

OVERVIEW OF LITERATURE ABOUT ENABLING RISK FOR PEOPLE WITH COGNITIVE DISABILITIES IN CONTEXT OF DISABILITY SUPPORT SERVICES

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Overview of Literature about Enabling Risk for People with Cognitive Disabilities in Context of Disability Support Services.

This overview is based on a review of the peer reviewed and grey literature on risk and the practice of front line staff in supporting service users with cognitive disability. Our aim was to explore the questions: 1) What are front line staff experiences of enabling risk? 2) What are the barriers and facilitators that confront front line staff and others involved in disability support services in enabling risk for people with cognitive disabilities in particular people with intellectual disability or acquired brain injury? 3) What are the characteristics of models for risk enablement with people with cognitive disabilities?

Much of the literature has a broad focus on community care services generally, concerned with generic groupings of service users but also specific groups such as those with dementia or poor mental health. Rather less is primarily concerned with support in the context of disability services and people with intellectual disabilities, and very little in respect of people with acquired brain injury. Our initial searches of three data bases for peer reviewed literature identified over 1001 items, many of which concerned broad policy, sociological or psychological aspect of risk. Some of these were already familiar to us, and provided the background for the review. These items were reviewed and by excluding items that were not directly pertinent to our questions, we retained 37 peer reviewed papers that were analysed in some detail. An internet search using Google identified 48 reports, policy or guidance documents from the grey literature including various training programs and models for risk enablement or management. This summary draws out the main themes in the peer reviewed literature on supporting risk and summarises several of the models identified for guiding supported decision making that incorporate risk enablement. The vast majority of the literature is situated in the UK context, with several from the Netherlands. The research reported is predominantly exploratory, qualitative and small scale.

The Broad Landscape of Risk

Risk Society – Shifting Responsibility to Individuals from Governments and Institutions

Beck (1992) suggests that social changes associated with modernity led to the emergence of risk as a central feature of society, generating what he termed the ‘risk society’ – a growing concern with identifying and managing future hazards. He suggests that neo-liberalism changed the role of government as a primary manager of risk through welfare states, by

shifting responsibility for services and associated risk to civil society organisations and individuals. For example, greater expectations that individuals should manage risks to their own health by taking private insurance and adopting healthy lifestyles or closing large institutions and moving responsibility for care of people with disabilities to smaller community based organisations. Shifting responsibilities of government are clearly seen in social policy trends since the 1990s such as the growth of contracting out government services to private for profit or non-government organisations and introduction of individualised funding mechanisms such as the National Disability Insurance Scheme (NDIS) which places not only control but also risk in the hands of individuals.

Such shifts have been largely supported by service users and advocacy groups who have sought greater control over decisions about their own lives and choice about the types of services they receive, and how and by whom they are delivered. The arguments have been that block funded services offered little consumer choice and leave control over decision making with governments or welfare professionals who too often adopt paternalistic stances towards service users, and make decisions based on imperatives associated with rationing scarce resources or expert knowledge.

New perspectives on supporting people with cognitive disabilities to make decisions and exercise choice are developing in parallel with the service model of individualised funding. The UN Convention of the Rights of People with Disabilities (2006) challenges traditional models of substitute decision making through use of guardianship which effectively removes an individual's right to legal agency. The Convention brings to the fore ideas about supported decision making – the right of people with cognitive disability to the support they need to make their own decisions, rather than decisions being made for them either through informal or substitute decision makers. Decision making and risk go hand in hand, suggesting that issues of risk are likely to be a key component of supporting people with cognitive disability with decision making.

Key Concepts and Tensions

At the heart of the concept of Risk is uncertainty - the probability that something will happen in the future – *the risk of* something is the chance of it happening if a particular decision or action is taken. Risk is used in many different contexts, and the way it is understood and the situations to which it is applied vary widely, suggesting the importance of identifying contexts and perspectives when thinking or talking about it. Technically neutral, risk is often

interpreted negatively - the chance that something negative or harmful may happen. The language of risk is varied - it is used as a noun to refer to future situations that may involve positive but usually negative outcomes – for example deciding to live on your own might be considered by a supporter as too much of a risk - it is also used as verb, being exposed or having been exposed to positive or negative outcomes – for example she risked being lost by going out alone.

Risk occurs in multiple domains, including financial, psychological wellbeing, health and physical safety. For service users, questions about risk arise from their actions or preferences in the context of broader planning or decision making about their life. Such decisions are often made with support of professionals in roles such as planner, Local Area Coordinator or case manager. Service users also make decisions that involve issues of risk in their day to day lives and interactions often with assistance from direct support staff. Risks may be associated with a decision a service user intends to make or has made, or from actions they have taken including their behaviour (which may be a means of communicating unhappiness or dissatisfaction). Though often more implicit, issues of risk also arise from the actions of support workers or other human service staff when they make decisions about what support to provide, whether to intervene in a situation, or to mediate decision making for a service user.

Service system reform and the new rights paradigm bring to the surface competing expectations. On the one hand, supporting and respecting service users' rights to make decisions and exercise control over their own lives and on the other expectations about ensuring their safety and wellbeing. The juxtaposition of risk, choice and control have become major issues for organisations and their frontline staff. Staff have to consider the balance between being protective of a person to eliminate risk while respecting individual freedom and autonomy to make choices that may involve an element of risk - living a full life and exercising choice and control while being safeguarded (Lafferty, McConkey & Simpson, 2012). Questions arise such as - to what extent can staff support a service user to make decisions or behave in ways that might result in harm to him or herself or others – when is it legitimate to intervene or override preferences? What risks should a service user be enabled to take in deciding to pursue something that is important to them, their sense of self, their aspirations or psychological wellbeing?

Closely allied to expectations about the rights of service users to make decisions that involve risk of a perceived negative outcome are fundamental questions about service users'

vulnerability, safety and protection from harm as a result of the actions of staff or service systems rather than their own actions or decisions. The issue of ‘safeguarding’ ‘vulnerable’ people/service users is prominent in the UK and increasingly on the agenda of the Australian disability service system following media and public enquiries exposure of abuse in services. Indeed, some writers suggest that service users are much more likely to suffer harm from the actions of services than as a result of their own decisions or action (Kilcommons et al., 2012). It is notable that the NDIS has framed issues of risk, service quality and safeguarding together in the high-level framework about governance of service delivery (Department of Social Services, 2016).

Risk is about the future and the probability of something occurring – be it negative or positive, beneficial or harmful. In contrast, ideas about vulnerability or being vulnerable and thus safeguarding or the need to be safeguarded refer to the present and are applied to whole classes of people in terms of their inherent characteristic or external factors. Vulnerable people are seen as unable to protect themselves, make judgements and their reliance on service provision exposes them to increased risk of abuse.

Parley (2010) argues that risk and vulnerability are closely linked. However, when risk is considered alongside vulnerable people it is usually cast in negative terms, service users are regarded as passive non-active players – risk is something that might happen to service users because of their situation and caused by others around them. In contrast when rights and risk are considered together a positive or action orientated perspective on risk taking is more likely, service users are active agents and the risk is associated with their preferences and decisions.

Multiple Perspectives on Risk

A Regulated Space

Legislation and policies aim to regulate or manage risk at government, organisational, employee and service user levels. As a result, risk is discussed at multiple levels within community service organisations. For example, concerns for the organisation as a whole might be in terms of damage to reputation, compliance with legal obligations about things such as the safety of employees, financial viability, corporate governance, external standards or audit requirements about quality of services, and avoidance or management of factors that may interfere with expansion or commercial success. Various types of legislation and policy govern the way organisations must avoid risk, for example to the health and wellbeing of

their service users and employees (generally known as Occupational Health and Safety). Individual employees as well as the organisations for which they work must comply with external requirements about for example, safe work practices to avoid harm to themselves and others. They must also comply with a common-law duty of care to service users which entails a responsibility to take reasonable action to prevent harm occurring to the people they support.

Risk and Service Users with Cognitive Disability

A recurrent theme in the literature is the reminder that issues of risk are particularly important for people with cognitive disabilities. Inherent in cognitive impairment are difficulties with abstract concepts, planning ahead and making judgements that impede foreseeing or understanding risks, and capacity to weigh up positive and negatives of proposed actions. It is difficulties such as these that are often the reason a person with cognitive disability is a service user and receiving support (Williams & Porter, 2017; Greenspan, Switzky, & Woods, 2011). Fyson and Kitson (2007, p. 434) bluntly sum this up “a plea for a recognition of the obvious (if unspoken) reality that if these people were able to be fully independent and to make important life choices without support then they would not be receiving state-funded services in the first place”.

As Fyson and Kitson (2007) suggest the use of services, and thus the term *service user* is important in the context of risk. It signifies a relationship with an organisation and particular staff where there is likely to be a *duty of care* towards the service user, and thus an assumed right or duty placed on them to intervene in certain circumstances to avoid harm to them. Issues of capacity, a contested concept in the paradigm of human rights, likely arise in thinking about risk for people with cognitive disabilities and the duty of care of organisations and staff in the following ways.

- 1) Does a service user have ‘capacity’ i.e. a full understanding of all the risks, to both harm and wellbeing, involved in a decision that a worker (or others) consider ‘risky’ and ‘unwise’, and if so has the decision-making process been documented and reasonable action taken by those with a duty of care to minimise any identified harms. Have those with a duty of care acted in the way a reasonable person in their situation might act taking all the circumstances into account.

- 2) Is a service user planning to take a ‘risky’ decision that may result in harm to themselves (or others), and due to their cognitive impairment, those with a duty of care judge they do not

fully understand the risks involved i.e. may not have capacity. If this is the case, some form of intervention may be warranted to protect the person from harm. Certainly, there should be a rigorous process to support the service user's decision making, and to enable the risky decision to be made by considering the severity, likelihood, positive and negative aspects of the risk, and documentation of this process of support. Perhaps too, in this type of situation, a person with a duty of care may have to consider whether steps to appoint a formal substitute decision maker or make a substitute decision are warranted.

In the UK, the provisions of the Mental Capacity Act (2005) enable workers to determine a service user's capacity on a decision by decision basis. The Act endorses their intervention to make a best interests decision for an individual who does not have capacity for a particular decision. A small study by Williams et al. (2014) highlighted that many of the 'best interests' decisions made by front line professionals were forced by a change in the circumstances of a service user or that of a third party, such as decline in health, hospitalisation or change of accommodation, which meant they faced risks that hadn't been present previously. They found that three functions were necessary in supporting decision making where risk was involved, which could be done separately or by the same person - leading the best interest process (organising meetings, ensuring records were kept, contacting relevant parties), chairing best interests meetings (sharing information and ensuring everyone had a say) and taking responsibility for the actual decision. This study pointed to the importance of decision making as a joint process that involved interaction with the service user and others involved in their life to resolve issues and reach consensus if possible.

In Australia, the processes are not as clear as the UK, as reliance is placed on the least restrictive alternative of informal substitute decision making. Although some service users may have a guardian appointed to make decisions on their behalf, informal substitute decisions are often made for people with cognitive disabilities by family or workers without recourse to formal processes. There is, however, little to guide supporters in thinking about supporting decision making or enabling risk (Douglas, Bigby, & Knox, 2015).

Importantly, people without cognitive disabilities not using services are generally free to make unwise and risky decisions without interference. Expectations about intervention in another's decision making only arises when there is a question about the person's capacity to make judgements about a risk they are going to incur or if a person is a service user and owed a duty of care by an organisation or worker.

A Positive or Risk Enablement Approach

Perception is a significant facilitator or barrier to risk taking. Perceptions of risk are subjective and determine the way it is enabled or managed. Despite early work on actuarial approaches to calculating and managing risk in organisations, Kemshall (2014) argues that the rational prudential approach to gathering information about probabilities does not work in the human services. She claims risk is dynamic, contextually situated, and whether something is identified as a risk depends on the priorities of the person and the meaning attached to their behaviour. Her view is clearly that a person centred and contextual approach must inform all thinking about managing risk.

The positive nature of risk – the potentially beneficial outcomes of actions or decisions have had little prominence in community care despite the fact that risk taking plays a central social role for example, in business and pastimes such as sport and associated gambling (businesses or community organisations take risks, expecting positive outcomes, by deciding to invest in new services or new staff; punters bet on the outcome of many kinds of sports events). For service users, even what might seem like minor risks such as deciding to do something different or go out with a friend rather than a paid staff member can have positive outcomes particularly if it is something that is important to the service user, or entails having a new experience, developing new skills or learning about their own limitations. Conversely, avoiding risks may have a negative effect if service users are not able to have a new experience or do something important to them, although this aspect of risk often rates little mention.

Some commentators suggest that the positive aspects of risk are more likely to be recognised for service users with intellectual disability than other groups (Mitchell & Glendining, 2008). In the field of intellectual disability, positive risk taking and the idea of ‘dignity of risk’, as a way of expanding experiences and learning dates back to the writings of Robert Perkse in 1982. Additionally, the principles of normalisation (Wolfensberger, 1991) have been powerful in framing risk as part of everyday life, that people with intellectual disability should experience and from which much can be learned (Tindale, 1997).

The growing focus on enabling risk for service users in the community care sector stems from more positive ideas about the benefits of taking risks. Risk enablement is becoming preferred language, signifying differences between risk associated with decisions of individual service users about things important to them, and risk associated with wider

organisational issues. Thus, it might be useful to think about enabling risks for individuals and managing risk for organisations.

Much of the community care risk literature refers to the tensions between supporting service user choice and control while ensuring their safety and wellbeing as a binary – choice versus protection as either or options to be weighed against each other (van Hooren et al., 2002). Rational and procedural steps to deal with this tension are set out in guidance documents, such as *risk identification, risk assessment, risk management and risk mitigation*. Some of the literature takes a more positive stance referring to *risk benefit assessment* – assessing the risk of harm if particular action is taken weighed against the benefit to wellbeing or quality of life if the action goes ahead and the risk of loss of wellbeing or quality of life if it does not (Sawyer & Green, 2013).

The risk enablement literature proposes a less binary and more individualised and positive approach to assessing and managing risk that more explores positive effects of taking risks and reduces the negative effects of avoidance. The aim is to find ways to enable service users to pursue things important to them in ways that minimally interfere with a chosen action but which also reduces the risk of harm and/or minimises harmful impact should a negative outcome eventuate. Thus, *risk enablement* is a process of supporting a person with cognitive disability to make judgements that enable him or her to exercise choice and control and take actions important to them while being protected from harm (Department of Health, 2010).

Risk enablement plans identify and summarise the positive and negative risks of a preferred decision – the likelihood of a positive outcome and its importance to a person - the likelihood of a negative outcome, and its severity or impact on the person or others - develops action plans that enable a person to undertake the activity safely with minimum change to its nature and minimise any harm that may eventuate (Department of Health, 2010).

Empirical Research about Risk Enablement Practice

There is considerable commentary about the importance of risk management and the broad issues to be considered in the context of supporting service user choice and decision making. However, there is little empirical research about the practice of either risk management or enablement and the associated facilitators and barriers.

Front Line Professional Social Workers

Much of the UK literature is generic and context specific, concerning front line professional social work staff involved in needs assessment, rationing resources, determining individual

budgets, care management, or safeguarding processes (see for example, bodies of work on personalisation and individual budgets led by Manthorpe and Glendinning).

Some of the early 1990s UK literature on risk suggested that procedural guidance might strip front line social workers of the ability to make judgements based on their professional training. Either this did not eventuate or has now been overtaken, as Stalker writing in 2003 (p. 228) suggested “rather than try to calculate the incalculable, social workers need to regain their former status as experts in uncertainty”. She goes on to describe what the key characteristics of their approach should be to enabling risk, “They should develop mutually trusting, respectful relationships with their clients, make fine judgements about risk and dare to work creatively and innovatively”.

Robertson and Collinson (2011) in a study of mental health and intellectual disability services illustrate the complexities involved for front line professionals in enabling risk, such as supporting a person to take a short-term risk in order to achieve a longer gain. They suggest that risks are never predictable and workers’ judgements should be based on “awareness of circumstances rather than firm rules” and “doing the best they can do at the time”. Other elements of good practice suggested were; use of knowledge about the person; being aware of changing dynamics of risks; support from colleagues in thinking through complex trade-off of benefits against adverse outcomes and a trusting relationship between service users and workers. They point out too, the dangers of extreme risk climates which are either too reckless or too risk averse. This study highlighted the context specific nature of risk, suggesting that there are likely to be less environmental dangers involving weapons or drugs for service users with intellectual disability compared to those with mental health or drug issues. Although the authors suggest a more positive emphasis on giving control to service users in intellectual disability services, in their view direct support staff in these services were often less well trained than other fields, and less confident or able to appreciate the benefits of risk taking.

It is difficult to locate Australian positions corresponding to those of the UK social workers considered in the literature. In the UK, there appears to be a greater likelihood that tertiary trained professional social workers occupy front line assessment, planning and case management roles which means they bring professional practice frameworks and pre-existing knowledge and skills in ethical decision making to these roles. In Australian community care, services oversight and management of resources has been more dispersed than the UK local government system and professional declassification of traditionally social work positions in

the early 1990s has meant where there are similar positions to those held by social workers in the UK in Australia they are open to a broader and more diverse workforce with tertiary or VET qualifications.

The only large Australian empirical research on risk and front line practice in disability and community care services has been a study by Sawyer et al. (2009; Sawyer & Green 2013). Their findings challenge the growth of procedural approaches to risk, showing that front line professional workers in aged care, mental health and disability services have simply folded risk into their practice and are reflective, nuanced, and insightful in the way they engaged with it. The front line staff in this study drew on their professional and personal values, life experience and understanding about both context and the nature of service users disabilities to make judgments about supporting people who they thought may have been putting themselves at risk. The study identified two types of risk rationalities among front line professionals 'positive' and 'critical', and a third type, 'compliant' which was held only by direct support workers (discussed in a later section). Those with a positive rationality endeavoured to ensure safety for other workers and clients by integrating risk management into their practice and drawing on professional values and frameworks of ethical decision making. In particular, they saw the quality of their professional relationship as part of the therapeutic process and a key element of reducing or managing negative risk taking in their work particularly with service users with mental health problems. They saw procedural guides for managing risk and tools, such as risk alert stickers, as helping to strengthen practice, and making them more self-reflective. In contrast professionals with a critical risk rationality saw risk management procedures as constraining their practice and disadvantaging clients by detracting attention from relationships and labelling clients negatively.

This important study suggests that training and experience of front line professionals equips them with frameworks for practice and decision making to enable risk, and directs attention to the educational preparation and continuing professional development opportunities available to the various disciplinary groups who constitute front line professions in the disability sector.

Two Australian studies which investigated processes of case management with people following brain injury suggests the importance of risk tolerance and support to take low risks to good practice and in increasing the autonomy of this group (McCluskey, Johnson, & Tate, 2007; Mooney et al., 2009).

Stakeholders Perceive Risk Differently

Reflecting a broader theme running through the literature about the importance of perception to thinking about risk, several studies identify differences between the various stakeholders involved in decision making about risk (Power, 2008; Faulkner, 2012; Almack, Klegg, & Murphy, 2009). In a study that sought the views of older people as service users as well as people with intellectual disability, Faulkner (2012) found service users were concerned about risks posed to their independence, and felt that professionals valued protection and safety at the expense of dignity, autonomy, self-determination and family life. Service users felt that too often decisions were made by others without their involvement. Several studies that have sought the experiences of families of young people or adults with intellectual disability suggest they are sceptical of new policy agendas about choice and, like some support workers, do not see some choices as possible or more positive risk taking as practical. While Almack et al. (2009) provide a detailed exposition of parental perspectives founded on their experience and engagement in the lives of their adult children, other writers tend to be dismissive of parental perspectives characterising them as overprotective (Power, 2008). Though only a small body of work, these studies reflect research about the difficulties often experienced in families and service providers working together (Bigby & Fyffe, 2012, Bigby, Webber & Bowers, 2015) and reiterate themes in the social work practice literature about the need to take into account the multiple perspectives different stakeholders bring to assessing any situation (Bigby & Frawley, 2010).

Several studies identify differences in perspectives on risk between direct support workers and front line professionals. In their Australian study, Sawyer and Green (2013) found direct supporter workers were more compliant and rule bound and less reflective about risk than front line professionals. A qualitative study by Robertson and Collinson (2011) in the UK of mental health and intellectual disability services found a lack of coherence in approaches to risk across different levels of these organisations, in particular differing perspectives between front line support staff and professionals in supervisory roles. This latter group felt they received inconsistent organisational support and were left to create their own guidance for staff about risk. They were frustrated with what they saw as the lack of understanding by front line staff about the risk, and failure to use an individualised and strengths based approach or see management of risk as a collective endeavor.

Front Line Support Staff Practice to Support Choice or Enable Risk

Few studies have specifically examined the risk management or enablement practices of front line direct support workers in disability services but issues of risk are often implicit in research about their practice. A small but significant body of work from the UK (see for example studies by Finlay et al., 2008a & 2008b; Jingree & Finlay, 2008; Jingree, Finlay & Antaki, 2006; Jingree, 2015; Dunn, Clare, & Holland, 2010) and Australia (see studies by Bigby, Knox, Beadle-Brown, Clement & Mansell, 2012, Bigby, Knox, Beadle-Brown, & Clement, 2015; Bigby & Beadle-Brown, 2016) has investigated the practice of direct support workers in supported accommodation services for people with intellectual disability.

Concerned with micro day to day practice, these studies have used qualitative observational methods to collect and analyse data, such as ethnography, sound and video recordings and conversational analysis. Methods such as these avoid the social desirability that arises in relying on staff self-report. This research exposes the difficulties staff grapple with in supporting choice and the rhetorical devices they use to justify their often restrictive actions. Conducted in different contexts over an extended period of time these studies reach similar conclusions, suggesting that staff practice is frequently disempowering, and overrides rather than enables service user choice and positive risk taking. These studies have demonstrated support worker practice to be inflexible, risk averse and taking a protectionist approach to duty of care. However, issues of risk are difficult to untangle from other reasons for overriding service users' wishes which include staff values, practicalities, lack of staff skills, and perceptions of conflicting roles, limited time, and organisational imperatives.

The conversational analyses undertaken by Finlay, Jingree and Antaki indicate that staff justify curtailing choice through asserting the need to take account of social acceptability and the practicalities of acting on preferences, and use extreme or worst case examples of what might eventuate. Australian studies of staff culture in group homes illustrate the very different assumptions about the purpose of their work and regard for service users that inform practice in underperforming compared to better group homes (Bigby et al., 2012). This research shows that across all types of group homes staff tend to default to the 'golden rule' of using themselves as the reference point for decision making by thinking about 'what would I want if I were in this person's shoes' rather than 'what does this person who is in this position want' (Bigby, Knox, Beadle-Brown, & Clement, 2015). A UK study similarly showed staff reliance on their own values and experiences to reach 'best interests' decisions for the people they supported (Dunn, Clare, & Holland, 2010).

Though portraying a negative picture of staff practice, this body of work demonstrates the influence of staffs' underlying values and judgement about the feasibility or otherwise of translating into practice current policy directions about risk enablement. This work also illustrates the high degree of discretion exercised by staff about compliance and putting risk management plans into action.

A qualitative UK study by Hawkins, Medley and Holland (2011) showed front line support staff failed to comply, and in some instances, actively undermined service wide risk plans for service users with Prader Willi syndrome. The authors reflected on the disadvantages of standardised and procedural approaches to risk that had failed to take account of knowledge about individuals. They suggested the need for individualised and collaborative approaches to development of plans that involved, staff, managers and services users and provided opportunities for staff to make informed and reflective judgements about their actions and compliance with plans. Support for this type of individualised rather than rule based or procedural approach that is inclusive of service users and involves collaboration with others involved in a person's life is consistently found in peer reviewed papers that comment on or have investigated elements of risk management practice (Robertson & Collinson, 2011; Greenhill & Whitehead, 2010; Vallenga et al., 2006, 2008)

A very small qualitative New Zealand study identified a positive theme of 'engaging with risk' associated with the introduction of active support in a service for four people, three of whom had an acquired brain injury (Graham, et al., 2013). Expectations of power sharing between staff and service users and the facilitation/enabling model of active support appeared to provide a catalyst for staff to discuss, anticipate and plan for risk, meaning they became more risk aware rather than averse, and enhanced their critical reflection and team work. A larger body of research about active support in services for people with intellectual disability has not considered risk specifically but has consistently found a positive impact on service user choice and control when active support is used by direct support staff (see Mansell & Beadle-Brown (2012) for overview of this work).

The study by Hawkins and colleagues (2011) and several others (van Hooren et al., 2002; Vallenga et al., 2008) focus on particular sub groups of service users with intellectual disability (Prader Willi syndrome and epilepsy) living in supported accommodation services. Their health conditions mean these service users have heightened risk of harm if their choices about food or lifestyle are unrestricted. These studies illustrate the value of different types of knowledge, in these cases expert knowledge about a person's genetic or medical condition

and associated behavioural manifestations, in informing risk enablement plans together with more holistic knowledge about the person and their own preferences. Vallenga et al. (2006) found that families' high levels of anxiety about risk of harm from seizures were not necessarily related to the severity of risk, and yet played a big role in decision making. Staff based their decision making about restricting choice on limited data about the occurrence of seizures, did not evaluate effectiveness of strategies, and tended to be reactive rather than proactive in managing risk. Suggested ways to improve practice were to tailor information more carefully to service users' cognitive ability, and adopt a more methodical approach to making judgements by collecting data about specific incidents of harm and the circumstances when these occurred. The authors suggest continuous evaluation of plans would make it possible to more finely tune the application of protective measures to the severity of the seizures at any time, and avoid using restrictive measures simply because of familiarity and habit.

Models for Enabling Risk

A follow up action research study with people with epilepsy conducted by Vallenga et al. (2008) proposed a model of risk management for people with epilepsy that was person centred and emphasised consensus among the staff team. The phrases in the model were; risk analysis, consensus about risk, consensus about risk management, commitment to risk management and inclusion in care plan. The study found that the need to reach consensus encouraged staff to be less reactive and restrictive and more willing to seek out measures that reflected client's wishes. Shared decision making meant the staff team became less task orientated, more coherent in observing and evaluating problems, and individually more reflective. A good risk management decision was defined as one taken on the basis of accurate and recent information. The model meant that individual guidelines were developed for each service user specifying a minimum level of protection which provided a framework within which individual staff could support service user choices when necessary.

In order to avoid paternalism Greenhill and Whitehead (2010) suggest that frameworks for thinking about risks should be based on the rights embedded in the UN Convention on the Rights of Persons with Disabilities. Their framework was primarily concerned with risks associated with service users' challenging behavior, and the importance of proactive rather than reactive strategies. They suggest service users must be included in their own risk assessments, and these should be open, explicit in acknowledging risk and guided by the principles of fairness, respect, equality, dignity, and autonomy (FREDA). In their view

interference with the rights of a person to make their own decision should only arise from protecting a person from harming themselves, from being harmed by others, or protecting others and should be proportionate to the risk, i.e. “appropriate and not excessive in the circumstances”. The authors refer to a number of tools to support their proposed framework in practice, ‘Keeping me safe and well screen’, for example but give little indication of how these are applied in practice or evidence about efficacy.

In a philosophical consideration of autonomy and its application to people with Prader Willi syndrome, van Hooren and colleagues (2002) suggested that the dichotomy between respecting choice and autonomy on the one hand and paternalism or safety on the other and trying to weigh up the two was too crude. Rather they suggest greater attention be given to relational aspects of care, and use of a more differentiated framework that creates space for interpretation and deliberation about choice or preferences. In this type of deliberative model choices and values are less fixed. They use the example of a person with Prader Willi syndrome deciding to have half a piece of standard cake rather than a full piece of a non-sugar variety to illustrate the processes of continual learning and interpretation that can occur in deliberation and may open up new perspectives.

Tindale (1997) reflecting on experiences as a senior manager of a large service for people with intellectual disability suggests the importance of a positive risk culture that minimises reactive responses to risk. He suggests that organisations need to learn through debriefing when things go wrong but also sharing experiences when things do not go wrong but might have done.

Gadow and Riches (2014) developed a clinical risk model for the NSW Government which is quite complex to follow and appears to be specifically targeted at tertiary qualified professionals working from a clinical perspective.

A small literature has investigated indicators for risk of sexual offences and probabilities of re-offending for service users with cognitive disabilities (Hutchinson, Lovell, & Mason, 2012). This is a very specialist area of knowledge and practice, for which specific tools and predictive checklists based on research about the patterns of offending have been developed to support risk enablement.

More Formal Risk Management or Enablement Models

Models for supported decision making, and risk enablement or management are found in policy or guidance documents in the UK and Australia. Those in the UK are rather similar

and emphasise basic tenets of a person centred approach, thinking or planning that dominate intellectual disability policies (see Neil et al., 2009; Methven, 2009). For example, Neil et al. (2009) sets these out as; the person at the centre, involving others and regarding them as partners, a focus on what is important to the person, intent to build connections to community, go beyond traditional services and listen and learn from the person. Guidance documents are normative rather than evidence based and most are targeted at a wide range of users and staff in social care services and do not focus solely on people with cognitive disabilities.

Approaches to risk revolve around first an understanding of what is important to the person, and then identifying the risk, and scoping the scale, frequency, likelihood, severity of potentially negative consequences of an action/decision, and then thinking about reducing the likelihood of negative things happening, by redirecting the preferred action to a less risky option or continuing with the action and reducing the likely harm should the negative outcome eventuate. Motherhood statements suggest the need for staff to weigh choice versus protection - this against that- which while highlighting the necessity for judgement and discretion shed little light on how this should be done.

UK models are situated in the context of the Mental Capacity Legislation and assumptions that service users did not have capacity to make an informed decision and there is a need for a worker to step in to make a best interest decision. Care must be taken in interpreting these models for the Australian context. Briefly, these include:

UK Department of Health 2007 'Independence, choice and risk: A guide to best practice in supported decision making'

A straightforward model to support decision making that considers issues of risk as part of a supported decision making framework. A strong person centred approach runs through the whole document. The Social Care Institute of Excellence 2010 guide 'Enabling risk, ensuring safety: self-directed support and personal budgets' (Carr, 2010) is based on this document.

The guide asserts the philosophical position that risk can be beneficial, protection needs to be balanced against choice and control and people have the right to take risks as long as this doesn't put others at risk of harm. Exercising choices inevitably involves taking risks and in the context of service provision raises questions about safety and who is responsible if something goes wrong. Supporters need to be aware of the relevant legislative context in which they work which includes: duty of care, human rights, health and safety, mental

capacity or guardianship provisions. Legislative provisions may conflict, for example the use of human rights law to support the rights of service users may need to be balanced against occupational health and safety provisions - i.e. a person's right to choice against the wellbeing of carers. This document defines *duty of care* as an obligation placed on the individual requiring that they exercise a reasonable standard of care while doing something or omitting to do something that could foreseeably harm others. For an action at law of negligence there must be an identifiable duty of care. If someone has mental capacity to make decisions they can choose to live high level of risk, and if they have consented to risk there may be no breach of duty of care. However, it is suggested the state is not obliged or may not be willing to fund risk.

Everyone sees risk differently, often negatively and it is often used to stop people doing things. Risk is dynamic, fluctuates over time and is specific to the context of each individual rather than objective. Perceived risks need to be tested and assessed to see if they are real. Judgements about what is reasonable risk involves striking a balance between empowering people to make choices while supporting them to take informed everyday risks. Putting these principles into practice means supporting choice, recognising elements of risk, understanding implications or consequences of choices and associated risks, and planning to manage identifiable risks and documentation of the processes used. Decisions about risks should be made jointly with the person, and should also draw on knowledge about what's important to them based on person centred planning processes. Supporting decisions involving risk are likely to make it necessary to work across systems and team working, coordination and consistency. Professionals will need to take account of their own profession's ethics in managing risk.

UK Department of Health 2010 'Nothing ventured nothing gained – risk guidance for dementia'

This is the only model identified with an explicit risk enablement approach. It is geared towards people with dementia and declining capacity for judgement but its four steps have the potential to be applied to other groups of people with cognitive disability.

In summary, the framework has four steps:

1 Understanding what's important to the person. This step uses a wellbeing or quality of life framework to understand what is important to the person generally and in terms of the specific issue in question. Attention is particularly given to psychological and social needs. Key questions to think about are, how does this particular activity contribute or take away

from the person’s quality of life? To what extent is this activity potentially harmful? What are the positives associated with an action compared to the likelihood of harm?

2 Identifying key risks and impact. This step involves identifying risk areas, understanding the impact of the risk inherent in an activity that is important to the person and mapping the risk, its likelihood of occurring and severity. The mapping can be done from the perspective of the person and others involved in their life. For example,

Risk area	What would be the impact if harm happened?	How likely (H/M/L)		How severe (H/M/L)	
		Myself	Others	Myself	Others
New activity/ break of routine	Example: dancing leads to tiredness and dizzy spell				
Doing something alone	Example: goes to Post Office – gets lost on the way and cold				
New relationships	Example: invites new ‘friend’ home – leads to exploitation				
Financial loss or loss of belongings	Example: pays someone to clean windows but not done – conned/exploited				

3 Assessing the impact of risk. This step develops a personal risk portfolio which provides a framework to think about where an identified risk sits in terms of negative and positive impacts. The personal risk portfolio or heat map can be developed as a trigger for discussion about weighing the severity of negative risk against positive aspects and thinking about actions that can be taken to minimise harm without changing decisions or actions that are important to quality of life.

Personal Risk Portfolio ('heat map')

Contribution to quality of life

High	Maximise safety enhancement and risk management protect the individual and manage the activity	Carefully balance safety enhancement and activity management to protect the person	Minimal safety enhancement necessary – carry out with normal levels of safety enhancement
Medium	Substitute can the same personal benefit be delivered in a different way seek different activities?	Carefully balance safety enhancement and activity management to protect the person	Minimal safety enhancement necessary – carry out with normal levels of safety enhancement
Low	Do not allow level of risk is not related to the benefit/value to the person find alternatives	Challenge real value of the activity to the individual seek alternatives that are more attractive and lower risk	Allow the activity or seek alternatives that will provide a better relationship with their needs
	High	Medium	Low

Risk of harm or quality of life to the individual

4 Risk enablement, management and planning. This step is focused on enablement and ways of managing negative risks and promoting safety without interfering with a person’s chosen activity. This may be done in various ways: changing the environment around the activity; changing the way the person takes part in an activity that reduces risk but still respects choice; minimising the impact of the consequence or harm to the person or others if things go wrong and the risk eventuates (reducing the harm). Things to think about may be changing arrangements for carrying out the chosen activity, such as where it takes place, how it happens or finding alternative ways to enable a person’s choice to be carried through to action. At this stage, a plan for enabling the risk can be written that sets out ways of respecting choices or enabling an activity with as little change as possible and minimising harmful consequences, the resources required and responsibilities for carrying it through.

Risks, safety enhancements, harm reductions, resources and responsibilities

I value this activity*	The risks associated with this activity are...	How I can enhance my quality of life	How I will manage the risk
<i>Playing golf is a key part of my retirement. I enjoy socialising, being outside in the fresh air and the exercise</i>	<i>I am at risk of getting hurt by wandering in 'line of fire'. I get very tired which leads to feeling distressed</i>	<i>My friend, Fred, has a good understanding of my current needs and I will only play golf when Fred is around. My wife or the CPN will provide Fred with the information he needs to continue to accompany me on the golf course. Fred and I will play golf for a short period of time and take a rest in the club house</i>	<i>I will not play golf if Fred is not available to come with me</i>
<i>I enjoy cooking. I've cooked all my life for my family and it's important to me to continue to look after myself</i>	<i>I've left the cooker on a couple of times and burnt a pan. There's a risk that a fire will start and cause harm to me and my neighbours</i>	<i>A gas shut off valve will be fitted to the cooker and an extreme heat sensor will be fitted in the kitchen</i>	<i>If further problems occur with cooking I will talk with my care manager about alternative options such as using a microwave, arranging for someone to cook with me, or having meals delivered</i>

UK Department of Health 2007 'Best practice in managing risk, Principles and evidence for best practice in the assessment and management of risk to self and others in mental health services'

This document also includes a more detailed workbook. This model is primarily geared to users of mental health services who do not necessarily have cognitive disabilities.

UK 'Mental Capacity Act 2005 Code of Practice'

Decision making is the primary focus of this checklist and code of practice that includes some consideration of risk related issues.

A range of other UK documents were located in our searches that were local rather than national but tended to replicate, sometimes with more detail, the approaches set out in the national guidance documents. We also identified various Australian and NSW policy

documents that set out state and organisational risk policies and management frameworks for disability service organisations and their staff. The language used is fairly similar across these types of documents but it is noted that the term ‘risk treatment’ is used in the NSW policy documents to discuss ways of reducing potentially negative effects. We have not summarised these documents as they are essentially setting out policy rather than guidance and practice approaches for front line staff.

NDIS Quality and Safeguarding Framework, Department of Social Services 2016.

This is a broad overarching framework that considers issues of risk in the context of the NDIS and governments’ responsibility for safeguarding people using the scheme. The NDIS is based on principles of human rights, a presumption of capacity to exercise choice and control, national consistency, proportionality and risk responsiveness. The framework refers to similar tensions found in UK frameworks and the literature, asserting that it is designed to balance appropriately the need for protections that meet governments’ duty of care obligations with the need to enable participants to take reasonable risks so they can reach their goals.

“Strategies for reducing harm need to be weighed-up against the likelihood of harm occurring and its severity, and the impact this will have on choice and control. This allows for the dignity of risk, which includes “supporting people to take informed risks to improve the quality of their lives”

The framework talks about risk in various ways but primarily in terms of risk to service users (scheme participants) arising from the use of services and actions of others. Risk is framed as something that happens to people, and suggests that at an individual level some people, such as women or people with more complex needs, may be more at risk than others, such as people with significant social networks. The degree of risk may be associated with types of support or service a person uses, varying according to the degree of contact or intimacy involved in providing support, where support occurs and how much surveillance there is. The term proportionality is used to suggest that the response to risk should be in proportion to the degree of risk. Similar to the literature and other frameworks, this document suggests that approaches to risk should be person centred and tailored to individual strengths, needs and circumstances in order to increase or decrease risks inherent in certain types of support.

Three domains for addressing risk are set out – developmental, preventative and corrective. Strategies in the developmental domain aim to strengthen the capability of people with

disability, the workforce and providers and thus avoid harm arising from risk. Those in the preventative domain aim to prevent harm by ensuring services are of high quality and do not put service users at risk of harm through abuse or poor practice. The corrective domain is intended to resolve problems, enable improvements to avoid problems recurring and provide system oversight.

The preventative domain appears most pertinent to issues of risk arising from decisions of people with cognitive disability themselves rather than the actions of others. An aspect of this domain is inclusion of safeguards as part of the individualised planning, implementation and review process. The presumption of participant capacity in the NDIS Act (2013) scheme encourages the use of supported rather than substitute decision making but has provisions for nominees to be appointed when necessary and the potential to fund access to decision making support. The framework suggests that the planning process will identify people at higher levels of risk and a risk assessment could be incorporated into a person's plan. During the planning stage, a planner may discuss ways to manage risk, ask questions about a participant's personal perceptions of safety, informal safeguards, their vulnerability to exploitation, abuse, financial risk and assistance needed to support plan implementation or manage their funding. Participants who are identified as vulnerable to exploitation or abuse or lack the ability to manage their plan, may have access to a support coordinator to help implement their plan and understand risks associated with different providers.

The emphasis is on risks from the actions of others and it is not clear whether service coordinators will fill the types of roles filled by social workers in the UK who play a significant role in mediating risks associated with service user decisions. Some of this type of work, currently undertaken by the variously constructed Offices of the Public Advocate or Public Trustees in different states, is likely to continue although how the NDIS will impact on the functions of these offices is not clear.

Recurring Themes about Good Risk Enablement Practice - Implications for Development of Training in NSW

Consistent themes about positive approaches to risk are raised in the small scale studies about perceptions of risk, and the experiences of front line professionals or direct support workers which recur in guidance documents. These are summarised as:

- Issues of risk are a key part of supporting decision making for people with cognitive impairment.

- Though technically neutral risks are often interpreted negatively.
- Perceptions of risk are subjective and views often differ among groups involved in the lives of people with cognitive disabilities.
- Risks are contextually situated and dynamic meaning that information for decision making must be up to date, individualised and context specific rather than generic.
- Different sources of knowledge, including specialist knowledge should inform decisions about risk.
- The perspective of the person themselves should be at the centre of decisions about risk.
- Rule based or procedural approaches that apply to whole groups of people rather than individuals can be overly restrictive or protective, and staff may not follow this type of approach.
- Staff working together to reach consensus about identification and enablement of risk can lead to more reflective and creative approaches.
- Thinking about risk should be rooted in relationships of trust between work and client, to ensure significance of choices to the person are understood and enable control over risk to be negotiated.
- Professional front line workers incorporate issues of risk into existing practice and ethical decision making frameworks.
- The practice of direct support workers can restrict choice and positive risk taking by prioritising protection and practicalities.
- Direct support workers fear blame and retribution doubting that organisations will support risk taking when outcomes do result in harm.
- Organisational approaches to risk may not be coherent, as imperatives to avoid risk to reputation may not align with positive risk taking for service users.
- Organisations should take proactive rather than reactive approaches to risk and foster a positive culture of risk.
- Protection of human rights might provide a framework for thinking about risk.
- A collaborative approach involving service users and others important in their lives such as families and service providers should be used.
- Thinking about decisions should avoid binaries of choice v protection and adopt a more deliberative and interpretative approach in which choices and values are not fixed but open to discussion.

The empirical literature identifies problems with procedural guidance for staff or rules that apply to groups of service users. There is consensus that risk enablement processes should be person centred - reflective of individuals' wishes, context, the particular situation and circumstances of the risk and minimise any changes to the preferred action. This suggests it is preferable for staff to have a set of principles as a reference point to inform their judgements rather than prescriptive procedures. The use of principles can help to identify what is

important in a specific decision, the process of weighing up positive and negatives of the risk, and in findings ways to enable choice without imposing restrictions.

As well as being person centred, the literature suggests that risk enablement plans should be collaborative i.e. developed and shared with the service user and others both formally and informally involved in their lives. All of this literature points to the need for service users, providers and others involved in their lives to share their differing perceptions of risk and the reasons behind these differences. Underlying this is the importance of skilled facilitation of discussion or negotiation of consensus between competing perspectives.

Although the evidence base underpinning these themes is relatively weak, it does provide some indicators for preparing risk enablement plans and practice suggesting that these should be: individualised; not procedural or rule based but informed by principles that can be applied to each situation; informed by different sources of knowledge, strengths based, least restrictive and least disruptive of rights particularly choice, developed collaboratively with the service user and other people and organisations involved in their life in order to reach shared understanding; and use a deliberative rather than binary approach to thinking about possibilities.

Risk is discussed from many different perspectives in the literature. Most commonly it is considered in the context of decision making of service users and the role of professionals or direct support front line staff in respecting choice and enabling the risks important to the person's quality of life inherent in decisions to be made. An enablement approach that recognises the positive impact of taking risk is increasingly reflected in guidance and policy documents, together with an emphasis on the rights of service users to be supported to make decisions about their own lives. Issues of risk are integral to supporting decision making.

We have incorporated consideration of risk into the practice framework for supported decision making (the framework) developed previously (Bigby & Douglas, 2016) to avoid unnecessary confusion between risk enablement and support for decision making, or proliferation of frameworks. Alignment between indicators of good practice for enabling risk and the support for decision making framework is evident, particularly elements of the framework, such as knowing the person and orchestration of supporters. Enabling risk can be incorporated into step 4 of the framework and the following principles provide the basis for support in this step.



Principles to guide discussions about risk enablement at step 4

- Person centred
- Collaborative
- Deliberative
- Contextualised
- Enabling preference by
 - Positives first
 - Minimization of harm (e.g. finding alternative ways of reaching the same goal)
 - Least change to preferences (least modification to preferred action)
 - Proactive not reactive
 - Defensible (through documentation and taking into account relevant legal and policy)

A self-paced training program and set of online multi-media resources have been developed based on this literature review, consultation with a group of people with intellectual disabilities from NSW Council on Intellectual disability, and a pilot of the training program with direct support workers from one organisation in NSW. The final resources are available at <http://www.enablingriskresource.com.au/>

References

- Almack, K., Clegg, J., & Murphy, E. (2009). Parental negotiations of the moral terrain of risk in relation to young people with intellectual disabilities. *Journal of Community and Applied Psychology, 19*, 286-298. doi: 10.1002/casp.992.
- Beck, U. (1992). *Risk society: Towards a new modernity*. London: Sage.
- Bigby, C. & Douglas, J. (2016). *Support for decision making: A practice framework*. Living with Disability Research Centre: La Trobe University.
<http://hdl.handle.net/1959.9/556875>
- Bigby, C., & Beadle-Brown, J., (2016) Culture in better group homes for people with severe and profound intellectual disability. *Intellectual and Developmental Disabilities, 54*, 316-331 <http://www.aaidjournals.org/doi/pdf/10.1352/1934-9556-54.5.316>
- Bigby, C., & Frawley, P. (2010). *Social work practice and intellectual disability*. New York: Palgrave Macmillan.
- Bigby, C., & Fyffe, C. (2012). Services and Families Working Together to Support Adults with Intellectual Disability. *Proceedings of the Sixth Annual Roundtable on Intellectual Disability Policy*. Available on line LaTrobe University repository
<http://hdl.handle.net/1959.9/493044>
- Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., & Mansell, J. (2012). Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability. *Intellectual and Developmental Disabilities, 50*(6), 452-467. doi: 10.1352/1934-9556-50.06.452.
- Bigby, C., Knox, M., Beadle-Brown, J. & Clement, T. (2015), 'We Just Call Them People': Positive Regard as a Dimension of Culture in Group Homes for People with Severe Intellectual Disability. *Journal of Applied Research in Intellectual Disability, 28*: 283–295. doi:10.1111/jar.1212
- Bigby, C., Webber, R., & Bowers, B. (2015). Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work, 68*(4), 453-468. doi: 10.1080/0312407X.2014.950678.
- Carr, S. (2010). *Enabling risk, ensuring safety: Self-directed support and personal budgets*. UK: Social Care Institute for Excellence.
- Department for Constitutional Affairs, United Kingdom. (2005). *Mental Capacity Act 2005 Code of Practice*. UK: The Stationery Office.
- Department of Health, United Kingdom. (2007). *Best practice in managing risk, Principles and evidence for best practice in the assessment and management of risk to self and others in mental health services*. UK: Department of Health.

- Department of Health, United Kingdom (2007). *Independence, choice and risk: a guide to best practice in supported decision making*. UK: Department of Health.
- Department of Health, United Kingdom. (2010). *Nothing ventured, nothing gained: Risk guidance for people with dementia*. UK: Department of Health
- Department of Social Services, Australia. (2016). *NDIS quality and safeguarding framework*.
- Douglas, J., Bigby, C., Knox, L., & Browning, M. (2015). Factors that underpin the delivery of effective decision-making support for people with cognitive disability. *Research and Practice in Intellectual and Developmental Disabilities*, 2(1), 37-44. doi: 10.1080/23297018.2015.1036769.
- Dunn, M. C., Clare, I. C. H., & 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. *Journal of Intellectual Disability Research*, 54(2), 144-160. doi: 10.1111/j.1365-2788.2009.01228.x.
- Faulkner, A. (2012). The right to take risks. *The Journal of Adult Protection*, 14(6), 287-296. DOI: 10.1108/14668201211286066.
- Finlay, W. M. L., Antaki, C., & Walton, C. (2008a). Saying no to the staff: an analysis of refusals in a home for people with severe communication difficulties. *Sociology of Health and Illness*, 30(1), 55-75. doi: 10.1111/j.1467-9566.2007.01028.x.
- Finlay, W. M. L., Antaki, C., Walton, C., & Stribling, P. (2008b). The dilemma for staff in ‘playing a game’ with a person with profound intellectual disabilities: empowerment, inclusion and competence in interactional practice. *Sociology of Health and Illness*, 30(4), 531-549. doi: 10.1111/j.1467-9566.2007.01080.x.
- Fyson, R., & Kitson, D. (2007). Independence or protection – does it have to be a choice? Reflections on the abuse of people with learning disabilities in Cornwall. *Critical Social Policy*, 27(3), 181-186.
- Gadow, F., & Riches, V. (2014). *Practice guide to person centred clinical risk assessment*. Centre for Disability Studies: The University of Sydney.
- Graham, F., Sinnott, K. A., Snell, D. L., Martin, R., & Freeman, C. (2013). A more “normal” life: Residents', family, staff, and managers' experience of active support at a residential facility for people with physical and intellectual impairments. *Journal of Intellectual & Developmental Disability*, 38(3), 256-264. doi: 10.3109/13668250.2013.805738.
- Greenhill, B., & Whitehead, R. (2010). Promoting service user inclusion in risk assessment and management: a pilot project developing a human rights-based approach. *British Journal of Learning Disabilities*, 39, 277-283. doi: 10.1111/j.1468-3156.2010.00664.x.
- Greenspan, S., Switzky, H. N., & Woods, G. W. (2011). Intelligence involves risk-awareness and intellectual disability involves risk-unawareness: implications of a theory of common sense. *Journal of Intellectual & Developmental Disability*, 36(4), 242-253. doi:https://dx.doi.org/10.3109/13668250.2011.626759

- Hawkins, R., Medley, 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. *Journal of Intellectual Disability Research*, 55(9), 873-884. doi: 0.1111/j.1365-2788.2011.01445.x.
- Hutchinson, J., Lovell, A., & Mason, T. (2012). Managing risk: A qualitative study of community-based professionals working with learning-disabled sex offenders. *Journal of Psychiatric and Mental Health Nursing*, 19(1), 53-61. doi: 10.1111/j.1365-2850.2011.01754.x
- Jingree, T. (2015). Duty of care, safety, normalisation and the Mental Capacity Act: A discourse analysis of staff arguments about facilitating choices for people with learning disabilities in UK services. *Journal of Community and Applied Social Psychology*, 25, 138-152. doi: 10.1002/casp.2202.
- Jingree, T., Finlay, W., Antaki, C. (2006). Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meeting. *Journal of Intellectual Disability Research*, 50, 212-226
- Jingree, T., & Finlay, W. (2008). 'You can't do it...it's theory rather than practice': Staff use of the practice/principle rhetorical device in talk on empowering people with learning disabilities. *Discourse & Society*, 19(6), 705-726. doi: 10.1177/0957926508095890.
- Kemshall, H. (2014). Conflicting rationalities of risk: disputing risk in social policy – reflecting on 35 years of researching risk. *Health, Risk & Society*, 16(5), 398-416, doi: 10.1080/13698575.2014.934208.
- Kilcommons, A.M., Withers, P. & Moreno-Lopez, A. (2012). Do service users with intellectual disabilities want to be involved in the risk management process? A thematic analysis. *Journal of Applied Research in Intellectual Disabilities*, 25(5), 433 – 444. DOI: 10.1111/j.1468-3148.2012.00684.x
- Lafferty, A., McConkey, R., & Simpson, A. (2012). Reducing the barriers to relationships and sexuality education for persons with intellectual disabilities. *Journal of Intellectual Disabilities*, 16(1), 29-43. doi: 10.1177/1744629512438034
- Mansell, J. & Beadle-Brown, J. (2012). *Active support: enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.
- McCluskey, A., Johnson, M., & Tate, R. (2007). The process of care management following brain injury: A grounded theory study. *Brain Impairment*, 8(3), 293-311. doi: 10.1375/brim.8.3.293.
- Mental Capacity Act 2005 (UK)*.
- Methven, S. (2009). A positive approach to risk requires person-centred thinking. *Tizard Learning Disability Review*, 14(4), 25-28. doi: 10.1108/13595474200900035.

- Mitchell, W., & Glendinning, C. (2008). Risk and adult social care: Identification, management and new policies. What does UK research evidence tell us? *Health, Risk & Society*, 10(3), 297-315. DOI: 10.1080/13698570802163677
- Mooney, O., Doig, E., & Fleming, J. (2009). Risk assessment and management for providers of community-based rehabilitation to people with acquired brain injury: Health professionals' perspectives. *Disability and Rehabilitation*, 31(6), 500-507. doi: 10.1080/09638280802092097.
- National Disability Insurance Scheme Legislation Amendment Act 2013* (Cth) (Austl.).
- Neil, M., Allen, J., Woodhead, N., Sanderson, H., Reid, S., & Erwin, L. (2009). A positive approach to risk requires person-centred thinking. *Tizard Learning Disability Review*, 14, 17-25
- Parley, F. F. (2010). What does vulnerability mean? *British Journal of Learning Disabilities*, 39, 266-276. doi: 10.1111/j.1468-3156.2010.00663.x
- Power, A. (2008). Caring for independent lives: Geographies of caring for young adults with intellectual disabilities. *Social Science and Medicine*, 67, 834-843. doi: 10.1016/j.socscimed.2008.05.023.
- Robertson, J. P., & Collinson, C. (2011). Positive risk taking: whose risk is it? An exploration in community outreach teams in adult mental health and learning disability services. *Health, Risk & Society*, 13(2), 147-164. doi: 10.1080/13698575.2011.556185.
- Sawyer, A-M., Green, D., Moran, A., & Brett, J. (2009). Should the nurse change the light globe? Human service professionals managing risk on the frontline. *Journal of Sociology*, 45(4), 361-381. doi: 10.1177/1440783309346478
- Sawyer, A-M., & Green, D. (2013). Social inclusion and individualised service provision in high risk community care: Balancing regulation, judgement and discretion. *Social Policy and Society*, 12(2), 299-308. doi: 10.1017/S1474746412000590.
- Stalker, K. (2003). Managing risk and uncertainty in social work: A literature review. *Journal of Social Work*, 3(2), 211-233. doi: 10.1177/14680173030032006.
- Tindale, B. (1997). People with learning difficulties: citizenship, personal development and management of risk. In H. Kemshall & J. Pritchard, *Good practice in risk assessment and risk management 2: Protection of rights and responsibilities*, pp. 113-117. London: Jessica Kingsley.
- United Nations. (2006). Convention on the rights of persons with disabilities. Retrieved May 22, 2017, from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Vallenga, D., Grypdonck, M. H., Tan, F. I., Lendemeijer, B. H., & Boon, P. A. (2006). Decision-making about risk in people with epilepsy and intellectual disability. *Journal of Advanced Nursing*, 54(5), 602-611. doi:http://dx.doi.org/10.1111/j.1365-2648.2006.03870.x

- Vallenga, D., Grypdonck, M. H., Tan, F. I., Lendemeijer, B. H., & Boon, P. A. (2008). Improving decision-making in caring for people with epilepsy and intellectual disability: An action research project. *Journal of Advanced Nursing*, 61(3), 261-272. doi:<http://dx.doi.org/10.1111/j.1365-2648.2007.04477.x>
- van Hooren, R.H., Widdershoven, G.A.M., van den Borne, H.W. & Curfs, L.M.G. (2002). Autonomy and intellectual disability: the case of prevention of obesity in Prader-Willi syndrome. *Journal of Intellectual Disability Research*, 46(7), 560 – 568.
- Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., & Heslop, P. (2014). Best interests decisions: professional practices in health and social care. *Health and Social Care in the Community*, 22(1), 78-86, doi: 10.1111/hsc.12066.
- Williams, V., & Porter, S. (2017). The meaning of choice and control for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 30, 97-108. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12222>
- Wolfensberger, W. (1991). Reflections on a lifetime in human services and mental retardation. *Mental Retardation*, 29(1), 1-15. Retrieved from <http://www.proquest.com>