowing rather than broadening the options. A mother said she might suggest,

...a limited range of two or three things to select from rather than the more opened questions of what do you want to do for your program for the next year?...It was more like what are we going to do, go to the gym or gardening, which one is it you would like, that sort of thing.

That remaining neutral was less important to family members than workers or lawyers may be explained by their close relationships to the person with cognitive disability and their own stake in decisions. As some of these examples have illustrated, decisions made by the person with cognitive disability were likely to have a significant impact not only on themselves but also on their close family members.

#### *Seeking advice and back up*

Lawyers in particular talked about seeking advice if they felt they did not have a full understanding of an issue or how to support a person with cognitive disability. They talked about the advice and follow up support for implementation of decisions they sought from legal centres or agencies that specialized in support for people with cognitive disability. They said for example,

...if we don't understand fully how to work with someone who uses a particular form of communication, we'll get advice and support from somebody who does before we meet with them and when we meet with them (lawyer).

[Name of disability support organisation] are really good at picking up cues I don't or am too busy to do....and the other thing is, what happens after a court hearing I'm talking to her or writing, suggesting what needs to be done and sometimes I'll ring the client and say have you done X Y Z and they haven't so then I will contact disability services and say I'm really concerned that although the client says they do X Y Z, they still haven't done it, can you get in touch with them and try and assist them, because I can't do all that.

Most of the family members who participated in the study were members of carer support groups. They talked about the value of the insights from other families in similar situations to their own and the support they gained from those groups.

Workers spoke more than other participant groups about their need for support with their role as decision making supporters. They saw two aspects to this. First was the need for access to immediate direct support for them to talk through the 'moral dilemmas' that came up day to day. Usually this was through easy access to a supervisor or a contracted resource, such as the external staff counselling service one organisation used. Support from a supervisor might also be followed up by contact with others with relevant expertise. They said for example,

...generally your first port of contact would be the coordinator. And then the coordinators got to work out which way...or how it's going to be dealt with... Management could engage external support when required; we did have someone from the BIS [Behaviour Intervention Services] team come afterward (worker).

I engaged my manager at the time. We engaged OPA, we got an independent advocate. We ended up going off to VCAT (worker).

Many workers felt that access to support such as that discussed above was not sufficiently embedded in organisational processes and procedures which meant too often they were left without the support they needed. One said for example,

The line manager [was] stretched over this many houses and they've got these new roles and they're being trained for this and that... and we don't know it's alright to go 'ok, go up the next step of the ladder' or phone them, or find another (worker).

The second aspect of supporting workers in their role as decision making supporters was the broader willingness of an organisation to tackle the more systemic issues they identified in their day to day work. For example, systems for communication were needed in organisations where the staff changed from day to day, so that workers could be better briefed about issues arising that affected decision making. Also, schedules need to be flexible as the time involved in supporting people to make decisions could take longer than predicted. Workers said for example,

What I needed was a communication book because...I'm the staff that's there today, there's someone else that's there tomorrow and another person.... there's all these other people that are coming into the picture as well that have an influence (worker).

Some things take a lot longer than maybe it would for you or I would to do but time is a different animal. At times that doesn't fit in well with house timetables or schedules.

When problems arose as a consequence of such systems not being in place, workers risked taking responsibility for and having to deal with what were essentially structural issues.

It was like you're tackling the situation and thinking I need to solve it within my self- No, this is a structural problem that's creating consequences for everybody (worker).

Workers called for stronger and more supportive relationships with their managers to provide back up to them. They said for example,

You need to have good relationships- stronger relationships with the people within the organisation and drop the title. And learn from each other and know each other's there to communicate (worker).

I want the organisation to have that communication process between me and

other staff members, the line manager (worker).

*Person-centred - tailoring support to the individual*

The overarching theme of person centeredness, tailoring support to the individual, was evident in all the specific strategies of support for decision making that participants illustrated from their own experience. As one lawyer said,

They might have capacity to do some things, but not to do other things or to make some decisions and not to make other decisions. So of course we look at every single individual person as an individual person and work out, as best we can, what their situation is as far their capacity to make decisions (lawyer).

The pre-requisites for tailoring support to the individual were twofold: 1) supporters needed to have a relationship of trust with the person; and 2) know the person well.

Talking about what was important in a trusting relationship and how they approached it participants said for example,

everybody is different and every technique is different so you have to sit there and kind of work out where am I pitching it, what is going to give me a rapport with this person, what are their values and so on, so you do that and I think you really need to establish that trust because you are then going to talk about issues that they are probably finding very distressing, can't articulate really what they want, feel that life has been taken out, control has been taken away (lawyer).

...there has to be a really big component in listening skills so it is really listening to as wide a range as possible but listening to the people, very often workers when they are on an initial assessment or something have got the solutions before they start and they've got the outcomes and they will tick the boxes. They really need to listen and build up trust before major decisions are made ...really need to listen and build up trust before major decisions are made (family member).

Knowing a person well, meant understanding an individual's cognitive capacity, life experiences, personality, strengths and weaknesses and modes of communication which enabled supporters to tailor their approach to support. As one family member

said, “to work with the person you’re helping to make the decision you need to have as much information about that person as possible and what their needs are”. Talking about their approach to support, participants also highlighted the value of knowing more intangible things about the person. They said for example, “she is that kind of personality...she’s a people sort of person, happy to go with the flow” (worker) or “depends what it is and what else is going on and how stressed she is. When she is really stressed she just can’t think” (family member).

Family members took it for granted that they knew the person well given the longevity of their relationships. However, time and specific effort were required by workers and lawyers to get to know a person. One family member said about her son for example, “a support worker may take something like six good months to really get to know who he is”. Lawyers without the luxury of time talked about their strategies for establishing a relationship of trust with and getting to know a person, saying for example,

He had footy posters all over the place so after I explained who I was and what I was doing, I said how could you possibly barrack for Essendon, the Cats are the people we need to barrack for so I tried to build a bit of a rapport up, a bit of a banter.

Despite the focus on individuality, several characteristics across people with cognitive disability were repeatedly highlighted by families, workers and lawyers. These included lack of confidence in making decisions and limited experience of possible options, stemming from the limited expectations and protectionism of past care regimes. Difficulties associated with the cognitive capacity of people with cognitive disabilities were also noted. These difficulties included comprehending the information needed to make informed decisions, future or associated consequences of a particular course of action, and the impact of practical factors that may limit options such as money and risk. Taking account of these and other individual characteristics were captured in four key strategies of support for decision making: 1) attention to communication; 2) education about practicalities and consequences; 3) listening and engaging; and 4) creating opportunities. Table 2 provides examples of each of these strategies of support for decision making illustrated through participant quotes.

Table 2. Tailoring support to the individual: Common strategies of support for decision making

<p><b>Attention to Communication</b></p> <p><i>Pitching information and communication at the right level</i></p> <p>I had to work out what level to pitch it at, whether I was pitching it at a really base level or whether I had to move up...It's got to be very basic (family).</p> <p>So we try and use plain English, really simple plain English (lawyer).</p> <p>Breaking it down; breaking it down... 'you understand this, let's move slowly through this'; not doing it in great hunks. Just doing it slowly over a period of time. It takes a while...(lawyer).</p> <p>Some people use different kinds of assisted communications, facilitated communication or picture or story boards, or electronic devices (lawyer).</p> <p>In my daughter's case it is a matter of pictures, showing, doing, tangibility (family).</p> <p>Some might just need information to make a decision, but others will need information explained maybe through pictures or audio or whatever (worker).</p> <p><i>Awareness of verbal and behavioral clues</i></p> <p>Oh if there is something she doesn't like to eat, she'll just push it away (family).</p> <p>If she wants to go swimming, she'll get up... ready to go (family).</p> <p>If he doesn't want to get up, he will go stiff which says to you I'm not interested in getting up for any reason, just want to stay put, so it is about reading his body language, his facial expressions and gestures (family).</p> <p><i>Checking back for understanding</i></p> <p>...usually people say yes and nod and then you will try and say can you tell me in your own words what I'm saying... just focusing on as best you can simple language and maybe repetition of what you've said and searching for clues as to what degree you're being understood, asking people to repeat things back to you in their own formulation, their own expression... (lawyer).</p> <p>Going back over things several times to make sure what we are saying is understood and what we've been told is, we're understanding what the person is trying to tell us and giving them the various options, legal advice and the various options (lawyer).</p>
<p><b>Education about Consequences and Practicalities</b></p> <p><i>Making it understandable</i></p> <p>It's breaking it down into little steps, so this is the first thing we have to consider and then, if you have a solution for that, then this is the next thing we have to consider... just take a little step at a time because sometimes that's all you can do (family).</p> <p><i>Do the research – present the options and pros and cons</i></p> <p>my view is to research it so I can see a big picture (family).</p> <p>I assemble a collection of appropriate items for this particular decision (family).</p> <p>I'll search and I'll bring him some brochures and I'll give him as much choice as- stuff he hasn't even considered - I'll give to him to...so he can broaden his...you know thing for life... For example you want to go in a hot air balloon...riding on a motorbike. And this particular person did. You know, they've gone in the Harley rides and stuff. And it's something she never thought you could do. Um, been in an air plane- like, you know, a little</p>

light plane once upon a time (worker).

*Explain consequences of decisions and that priorities can be undermined by small decisions*

We do say ‘okay so you wanted this certificate, well these are some classes you can do for that are you happy to do that class?’ (worker).

...so you provide as much information to them as possible so that they can make an informed decision (family).

...just being pretty sure that if they choose option C that they realize there’s a downside to that, maybe this would happen if we do option C but if you still think that’s the best thing to do (lawyer).

[asking] what do you see as the outcome for that? What are some of the consequences? What do you hope to achieve out of it? (worker).

It was about ensuring the person “really understands the reality of what they want...you need to think carefully about whether you are going to take legal responsibility for these acts that you are alleged to have done because if you do there will be legal consequences. The driver’s licence scenario, if you tell me you are guilty of this offence then the law says I have to do X Y and Z, take your licence for a year, fine you and so on (lawyer).

So we talked about all of her options and she was very concrete...if she wasn’t sleeping with someone and she was on the pill then she wouldn’t take it every day so she was...so depo was the best solution for her and we worked through that and she understood that (lawyer).

### **Listening and Engaging to ensure all Options are Considered**

*Attentiveness to will and preference*

listen to what they say (family).

nobody even listens to a person with intellectual disability... so it is important to hear what the person thinks, what they think their problem is, what they want and sometimes they’re not sure what their problem is (lawyer).

*Taking the time*

you have to actually help them think through... you’ve got to put the time in to actually helping them think through their situation (lawyer).

...repetition... and this is what happens, we’ve got to talk about it and she’s got to digest it and she’s got to think about it and I say ‘now remember, we talked about that...and this is the next...what do you think?’ (family).

it takes a lot of time and energy to go through that process (family).

you need patience, time (worker).

over a time span that might even be two weeks if you’ve got that sort of time (family).

Every new decision takes time. It’s not like oh well he’s learned now to make decisions and that’s going to work, no it is not going to work faster (family).

it is with a great deal of, takes a lot of time and energy to go through that process and as a parent you go, just do it (family).

### **Creating Opportunities**

*Active reframing that invites participation – what do you think*

Where have you been? Where would you like to go back?, What did you like about this place?...and just looking at all those little things...What do you think?’ Really that was 99 percent ‘What do you think? What do you think? What do you think?’ (worker).

*Providing a sounding board to talk through*

I think you all do it too when you have to say you don't realize, you're talking during your classes and they are expressing their concerns and wishes. And you talk it through with them, just that process of having a sounding board (worker).

*Acknowledging low expectations and building confidence*

...they've got to be given the chance to make it....you might think 'oh, they won't be able to do that'. But you've got to say 'give it a shot (worker).

[lack] "ambition...so that if you asked them 'what would you like to have for a Christmas present?' she doesn't have an aspiration or ambition or a desperate need to have a particular item" (family).

...they're not used to making those decisions or haven't been given the choice or the power to make decisions- (even) something simple (worker).

So you can't just say well she can't make decisions because she's intellectually disabled, in actual fact she can make decisions and she makes some good decisions (family).

they're saying what they think you want to hear (family).

### **Dilemmas and Tensions in Support for Decision making: Juggling Rights, Risks and Practicalities**

Dilemmas for those who provided support for decision making originated in the very need of people with cognitive disability for support; their reliance on others for knowledge to inform decision making and for resources to put decisions into effect. Dilemmas arose therefore from the power and influence that supporters could potentially exercise in the lives of people with cognitive disability. Remaining neutral and enabling the person to exercise their human right to make their own decisions posed significant challenges for supporters and one worker said, "with great power comes great responsibility".

Strong forces countered the preferred neutral stance by workers and lawyers to support for decision making and mediated support by family members. Tempering forces stemmed from assumptions about the directions a person's life should take and what was in their best interests, the limitations on possibilities imposed by organisational imperatives to manage risk and the impact of perceived practicalities on options considered. Support for decision making often involved juggling rights, practicalities and risks, which one support worker likened to "twirling plates on a stick" Inevitably such juggling tempered the extent to which the will, preference and rights of the person with cognitive disability were reflected in decisions they were

supported to make or were made on their behalf.

*Remaining neutral - impact of implicit assumptions*

As noted earlier, family members placed less emphasis than lawyers and workers on support for decision making that was neutral. They were keen to embed support for decision making in an overarching philosophy for a person's life, such as to live independently or have a job. In doing so, they actively tried to ensure that the advice or influence of supporters followed a consistent direction by selecting workers or assembling others around the person who held similar views to their own. For example family members said,

I make sure all the people around her, whether in a recreational setting, educational setting, with friends' families or our own extended family, they understand what my expectations are.

You have to make sure that every person in that network is absolutely clear about what the end game is, what the vision is and that we're here to assist [name of person] to go on that journey to the best of her ability.

it's not just simply saying to a person such as my daughter what would you like to do, it's a matter of curating the options which are appropriate ...including providing options which fit [and] are curated for that individual.

Adopting specific visions influenced the decision making agenda and the options likely to be considered in respect of specific decisions.

Similarly, assumptions made by family members or workers about a person's capacity to be involved in decisions and limitations imposed by resources effectively drew boundaries around decision making agendas and options considered. Family members talked for example about allowing the person with cognitive disability to "make decisions where he can do it safely" and giving "autonomy and as much scope to make her own decisions as we can". Workers talked about,

...identifying what an issue is for somebody and presenting them with options of what is available to them and what's achievable and practical for the person.

...being conscious to not direct them towards what you might think is right for them but rather presenting the information and getting to them to get to their

own conclusions. It also involves being “supportive to point out what is reasonable and possible.

As illustrated then, the overall stance adopted by a supporter often had hidden assumptions about what is in a person’s best interests (the type of life they should lead or is best for them) and resulted in unarticulated boundaries being placed around a person’s decision making agenda (the type of options that are appropriate or within their capacity).

There were several instances for example where family members recalled giving advice about the pre-requisites for leaving home that reflected a particular value position about independence that would effectively delay any decision. One mother advised her daughter that if she wanted to leave home she had to “learn how to cook and to budget independently”. Another mother told her daughter, who was also planning to get married, that she had to “learn, to be independent in cooking and budgeting, paying your bills, learn how to not use too much electricity or gas, cost too much money”. Another mother recalled a conversation with her daughter’s fiancé about the timing of his marriage during which she had suggested a time frame that would delay it for more than 20 years. She said,

[Fiancé] said when could they get married and they were both there and I said well [daughter] was 32 at the time and he was 18 years older so he was 50 then. So I said ‘how about when [daughter] is 50, does that sound okay?’, ‘yeah that’s fine, that’s fine’. He said ‘I’ll wait, she’s worth it’.

Implicit value based assumptions embedded in support for decision making and the more explicit ways of shaping decisions identified in the data may not be evident to the person with cognitive disability, but they can clearly undermine their right to choose the shape of their own decisions.

#### *Tensions caused by conflicting perspectives among supporters*

Differing views among supporters about the implicit or explicit assumptions embedded in their support for decision making led to tensions among them and dilemmas for both family members and workers. For example, one worker talked about the frustration experienced by staff in the service where she worked, when the family effectively removed intimate relationships from the decision making agenda. She said,

we've had young people that want to have a relationship with each other and that has not happened for them for...and they are not spiteful malicious reasons. But families have concerns, they have safety issues, they have ideas about what that would mean... it's easier sometimes to just say 'no' rather than negotiate what it would mean for these two people to actually have a relationship.

Family members, lawyers and workers all talked about the difficulties of resolving differing stances of supporters and resultant conflict, saying,

... so you have [medical] people who say I'm here to assist you, I'm really trying to do the best thing for you, to look after you I want to protect you, where the lawyer comes in and talks about human rights, supported decision making..... I'm a doctor, just here to make you well, do the best, and that's perfectly fine, they have taken the Hippocratic oath....sometimes that doesn't gel with the legal approach of self-determination, everybody has the right to make a bad decision (lawyer).

You all [staff] obviously need to be on the same page with each individual student... [not] one of us is giving some sort of guidance and then I'm giving the complete opposite sort of thing (worker).

Family members were particularly frustrated by workers who they felt often undermined them and the long term health and well-being of the person with cognitive disability by putting in their "two cents worth".

too often people think they're being kind to let her have a little treat and little treats only become an iced coffee which is full of ice cream and sugar and I don't want to be critical of staff because they want to have happy people around them and [daughter] will gravitate to choices which are not going to help her from a health and weight point of view (family member).

None of the participants talked about formal avenues to resolve conflict among various supporters involved with a person with cognitive disability. It seemed however, that rather than being openly discussed, conflict was sometimes dealt with through underhand or disrespectful means. One worker said about a family for instance, "I don't pay a lot of heed to what she says" and another said,

...all you can do is be the portal to that client and what's best for that client.

And sometimes that's inclusive of their parents. And other times its diplomacy with the parents but still getting the client to where they need to be.

Family members who directly managed a funding package and employed support workers talked about removing workers who did not agree with their stance. One said for example,

If we find someone he doesn't gel with, who is not meeting the goals, we ask them, whoever we're employing with; we ask 'can we have a change?'

*Stepping out of neutral: Taking over to manage risk and best interests*

In earlier sections, we have described the way participants talked positively about the shift to a rights paradigm and the new concept of providing support for people to make their own decisions based on their own preferences, irrespective of whether they were 'good' or 'sensible'. Nevertheless it was evident that when family members thought a particular decision was too 'risky' and might threaten a person's long term health or best interests, they 'stepped in,' reverting to a model of substitute decision making. Family members said for example, "[It's] very difficult there are times when we have to say look this is what you need to do", and "there are times when we just step in and say no we're going to make this decision". These situations included determining life-long goals, health issues, and readiness for relationships, marriage and parenthood. For example, one mother spoke about stepping in when her daughter decided not to have a pacemaker battery replaced because the appointment conflicted with a social engagement,

Like when she had to have a pacemaker replaced. She said 'no way...we have a sausage sizzle at work, I'm not going'. And I said you have to go, your battery will go flat and you'll drop dead...When her daughter continued to object the mother said she 'started digging my heels in' and claimed parental authority, saying 'I'm your mother and you'll do as you're told'.

Another family had insisted their adult son return home:

...we found out he was throwing out my meals and he was...living on fruit loaf... so we said 'no it's not working when you do things like that'. But he was most adamant wasn't he so then we had this decision, 'I'm sorry mate you're going to have to come back inside'. He does have his own room at the

end of the house. He's still pretty independent but he has to walk past us and we can monitor.

Similarly, workers seemed willing to support a person's own preferences "to the point of what is reasonable and possible". For workers, stepping in involved weighing up the person's right to self-determination with a judgment about risk of harm, and the duty of care they owed to a person. They also had to consider the potential consequences to themselves of not acting or making a poor judgment about a situation that might later be questioned. One worker said for example, "at the back of your head that if something goes really wrong somewhere, you're involved in any decision making are you going to end up in the coroner's court?".

The account given by one worker about a young woman who had epilepsy illustrated some of the tensions workers faced. The young woman had recently had a seizure and a fall and the worker questioned whether she should have anticipated the risk and prevented the fall,

She had a seizure, and she fell down and she hit her head. And I was working with and she didn't want me right next to her...it was that sort of 'Should I have been next to her?' and then it's like 'Nah, I can't be next to her every single second.' She doesn't want that...it would drive her nuts to have someone constantly hovering all the time. She's 20 year old. She needs to have her space. And I'm not going to catch her if she goes down anyway because I could hurt myself. So, rule number one: you don't catch people. If you can support the head, fine, but otherwise... But yeah, she went down very quickly and she did hit her head. It's just one of those things that are sad.

This situation had also created potential conflict between the worker and the young woman's family, as the worker said, "yes, mum would like us to be glued next to her".

Workers expressed significant frustration with the levels of risk adversity in the disability support organisations that employed them, which at times placed them at odds with both family members and their employers. Some workers thought decisions about managing risk did not relate so much to a duty of care to the person with cognitive disability but rather to the reputational or financial risks to an organisation. As one worker said,

So often OH&S is trotted out or privacy legislation, if I hear that one more time; ‘Oh no we can’t do it because of the privacy legislation’ or ‘it is an OH&S issue’, those have become the big excuses for ‘we can’t do what people want’.

Another source of frustration that created tensions for both workers and families was balancing the rights of family members with those of the person with cognitive disability. This tension occurred particularly when following through and implementing or respecting decisions made by others. For example, one worker spoke of managing the admission of a person with cognitive disability to a respite facility when this person would clearly rather have been in his own home. The worker said,

He came to respite and personally, I think it was wrong... He was screaming-kicking and screaming and it was just really sad and it’s like ‘no’. That’s not fair. On him, on us.

The worker noted the legal expectation that the individual’s choice should be respected but that was not an option in this case, saying, ‘if someone’s a legal guardian then they can legally make that decision for them to go into respite’.

In contrast family members talked about their rights being secondary and usurped by decisions made by their family member with cognitive disability that they were bound to respect. For example, one mother talked about her son with cognitive disability refusing to use a taxi. This decision meant she had to provide all the transport, she said,

He refuses to go in a taxi ...so now I have to get him there and get him home every day, five days a week...Their rights override our rights when it comes down to this.

#### *Dilemmas posed by resource constraints*

All participants expressed frustration about the implicit and explicit boundaries that limited financial resources, access to services or group living situations placed around the options and decisions open to people with cognitive disability. One young woman said that once a week a woman from her local council took her to the shopping centre for an outing, “instead of staying in the house”. While she quite liked going to “have a coffee, walk around”, she didn’t have a choice about where she went because “...it’s from the Council, she can’t take me anywhere else, has to be around

here”. Other participants said for example,

He needs sports programs and not all of the service providers have a lot of sports programs (family).

the waiting time [for supported housing] here in the eastern region is something like 18 years (family).

The question about when realism and pragmatism should enter decision making processes was highlighted by many participants. They said for example, people sometimes had unrealistic ideas or expectations such as playing “full forward for the Western Bulldogs next year” (family); going to Paris for a holiday or America for camp (worker); or even just deciding you would like to go to a movie with a friend that afternoon when the friend lives on the other side of town” (family member). Their answers were very grounded in the realities of day to day living rather than the philosophy of human rights.

...so it is about trying to be real about stuff too and just, this idea you’ve got is a really nice idea but to put it in place you need to think ahead (family).

...And another thing that will happen is in a group situation, like five people that we work with, sometimes you’ve got to re- schedule their choice (worker).

Making the type of judgments embedded in the comments of family members such as what is reasonable, real or within a person’s capacity, are central to the challenge of providing support for decision making to people with cognitive disability.

### **Discussion**

These findings reflect some of the factors already identified in the literature about the process of support for decision making and the factors that enable or obstruct good support. The positive comments by the young people with cognitive disability about making their own decisions reflect the position of the rights movement and the importance to well-being of enabling people to make their own decisions (Neely-Barnes et al., 2008). The findings highlight the importance of relationships and the notion of a support system for decision making around the individual. A core underpinning principle was being person centred and tailoring support to the individual. This core principle was exemplified by four broad strategies used by

supporters: attention to communication, education about consequences and practicalities, listening and engaging, and creating opportunities. The study uncovered some of the dilemmas faced by supporters. These dilemmas included the degree of influence exerted by some, the need to resolve conflicting views among supporters, and restrictions imposed by implicit or explicit assumptions about what might be in a person's best interests, ways of managing risk and available resources. The findings point to issues that should be taken into account in thinking about training and support for workers, family members and lawyers who may be involved in providing support for decision making to people with cognitive disability.

Reflecting the literature, participants identified the broad scope of decisions making and range of decision types in people's lives. Most commonly they talked about day-to-day and major decisions. Day-to-day decisions were generally about engagement with others or activities requiring immediate and frequent support from only a small number of supporters, who may not be consistent over time, in a particular context. Major decisions in comparison had a longer time frame, and often occurred at the interface between a number of systems or settings and involved multiple supporters often with specific expertise.

Our findings showed that different decision making supporters were involved with a person depending on the type or the content of decisions. The absence of a typology of decisions makes it difficult to discuss the roles and varying needs for training and support of different decision making supporters in people's lives. Lawyers for example were involved in major decisions with long-term implications that happened infrequently. Workers were more likely to be involved in supporting frequent day-to-day choices and decision making, and pointed to the boundaries they were reluctant to cross in terms of involvement in bigger decisions with more far reaching implications. Family members provided support across the spectrum of decision types, and appeared to be particularly concerned with major life transition or health related decisions.

Importantly decisions were perceived as cumulative in nature, pointing to the link between types of decisions, and the implications of the backward and forward chain effect of many decisions. For example, day-to-day choices or decision making builds confidence and leads to experiences that can frame the options considered in bigger decisions. In turn, bigger decisions already made may curtail availability of day-to-

day options. The cumulative nature of decisions suggests the importance of identifying the range of people involved in support for the various types of decisions in a person's life, sharing knowledge among them and developing mechanisms for collaboration. We have referred elsewhere to this idea of orchestration as an element of effective support for decision making (Douglas et al., 2015). All training should incorporate an awareness of the roles that others play, and the cumulative impact of decisions in spheres of a person's life in which the supporter may not be a part.

Relationships were identified as a core process underpinning support for decision making, and supporters had differing types of relationships with the people they supported. Families, workers and lawyers were keen to normalise support for decision making by pointing out their own dilemmas in making decisions and the support they drew from others. The findings suggest however, that people with cognitive disabilities rely on others such as workers, family members or lawyers for support, with whom they often had formal or unequal relationships. Only one participant with cognitive disability, the young woman who had a circle of support, spoke about actively choosing the people from whom she received support and involvement of friends.

Unequal relationships between people with cognitive disability and their supporters potentially compromise their rights, and as our data suggested can lead to dilemmas for supporters and conflict among them. Our findings demonstrated the influence exercised by some supporters, particularly family members, through explicitly filtering or presenting information in particular ways or applying a more implicit vision or agenda. They showed too how at times influence could be countered by other supporters, although the lack of collaborative mechanisms meant this could happen in less than open ways at times. The study by Knox et al. (2015c) illustrates the way sub systems or dyads within a system of support can create countervailing forces and temper unequal relationships. This situation affirms the need for a network of supporters, rather than a single supporter for decision making.

The absence of relationships with friends or independent advocates with whom people are likely to have more equal relationships reflects the limited social networks and extreme social exclusion of people with cognitive disability and, particularly people with intellectual disability (Bigby, 2008). Having more freely given relationships and broadened social networks would contribute to the pool of others

people with cognitive disability could draw on for support with decision making. There can be little doubt that building social connections for people with cognitive disability is an important strategy to strengthen support for decision making, though to date there is only a small evidence base to inform such work.

Support for decision making was perceived by both workers and lawyers as an integral part of their work. Several issues are specifically relevant to lawyers. People with cognitive disability are over represented in many parts of the justice system (Dowse, Cumming, Strnadova, Lee & Trofimovs, 2014) meaning lawyers are likely to encounter this group of people frequently in their practice. Thus, attention to lawyers' skills is an important issue. Lawyers were the only group of participants with a clear and unequivocal understanding of the rights-based approach that is central to the UNCRPD and debates about supported decision making. Our data suggests that although lawyers had a good understanding of a rights-based approach to support for decision making, the system in which they work created obstacles to being able to achieve it effectively. They had limited time to build relationships of trust and or opportunities to get to know an individual well, both of which they saw as fundamental to good decision making support. These factors reinforce the importance of orchestration of support. It is important for lawyers, and indeed others in this type of position such as guardians, to recognise and work with other supporters who have broader or more nuanced knowledge about the person. Through collaboration they can compensate for gaps in their own knowledge about the person. Thus, they also need to have well developed skills to collaborate and mechanisms to facilitate short and longer-term collaboration.

Lawyers identified similar strategies for supporting decision making as other participants. They talked more often than others about getting 'back up' input about communication and understanding the impact of cognitive disability on comprehension. Their search for support suggests they may need and appreciate training to better adapt their decision making support strategies with respect to attention to communication, education about consequences and practicalities, listening and engaging, and creation of opportunities in line with the broad characteristics of people with cognitive disability as a group as well as the unique needs of each individual.

Workers in disability support services had a broad understanding about support

for decision making and easily used the language of rights to describe their perspectives. Their actual descriptions of providing support suggested however that they lacked a strong conceptual grasp of the changes necessary to shift from a best interest to a right to choose perspective. While they were critical of the continuing prevalence of paternalistic support practices, they were less able to illustrate different rights-based approaches such as those embedded in the UNCPRD and the recent report of the ALRC. Despite talking about rights, it seemed that the frames of reference uppermost in workers minds continued to be risk management, duty of care and best interests which can tend towards protectionism and restriction of rights rather than enabling practice frameworks.

These findings suggest that workers need support to think more deeply about and apply the key concepts embedded in the principles of supported decision making. They need practical examples of support based on a person's will, preference and rights, compared to a best interests approach. It is only by fully understanding first principles and working through examples of implications for practice that support workers will be equipped to effectively tackle the dilemmas of judging risks and withstand risk adverse organisational imperatives.

Workers provided rich examples of tailoring support to the individual and broad strategies to support decision making. They reinforced the positive effect that attitudes can have on creation of opportunities for choice and decision making identified in the literature. They also identified additional strategies such as attention to communication, listening and engaging, and educating about consequences. Such strategies warrant further analysis to clarify potential component parts and could form the basis for skills training for workers, families and lawyers alike.

Workers were also keenly aware of the importance of remaining neutral and being self-reflective in order to support decision making and their perspective reflected some of the findings by Ellem et al. (2013). They valued assistance in their own support role gained through reflective supervision or opportunities for consultation provided by external employee support programs, but expressed concern about their availability.

Importantly, processes and strategies used by participants to support decision making are not unique to support for decision making. They are part of the

foundation of good person centred support, particularly for communication and Active Support that aim to enable engagement in meaningful activities and relationships. The association between Active Support and creation of opportunities and support for choice making suggests this would be a valuable element of basic training for all workers. The overlap between foundations of person centred support and strategies to support decision making suggests there is a need to firmly incorporate them into basic education and training for workers as core to their practice rather than an optional or additional component. Better embedding skills necessary for support for decision making in training of all support workers may also serve to counter the conditional approach adopted by workers whereby support for preferences is heavily qualified by questions of risk, resources or capacity.

In contrast to workers, family members spoke less of a need for self-awareness. They showed little evidence of insight into the potential boundaries created by their own overarching vision for a person's life and implicit assumptions about capacity, risk and resource availability. Some family members also seemed unaware of the implications of adopting a rights-based approach and had only a superficial understanding of the UNCRPD. Older families have seen many changes in service system values and approaches to support during the lifetime of their relative with cognitive disability. Change has not always been welcomed, nor have resultant adjustments been easy to make. As rights-based support for decision making becomes the norm, the magnitude of foreshadowed changes emphasises the need to provide advice and support for families, in the form of peer support, training and supportive opportunities to reflect on and further hone their strategies of decision making support.

A key tension for families and workers in this study was conflict between them and a lack of trust in each other. Families saw support workers undermining their roles as decision making supporters and workers at times disregarded families whom they perceived as acting contrary to the well-being of the people they supported. There are several ways of tackling the issue of conflict among supporters.

One way to think about conflict among supporters is in terms of a system and its various sub systems which can work together, operate in parallel with each other or work in different directions. Such a system is illustrated in the case study of Beau and his two supporters described by Knox et al. (2015c). Work on relationships between

family members and services has highlighted the conflict between sub systems of workers and family in a person's life, and the absence of collaborative mechanisms or channels of communication to enable them to work more easily together and resolve differences (Tiffen & Kolmus, 2013; Bigby, Webber & Bowers, 2014). Our study too identified an absence of collaborative mechanisms. Circles of support and micro boards are proposed in the literature as ways of bringing people with divergent views together to broaden potential options and enrich decision making support. Mechanisms of this nature to orchestrate support, by enabling supporters to work together and supporting the expansion of support networks and inclusion of friends and acquaintances are clearly needed. They will both help to counter the unbalanced influence of some decision making supporters and resolve the tensions between supporters that pose dilemmas for workers and families alike. There is however little research evidence about the methods or success of circles of support or micro boards, and it is here that demonstration projects and action research is needed. Such a project has been initiated on a small scale with philanthropic funding by Inclusion Melbourne.

Another approach is to develop ways to assist supporters that give them opportunities for reflective spaces to discuss the tensions they confront in providing support, in balancing rights and risks, and keeping the person they care deeply about safe. Building capacity for self-awareness and reflective discussion potentially enables supporters to recognise their hidden assumptions and the implicit parameters embedded in their support for decision making. Making the implicit explicit enables assumptions to be more easily interrogated and moderated and enables alternative perspectives to be built. Alternative perspectives also bring with them opportunities to enhance understanding and develop novel strategies.

### **Conclusions and Recommendations**

The literature review undertaken as part of this study has highlighted the absence of a strong evidence base about the best practice in support for decision making. Whilst highlighting the need for ongoing research, both the literature and fieldwork do provide some insights into the processes used by supporters, as well as the dilemmas they face in providing people with cognitive disability with support for decision making. Based on these we make the following tentative recommendations about elements that should be taken into account in policy, practice and the development of

relevant training resources.

- Informed by a human rights perspective, and articulated in section 12 of the UNCRPD, supported decision making is in many ways a break from philosophies of the past. Family members and some people in paid supporting roles are not necessarily fully informed nor convinced by the philosophical underpinnings informing supported decision making. Lack of full engagement and commitment to the fundamental philosophy inevitably undermines effective support with decision making. Supporting people with cognitive disability to make decisions should be underpinned by the philosophical principles of supported decision making. There are various interpretations of supported decision making and debate about its formal adoption into legal structures in Australia, however the Law Reform Commission (2014b) has clearly articulated for key national decision making principles that capture a rights perspective to support for decision making. These are principles are:

***Principle 1: The equal right to make decisions***

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

***Principle 2: Support***

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

***Principle 3: Will, preferences and rights***

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

***Principle 4: Safeguards***

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

- Supporting people with cognitive disability to make decisions requires knowledge about and skills in communication with people with varying levels of cognitive disability, self-awareness and reflection, conflict resolution, and the range of potential strategies identified in this study for tailoring support for decision making to individuals.
- Supporting people with cognitive disability to make decisions frequently involves tensions and dilemmas including managing power differentials, the risk of undue

influence, and negotiating the inherent tensions between enabling rights and managing risk. Those in a supporting role require opportunities to explore, in a safe environment, these dilemmas and the ways in which they can address these.

- Collaboration between the different supporters involved in the life of a person with cognitive disability, and strategies to identify others who might potentially become involved in supporting decision making, is essential. Practitioners require understanding of the differing roles, contexts and challenges confronting different types of supporters.
- Supporting people with cognitive disability with decision making is a complex and at times challenging process. All supporters, whether they are family members, support workers or lawyers need ongoing opportunities for training and supportive environments to reflect on the tensions they confront, further enhance understanding and hone their strategies of decision making support.

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## **Appendix 1**

### **Detailed literature search strategy**

A systematic search of the peer reviewed literature was undertaken and completed in September 2014. The search was guided by the broad research question: ‘what is the research evidence about the processes of providing support for decision making of people with intellectual disability or acquired brain injury and what are the enablers and barriers to support for decision making?’.

The search strategy incorporated a search of electronic databases. The search comprised the following three steps. First, consultation with a qualified librarian identified four relevant electronic databases to search: PsychINFO, CINAHL, Sociological Abstracts and Scopus. The following terms were searched in either the title, abstract, heading word, table of contents, key concepts: "intellectual\* disab\*" OR "intellectual\* handicap\*" OR "intellectual\* impair\*" OR "intellectual\* disorder\*" OR "development\* disab\*" OR "mental\* handicap\*" OR "mental\* disab\*" OR "mental\* retard\*" OR "down\* syndrome\*" OR "acquired brain injur\*" OR "traumatic brain injur\*" OR "cognitive impairment" OR "cognitive disab\*" OR "cognitive disorder" AND support\* AND "decision making". No time limits were applied. The combined searches of the four databases (excluding duplicates) produced 1642 references which were imported into Endnote.

Papers then were excluded if they did not specifically address intellectual disability or acquired brain injury; or involved children rather than adults; or focussed on measurements for assessing capacity. From this process the 1682 references were reduced to 182. Abstracts of all remaining articles were located and two researchers (MW and ST) reviewed the abstracts to exclude articles that were not research based and did not address processes of supporting people to make decisions. Studies relating to building capacity to make decisions (eg. group empowerment programs) were included. The nature of decisions involved included end of life decision making, financial decision making; deciding to have a baby; deciding to participate in research, exercising choice. Where articles were assessed differently they were discussed among the two reviewers to reach a decision This process reduced the number of articles to 108.

The two chief investigators CB and JD reviewed these 108 paper. Further

exclusion criteria were applied: not published in a peer reviewed journal post 2000, experiments re choice making in artificial as opposed to real life settings, focus on lack of choice/ decision making only i.e. describing the problem rather than the processes of SDM, literature reviews without a methodology. Following a thorough assessment of the articles, and review by all members of the team of any articles where there were differences of opinion, a further 59 articles were excluded leaving a total of 49. Then three papers were added which were in press at the time bring the total to 59. The reference lists of 3 literature reviews excluded on the basis of their lack of methodology identified 3 further articles that met the inclusion criteria bringing the total to 54.

Appendix 2 Summary of literature

Reference	Research Study aims Methodology	Context Type of decisions are involved Where research took place	Participants Nature of the disability? Age range and number of participants	SDM processes Overall steps or process. Mechanism or framework	Individual processes Steps or processes occurring for the individual with cognitive disability.	Supporter/s Processes Role of supporter/s doing to enable SDM	Social Structures Enabling social structures enabling Documented barriers documented	Outcomes of SDM Outcomes of SDM
<b>Enablers – individual staff attitudes or practices</b>								
Agran, M., Storey, K. & Krupp, M. (2010). Choosing and choice making are not the same: Asking “what do you want for lunch?” is not self-determination. <i>Journal of Vocational Rehabilitation</i> , 33(2), 77-88.	<u>The Research aims:</u> To explore the types of choices being made; extent/nature of support provided to consumers; and the relationships between support needs and the above in different types of employment programs. <u>Methodology:</u> Quantitative. Survey re choice-making opportunities, and support provided.	<b>‘Choice-making’</b> in employment programs (where to work; task to do; who to support them; who to work with; lunch; what to do after work) and self-determination.  USA	<u>Nature of disability:</u> was varied (Cognitive disability/ <b>ID</b> , mild learning disability, mental illness, <b>ABI, mild to severe</b> ). <u>Sample:</u> 114 (aged 16+) respondents with (above disabilities) from 9 adult employment providers (including people from urban and rural area).			People who taught choice making/problem solving were: most frequently a job coach with parents, teacher or other (i.e. doctors, psychologist, relative) being less frequently identified (p. 83). Most respondents reported that support staff took choices seriously (p. 81, 84). No exploration of actual skills taught or process of creating opportunities for choice making (cited as a limitation by authors) (p. 85).	<b>Barrier for people with higher support needs:</b> Respondents requiring intermittent or limited support needs were given more opportunity for, and taught choice-making/problem solve more than those with a pervasive level of support (p.82).	Limitation: no consideration of the impact of choices on respondents’ experience/quality of life (p 85).
Antaki, C., Finlay, W., Walton, C. & Pate, L. (2008) Offering choices to people with intellectual disabilities: An interactional study. <i>Journal of Intellectual Disability Research. Journal of Intellectual Disability Research</i> , (52)12, 1165-1175	<u>Research aims:</u> To identify how staff offer choice with a particular focus on the conversational practices and the unwanted consequences associated with these practices (if any). <u>Methodology:</u> Qualitative. Ethnography combined with conversation analysis.	<b>Choice</b> in both structured group meetings and, more casually, during routine tasks. Choices were largely about meal, holiday or leisure planning.  A residential service located in the South of England, UK.	<u>Nature of disability:</u> <b>ID</b> requiring “some level of support” with ADLs and accessing services) as well as communicating with people outside of the home ( <b>mild to moderate?</b> ). <u>Sample:</u> 5 men with ID (one man with Down Syndrome) who required “some level” of support with ADL and communication.	Conversational practices in offering choice.		Six staff practices re offering choice. 1. "Two-option simple alternative in one questions" - two variants: first, a conversational variant (i.e. "do you want ... or ...?"); and, second, a staff member asked open question then verbally offered two choices each accompanied by a physical cue (i.e. tapping of a fist on the table to associate each alternative with a hand) (pp. 1167-1168). 2."Open question plus understanding check of answer": simple open question followed by a pause then a confirmatory question. Dependant on staff’s ability to recognise/interpret answer. (p. 1168). 3. "Open question plus immediate multi-option alternatives": As above without pause for answer and instead immediate offering a		All six staff practices could be successful in facilitating choice “when deployed sensitively”(p. 1173). However, unwanted consequences of the staff practice were observed. Asking for clarifications or offering checks in a series (i.e. Questions plus multiple alternatives/list) may have the consequence of prompting resident to change their mind or be interpreted by the resident as a hint their first answer (if answered before list was finished) was wrong (p. 1171). Dilemma for staff in asking for verbal test to ensure informed decisions - can be confusing for resident and lead to no confirmation that their decision was informed (see 1171-1173).

						<p>list of options (pp. 1168-1169).</p> <p>4. "Open question plus immediate single option": As above but with only a single option offered immediately after initial open question (p. 1169).</p> <p>5. "Open question repaired to one-at a-time alternatives": as above but followed by offering alternatives in a series (pp. 1169-1170).</p> <p>6. Closed question: requiring a yes or no answer. Appropriate when the answer is highly predictable (i.e. preference had been previously stated and it was being confirmed after time had passed) (p. 1170).</p> <p>Recommendations: Lists of more than two options risk confusion dependant on nature of response. If multiple options need to be offered, either a). finishing with an open question or b). Follow up by presenting a small number of options indicated as possible answers by the person. When there are two options, presenting options with physical/non-verbal cues (i.e. fists knocking of each hand) and repeating with non-verbal cues to check decision was successful (p. 1173).</p>		
<p>Garcia-Iriarte, E., Kramer, J. C., Kramer, J. M. &amp; Hammel, J. (2009). "Who did what?": A participatory action research project to increase group capacity for advocacy. <i>Journal of Applied Research in Intellectual Disabilities</i>, 22(1): 73-83</p>	<p><b>Research aims:</b> to increase the advocacy capacity of a self-advocacy group and create strategies to increase involvement, control of process and decisions by participating members with ID.</p> <p><b>Methodology:</b> Qualitative, Participatory Action Research. Data collection occurred through: focus groups with members of the self-advocacy group; participatory engagement by a researcher acting as an advisor for self-advocacy group meetings;</p>	<p>Group decision making in a self-advocacy group (i.e. Fundraising).</p> <p>U.S.A.</p>	<p><b>Nature of disability: ID</b> (unsure of level of disability (. <b>Participants:</b> 16 regular members of a self-advocacy group (associated with a community organisation and a "People First" chapter). Members were aged 24 to 53 years-old, two were female and 14 male, 10 members were of "Latino/a"</p>	<p>Four types of support documented: member support; strategies as support; advisor support; and system supports (pp. 17-19).</p>	<p>Participation did not lead to control (p. 17). <b>Member support:</b> provided by members to other members allowed the group to feel a greater sense of control (i.e. When the accessible agenda wasn't photocopied, a member who could read it aloud) (p. 17).</p>	<p><b>Strategies as supports:</b> were the resources, structures and processes used to prepare and run meetings (p. 18). Accessible supporting tools were developed in research process including the "Who did what checklist" (see p. 14 for more info) to facilitate and prompt reflection on member participation/control (p. 14) and an accessible agenda template (see pp. 14, 16) to enable members to set agenda items (p. 14). It negatively impacted participation when strategies were not put in place (p. 18). <b>Advisor support:</b> that enable</p>	<p><b>System support:</b> the support of organisations and funding bodies was crucial (i.e. through providing spaces, advisors, material resources, funding for activities). Government funding cuts reduced the capacity of the group to advocate due to the constant need for fundraising (p. 19).</p>	<p>Members achieved control more regularly when supported by advisors (i.e. through supporting members to write the agenda) (p. 17).</p> <p>Of the four types of support, <b>member support</b> was the most conducive to member control. (Appropriate) <b>Strategies as supports</b> increased the group's control (p.18). <b>Advisor support</b> was instrumental in keeping the group in existence and had potential to facilitate member support but this was not always the case (p. 18). <b>System support</b> had a crucial influence over the group's capacity to</p>

	and "reflexivity" (using appropriate tools for members and researchers to reflect on action) (see p. 12-13).		backgrounds, two were African American and four were Caucasian. Two advisors (employees of the community organisation) were involved and three researchers acted as advisors.			participation was responsive to group needs and focussed on group strengths. Advisor support that was conducive to member control was dependant on the manner in which it was provided. For example, support that encouraged members to discussing/debating ideas, even if they that were deemed not in the interest of the group, led to control (as opposed to immediately dismissing unsuitable ideas) (p. 18).		self-advocate (p. 19).
Kjellberg, A. (2002). More or less independent. <i>Disability and Rehabilitation</i> , 24(16), 828-840	<u>Research aim:</u> to examine how people with learning disabilities conceive their opportunities to participate in decision making in two arenas: leisure and work. Additionally, explores the factors that facilitate and hinder decision making in these contexts. <u>Methodology:</u> Qualitative. Semi-structured interviews with people with ID re if/when/how they made decisions. In each arena (leisure and work), the participants were coded as either independent, interdependent or dependant and grouped according to their combination of codes.	<b>Decision making</b> in a work context (i.e. What tasks to do, which colours to make products) and in leisure time (i.e. how to spend money, where/when to go out, what activities to do, etc).  Sweden.	<u>Nature of disability:</u> <b>Mild to moderate</b> learning disability/ <b>ID</b> . 4 participants were also living with hearing, visual or motor impairments. <u>Sample/Participants:</u> 23 people with ID participated in interviews (15 women and 8 men aged between 22 and 63 years with varied living arrangements).		<b>Five "profiles" of decision making:</b> 1. Dependant in both work and leisure arenas (n=3). 2. Interdependent in the leisure and dependant in the work (n=4). 3. Independent in leisure and dependant in work (n=4). 4. Interdependent in leisure and interdependent in work (n=6). 5. Independent in leisure and interdependent in work (n=6) (pp. 830, 832-837). <b>Factors that enable decision making participation:</b> Control over finances (p. 833); having their own space/belongings (p. 835); some tasks at work that are flexible (i.e. writing tasks) (p. 836). <b>Factors that hinder decision making participation:</b> some tasks at work (i.e. rigid tasks that have to be done a specific way) (p. 836).	<b>Factors that hinder decision making participation:</b> attitudes of staff (i.e. different opinions on choices made by participant, cost saving attitudes in the work place) (p. 833, 834); (rigid) routine in the work place (p. 833); when supportive staff leave (p. 837). <b>Factors that enable decision making participation:</b> having formal meetings where there are opportunities to participate in decision making (p. 835, 837); attitude of staff (i.e. support someone who expressed a desire to change jobs) (p. 836, 837). (Summary of enablers and facilitators p. 838).	<b>Factors that hinder decision making:</b> decisions made at municipality level regarding services (e.g. cutting programs, minimal opportunities for independent living) (p. 834, 836); and scarcity of education opportunities (p. 837). <b>Factors that enable decision making participation:</b> The formal/legislated right to have a "contact" (an independent person) (p. 834); right/access to education opportunities (p. 833).	
Renblad, K. (2003). How do people with intellectual disabilities think about empowerment and information and communication technology? <i>International Journal of Rehabilitation Research</i> , 26(3), 175-182	<u>Research aims:</u> to explore the views of people with ID on issues related to empowerment and information and communication technology (ICT). <u>Methodology:</u> Qualitative. Data gathered through original sources/reports from a conference, observation at a conference, group	<b>Influence/empowerment</b> (specifically covered decisions/influence in the areas of money, living arrangements, love life).  Sweden.	<u>Nature of disability:</u> <b>Mild/moderate ID</b> . <u>Sample/Participants:</u> Observed conference/focus groups: "35 men and women of different ages". Interviews with 4 participants who attended the		Participants felt they were generally unable to exert control at home, work, in leisure time or socially. However, they felt it was important to be able to plan and influence these areas of life as well as to be treated with respect and to be able to say what they are thinking (p. 178, 181).  One participant shared that	Participants experienced challenges when their opinions differed from the staff supporting them and felt they were not "on an equal footing" to the rest of society (p. 178). However, participants expressed that "good staff, supervision and guidance" was important (p. 178).  Participants expressed that,		

	interviews/focus groups and individual interviews. Specifically, data were gathered about experiences of ICT, level of empowerment/influence and how they express empowerment.		conference (p. 177).		<p>in work he could not make decisions about everything so it was important for him to first speak with others to prevent adverse outcomes (p. 180).</p> <p>Participants reported instances where they did not feel able to express an opinion, were afraid to do so or felt they weren't trusted (p. 181).</p> <p>ICT (i.e. the internet, TV, phones) was considered important and was used to gain information in various areas (among other things) (p. 181). However, sometimes participants had trouble understanding words or could not decide what info was important. Easy-to-read pieces and/or those accompanied with pictures were preferable (p. 178).</p>	especially during medical appointments, it was useful to have things written down to review later with supporters (p. 178).	
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**Enablers –planning practices**

Espiner, D. & Hartnett, F. M. (2011). 'I felt I was in control of the meeting': Facilitating planning with adults with an intellectual disability. <i>British Journal of Learning Disabilities</i> , 40(1), 62-70	<p><b>Research aims:</b> to examine the views of adults with ID, their supporters and key staff re a newly introduced "person-centred facilitation" approach to personal plan development.</p> <p><b>Methodology:</b> Mixed methods though largely qualitative. People with ID participated in semi-structured interviews, and questionnaires were given to supporters and key staff. Interviews and questionnaire content was focused on plan development, preparation, meeting facilitation, plan design/content and learnings/follow up.</p>	<p><b>Goal setting/Aspirations</b></p> <p>Decisions related to a person's dreams, aspirations and lifestyle goals (i.e. making new friends, finding family, living arrangements, work, etc).</p> <p>New Zealand.</p>	<p><b>Nature of disability: ID</b> (no indication of level of disability).  <b>Participants:</b> Ten adults with ID (five men and five women), ten supporters (family members, carers and/or advocates) and key staff.</p>	<p>A role devoted to facilitating person-centred planning was introduced. Its key function within the org was to ensuring the person's voice is captured in his/her plan.</p> <p>Facilitator trained in the following: person-centred values, facilitation skills, effective communication skills (primarily listening), problem solving, group dynamics, accessible communication formats, networking and identifying community resources (p. 63).</p>	<p><b>Ownership and outcomes:</b> People with ID who helped construct their plans (i.e. creating a scrap book) took greater ownership over their plan (p. 67).</p> <p><b>Promotion of self-determination:</b> People with ID were aware of the level of personal responsibility that came with greater involvement and control. They identified support and sought it out. People with ID also realised they did not have to agree and/or could change their mind (p. 68).</p>	<p><b>Ownership and outcomes:</b> accessible plans enabled people with ID to remember the content and increased their motivation re goals (p. 67).</p> <p><b>Deep and ongoing listening:</b> facilitator created a forum where the person with ID felt listened to and that their voice was acknowledged - this was considered to be one of the best parts of the experience by the person with ID (p. 64).</p> <p><b>Planning and co-ordination:</b> Facilitators involved the person with ID in the planning for the plan development process (i.e. inviting family members, choosing a venue and time, brainstorming and discussing their aspirations before meetings) (p. 66)</p>	<p><b>Understanding and involvement:</b> the approach led to greater involvement of the person in the development of the plan. People with ID had a greater understanding of the plans purpose and were able to articulate this (p. 65).</p> <p><b>Promotion of self-determination:</b> The approach led to a greater sense of involvement and control by the person with ID (p. 68).</p>
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**Enablers – relationships**

Burgen, B. (2010). Women	<b>Research aims:</b> To develop	<b>Types of decisions:</b>	<b>Nature of</b>		An enabling factor is	75% were assisted to make		50% proceeded to have
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<p>with cognitive impairment and unplanned or unwanted pregnancy: A 2-year audit of women contracting the pregnancy advisory service. Australian Social Work, 63(1), 18-34</p>	<p>an "understanding of the experiences of women with ID and... ABI in relation unplanned or unwanted pregnancy" (p. 25). Data were also compared with a previous, unpublished audit of all Pregnancy Advisory Service (PAS) services users and a literature review was conducted. <u>Methodology</u>: A mixed methods study using client records (i.e. case notes) of the PAS at the Royal Women's Hospital as data sources. Descriptive statistics and qualitative data were garnered from records.</p>	<p>reproductive <b>choices/decision making</b> regarding unplanned or unwanted pregnancy.  Melbourne, Australia. ??</p>	<p><u>disability: ID &amp; ABI</u> (unsure of level of disability) <u>Sample/Participants</u>: Total 20 women - 18 women with an ID and two women with an ABI who accessed support from PAS between 2005-2007.</p>		<p>familiarity with service/workers (i.e. an existing relationship with a worker) (p. 28). Many women weren't aware of the PAS workers role and some women assumed the PAS worker had an agenda regarding their decision to continue with the pregnancy (pp.28-29). Due to delayed contact with the services (post-12 weeks), many women's options were limited. Themes regarding delayed contact were largely around conflict between the woman's wishes and supporters (i.e. feeling pressure to have an abortion) and two were in violent relationships. Literature suggests this can be associated with delayed recognition of the early signs of pregnancy (p. 30).</p>	<p>contact with the service - 7 by their mothers, 7 by a workers and 1 by a friend. Most women were accompanied to the first appointment by a support person and were happy for that support person to "act as 'a kind of intermediary or interpreter'" (p. 27).  25% indicated their wishes conflicted with those of their family, partners or other support figures (p. 27). Literature indicates that education and information regarding sexual and reproductive health is not accessible/appropriate for women with an ID/ABI. This has also been linked to delayed service contact. For information to be accessible to this group, it needs to be repeated and reviewed with women across the reproductive years (p. 31).</p>		<p>abortions compared with 80% of general PAS service users - this is attributed to 25% of the women having limited choices due to delayed contact with the service (p. 29). Women who felt pressure to have an abortion received "support and advocacy" to continue their pregnancy if they chose to (p.30).</p>
<p>Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. <i>Journal of Intellectual Disability Research</i>, 54(2), 1004-1014</p>	<p><u>Research aims</u>: to "explore the leadership development of individuals within the US self-advocacy movement" (p. 1005). <u>Methodology</u>: Qualitative. In-depth interviews with leaders exploring their life-stories. Some interesting and relevant points raised but not directly/explicitly speaking of decision-making – Does that still fit with the criteria?</p>	<p><b>Leadership</b> and associated decision making/independence in self-advocacy.  USA.</p>	<p><u>Nature of disability: ID</u> (no discussion of level). <u>Participants/Sample</u>: 13 leaders in the self-advocacy movement (6 female and 7 male, aged between 21 and 61).</p>		<p>Leaders had experienced oppression throughout their lives and the self-advocacy movement was a form of resistance to this oppression. Some felt that their experiences of oppression (e.g. constantly having to prove themselves) contributed to their leadership skills (p. 1007-1008).  Many leaders told of an ongoing "struggle for independence from parents" (p. 1009).</p>	<p>Leaders received support from, and cited role models in, their family. Families provided an environment of acceptance for many. However, some participant said that family members could contribute to oppressive forces (p. 1008-1009).  Many said friends supported them to take risks "at key moments in their lives" - this aided in gaining independence from parents (p. 1009).  Many leaders spoke of a "key support person" who introduced them to self-advocacy and had a long-standing, trusting relationship where their role was to build the confidence of participating leaders (p. 1009).  Volunteer experience, sitting on boards and leadership</p>		

						workshops aided participants in developing skills for participating in, for example, organisational decision-making (p. 1010).		
Conder, J., Mirfin-Veitch, B., Sanders, J. & Munford, R. (2011). Planned pregnancy, planned parenting: Enabling choice for adults with a learning disability. <i>British Journal of Learning Disabilities</i> , 39(2), 105-112.	<u>Research aims:</u> to highlight key issues related to informed decision-making as experienced by six people with a learning disability/ID during pregnancy and early parent-hood. Part of a larger longitudinal study into the experience of parenting for people with a learning disability/ID. <u>Methodology:</u> Qualitative. Data gathered in repeated interviews over a three year period. The initial interview was semi-structured followed by increasingly more focused interviews.	Reproductive and parenting <b>choice/decision-making.</b>  New Zealand.	<u>Nature of disability:</u> Parents with a learning disability/ID (not including people with ABI or mental health related disabilities) (unsure of level of disability) <u>Participants/Sample:</u> sample of six parents - including two single parents and two couples. Some data was also gathered from other family members and worker to fill gaps though the stories of the parents themselves took precedence.		Parents had mixed knowledge of contraception, fertility and the early signs of pregnancy (p. 110-111). There was evidence of active decision-making by all mothers (p. 110).	Assessment and planning for the future (beyond the birth of the child) was key to successful parenting as was flexible services that were able to adjust their service to respond to the unique needs of each parent/s (p. 110-111). Education is key - regarding fertility, contraception, timely responding to unplanned (consensual or not) sexual encounters, and alternative contraception. Parents did not recall anyone discussing if they wanted to be a parent or what it would mean for them if they became a parent/how they would manage (p. 110-111). Family is key - participants remembered more of education/information coming from family members and family played a critical role in support for successful parenting. It was recommended that family members be informed of parenting with support success stories. Parents without family support face barriers expressing needs and advocating for themselves (p. 111).		Family support, assessment and planning during (supported) decision-making phase were key for positive parenting outcomes (p. 111).
Knox, L., Douglas, J. & Bigby, C. (In press). "I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents. <i>Neuropsychological Rehabilitation</i> .	<u>Research aims:</u> "to explore the processes used by adults with severe TBI and their parents in making decisions about life after injury" (p. 2). <u>Methodology:</u> Qualitative. Constructivist, grounded theory approach. Multiple in-depth interviews were conducted with people with TBI and one of their parents. Part of a larger study into decision making for people with TBI.	<b>Decision making</b> (e.g. financial decisions).  Eastern states, Australia.	<u>Nature of disability:</u> <b>TBI/ABI. Moderate to severe</b> disability. <u>Participants:</u> Four people with TBI (3 males and one female, aged 27 to 47) and four parents (one parent of each participating person with TBI) (p. 9, 42).	"A guiding construct of reimagining the future was evident in participants' changing approach to decision-making over time" (p. 12).	<b>Enabling factors to "joint decision making":</b> Having had a positive relationship based on "trust and understanding" pre-injury was important and made the joint decision making process easier (p. 13).  <b>Strategies to reduce parental involvement:</b> Participants employed these strategies because they desired autonomy (p. 19). Related to parents' strategies to reduce their	<b>Enabling factors to "joint decision making":</b> Parents and people with TBI went through a process of accepting and developing a joint understanding the nature of TBI and its implications for the person - especially the impacts on decision-making (p. 14-15). This lead to development/negotiation of support strategies to "overcome cognitive impairment" and increase participation in decision-making. A part of this was		

					input in decisions, participants with TBI began to make more decision without parental support and withheld some info from them (p. 22). Participants and parents enlisted support from siblings and friends (p. 22-23).	regular contact with parents for advice and reassurance or redirection of the decision-making process/focus based on what is important to the person with TBI (p. 15). Parents evaluated the potential financial or physical risks and regulated their involvement in decision making on this basis (p. 16-17). "(P)arents often maintained a level of oversight" re finances (p. 18). Parents acknowledged the risk little opportunity for independent decision making in some areas had to the person with TBI's sense of self - this was weighed up when determining intervention (p. 18). Parents were most comfortable/active in shared decision-making in areas where they had expertise (p. 19). <b>Strategies to reduce parental involvement:</b> Parents employed strategies to reduce involvement because they were aware that they would not be available to support the person with TBI forever (p. 19). Parents withdrew support or reduced the level of support through going away for a short period or through defining limits on support (e.g. if spending over \$100- dollars) (p. 20). Parents reduced or put boundaries on the amount/type of contact with child with TBI (p. 21).		
Knox, L., Douglas, J. & Bigby, C. (In press). 'The biggest thing is trying to live for two people': Spousal experience of decision-making participation after TBI. <i>Brain Injury</i> .	<u>Research aims:</u> "to understand how the spouses of individuals with severe TBI experience the process of participating in making decisions with their partners" (p. 1). <u>Methodology:</u> Qualitative. Constructivist, grounded theory approach. Multiple in-depth interviews were conducted with spouses. Early interviews were about examples of decisions made since	Major life decisions (i.e. Purchasing a house, having children) and every-day <b>decision making</b> .  Eastern states, Australia.	<u>Nature of disability:</u> <b>TBI/ABI. Moderate to severe</b> disability. <u>Participants/Sample:</u> Four spouses of four people with TBI.	<b>Decision making process</b> of couples had 6 phases: 1. Remaining vigilant to decision making opportunities. 2. Recognising and initiating a decision. 3. Evaluating involvement. 4. Taking action. 5. Living with the outcome. 6. Reflecting on the process (p. 14-15).	<b>1. Remaining vigilant to decision making opportunities:</b> Spouses indicated that the person with TBI "had difficulty responding to these opportunities" (for decision-making and planning) due to cognitive impairment (p. 15). <b>4. Taking action.</b> There was generally little involvement of the partner with TBI (p. 20). Spouses determined the "means" of the partner's	<b>The relationship was paramount.</b> It was key for spouses to understand the nature/implications of the person's TBI (p. 10). Seeing the persons with TBI in a positive light and wanting to share a life (including decision-making) was key as was being committed and adapting decision-making approach for the sake of the relationship (p. 11). Negotiating a means of communication (often		

	<p>injury, significant life decisions, recent decisions while later interviews became more focused based on early data analysis (p. 6-7). Part of a larger study into decision making for people with TBI.</p>				<p>participation through selection a "well-defined" portion of the decision for them or through providing the partner with the opportunity to "endorse" or reassure the spouse re the decision (p. 19).</p>	<p>negotiated through trial and error in lieu of existing information for spouses) played an important role (p. 12). Relationships evolved and were dynamic. Positive and negative past experiences impacted approach to decision-making (pp. 13-14).</p> <p><b>1. Vigilance to decision making opportunities:</b> Spouses took the lead re decision-making. One strategy to cope with the demands or the role and save energy was to minimise decision making through "routinising" some aspects of life (p. 16).</p> <p><b>2. Spouses were the ones to recognise and initiate a decision</b> (p. 2).</p> <p><b>3. Spouses evaluated the involvement</b> level appropriate for their partner. They took into consideration the effort meaningful involvement of their partner would involve and the time available. They made adjustments to the info provided to the person with TBI (the amount/type of info) (p. 17-18). Spouses "weighed up the potential outcomes of" not/involving their partners and considered risk of physical, financial, emotional and interpersonal harm/difficulties (p. 18).</p> <p><b>4. Taking action.</b> Spouses often lead the action process. They determined the possible options, considering the current context, the viability of options and the means for their partner's participation (p. 19). Spouse supported their partner to carry out the actions required through "practical support or cognitive scaffolding" (p. 21). For some decisions, the spouse would initiate the decision making process but "opt out" and leave the decision making to the partner. The rationale behind "opting out" was to:</p>		
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						avoid conflict, respect the partner's desire to deal with certain decisions independently, reinforce their partner's sense of autonomy or avoid disruption/investment of resources (pp. 21-22). <b>6. Reflecting on the process.</b> The outcomes and implications of the decision for the relationship were considered by spouses in an evaluation process (p. 23).	
Mill, A., Mayers, R. & McDonnell, D. (2009). Negotiating autonomy within the family: The experiences of young adults with intellectual disabilities. <i>British Journal of Learning Disabilities</i> , 38(3), 194-200	<u>Research aims:</u> to explore "the perspectives of young people with ID on their transition to adulthood" especially regarding negotiating autonomy with parents (p. 194). <u>Methodology:</u> Qualitative. Life story approach. Conducted 2 semi-structured interviews with participants re their life roles, relationships and goals as well as how they negotiated autonomy.	<b>Autonomy.</b> Sydney, Australia	<u>Nature of disability:</u> <b>ID</b> no info re level. <u>Sample/Participants:</u> 6 young people (aged 18 to 25 years, 4 female and 2 male) living with one or both parents and siblings.	3 approaches by young people re negotiating independence: <b>The defiant approach</b> – (one participant's approach) characterised by frustration/dissatisfaction, active protests of "parent's interference", attempts to "demonstrate decisions can be made independently", and seeking opportunities for autonomy "outside of family sphere" (p. 197); <b>The passive approach</b> - characterised by no desire for changes, received support to be independent with supervision, happy to be independent/make decisions in areas suggested and supported by family (p. 197-198); <b>The proactive approach</b> - characterised by the young person seeking greater autonomy and being "supported and even challenged by their parents to do so", had freedom to learn from their own mistakes and was involved in family decision-making (p. 198).			Congruence between perceived and desired levels of autonomy as well as parental support important for satisfaction (i.e. the passive and proactive approaches) (p. 198).
Schellely, D. (2008). Problems associated with choice and quality of life for an individual with intellectual disability: A personal assistant's reflexive ethnography. <i>Disability &amp; Society</i> , 23(7), 719-732	<u>Research aims:</u> a reflexive ethnography exploring the attempts of live-in "personal assistant" to "integrate, improve the quality of life of, offer choice and self-determination to, and, ultimately, to measure and improve service delivery" for a man with autism.	<b>Self-determination and choice.</b> USA	<u>Nature of disability:</u> <b>Autism</b> (level not explicit). <u>Sample/participants:</u> A 22 year old man with Autism and his live-in personal assistant.		The person with autism being supported by the author had difficulty with "abstraction" (e.g. thinking/predicting his feelings at a different time, at a different location) (p. 724-727). This poses challenges for establishing the person's subjective quality of life and for goal	The author adopted a "Father" role and noted his infantilising of the person with autism he supported. The author cited this was problematic but concluded that a level of this was necessary. He speculated that this was due to the person's difficulties or perhaps is due to the way the service system	The author described narratives of normalcy (and difference) and its problematic history (i.e. Post-deinstitutionalisation efforts to "integrate", what/who determines normalcy?) (p. 272-278). However, the author acknowledges the value in knowing differences in thinking (be they due to a person's disability or personality) (p. 727).

	<p><u>Methodology</u>: Qualitative. Using reflexive ethnography to critique social processes and reflect on practice. Presented as a journal describing observations, interviews and reflections.</p> <p><b>NB</b>: Please refer to original text to get full narrative/context to the author's reflective process.</p>				<p>setting (p. 727). Interviewing to gather subjective quality of life and set goals was not helpful in light of these difficulties. The author's attempts to interview the person were marginally more successful because he had lived with him for a period of time (p. 724-727).</p>	<p>is structured (See p.722, 727-728).</p>	<p>The author contrasts ideas of normalcy and integration to ideas of inclusion and the social model of disability (where the onus for change is on society). There were examples of occasions where social groups effectively "lowered barriers that otherwise disable" the person with autism the author supported (See pp. 722-723, 727-729).</p>	
<p>Suto, W., Clare, I., Holland, A. &amp; Watson, P. (2005). The relationships among three factors affecting the financial decision-making abilities of adults with mild intellectual disabilities. <i>Journal of Intellectual Disability Research</i>, 49(3), 210-217</p>	<p><u>Research aims</u>: to investigate the relationships between three variables (see methodology below) and financial decision-making abilities for people with mild ID (p. 211).</p> <p><u>Methodology</u>: Quantitative. Part of a larger study on financial decision-making among adults with ID (p. 211). Variables tested were: intellectual ability (Wechsler Abbreviated Scale of Intelligence), financial decision-making abilities (using a series of vignettes followed by an interview), decision-making opportunities (choice questionnaire) and understanding of basic financial concepts such as quantity, numbers and money (p. 211).</p>	<p>Financial <b>decision-making</b>.</p> <p>UK?</p>	<p><u>Nature of disability</u>: <b>Mild ID</b>.</p> <p><u>Sample/Participants</u>: 30 adults with mild ID (mean age was 34.8 years, 18 men and 12 women) (p. 212).</p>		<p>The hypothesis that "intellectual ability contributes to the acquisition of basic financial understanding" was supported in the findings and a significant relationship between the two variables was found. The authors assumed it was uni-directional relationship with intellectual ability determining basic knowledge of financial concepts (p. 213, 215).</p>	<p>A strong relationship between basic financial understandings and decision-making opportunities was found. The authors assumed it was a reciprocal relationship (p. 215). A strong relationship was found between financial decision-making abilities and decision-making opportunities. Similarly, this relationship was assumed to be reciprocal (p. 215).The data suggests the importance of supporting a basic understanding of financial concepts as well as facilitating opportunities for financial decision-making in increasing people's ability to make such decisions (p. 215).</p>		
<p>Timmons, J.C., Hall, A.C., Bose, J., Wolfe, A. And Winsor, J. (2011). Choosing employment: Factors that impact employment decision for individuals with intellectual disability. <i>Intellectual and Developmental Disabilities</i>, 49(4), 285-299.</p>	<p><u>Research aims</u>: to explore "the factors that shape the employment-related decisions" of people with intellectual/developmental disabilities.</p> <p><u>Methodology</u>: Qualitative. Participatory Action Research. Semi-structured interviews with people with ID and follow up interviews with their family members and employment support workers regarding employment history, factors that influenced their current job,</p>	<p>Employment <b>decision-making</b>, planning and goal setting.</p> <p>Massachusetts, USA.</p>	<p><u>Nature of disability</u>: <b>ID/developmental disability</b>. No explicit indication of level.</p> <p><u>Sample/Participants</u>: 16 adults with ID, 13 family members and 15 interviews about 15 adults were conducted with ID with 9 staff.</p>		<p>Personal preferences/reason (e.g. earnings, productivity/contribution, perception of social status/admiration and social connections at work) impacted decisions about employment (p. 293-295). Family history and role modelling was an influential factor, particularly in instilling beliefs about the importance of work for "adulthood" (p. 289, 295). Schooling history had an influence on people's preferences regarding work.</p>	<p>The culture/philosophy of the community rehab provider/employment service influenced decisions (e.g. regarding job readiness or readiness to work "outside" of the sheltered employment environment) (see p. 290-292). Job development workers played a large role in influencing employment decisions. They were often viewed as "experts" by family and the person and could have a lot of influence of decisions (i.e. through presenting jobs in positive</p>		

	challenges, and satisfaction level.				For many their first exposure to work and career planning was at school. Many received encouragement regarding goal setting and experienced an increase in self-confidence (p. 289-290, 295). Negative early work experiences impacted the confidence of some participants and influenced their preference for sheltered employment. These negative experiences were often due to employer unfamiliarity with the support and training needs of people with a disability. The negative impact of these experiences could be mediated by family or professionals through raising awareness that it was not the fault of the person with ID (p. 290).	light). Many job development workers attempted to "strike a balance between supporting the person to make good decisions and allowing" independence by going through the pros and cons or the consequences of a decision (p. 292). Some people felt they didn't have a choice re accepting/declining work. Family were minimally involved and wished to be more involved. However, some were wary not to impinge on the person with IDs autonomy (p. 292-293).	
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**Enablers – specific practice approaches**

Beadle-Brown, J., Hutchinson, A. & Whelton, B. (2008). A better life: The implementation and effect of person-centred active support in the Avenues Trust. <i>Tizard Learning Disability Review</i> , 13(4), 15-24	<u>Research aims:</u> to describe the process of implementing Person-Centred Active Support (AS) in six residential services and to evaluate its effect on service users and staff. <u>Methodology:</u> Quantitative. Using observational measures and a series of scales/questionnaires. Measures were service user meaningful engagement in activity and staff contact/support (p. 18).	<b>Person-centred Active Support.</b>	<u>Nature of disability:</u> people with <b>ID</b> with (generally) <b>high support needs</b> . <u>Sample</u> of 29 individuals (aged between 20-61 years) with very high support needs.	The effects of implementing a person-centred active support (AS) model. (More detail on implementation process pp. 16-18).		Increase in quality of staff support (as measured by the AS Measure) (p. 20). Percentage of staff who reported their manager modelled good practice increased (from 42% to 78%) and the percentage reporting their manager gave them feedback increased (48% to 81%) (p. 21).	<u>Outcomes of implementing AS.</u> Percentage of time individual with ID spent engaged in meaningful activity increased significantly. This was accompanied and attributed to a 300% increase in "facilitative staff support" (p.19-20). Decrease in self-injurious behaviours, stereotypic/repetitive behaviours and challenging behaviour (p. 20).
Beadle-Brown, J., Hutchinson, A. & Whelton, B. (2012). Person-centred active support - Increased choice, promoting independence and reducing challenging behaviour. <i>Journal of Applied Research in Intellectual Disabilities</i> , 24(5), 291-307	<u>Research aims:</u> To evaluate the effect of implementing an active support (AS) model on service users in six residential services (same broader research project as Beadle-Brown, Hutchinson & Whelton (2008) above). <u>Methodology:</u> Quantitative.	<b>Person-centred Active Support.</b> Decisions related to: food, sleep, decorating, clothing, sleeping, bathing, purchases, outings, medications, expressing affection, minor	<u>Nature of disability:</u> <b>ID</b> with very <b>high support needs</b> . <u>Sample:</u> 29 individuals living in six community-based residential homes. Aged between 20-61 (mean 44).	As with Beadle-Brown, Hutchinson and Whelton (2008) this study is not focused on SDM per se but an interesting evaluation of the impacts of a similar model (AS) that encompasses choice-making.  Person-centred AS model encompasses encouraging people to try new things in			Overall choice making significantly increased post-intervention from 32% (pre) to 50%. Most significant increases were in the areas of: food to buy, eat/leave on plate; snacks/dessert to eat; choice of personal hygiene products; when to visit friends; and what to buy or do with personal money (p. 298). The only areas where choice did not increase

	Observational, momentary time sampling using a pre-post-intervention design. Various scales/questionnaires. Measures: Active support; engagement and assistance; participation in community/daily life; choice; independence and reduced challenging behaviour; as well as the staff experience.	vices (i.e. Smoking, drinking, etc).  South-East England.		order to discover preferences and thus aid in choice-making (p. 304).				were whether to take medication and whether to engage in minor vices (p. 304). The study provides evidence that implementing AS can increase choice making opportunities and that AS is associated with increased staff support as well as higher levels of assistance, engagement and participation in ADLs. Additionally, provides some evidence that AS reduces challenging behaviours (p. 303).
Koritsas, S., Iacono, T., Hamilton, D. & Leighton, D. (2008). The effects of active support training on engagement, opportunities for choice, challenging behaviour and support needs. <i>Journal of Intellectual and Developmental Disability</i> , 33(3), 247-256	<u>Research aims:</u> "to evaluate active support (AS) staff training program and investigate" group home staff perceptions of residents' engagement in domestic activities, opportunities for choice, frequency of challenging behaviour and levels of support needs (p. 247). <u>Methodology:</u> Quantitative. Support workers completed scales for each resident at 3 points in time: prior to staff completing an AS training program (baseline), immediately post-training and 6 months post training (follow up). Scales measured: engagement in domestic activities, opportunities for choice, frequency of challenging behaviour and levels of support needs.	<b>Active support/choice opportunities.</b>  Metro Melbourne, Australia.	<u>Nature of disability:</u> <b>ID</b> (7 residents with <b>moderate</b> ID and 2 with <b>severe</b> ID). <u>Sample/Participants:</u> 11 Support workers and 12 adults with ID (aged between 27 and 57 years) residing/working in three group homes.	An AS training program for support worker staff was provided. The training program was tailored to the staff group following observations of the group homes by trainers and consisted of 3 days of classroom style training and 2 days of 1 on 1 training (p. 250). [A small amount of additional detail provided re training program in text].				There was an increase in overall choice following AS training which was maintained at follow-up though most choice sub-scales did not show sustained improvement (p. 253). There were initially increased perceptions of choice regarding domestic activities and money/spending post training. However, it had decreased at follow up (pp. 250-250). No change to choice in areas of health, social activities, community access and personal relationships (p. 253).
Ellem, K., O'Connor, M., Wilson, J. & Williams, S. (2013). Social work with marginalised people who have a mild or borderline intellectual disability: Practicing gentleness and encouraging hope. <i>Australian Social Work</i> , 66(1), 56-71	<u>Research aims:</u> Explore the practice approach of a non-government organisation that supports people with mild or borderline ID specific attention to the challenges and opportunities for practitioners in supporting people. <u>Methodology:</u> Qualitative. Semi-structured interviews with practitioners using the organisations practice	<b>Self-determination/decision-making</b>  Decisions re: relationships (i.e. Who to spend time with).  Brisbane, QLD.	<u>Nature of disability:</u> Person with <b>mild/borderline ID</b> . <u>Participants/Sample:</u> 11 staff members of an Non-government org.	The approach of the organisation/workers was made up of four categories: building relationships, building resources, building knowledge and building decision making.				Workers must "suspend their own judgement of a situation" and "resist the urge to take over" – as this can undermine the person's sense of autonomy and have unforeseen impacts on a person's life (p. 62). People with ID may have difficulty expressing their wants. Thus it is a challenge for workers to be truthful to a "person's real expressions" (p. 66). Workers practiced "deep listening" to seek the core

	framework as a guide (covered building relationships, resources, knowledge and decision making).					messages behind people actions (p. 66). Core messages may be quite different to what is immediately presented and it may take a long time to understand (p. 68). Finding core messages involves taking a "gentle, intuitive approach" (p. 68). Building decision-making requires ample "reflection, persistence, trial and error" (p. 66). Workers caution against: pretending to understand a person or colluding with harmful decisions and stress continually questioning their own judgement about actions that may be harmful when they may be beneficial (p. 66).		
Rosow-Kimball, B. & Goodwin, D. (2009). Self-determination and leisure experiences of women living in two group homes. <i>Adapted Physical Activity Quarterly</i> , 26(1), 1-20	<b>Research aims:</b> to describe/understand the opportunities for self-determination with regard to leisure for women with ID in two group homes. <b>Methodology:</b> Qualitative. Two case studies using data from interviews with staff, women with ID, participant observation and other documentation (i.e. log books).	<b>Choice, self-determination</b> re leisure activities.  Canada.	<b>Nature of disability:</b> <i>ID</i> (no mention of level but were required to be able to communicate verbally). <b>Sample/Participants:</b> 5 women with ID aged between 44 and 60 years living in two different group homes. 5 support staff from each group home.	Two contrasting approaches at each of the two group homes:  " <b>Elm Home</b> " Home leisure time or outings were supervised and self-directed leisure or supervised and staff directed. Women awaiting connections with others (i.e. waiting for phone calls from family and friends not making them) (p. 9). Staff would do things for the women and there was little emphasis on skill development (p. 10-11).  " <b>Cairn Home</b> " Leisure time was independent and self-directed or staff-supported and self-directed leisure. There were independent and accompanied outings and the women actively connected with family and friends (p. 9). Staff provided tailored support when needed/desired support and faded it back as the women gained confidence and new skills. Staff recognised risks were associated with self-determination (p. 15).	" <b>Cairn Home</b> ": <u>Leisure at home</u> was spontaneous and chosen independently by women (i.e. perusing hobbies, watching TV shows of their choice, spending time in their private spaces/rooms which they controlled or in other spaces devoted to specific activities) (p. 13). The women were free to use the telephone to connect and arrange <u>leisure with family and friends</u> . They did so regularly and asked for support as needed (p. 15).	" <b>Elm House</b> ": Staff supervised and guided/directed <u>leisure at home</u> with little opportunity for residents to exercise self-determination. In desired activities where women didn't have some of the skills required (i.e. reading a recipe with baking) staff completed task for them rather than supporting them in some areas or developing new skills (p. 10). <u>Outings</u> were supervised by staff with staff directing activities (i.e. controlling money and approving purchases) (p. 11). Organisational policy made it difficult for women to pick their own activities (p 11-12). <u>Leisure with family and friends</u> was scheduled and the women awaited contact from family/friends. Staff used scheduled outings with family and friends for behaviour management (i.e. threatening to cancel outings) (p. 12).  " <b>Cairn Home</b> ": staff supported self-determination and facilitated independence with <u>leisure at home</u> (i.e. with TV colour coding the remote for ease of independent use by the women or supporting with reading out the recipe		

						for cooking) and recognised the women's contributions (i.e. in log) (p. 13). <u>Outings</u> were both independent and accompanied. Staff spent time teaching the women skills and worked towards independent in outings (i.e. by gradually reducing guidance). During accompanied outings staff supported the women through providing transportation. The women had independence once they arrived at the destination with staff supporting in the background with some encounters/tasks (at the checkout) (p. 14).		
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**Enablers – presentations of choices**

Cobigo, V., Morin, D. & Lachapelle, Y. (2009). A method to assess work task preferences. <i>Education and Training in Developmental Disabilities</i> , 44(4), 561-572	<u>Research aims:</u> to test/evaluate a tool to assess vocational preferences. <u>Methodology:</u> Mixed methods. Quant data collected through observation of sessions using work task preference assessment method to determine preference and reliability - variables included frequency of selection/refusal, positive behaviours, on-/off-task behaviours. Qualitative data gathered from job coaches regarding the experience of using the method, areas for improvement and overall effectiveness.	Work task <b>preference and choice</b> making.  Quebec, Canada.	<u>Sample/Participants:</u> 16 job coaches working with 19 people with an ID, 8 were female and 11 were male, aged from 23 to 58. <u>Nature of disability:</u> the 19 people with <b>ID</b> were all living with " <b>profound deficits in adaptive skills</b> " and limitations communicating/ understanding language (p. 562).	<u>Work task preference assessment method:</u> 1. Present two options at a time with two tangible objects (or pictograms) associated with the task option at equal distance from each other to the person making the choice. Ask the person to pick one (record refusals/selections). 2. If a choice is made, the person is prompted to work on the selected task for a 3 minute period (records taken of on-task/off-task time and positive/negative emotional behaviours). 4. The next two options are presented and trialled as above. 5. After all options are presented once, all possible pairs of options are presented and tested with the same information recorded.  From the above process and info collected, percentage of choice and refusal are calculated as well as off-task and positive emotional behaviours are calculated providing a profile of preferences ( <b>more details re process p. 571</b> ).	The most reliable indicator of preference was frequency of physically selecting task (p. 571). Unreliable/inconsistent indicators of preference: on-/off-task behaviours and positive emotional behaviours (p. 571).	(See SDM process column for full description of systematic process and supporter's role). Supporters (16 job coaches) found the method to be a valuable and effective way of determining a person's preferences. They recommended making the assessment process simpler and appreciated initial training/ supervision during first sessions (p. 571). Alternative methods cited for p. 571.	Contextual factors impacted preferences made by person with ID (i.e. Distractions in the room).	
Tasky, K. K., Rudrud, E. H.,	<u>Research aims:</u> to evaluate	Task (i.e. Leisure,	<u>Nature of</u>					All 3 individuals increased their

<p>Schulze, K. A. &amp; Rapp, J. T. (2008). Using choice to increase on-task behavior in individuals with traumatic brain injury. <i>Journal of Applied Behavior Analysis, 41</i>(2), 261-265</p>	<p>the effects of choice of task on increasing on-task behaviour for adults with traumatic brain injury (TBI). <u>Methodology:</u> Quantitative. Data re "on-task" behaviour was collected using momentary time sampling under two conditions/phases. In the first phase participants were given a list of three tasks and asked to complete them in order given. In the second phase they were told to choose three tasks from a list and could change the order at any time (p. 261-262). Participants were each tested repeatedly under both conditions.</p>	<p>self-care, organisational tasks) <b>choice</b>.  ?</p>	<p><u>disability:</u> <b>TBI/ABI</b> "varied levels" (see pp. 261-262). <u>Participants/Sample:</u> 3 participants (all female, aged 21, 27 and 42 years old) in an inpatient rehabilitation setting.</p>					<p>on-task behaviour when they had the opportunity to choose tasks and decreased on-task behaviour when they were assigned tasks (p. 263).</p>
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**Enablers individual/group training skill development**

<p>Cooper, K. J. &amp; Browder, D. M. (2001). Preparing staff to enhance active participation of adults with severe disabilities by offering choice and prompting performance during a community purchasing activity. <i>Research in developmental disabilities, 22</i>(1), 1-20</p>	<p><u>Research aims:</u> to evaluate the effects of a multi-component staff training package on the number of choice opportunities and choices made by adults with an ID in a community purchasing situation. <u>Methodology:</u> Quantitative. Measured number of choice opportunities offered by staff and performance of person with ID in choice opportunities following the delivery of a training program for staff to use the least intrusive assistance method and to honour choice. Training including a self-management training component. Baseline, post-intervention and maintenance data was collected and compared.</p>	<p><b>Choice/Decisions</b> in a "community purchasing" setting (i.e. Fast food restaurant) including which door to enter the restaurant; what food/drink to order, sugar/napkin/condiment selection, where to sit.  U.S.A.</p>	<p><u>Nature of disability:</u> Adults (aged 46 to 61 years) with <b>dual diagnosis</b> and/or <b>severe to profound</b> developmental disabilities/<b>ID</b> who communicate nonverbally (p. 4). <u>Sample:</u> 4 staff (graduate students employed by an organisation that provides education to adults with "severe disabilities") and 8 adults with developmental disabilities (p. 4).</p>	<p>Multi-component training package for staff (with a self-monitoring/reflective element to support maintenance of outcomes) on using the least intrusive technique in assisting and honouring choice in a community purchasing situation.</p>		<p>Supporters (in this case staff) were trained in a minimally intrusive method of assisting and honouring choice. The process was: first, to offer choice (i.e. "which one do you want?" while guiding the persons with IDs hand across two options); then to wait 5 seconds for performance by the person with ID (i.e. choice to be made); following the 5 sec delay, provide a prompt (list of appropriate prompts provided with appropriate gestures/hand guiding); wait 3 seconds for performance/choice to be made; if no choice is made, staff member says "I'll make the selection for you" (<b>for more detail re; process, see , pp. 5-8</b>).</p>		<p>The evaluation found that the training package was effective in the following: Increased <b>no. of choice opportunities</b> offered by staff which was maintained at follow up; <b>no. of staff prompts</b> increased and was maintained at follow up; and improved <b>performance of person with ID</b> in making a choice and was largely maintained at follow up). The level of prompting needed by the person with IDs performance in a choice situation was scored and improved following intervention and further improved at follow up (p. 10-12).</p>
<p>Duke, E. &amp; McGuire, B. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. <i>Journal of Intellectual Disability Research, 53</i>(8),</p>	<p><u>Research aims:</u> to determine if capacity to make sexuality-related decisions was improved by a 10-week, one-to-one education program</p>	<p>Capacity to make sexuality related <b>decisions</b>.  Ireland.</p>	<p><u>Nature of disability:</u> <b>Moderate level of ID</b> <u>Sample:</u> 4 participants (2</p>	<p>An education program adapted from "Living your life" - a sex education tool for teachers in both a mainstream schools and specialist schools for people</p>				<p>All participants improved their knowledge in all measured areas (safety practices, physical self knowledge, sexual functioning and choices and consequences). Higher scores</p>

727-734	adapted to be suited for people with an ID. <u>Methodology</u> : Quant. Single subject, multiple baseline design (multiple participants tested pre- and post-intervention as well as during follow up and scores compared individuals over time. Using an established instrument, four items were assessed: 1. change in knowledge of safety practices, 2. change in knowledge of physical self, 3. change in knowledge of sexual functioning, and 4. change in knowledge of choices and consequences.		male, 2 female, aged 22 and 23 years) with no previous sex education who were residents of a group home.	with learning disabilities. The education program was delivered in a one-to-one format, twice weekly for 10 weeks and was tailored for each individual (see p. 729 for more detail).				on scale used are correlated with greater capacity to make sexuality-related decisions (p. 732). Three participants were followed up after 6 months. There was some reduction in knowledge of physical self/sexual function/choices and consequences but no reduction in knowledge of safety practices (p. 732).
Heller, T., Miller, A. B., Hsieh, K. & Sterns, H. (2000). Later-life planning: Promoting knowledge of options and choice-making. <i>Mental Retardation</i> , 38(5), 395-406	<u>Research aims</u> : To evaluate the effectiveness of a person-centred later-life planning training program for older adults with ID. Particular attention paid to the effectiveness of increasing participation in choice making, goal setting and barriers/supports to achievement of goals. <u>Methodology</u> : Mixed methods - largely quantitative. Tested (a). Knowledge of later-life issues/options, (b). Amount of choice, and (c). Life satisfaction. Also gather qual data on goal setting - specifically types of goals set, progress in achieving goals, and barriers/support to achieving goals. Quant data was gathered pre- and post-training (1 month after training) and compared to a control group. Qual data was gathered two and 10 months following training.	Later-life <b>decisions</b> (i.e. Leisure activities, living arrangements, etc).  Illinois and Ohio, USA.	<u>Nature of disability</u> : <b>Mild to moderate ID</b> (including Down Syndrome). <u>Participants/Sample</u> : 60 adults with ID aged over 50 years for those without down syndrome and over 35 years for those with down syndrome (due to earlier onset of ageing). Aged range between 35 and 84 years (p. 397).	A person-centred later-life training program attended by adult with ID and a carer/family member. Additional sessions held solely for family members and staff.  The curriculum included information about a number of experiences and specific choices related to ageing (i.e. retirement, health, leisure activities, etc). A large portion of the training program was devoted to teaching people about making choices, setting realistic goals and making actions plans. Some of the choice-making sessions were taught by a peer trainer (see pp. 396-397, 399-400).	The most frequently cited barrier to goal attainment by people with ID was physical/cognitive limitations followed by financial limitations, then health problems (p. 402).	The most frequently cited <b>supports</b> re goal attainment was from <b>support from staff</b> - including instrumental support (i.e. sourcing supplies, changing work schedule, accompaniment, setting up work areas) and emotional support (i.e. encouragement, willingness to talk).  Second most cited was <b>support from family</b> including giving the person time, accompaniment, supplies.  Major <b>barriers</b> re goal attainment were <b>lack of family or staff support</b> (i.e. not having time to provide support, not thinking the goal was appropriate, not thinking support in this was part of their role/job) (p. 402).	The third and fourth most frequently cited <b>supports</b> were the availability of <b>transport</b> and <b>peer and community support</b> (largely emotional support in the form of encouragement) (pp. 401-402).	<u>Training outcomes</u> : increased knowledge and increased number of choices being made by participants. No significant increase in life satisfaction found - authors suggested this may have reflected follow up testing occurring too close to the intervention (p. 400-401).
Khema, I. (2000). Increasing independent decision-making skills of women with mental	<u>Research aims</u> : to evaluate the effectiveness of two decision-making training approaches (a cognitive	<b>Decision making</b> re interpersonal situations involving abuse.	<u>Nature of disability</u> : <b>Mild to moderate ID</b> . <u>Sample/Participa</u>	Two training programs:  1. <b>Decision making training</b> . Cognitive based decision				Both groups demonstrated increased independent decision making with the self-directed decision making training group

<p>retardation in simulated interpersonal situations of abuse. <i>American Journal of Mental Retardation</i>, 105(5), 387-401</p>	<p>decision-making approach and self-directed cognitive decision-making approach) in increasing independent decision-making in response to hypothetical interpersonal situations involving abuse. <u>Methodology:</u> Quantitative. Two intervention groups (cognitive decision-making group and self-directed cognitive decision-making group) were compared to a control group pre- and post-intervention. Participants were shown a series of vignettes and were interviewed re their assessment of the situations/problem, proposed action and rationale to determine independent decision-making. Additionally, participants completed a scale to determine their perceived locus of control (p. 391-392).</p>	<p>New York City, USA.</p>	<p><u>nts:</u> 36 women with ID aged between 21 and 40 years.</p>	<p>making skills (i.e. Identifying the problem, defining the problem, generating alternative choices and evaluating the consequences) (see p. 393 for more detail).</p> <p><b>2. Self-directed decision-making training.</b> As above with the addition of a motivational component that consisted of building awareness of personal goals and values re safety, privacy and respect and using goals determined by the person to evaluate decisions and consequences. Aim was to facilitate a sense of control in participants and, thus, increase motivation to make decisions/reach favourable decision (see p. 394 for more detail).</p>				<p>being slightly more effective (p. 396). Intervention groups demonstrated higher internal locus of control scores, with the self-directed decision making training group being slightly higher (p. 397).</p>
<p>Khema, I., Hickson, L. &amp; Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. <i>American Journal on Mental Retardation</i>, 110(3), 193-204</p>	<p><u>Research aims:</u> to evaluate the effectiveness of a curriculum designed to "empower women with ... [ID] to become effective decision-makers able to protect themselves against abuse" (p. 193). <u>Methodology:</u> Quantitative. Women who completed the training were compared to a control group re the following measures: knowledge of abuse concepts, decision-making skills and empowerment (which encompasses motivation and locus of control). Participants completed the scales pre-intervention, immediately post the first two units of the intervention and immediately post the 3rd phase of intervention.</p>	<p><b>Decision making</b> in situations of abuse. New York, USA.</p>	<p><u>Nature of disability:</u> <b>Mild to moderate ID.</b> <u>Sample/Participants:</u> 36 women with ID with a mean age of 34.31.</p>	<p><b>Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment (ESCAPE) Curriculum.</b> Expands on Khemka's (2000) study (see above) in incorporating motivational elements. Includes 3 units: Unit 1 - Knowledge of abuse and empowerment (i.e. healthy vs. abusive relationships, rights, strategies for intervening/reporting/coping. Unit 2 - Self-directed Decision-making strategy training (including both cognitive and motivational elements). Unit 3 - Structured support group where participants used their own experiences to review content of training (see pp. 195, 197-199).</p>				<p>Measures of knowledge of abuse concepts, empowerment and decision-making skills were all higher in the intervention group and maintained in follow up testing compared with the control group indicating the ESCAPE curriculum is effective (pp. 199-201). Stress-management was the only variable where there was no difference between the control and intervention groups (p.200).</p>

<p>Webb, J. &amp; Stanton, M. (2009). Better access to primary healthcare for adults with learning disabilities: Evaluation of a group programme to improve knowledge and skills. <i>British Journal of Learning Disabilities</i>, 37(2), 116-122.</p>	<p><b>Research aims:</b> to evaluate an education program aimed to enable people with learning disabilities/ID to better access primary healthcare. <b>Methodology:</b> Mixed methods. Qualitative data was gathered from adults with ID pre- and post-completion of the education program. Participants were quantitatively and qualitatively assessed pre- and post-education program regarding "competency to access health care" (symptom recognition, knowledge of GP and procedures at their local general practice and communication skills) (p. 118).</p>	<p>Health care <b>decision making.</b>  Essex, UK.</p>	<p><b>Nature of disability:</b> People with <b>ID</b>/learning disability who were able to communicate verbally (p. 117). <b>Sample/Participants:</b> 11 participants (no further details provided) (p. 117).</p>	<p>A 12 session education program designed to "empower individuals to better access health care" (adapted from 2 existing health education models) (p. 117-118, 121). The program included information sharing and skill development. Additionally, it aimed to increase social supports (i.e. through its group format at the participants' local GP practice and by involving carers/family members) (p. 117-118). Sessions covered a number of areas including general health knowledge, symptom recognition, supporters, decision-making and talking to the doctor/pharmacist, etc (p. 118).</p>	<p>Initially, participants described the barriers to accessing health care – (e.g. not having enough time in appointments, frustration when doctors spoke only to their carer, difficulty understanding medical terms and difficulty explaining what was wrong) (see p. 119). When assessed after the intervention 8 participants showed a statistically significant improvement in symptom recognition and "choosing an appropriate course of action" (p. 119). Five Participants recorded a statistically significant improvement when assessed in a role play booking an appointment (p. 120). Qualitative data collected following the education program found that participants were able to recognise symptoms and make decision regarding a response (p. 120). Additionally, participants had acquired new language which helped them communicate to health care professionals and had established long term health goals (p. 120). Many had new skills to aid planning health care visits, decision making and confidence (i.e. bringing in notes, personal health record tools) (p. 121).</p>			
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**Enablers – aid/ technology/design features**

<p>Davies, D. K., Stock, S. E. &amp; Wehmeyer, M. L. (2003). A palmtop computer-based intelligent aid for individuals with intellectual disabilities to increase independent decision making. <i>Research and Practice for Persons with Severe Disabilities</i>, 28(4), 182-193</p>	<p><b>Research aims:</b> to evaluate a prototype 'pocket compass' software operated on a "palmtop computer" (a form of assistive technology) in aiding people with an ID make task related decisions and follow instruction in a work context. <b>Methodology:</b> Quant. Compared participants'</p>	<p><b>Task related decision making</b> in a work place (i.e. the number of items required on invoice, which product to put in packaging, etc).  U.S.A.</p>	<p><b>Nature of disability: ID</b> (only indicator of level is IQ tests score – between 24 to 76) <b>Sample:</b> 40 (17 female, 23 male, aged between 18 and 54).</p>	<p>Support for decision making comes in the form of the "Pocket Compass" software for a hand held computer with a touch screen (a mainstream IT item). The software is designed to prompt a person with an ID through a task with visual and audio cues. It can be customised to be specific to the setting in which it is used (i.e. pictures of products</p>			<p>Previous literature was cited regarding the potential for mainstream technologies to have an inclusive or stigma reducing effect (p. 184).</p>	<p>Results suggest that the "Pocket Compass" software "can support people with ID to successfully navigate decision points in vocationally oriented tasks" (p. 191). The number of errors was significantly less with the software than without (p. 191).</p>
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	decision accuracy, task accuracy and if assistance was required with and without the 'Pocket Compass'.			being sorted, etc) (see pp. 184-185).				
Fisher, Z., Bailey, R. & Willner, P. (2012). Practical aspects of visual aid to decision making. <i>Journal of Intellectual Disability Research</i> , 56(6), 588-599	<b>Research aims:</b> Re-testing an existing visual decision-making aid (a visual calculator) that was evaluated as effective in supporting people with ID weigh up options. This study altered the test and aid to reflect how it might be used in schools/support services (i.e. Pen-and-paper format rather than computer program and provided training in a group format). <b>Methodology:</b> Quantitative. Testing performance (reasoning and impulsivity) and maintenance of improvements over time in a "temporal discounting task" (involving making a trade off between magnitude and delay of reward) using the altered visual calculator aid. Additionally, tested for maintenance of improvements in the above area without the aid.	<b>Decision making</b> "Temporal discounting skills" (i.e. making a trade off between magnitude and delay of reward) using the "trucks task" and the "planes task" (see p 589 for more details about temporal discounting and pp 591-592 for more details about the two tasks used).  U.K.	<b>Nature of disability: ID.</b> Due to exclusion criteria (required to have an understanding of concepts of quantity, more/less and now/later) "this was a relatively able cohort" ( <i>mild?</i> ) (p. 590). <b>Sample/Participants:</b> 14 adults with ID. 11 male, 3 female.	<b>A visual calculator aid</b> that translated information about 'pros' and 'cons' of choices into coloured bars (a green bar for good or red for bad). Each bar was raised with each addition of a pro/con intended to aid the process of reasoning in decision making (more details about the aid, task and procedure p. 590-592). A computerised version was evaluated as effective in a previous study. In this study, they developed a pen-and-paper version to increase its accessibility in the field.		In light of outcomes, delivering training to people with ID in using the aid in a group format proved to be effective (p. 596).		Participants performed better (i.e. by demonstrating 'orderly' rather than 'impulsive' or 'random' decision-making) using the amended visual calculator aid than in previous studies using a computerised version of the aid (p. 596). Performance with the aid was maintained after a 2 month follow up. Though retention of skills/knowledge was observed without the aid at 1 day follow up, retention was not maintained without the aid at 2 month follow up (p. 596). Participants who displayed higher impulsivity at baseline without the aid demonstrated self-control while using the aid. Some (not all) demonstrated increased self-control immediately after training without the aid as well (pp. 596-597).
Wennberg, B. & Kjellberg, A. (2010). Participation when using cognitive assistive devices - from the perspective of people with intellectual disabilities. <i>Occup. Ther. Int.</i> 17, 168-176	<b>Research aims:</b> to explore how people with ID experience participation in everyday activities with the aid of cognitive assistive devices (CAD) (p. 168). <b>Methodology:</b> Qualitative. Semi-structured interviews about CADs used by participants, how the person uses it, how they seek support with their CAD, etc (p. 170).	<b>Day-to-day choice</b> (i.e. Scheduling time, managing money).  Sweden.	<b>Nature of disability: Mild ID</b> <b>Participants/Sample:</b> Nine people with ID (2 males and 7 females aged 17-37 years) who used CADs.	CADs used: <b>"Handi"</b> - a hand held computer with a program for planning time and managing money. <b>"Time Rule"</b> - a timer that used a combination of visual and audio elements to count down time. <b>Weekly schedule</b> - a hard copy calendar that could be written on (p. 169-170).	Participants use of the CADs meant they were able to decide what they need/would like to do with their time, find out what they were due to do next, "have an overview of activities" they would like to do in a given period of time, plan and track money/spending, keep track of time, and do so with a greater level of autonomy/independence (p. 172).	Most participants received some support uploading new activities to the Handi though the level of support needed varied (p. 173). Staff and family/friend attitudes re using the CADs were sometimes barriers to use of the CAD (e.g. not uploading activities to the Handi when making plans) and some participants refrained from using the CAD with family/friends for "fear of irritating people" (p. 173).		Use of CADs had positive impacts to the participants' health (e.g. reduced stress levels). Participants also felt like they were more independent and had taken on a more "adult" role (p. 173). Participants found they needed less direction from staff and carers (p. 173).
<b>Enablers – broad contextual/ environmental factors</b>								
Neely-Barnes, S., Marcenko, M. & Weber, L.	<b>Research aims:</b> to examine the relationship between	<b>Choice</b> (i.e. Of schedule, what to	<b>Nature of disability:</b> 87%		Greater choice was associated with "smaller			More choice experiences were associated with greater respect

<p>(2008). Does choice influence quality of life for people with mild intellectual disabilities? <i>Intellectual and Developmental Disabilities</i>, 46(1), 12-26</p>	<p>choice, living arrangements and 3 indicators of quality of life (community inclusion, rights and opportunities for relationships) (p. 12). <b>Methodology:</b> Quantitative. Data gathered from a large survey conducted in Washington State USA (see p. 13-14). Measures used were: level of ID, living arrangements, choice, community inclusion, respect of person with ID's rights, relationships and use of a proxy respondent in completing the survey (p. 15).</p>	<p>do in free time, what to buy, home staff, case manager).  Washing state, USA.</p>	<p>had <b>ID</b> (46% <b>mild</b>, 28.1% <b>moderate</b>, 7.1% <b>severe</b>, 6.3% <b>profound</b> and 12.5% didn't have ID). <b>Sample/Participants:</b> Adults (aged 20 to 84 years, 49.6% male). 54.9% used a proxy respondent for some or all of the survey questions.</p>		<p>living arrangements" (p. 19). "Respondents who answered through a proxy" and those who had more severe ID experienced less choice (p. 19, 21, 22).</p>			<p>for rights by others, increased community inclusion and greater quality of life in general (p. 19, 22).</p>
<p>Robertson, J., et al. (2001). Environmental opportunities and supports for exercising self-determination in community-based residential settings. <i>Research in Developmental Disabilities</i>, 22(6), 489-502</p>	<p><b>Research aims:</b> to provide a detailed description of the opportunities for self-determination experienced by adults with ID receiving community-based residential supports and to identify the individual and environmental factors that influence variation in such opportunities (p. 489). <b>Methodology:</b> Quantitative. Part of a larger study. Data collected through interviews and questionnaires completed by managers and staff who knew the adults with ID. Data collected on the following measures: service setting (including size, location, staffing, budgets, institutional characteristics, etc), physical environment/layout, service adoption of active support model, characteristics/abilities of adult with ID, level/types of choice opportunities (p. 491-493).</p>	<p><b>Self-determination, choice and decision-making</b> (i.e. "mundane" choices such as what to eat and larger life decisions such as where to live and who to live with).  UK.</p>	<p><b>Nature of disability: ID</b> (average adaptive behaviour score of 150.2) (p. 494). No further detail provided. <b>Sample/participants:</b> 281 adults with ID living in community-based residential services participated. Average age was 45.5 and 60% of the sample were men (p. 494).</p>		<p>"Majority of participants had little or no opportunity to exercise self-determination over major life decisions" (i.e. Where and with whom to live, recruitment of staff) or more mundane decisions (i.e. where/when to eat) (p. 496). Participant ability was the most influential factor on opportunities for self-determination (p. 494, 496).</p>		<p>Other predictors of environmental opportunities for self-determination were: living in a environment that was physically "more home-like", having no previous experience of living in an institution, residing in a smaller setting, organisational supports/procedures for exercising control (i.e. active support/person-centred planning procedures, policies, etc) (p. 496, 497). Resource availability was not associated with increased opportunity for self-determination (p. 499). Higher staff ratios were associated with fewer opportunities for self-determination (p. 499).</p>	
<p>Ticha, R., Lakin, K., Larson, S.A., Stancliffe, R.J., Taub, S., Engler, J., ... Moseley, C.</p>	<p><b>Research aims:</b> to examine every day choice and support-related choices</p>	<p>Support related <b>choice</b> (e.g. Who/where they</p>	<p><b>Nature of disability:</b> People with</p>				<p><b>Residence type:</b> People living in their own homes had significantly more <i>everyday</i></p>	

<p>(2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. <i>Intellectual and Developmental Disabilities</i>, 50(6), 486-504.</p>	<p>for people with intellectual and developmental disabilities - particularly looking at the relationship between choice, level of disability and type of residence. <b>Methodology:</b> Quantitative. As a part of a large study people with ID were interviewed. The dependant variables of everyday choice and support related choice were examined in terms of their relationship with the independent variables of level of disability; "characteristics" such as age, behaviour patterns, etc; self-reported response patterns (i.e. percentage of questions answered by the person with ID vs. a proxy); and residence type and size (i.e. own home, family home, host family home, agency-operated homes of 1-3, 4-6, 7-15 and 16+ people with ID) (pp. 487-490).</p>	<p>live, staff who support them) and everyday <b>choice</b> (e.g. their daily schedule, how to use free time, how to spend money).  19 states in the <b>USA</b>.</p>	<p><b>ID/developmental disabilities.</b> 42.1% of sample were living with <b>mild ID</b>; 28.3% <b>moderate</b>; 15% <b>severe</b>; and 14.6% <b>profound</b> (p. 492). <b>Sample/Participants:</b> Total sample 8,892 adults with ID (with only 6,179 included in analysis related to everyday choice). Aged between 18 and 97 (22.4% aged 18-29; 21.3% 30-39; 35% 40-54; and 21.3% 55+), 23.9% of the sample primarily communicated nonverbally (p. 493).</p>				<p><i>choice</i> than those living in agency-run homes for 1-3 people (p. 498). People living in family homes, agency-run homes of 7-15 and 16+ people had significantly less <i>everyday choice</i> than those in agency-run homes of 1-3 people (p. 498). <i>Support related choice</i> was highest for people in their own homes and lowest in agency-run homes of more 4-6, 7-15 and 16+ people (p. 498). <b>Level of ID:</b> People with mild ID reported the most <i>everyday and support related choice</i> followed by those with moderate, then severe, then profound ID (p. 499-500). <b>Relationship between level of ID and residence:</b> People with mild to moderate ID had more <i>everyday choice</i> when living in their own homes, followed by those living in host families, small agency run settings (1-3 residence) and with family (p. 501). People with severe and profound ID had the most <i>everyday choice</i> in small agency run settings (p. 501). For people with severe ID, small agency-run homes were found to have the highest <i>everyday choice</i> followed by those living in their own home, with family and in larger agency-run homes (p. 501). For people with severe ID, small agency-run homes were found to have the highest <i>everyday choice</i> followed by living with a host family in terms of making everyday choice (p. 501, see 498-501 for more detail).</p>	
<p>Wehmeyer, M. L. &amp; Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. <i>Journal of Intellectual Disability Research</i>, 45(5), 371-383</p>	<p><b>Research aims:</b> to examine the impact of living/working environment on opportunities for self-determination, autonomy and choice (p. 371, 375). <b>Methodology:</b> Quantitative. Using three scales the researchers collected data on self-determination, autonomy and choice approximately 6 months before and after</p>	<p>Autonomy, self-determination, daily <b>choice</b> and major life <b>decision making</b>.  USA</p>	<p><b>Nature of disability: Mild (?) ID.</b> <b>Sample/Participants:</b> 31 adults with ID (aged 24 to 62 years old, 17 males and 14 females). "Eight were moving from a more to a less restrictive living environment" (i.e.</p>				<p>Results show that participants increased self-determination, autonomy and had more choice opportunities following the move to a less restrictive living and/or work environment (pp.378-379). 25 scored higher on self-determination scale after the move to a less restrictive work/living environment and 20 scored higher on the autonomy scale. The mean choice scale score significantly increased following the move to a less</p>	

	participants moved from a more restrictive living and/or working environment to less restrictive environment (p. 375). The choice scale was completed only by those who moved living environment (p. 377).		Institution to a group home/community or group home to community), 21 were shifting to a less restrictive work environment and 2 were shifting both living and work environments in the same period (p. 375).				restrictive setting (from 32.5 before to 37.2 after) (p. 378).	
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**Benefits of strong decision making support**

Neely-Barnes, S., Graff, J., Marcenko, M. & Weber, L. (2008). Family decision making: Benefits to persons with developmental disabilities and their family members. <i>Intellectual and Developmental Disabilities, 46(2)</i> , 93-105	<p><u>Research aims:</u> to "model patterns of family decision making and assess benefits to persons with developmental disabilities and their families" (p. 93).</p> <p><u>Methodology:</u> Quantitative. Using data gathered from family members in a large study in Washington state, USA (see pp. 94-95). "Latent profile analysis". Measures used were: disability and level of disability, support needs, family members involvement in decision making, informal support, types of services received, perception of case managers competence and satisfaction with services (p. 96-97).</p>	Family support with <b>decision making</b> (about service use and service planning, support workers, financial decision)  Washington state, USA.	<p><u>Nature of disability:</u> Mostly <b>ID</b> (5.9% didn't have ID, 18.6% <b>mild</b>, 50.6% <b>moderate</b>, 20.1% <b>severe</b> and 4.8% <b>profound</b> (p. 96).</p> <p><u>Sample/Participants:</u> Sample of 547 family members of people with development disabilities/ID (90.7% parents, 5.4% siblings and 3.9% other relationship). People with ID were 57.6% male (P. 96).</p>			<p>Four family decision making "classes":</p> <p><b>highly involved</b> in all areas (n=118); <b>involved in planning</b> (not day-to-day) (n=166); <b>involved in financial decisions</b> only (i.e. choosing agencies, knowing how much is being spent but not choosing support workers or planning) (n=75); and <b>uninvolved</b> in all items (n=188) (p. 98).</p> <p>Families were more involved with decision making when:</p> <ul style="list-style-type: none"> <li>- they were younger.</li> <li>- earned higher incomes (specifically, they were more involved in financial decisions).</li> <li>- when their family member with ID had a greater level of disability or support needs.</li> <li>- when they had more case manager contact (p. 98).</li> </ul> <p>"Families involved in planning received more informal support" (p. 98).</p> <p>When family members were highly involved in decision making, the person with ID received more services (regardless of other variables), family satisfaction with services was higher and family perception of service competence was higher (p. 100, 101).</p>	
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**Obstacles -influence and values/attitudes of others**

<p>Dunn, M.C., Clare, I.C.H. &amp; Holland, A.J. (2010). Living 'a life like ours': Support workers' accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. <i>Journal of Intellectual Disability Research</i>, 54(2), 144-160</p>	<p><u>Research aims:</u> to explore how the statutory regulation around substitute decision-making impacts the "practical and ethical dynamics" of supporting people with ID living in residential care homes in England. <u>Methodology:</u> Qualitative. Grounded theory. Interviews with support workers and observation of support worker care practices with regards to substitute decision making in practice.</p>	<p><b>Decision-making/choice</b> (e.g. holidays, leisure activities).  UK.</p>	<p><u>Nature of disability:</u> <b>ID</b> with <b>severe</b>/high care needs. <u>Participants/Sample:</u> 21 support workers and 23 adults with ID from 3 residential homes (p. 148-149).</p>	<p><b>Substitute decision making</b> for people without capacity as a part of the Mental Health Act (2005) (UK). Decision making is intended to be based on the person with ID's best-interests (p. 144-145). The "Best Interests Checklist" is intended to be used by the substitute decision maker to "weigh up objective and subjective info on the persons wishes, feelings, beliefs and values" (p. 145). Paid staff are encouraged to base these decision of the person "person-centred care plan" (p. 144-145).</p>	<p>Support workers tended to draw on their own personal experiences, daily routine, values, decisions, ideas of a meaningful life, etc in making substitute decisions (p. 150-152, 154). They were sceptical about using care plans to make decisions as they felt it wasn't realistic to capture the complexity of a person's identity in such a document and use of this would lead to repetitive activities (p. 150). They aimed to make decisions that lead to a life like their own and intended to increase day-to-day quality of life for the person with ID (p. 154). Many tried to increase the variety of experiences had by the person with ID in an attempt to "Overcome the repetition and limitations" of life in a residential home (p.152- 154). Support workers described the importance of risk-taking and spontaneity - things often not acknowledged/encouraged in organisational policy (p. 152-154).</p>		
<p>Ferguson, M., Jarrett, D. &amp; Terras, M. (2011). Inclusion and healthcare choices: The experiences of adults with learning disabilities. <i>British Journal of learning Disabilities</i>, 39(1), 73-83</p>	<p><u>Research aims:</u> to explore the health care choice making experiences of two groups of people with ID and their carers: those who regularly attend physio appointments and those who had regularly opted out of physio appointments. <u>Methodology:</u> Qualitative. Semi-structured interviews with people with ID and/or their in/formal carers and focus groups with health care staff. Interviews/focus groups covered the degree of involvement of people with ID in health care decisions and factors that impact decision making. <b>Query</b> methodological limitations.</p>	<p>Health care <b>choices/decision-making</b>.  UK.</p>	<p><u>Nature of disability:</u> learning disability/<b>ID (mild, moderate and profound)</b>. <u>Sample/Participants:</u> Data relevant to 21 people with ID (7 regular and 7 irregular attendees of a physio clinic). Four adults with ID were interviewed and 10 carers (both formal and informal) who cared for a further 10 adults with ID were interviewed. Four staff of the physio clinic participated in a focus group.</p>	<p>Participating people with ID felt they needed some support in making decisions and demonstrated a good understanding of "the healthcare intervention in questions" (p. 79).</p>	<p>Inclusion of people with ID in health care decision-making (and choice around meals) was limited (pp. 77 &amp; 79). Attitudes and communication skills of supporters (i.e. health professionals) were highlighted as a potential barrier to SDM (p. 80). Health care professionals saw their role as assessing for capacity and providing info (p. 79). In/formal carers recognised the importance of including people with ID in health care decisions but were reluctant to do so- if they did they would try to steer them to what they thought was the "right" decision (p. 79). Literature suggests this may limit development of choice-making skills and discourage choice-making (.80). Ideally carers said they would provide info/education to the</p>		

						person with ID and allow them to make a choice. However many didn't because they felt unable to make the person with ID aware of options available or their role in making decisions for themselves (the authors note literature regarding promotion of choice-making and options with people with ID) (p. 79).		
Healy, E., McGuire, B.E., Evans, D.S. & Carley, S.N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. <i>Journal of Intellectual Disability Research</i> , 53(2), 905-912	<u>Research aims:</u> to assess the knowledge, experience and aspirations of people with ID in regards sexuality and to examine their perceptions regarding sexual autonomy. <u>Methodology:</u> Qualitative. Focus groups (based on age and gender) were held with service users of a service for people with ID.	<b>Sexual autonomy.</b> Ireland.	<u>Nature of disability:</u> <b>ID</b> , varied levels (p. 907). <u>Participants/Sample:</u> 32 participants in 8 focus groups based on age and gender (3 x 13-17y.o. males; 6 x 18-30y.o. males; 11 x 31y.o. plus males; 6 x 18-30y.o. females; 6 x 31y.o. plus females).		Many participants felt that being in "personal relationships" was an individual's choice. Many expressed discontent with the restrictions placed on them in perusing personal relationships (pp. 908, 910).  Participants displayed an understanding of sex, sexual anatomy and one person was aware of the importance of consent. Many had an awareness of safe sex practices and contraception though there was some miss information in this area (p. 909). Knowledge was gained through formal sex education or through television and increased with age (p. 910).  Many participants aspired to have children and get married. However, many in the 31y.o. plus group felt they were not allowed to and perceived this as inequality (p. 910).	Many felt their relatives did or would not approve of them having personal relationships. Some kept their personal relationships hidden from relatives although some, particularly female participants, felt they could speak openly about relationships with their parents (p. 908).  Participants reported that services restricted having personal relationships or did not afford them privacy to do so. Though some participants were persistent about their right to have such relationships and felt that staff should facilitate the development of them (p. 908).		
Pilnick, A., Clegg, J., Murphy, E. & Almack, K. (2010). Questioning the answer: Questioning style, choice and self-determination in interactions with young people with intellectual disabilities. <i>Sociology of Health and Illness</i> , 32(3), 415-436	<u>Research aims:</u> to examine the interactions in transition meetings for young people with ID moving from child to adult services - particularly looking at how the principles of self-determination and choice are practically applied in these interactions. <u>Methodology:</u> Qualitative. Conversation analysis of 8 auto-recorded transition	<b>Self determination</b> re post high school transitions to continued education, work, etc.  UK	<u>Nature of disability:</u> <b>Moderate to profound ID.</b> <u>Sample/Participants:</u> Young people (18-19years) transitioning from child services to adult services. Meetings included 8 young people as well as attending family		The teacher/staff members chairing the meeting attempted to actively place the young person at the centre proceedings by "offering the floor" or clearly allocating listening roles and speaker roles. This did not guarantee the young person's control. Some young people declined the opportunity or could not think of anything to say in the moment (p. 421-422,	The broad and often abstract, compulsory agenda of transition planning meetings complicated interactions (i.e. required covering preferences and aptitudes over time and in different social/physical contexts) (p. 423, 429). Many parties were not clear on the meeting's agenda (422). Misunderstandings occurred (p. 424, 429).  Staff and family made		

	“multi-partied” planning meetings/leaver review meetings for young people leaving a special school.		members, teachers and care staff.		433).  Many young people had limited verbal communication capacities or were seen to give answers that were inconsistent with preferences/behaviour observed by family/staff in the past. These factors complicated determining if a misunderstanding had occurred (p. 427-428).	decisions about whether a young person’s responses were contextually appropriate - i.e. related to the intended time period (past, present and future); physical context (home, school or college); or topic (enjoyment as compared to aptitude) (p. 424-427). Answers were treated as "wrong" or overridden due to being deemed "contextually inappropriate" by staff/family attending the meeting (p. 428-429). Repeated questioning and unclear questions by a staff often lead to confusion or the answer viewed as "right" by staff at the meeting (p. 424, 429).  Some wishes were deemed in appropriate in a "wider sense" (i.e. choices that were seen as outside a person’s competency). Staff tried to more delicately and indirectly reject or delay these wishes (p. 431-432).		
Sowney, M. & Barr, O. (2007). The challenges for nurses communicating with and gaining valid consent from adults with intellectual disabilities within the accident and emergency care service. <i>Journal of Clinical Nursing</i> , 16(9), 1678-1686	<b>Research aims:</b> "to explore the challenges experienced by nurses in accident and emergency (A&E) service in assessing and providing care to adults with ID" (p. 1681) - with a focus on communication and gaining consent. <b>Methodology:</b> Qualitative. Data collected through focus groups with A&E nurses in Northern Ireland. Findings included 4 other themes that were not outlined in this paper (good practice, respect for individuals, lack of knowledge and dependence on carers) (see page 1681).	<b>Consent to medical treatment.</b>  Northern Ireland.	<b>Nature of disability:</b> Learning disability/ <b>ID</b> (no specific level of ID discussed). <b>Participants/Sample:</b> 27 A&E nurses from 5 hospitals in Northern Ireland (1 focus groups per hospital).			Nurses experienced communication difficulties in working with people with ID (p. 1681). They found it difficult to understand the person’s needs (p. 1681). Due to the rushed A&E environment, the time necessary to properly communicate was not always afforded to people with ID (p. 1682). A lack of information/documentation accompanying the person from other community services was reported (i.e. re communication needs of the person with ID, etc) (p. 1682). Participating nurses had difficulty gaining consent and some questioned its necessity (p. 1682). Many relied on carers for both communication and proxy consent – at times communicating solely with carers (p. 1682). Participating nurses lacked awareness of		

						the legal need to get the consent of all adults with ID (p. 1683).			
Goldsmith, L., Woodward, V. Jackson, L. & Skirton, H. (2013). Informed consent for blood tests in people with a learning disability. <i>Journal of Advanced Nursing</i> , 69(9), 1966-1976	<u>Research aims:</u> to explore the information needs and ways of facilitating informed consent for people with mild to moderate learning disabilities/ID in consenting for blood-tests. <u>Methodology:</u> Qualitative, ethnography. Observation of 6 participants with ID receiving a blood test and semi-structured interviews with 14 participants with ID.	Health care <b>decision-making/informed consent</b> - specifically consenting to a blood test. UK	<u>Nature of disability:</u> Learning disability/ID ( <i>mild to moderate</i> ). <u>Participants/Sample:</u> People with ID aged between 27 and 65 years.		Participants with ID saw themselves as being capable of having a level of independence and expressed that they wanted to be treated "not like children" (p. 1972).	There were inconsistencies in the consent procedures followed and the information requirements of people with ID were often not met (p. 1970-1971). If information was communicated it was done so verbally - no evidence of information provided in alternative ways (i.e. accessible leaflets) (p. 1970). Additionally, some health professionals did not explicitly seek consent (p. 1970).  Staff engaged a number of strategies to reduce apprehension for people with ID. Strategies included: using humour, involving person with ID in procedure, distraction, reassurance of no harm, regularly checking in to see if they were 'ok' (p. 1972).			
<b>Obstacles at service /policy /resource level</b>									
Hawkins, R., Redley, M. & Holland, A. J. (2011). Duty of care and autonomy: How support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home. <i>Journal of Intellectual Disability Research</i> , 55(9), 873-884	<u>Research aims:</u> to explore how support workers manage the conflicting duties of managing risk/duty of care and recognising a person's autonomy in a residential care service for people with Prader-Willi Syndrome (PWS). <u>Methodology:</u> Qualitative, ethnography. Participant observation at residential service and interviews with 14 staff and 8 residents with PWS. Organisational policy documents were also a data source.	General <b>autonomy</b> and independence (i.e. finances, movement in/outside the residence, long term goals, etc). A small rural village in the UK.	<u>Nature of disability:</u> <i>Mild to moderate ID</i> stemming from PWS (p. 875, 877). <u>Participants/Sample:</u> Interviews were conducted with 8 people with PWS/ID and 14 staff. Participant observation occurred in two settings - one where 23 people with ID who were "thought to be less able" resided, of whom 17 were living with PWS. The other was a "semi-independent" residence where 6 people with ID/PWS lived (p. 876). {Highly			Researcher observed two approaches adopted by staff in facilitating opportunities for people with PWS to exercise independence/autonomy. First was through <b>incorporating what opportunities they could into people's care plans</b> (within the organisational constraints). For example, including and going to effort to seek out employment for someone who desired it. However, this was difficult due to requirements of staff to supervise most of the time (p. 879). Second, staff <b>covertly facilitated opportunities for independence</b> that were counter to org policy using their professional judgement (i.e. allowing people to pay for their purchase or allowing people to go for a walk by themselves). Occasionally, there were adverse outcomes	There were barriers to independence at the service policy level (see p. 877 for detail re policies). Organisational policy explicitly placed more importance on risk management. Staff were reprimanded for using discretion and for "deviating from standardised care procedures" to create opportunities for participating people with PWS to exercise independence (p. 877).		

			restrictive enviro}			and in both instances where there were and weren't adverse outcomes staff were reprimanded (p. 879).		
Hodges, J. S. & Luken, K. (2006). Stakeholders' perceptions of planning needs to support retirement choices by persons with developmental disabilities. <i>Therapeutic Recreation Journal, 40</i> (2), 94-106	<u>Research aims:</u> to "ground the concept of retirement supports in the realities of involved stakeholders" (p. 97). <u>Methodology:</u> Qualitative. Focus groups with staff and family of an ID support service were conducted regarding issues related to successful retirement.	Retirement <b>decisions/choices.</b>  USA.	<u>Nature of disability:</u> "Developmental disability"/ <b>ID</b> (unsure of level of disability). <u>Participants/Sample:</u> Focus groups with 9 residential service providers, 5 family members, 7 vocational service providers, and 3 senior service providers along with 1 interview with a potential retiree.			<b>Barriers to retirement/retirement choices:</b> supporter apprehension re retirement (i.e. Loosing residential placement; routine disruption; loss of social connections through work; questions regarding the adequacy of supervision in retirement) (pp. 98, 100).	<b>Structural barriers to retirement/retirement choices:</b> A lack of retirement culture (p. 98); regulations (i.e. potential changes to a person's eligibility to live in a group home) (p. 100); and financial barriers if person loses income (p. 101).	
<b>Illustrations of exclusion from decision making and poor practice</b>								
Abreu, B. C.; Zhang, L. Et al. (2002) Interdisciplinary meetings: Investigating the collaboration between persons with brain injury and treatment teams. <i>Brain Injury, 16</i> (8), 691-704.	<u>The Research aims:</u> to gain an understanding of the nature of Interdisciplinary Team Meetings (ITMs); if they are client-centred; and types of collaborations that occur within them. <u>Methodology:</u> Qualitative. Descriptive. Multiple case studies. Participant observation by 5 interdisciplinary researchers.	<b>Collaboration</b> (with client), team meetings.  Decisions re treatment, rehab goal setting, discharge planning, etc.  USA	<u>Nature of disability:</u> Post-acute brain injury ( <b>ABI</b> ) in a residential rehabilitation setting. <b>Moderate</b> level of disability. <u>Sample:</u> 42 clients.	Client-centred interdisciplinary team meetings procedure.	Occasionally, clients were asked if they understood, if they had questions, etc. Process disempowered clients.		The ITMs "were not client-centred but rather team member- or discipline-centred" (p. 698). Client participation was decreased due to the attitudes and actions of team members (i.e. the perception that the info/tasks were too hard for clients due to cognitive factors) (p. 700).	
Antaki, C., Finlay, W., Sheridan, E., Jingree, T. & Walton, C. (2006). Producing decisions in service-user groups for people with an intellectual disability: Two contrasting facilitator styles. <i>Mental Retardation, 27</i> (1), 54-59	<u>Research aims:</u> To explore what facilitators of self-advocacy groups do and how they do it. Two case studies of staff facilitated self-advocacy groups with two different facilitation approaches (directive guidance style and short-circuit style). <u>Methodology:</u> Qualitative. Conversation analysis of two audio recorded meetings (group 1 at a day centre and group 2 at a group home).	Participation and <b>group decision making in self-advocacy groups</b> /"decision-making groups" to enable input from service users into service provision.  USA?	<u>Nature of disability:</u> People with <b>ID (no info re level of disability)</b> . <u>Sample:</u> case 1 was a "self advocacy group" in a day centre and was made up of 12 group members and 1 staff advisor; and group 2 was a "residents' meeting" at a group home that had 8 group members and 2	Two styles of group facilitation: <ol style="list-style-type: none"><li>1. Directive guidance style; and</li><li>2. Short-circuit style.</li></ol> (see p. 323 for more detail).		<b>Directive guidance style.</b> The facilitator "manages the running of the group... [brings out] the rational steps required" (i.e. problem definition, immediate response, preference for change, and suggestions for action) (p. 323). This process was driven by the facilitator not group members (p. 323).  <b>Short-circuit style.</b> The facilitator: focused on "the organizational aspects of the interaction; pre-empted the description of problems; reduced the alternative solutions; and move quickly to		Neither facilitator style was concluded as a successful means to reach the aims of a self-advocacy group – to "empowering members by giving them opportunities to speak for themselves, to raise issues of concern" or facilitating group member control (p. 340). Both advisors/facilitators held the power in the groups – assumed responsibility for covering business; "decided what utterances were reasonable"; "had the answers for members to work towards" and no opportunity for members to run the meetings were provided (p. 341).

			staff members.			propose, and to decide on, actions that fit the institutional agenda" (p. 324).		
Antaki, C., Finlay, W. & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. <i>Journal of Policy and Practice in Intellectual Disabilities</i> , 6(4), 260-266.	<u>Research aims:</u> Explore how everyday choices are offered to people with ID as compared with policy discourse about the importance of choice and decision making for people with ID. <u>Methodology:</u> Qualitative. Conversations analysis of data from a broader ethnographic study into residential services for people with ID.	<b>Choice.</b> "Minor but more frequent concerns of daily living" (p. 260) in two group homes in the UK. No evidence of major life decisions being made by residents (p. 264).	<u>Nature of disability:</u> all had a diagnosis of <b>ID</b> (one participant had down syndrome). In house 1 (5 adults) all participants needed a level of support with ADLs and to communicate with people outside the group home. In house 2, all participants required higher levels of support with ADLs and communication ( <b>moderate to severe?</b> ). <u>Sample:</u> 15 adults (age range: 34 to 65) from two group homes.			5 varieties of choice opportunities provided by staff: 1). Choice re: matters important to the organisation 2). Choice as running commentary (i.e. offering choice while already being escorted to the activity choice is related to) 3). Choice to cover a mishap 4). Choice to refuse an expressed preference 5). Choice among unspecified options for routine purposes (i.e. group choice-making with no attempt to establish the meaning of each option to people. Purpose of choice process to have recordable responses from residents) (p. 261-263). Overall theme of observed choice opportunities: staff controlled the agenda (p. 264). Choices were offered: for things people had no interest in; retrospectively to "gloss over" events that did not go to plan; or to generate recordable, "item-ticking" responses (p. 264).		
Bigby, C., Bowers, B. & Webber, R. (2011). Planning and decisions making about the future care of older group home residents and transition to residential aged care. <i>Journal of intellectual Disability</i> , 55(8), 777-789	<u>Research aims:</u> Examining care transitions from group homes to residential aged care for older adults with ID with particular consideration of: the planning process by staff, families and residents; and how decisions were made. <u>Methodology:</u> Qualitative, grounded theory. Using a sub-set of data from a larger study looking at pathways to residential aged care for older adults with ID.	<b>Decision making</b> regarding care transitions for older adults with ID - particularly decision making around transitions from group homes to residential aged care.  Vic, Australia	<u>Nature of disability: ID</u> (unsure of level of disability). <u>Sample:</u> Families and staff associated with 17 older people (aged between 49 to 81) with ID who had recently moved, or were likely to move, to a residential aged care facility (p. 779).	Informal key person (i.e. a relative or close person) succession plans by parents for older people with ID.	Decision-making was largely dominated by staff/professional with minimal family involvement and very little consideration of the resident's preferences (p. 786).	Two distinct processes for decision making: <b>"Hastily made" decision-making</b> process spurred on by a crisis. In some cases, a delay in such decision-making often meant "crisis" situation improved and the urgency of decision-making was gone (p. 785). <b>Collaborative, measured decision making</b> process where family and service work together to plan for the future (p. 784-785). "Informal key supporter" saw their role as an "'advocate', 'protector' or 'keeping an eye out'" for the person with ID in place of parents who had passed or parents who were ageing and planning for the future (p. 781). The efficacy of	The study recommended that key supporters be equip with knowledge about available statutory bodies to support DM by the person/family and to reduce the risk of staff/organisational/resource issues dominating the decision making process (p. 786).	Processes described in research not exemplary of SDM (p. 786).

						long-term parental planning re (nominating an informal key person to take up supportive roles in their place is affirmed by the study (p. 786).		
Chou, Y-C. and Lu, Z-Y. (2011). Deciding about sterilisation: Perspectives from women with an intellectual disability and their families in Taiwan. <i>Journal of Intellectual Disability Research</i> , 55(1), 63-74	<u>Research aims:</u> to explore the decision-making processes re "sterilisation" for women with ID and their families. <u>Methodology:</u> Qualitative. Semi-structured interviews with women with ID and family members of women with ID. Interviews explored the reasons for deciding to get either a hysterectomy or tubal ligation, who was involved in decision-making and how/when it was explained to the women with ID following the procedure.	<b>Decision-making</b> re hysterectomy or tubal ligation surgery.  Taiwan.	<u>Nature of disability:</u> <b>Mild, moderate</b> and <b>severe ID</b> . <u>Participants:</u> 11 family members of women with ID and 4 women with ID were interviewed (total: 15 interviews about 11 women with ID). Women with ID of interviewed family members were aged between 20 and 58, 8 were married, 8 had children, women had surgery (tubal ligation or a hysterectomy) when aged between 12 and 30 years old (pp. 65-66).		Women with ID were rarely involved in decision-making regarding getting surgery of this nature and no women with ID involved in this study were the main decision makers (regardless of level of disability) (p. 70-71).  Most women did not know of the surgery until after it had occurred when they felt pain and were informed (p. 70). One woman was angry she had not been able to give consent (p. 70).	For married women, decisions were made by husbands or parents-in-law and sometimes the women's parents. For unmarried women, the mother made the decision (p. 69-71).  Reasons for making the decision were: pregnancy prevention, economic reasons, concern re children having ID, concerns re the capacity of the women with ID to effectively parent, and to manage menstruation (p. 71).  Some family had not told the women with ID she had undergone the procedure because they were concerned she would not be able to understand or remember (p. 70).		
Gorfin, L. & Mcglaughlin, A. (2003). Housing for adults with a learning disability: 'I want to choose, but they don't listen'. <i>Housing, Care and Support</i> , 6(3), 4-8.	<u>Research aims:</u> to facilitate the involvement of adults with learning disabilities/ID "in service planning by asking them to identify their own needs and preferences" re housing. <u>Methodology:</u> Mixed methods. Face-to-face interviews with people with ID using an existing	Housing <b>decisions</b> .  UK.	<u>Nature of disability:</u> Learning disability/ <b>ID (mild to moderate?)</b> . <u>Sample/Participants:</u> 72 adults with ID (aged 22-79, 47 male and 25 female and 3 adults from "ethnic			Many participants felt powerless and refrained from sharing their preferences as they think they will not be acted upon and many had been dissuaded by family when they had shared a preference (p. 8).		

	housing questionnaire. (Part of a broader study that included focus groups with family carers and professionals).		minorities"). Participants lived in a variety of difference settings (most with family or in residential care) (p. 5).				
Hill, S. C. & Wooldridge, J. (2006). Informed participation in TennCare by people with disabilities. <i>Journal of Health Care for the Poor and Undeserved</i> , 17(4), 851-875	<b>Research aim:</b> examined the informed health care choices of people with a variety of disabilities who used TennCare - Tennessee's Medicaid "managed care program". <b>Methodology:</b> Quantitative. Phone survey conducted to test/explore the following: if adults with disabilities were less likely to receive information and choose their health plans/providers; if specific disabilities are associated with less access to information and if education promotes increased access to info; to describe the info sources of adults with a disability; and to assess which info sources are more useful/associated with choosing plans (see pp. 853, 856-858 for more detail on methodology).	Health care related <b>decisions</b> (largely participation in choosing a plan).  Tennessee, USA	<b>Nature of disability:</b> Includes a very broad population of people with disabilities ( <b>ID</b> , mental illness related disabilities, visual and hearing impairments and people who have difficulty communicating). <b>Sample/Participants:</b> Adults and children (under 65 years) with varied disabilities. Parents were interviewed for minor children and 15% of the participating adults required a "proxy" respondent (i.e. a family member). Total sample was 1,293 (883 adults and 410 children) (p. 856). No clear delineation of the number of people with ID that participated.				Intellectual disability was associated with less access to information about their plans. 11% of adults with ID sought info about their plans compared with 16% among people with other disabilities (p. 862). Intellectual disability was associated with less likelihood of receiving info from the state - 14% percent received written info from the state compared to 21% of all adults with disabilities. Less than 1% received information from a provider compared with 2% of all adults with a disability (pp. 862-863).
Huneke, N. T., Gupta, R., Halder, N. & Chaudhry, N. (2012). Difficult decisions: Are intellectually disabled patients given enough information to consent to medical treatment? <i>Journal of Intellectual Disabilities</i> , 16(4), 265-274	<b>Research aims:</b> evaluate current practice against best practice guidelines re consent to medical treatment by patients with learning disabilities. <b>Methodology:</b> Quantitative. Questionnaire given to patients with learning disabilities re their knowledge/understanding	<b>Decisions</b> re health care treatments.  Greater Manchester, UK.	<b>Nature of disability: ID</b> (unclear of nature of disability). <b>Sample/Participants:</b> 51 adults with ID completed the questionnaire. 20 male and 25 female with a mean age of 51.5			<b>Barrier?</b> The 8 patients who were assessed to have capacity made decisions re their medications. However, 2 patients had their medications altered without their consent. 37 patients were assessed not to have decision making capacity. Of which, 19 were not involved with discussion re their medication "or were unsure	

	of treatment (i.e. implications of not having/having treatment), if their knowledge was checked, involvement in decision making, and if they were assessed to have capacity (p. 267).		years. 22 lived in supported accom and 23 lived in privately funded care homes.			who helped them" (p. 271). 9 patients were helped by their doctor and another 9 were assisted by a carer or family member. However, only 4 patients had records of a formal assessment of capacity to make decisions (p. 271).		
McCarthy, M. (2010). Exercising choice and control - women with learning disabilities and contraception. <i>British Journal of Learning Disabilities</i> , 38(4), 293-302	<b>Research aims:</b> to explore the experiences of women with learning disabilities in being prescribed contraception as well as GPs contraception prescribing practices with this population. <b>Methodology:</b> Mixed methods. Semi-structured, in-depth interviews with women. Topics covered were: current/previous use and knowledge of contraception, experience of being prescribed contraception, decision making process, sources of info and support. GP completed a postal survey on the number of women with ID GPs had prescribed to, common methods of contraception recommended and responses to issues of capacity and consent.	<b>Decision making re</b> contraception.  UK	<b>Nature of disability: Mild or moderate ID/Learning disabilities.</b> <b>Sample/participants:</b> 23 women with ID (aged between 20 and 51). 162 GP took part in the postal survey.		"Most (14) women did not understand how their contraception worked" or why that method was recommended for them (p. 296). Few (5) women had made the decision to begin use of contraception themselves rather parents, GPs or staff had made the decision for them (p. 296). Most women were accompanied to appointments by support staff or a parent - this was the preference of all women involved as it made them feel more comfortable, safe and provided assistance with understanding and interpreting info (p. 296). None of the women were provided with accessible information and none were aware of their right to it though all would have liked to have received it (p. 297). Most women felt they could speak about contraception with staff, mothers or partners though none felt they could speak about it with other women with disabilities (p. 297).	93% GPs thought it was valuable for the women to bring a support person for purposes of aiding communication and increase chances of contraception being used appropriately (p. 296). GPs highlighted the risks of excluding the women through conversation being dominated by the GP and support person or a women's choice being "impeded" by support person. They also raised concerns about confidentiality (p. 296). No GPs were aware of the requirement to provide information in an accessible format (p. 297). GPs would seek proxy consent in the event of a person being assessed an unable to give informed consent and were unaware that this had no legal validity (p. 298).		
Renblad, K. (2002). People with intellectual disabilities: Activities, social contacts and opportunities to exert influence (an interview study with staff). <i>International Journal of Rehabilitation Research</i> , 25(4), 279-286	<b>Research aims:</b> to describe the relationship between activities, social network and influence over daily lives for 24 people with ID. <b>Methodology:</b> Mixed methods? Interviews with staff and one relative of 24 people with ID about their social contact, activities and possibilities for influencing those elements. Using interviews transcripts, 24 case descriptions were	<b>Influence over/Choice re</b> daily activities and socialising.  Sweden.	<b>Nature of disability: Moderate ID.</b> Many participants had multiple disabilities (i.e. Hearing impairment, mobility challenges, etc). <b>Sample/Participants:</b> 34 staff/relatives interviewed re 24 people with ID		Most participants had not chosen their work activities at the day centre but were "able to choose from within an existing framework" (p. 283). However, there were some instances where alternative arrangements were made for people who requested an activity not offered (i.e. transport to another day centre where the desired activities were offered) (p. 284). Participants did not choose			

	compiled and analysed		(no age provided). All people with ID worked at day centres and lived in either group homes, with family or in their own apartment.		who they worked with - this was determined by staff (p. 284). Participants expressed their dislike for activities or their contact with others in various ways - day centres often used questionnaires re: activities and participants excluded/refrained from talking to those they did not wish to work with (p. 284). Participants mostly had no choice in activities at home (i.e. hygiene, cleaning, who they lived with, spent time with) though some chose what they would eat (p. 284). Those who had their own apartments had more choice over who they spent time with and what they did (p. 284). Participants' leisure time activities were voluntary and some participants had a lot of control of their activities (p. 284).			
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### **Appendix 3**

Focus group and interview questions (for legal professionals, family members, disability workers) for people with cognitive disability (intellectual disability or acquired brain injury).

1. What does the term ‘supported decision making’ mean to you?
2. Can you think of a time you think you provided good help to someone with a cognitive disability to make an important decision?
3. What was your role and relationship to the person?
4. Can you tell me about the decision and what sort of help did you provide?
5. What went well?
6. What were the things you thought about in providing help?
7. What were the challenges; how were these overcome?
8. How might you do things differently in the future?
9. What advice would you give you to someone in a similar position providing support to some with cognitive disability?

## **Appendix 4**

### Interview questions for people with cognitive disability

1. Can you talk about some of the decisions you have made for yourself  
Prompt -give examples of day to day type decisions and larger decisions
2. Lets take one of these decisions:  
Can you tell me how you made the decision;  
What sorts of things did you think about;  
Who did you talk to about it;  
Who helped you make it?  
Can you tell me what happened?  
How did other people help you?  
Did you get enough help?  
Did someone else take over the decision?  
Was it good?  
What was good about it?  
What was hard about making this decision?
3. What would you like to happen next time you have to make a decision like this?
4. What would you tell people who might help you?